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FROM UNCONSCIOUS TO SELF-CONSCIOUS

COGNITIVE REHABILITATION FROM THE PERSPECTIVE OF SYMBOLIC INTERACTIONISM

A Thesis presented in fulfilment of the requirements

for the degree of Doctor of Philosophy

in Social Policy and Social Work

at Massey University

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ABSTRACT

There is increasing awareness and concern that psychosocial problems prevent people with brain damage reestablishing an acceptable quality of life. Changes in perception and cognition appear to alter a person's relationships, preventing a successful reintegration into the community. As a result, many researchers and rehabilitation practitioners have been calling for more holistic models of recovery which recognise the psychosocial domain and which offer strategies to counteract these problems.

In this study, the principles of symbolic interactionism are used to explore the experience of four people with traumatic brain injury. A life history was collected for each person and the four life histories were examined for common patterns and themes. A videocamera was then used to record their daily life in a residential rehabilitation programme. The film collected included formal one-to-one therapy sessions, group situations and informal interaction in the living areas, dining room and passageways etc. The four people (and also those with whom they interacted) were shown selected excerpts from this film and interviewed about what was happening. Several common themes emerged from this process and these themes are examined within a theoretical framework which recognises the central role of a *dual, interacting and interpreting self*, *creating meaning* through an *adapting* and *accommodating* process.

Theory and literature about brain damage and about inner brain processes is revisited from this perspective of the person as a *meaning negotiator* and some conclusions are reached about the impact of brain damage upon lived experience. In particular, the role of a *moral self* or *an inner conjured audience* is considered, as well as the role of *emotional intersubjectivity* within *relationships*. Some new insights are offered as to how people resolve the problem of continuing to interact with their world when it is difficult for them to make sense of it or interpret it, and how other people's responses influence this process.

The findings of the research suggest adaptations to both *settings* and *relationships* may be necessary for a successful recovery after brain injury. The importance of providing *scaffolding* of the meaning-negotiating process during a *liminal period* of recovery is noted. Some suggestions are offered as to interactive strategies which foster *adaptive, purposeful and independent* lifestyles. The thesis concludes that because realities are created through interaction, the principles of symbolic interactionism should become more central in the designing of rehabilitation programmes.

ACKNOWLEDGMENTS

Four years ago, when I enrolled in a post graduate research paper in the Department of Social Policy and Social Work, I began a process which has culminated in the presentation of this thesis. At that time, I had returned to academic study after a 13 year absence because of a vague but pressing need to explore more deeply and understand more fully the experience of the people I worked with. Associate Professor Andrew Trlin and Associate Professor Robyn Munford, my supervisors, took my vague sense of mission and helped me turn it into the goal-directed and fulfilling enterprise of a thesis. Over the years there have been many times when the production of this thesis threatened to overwhelm me but each time they have both been there to guide, encourage and support me. They have ploughed through thousands of pages in their efforts to reduce my effusive and disorganised passion for my subject into something other people could comprehend and learn from. I thank them both from the bottom of my heart.

Just as great a debt is owed to Professor Norman Denzin. From the moment that I discovered the term 'symbolic interactionism' I knew I had found the theoretical framework to make sense of the experiences I was observing at Waimarie. From that time onwards, every idea I was excited by, and wanted to explore further, I would discover that he had been there before me and had developed exactly the models of interactive and intra-active process which I needed to make the necessary connections between knowledge available about neurological disorders, and theory about phenomenological, interpretive and interactive experience.

The greatest debt however, I owe to the four men who agreed to be the central focus of my study as well as to the larger group they represented. Over the seven years I have worked with people who have brain damage I have been constantly awed by the way people faced with seemingly impossible obstacles respond. By sharing their experience, they have convinced me of the power of the human spirit to achieve a sense of integrity and wholeness no matter how serious the disability, given appropriate support. My thesis is an attempt to express in words, some small part of what these people live each day so that those who live and work with them may be better equipped to keep up with them.

I would also like to offer my sincere thanks to the families of these four men and to the staff and residents of Waimarie who were involved (often just as intensely) as participants in this study. Many of these people selflessly gave hours of their time and generously accepted my

examination and interpretation of sometimes very personal and sensitive experiences. I did not realise when I designed my study, just how much I would be demanding of people in my interviews with them, or how intrusive a videocamera could be, and yet I received only encouragement and enthusiastic support from others. Several people explained that they shared their experience in the hope this thesis might help others. As a symbolic interactionist, I regard this sharing as the greatest gift that one person can give another and only hope I have done them justice in my presentation of their experience.

Finally, I would like to thank my family. Over the last four years, I am uncomfortably aware that my husband and three children have constantly been sacrificed to the needs of this thesis. They have always unquestioningly accepted my need to put it first, however, and only ever given me love and understanding. It is because they took this approach that the last four years have been such a happy and positive time for me.

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INTRODUCTION

The consequences of traumatic brain injury[1] are so diverse that it is not possible to begin this thesis by offering a concise definition of the subject of the study. While many people who have experienced TBI have similar difficulties, there is no common set of characteristics which distinguish them as a group and the problems that do occur range widely according to the site, nature and degree of the damage. What can be said, however, is that many people with brain damage spend the rest of their lives with perceptual, cognitive, emotional and physical changes which dramatically alter their relationship to the world. Some of these changes are temporary and slowly diminish over the months or years following the accident, while others are more permanent, requiring major adaptations to lifestyle. Either way, these injuries are likely to demand major adjustment and reorganisation in the lives of people who experience them.

Dealing with these changes and managing an effective recovery and rehabilitation presents not only the people with the injuries themselves, but also (and perhaps to a greater degree) all those who live and work with them, with a number of challenges. These challenges are as compelling as they are intimidating, causing a wide range of ethical and interpretive dilemmas. When it is the consciousness which is the object of concern, the inadequacy of traditional, 'mechanistic' conceptions of health is most dramatically revealed. To regard the body as a machine subservient to the mind and responsive to treatment imposed by others, may be useful when the damaged part is a limb, an organ or a muscle. In this situation, it may be possible for someone else with expert knowledge to assess and measure the degree of impairment and to plot and manage the course of recovery, without extensive consultation with the person concerned. When it is the brain which is the object of treatment and rehabilitation, however, any assessing or therapeutic activity requires the active participation of the consciousness.

This thesis is an examination of the experience of four people with traumatic brain damage. In each case, the course of a life was abruptly interrupted, firstly with a period of coma and later with a longer period of recovery. None had managed, or was likely to manage, a complete recovery

[1] The term 'Traumatic Brain Injury" (often abbreviated to TBI) is favoured in recent literature, replacing the term 'brain injury' to maintain a distinction between those whose injury has been caused by some form of external impact and those who have brain damage as a result of a neurological disorder, or cerebro-vascular accident (CVA), as well as the term 'head injury' which may imply damage which does not affect the brain. Whenever the words 'brain damage', 'head injury', or 'brain injury' are used in this thesis, it can be assumed that the damage or injury was 'traumatic' in origin and that the brain as well as the head was damaged.

and each future had been irredeemably changed yet each managed some degree of a creative self-reconstruction despite the brain damage. Their stories provide an opportunity to enter a world in chaos and to examine the process of reorganising and regaining interpretive control over the future.

BACKGROUND TO THIS STUDY

The initial impetus for this research was a personal rather than a professional experience. I had a sister, Tory, who lived for nine years in what is called a 'persistent vegetative' or 'locked in' state[3] as a result of a car accident in 1980. Her eyes were open, yet because she had no definite way of communicating, her family and friends could only guess what was happening in her mind from the erratic variations in physical movement and facial expression she managed. Remarkably, although they were largely built from others' memories and these uncertain inferences, her relationships over this time were strong and enduring. There were many people who visited and wrote to her regularly throughout the nine years while many of those employed to care for her believed they had developed a close personal relationship with her and continued this relationship after they had moved on to different jobs. She also continued to be regarded as an active and important part of her family.

Looking back, it seems that Tory managed to sustain such rich relationships with her world because of other people's reaction to her situation. We became intensely interested in any small responses she made and began to adapt our own actions to promote and encourage further interactional dynamics. Gradually, a new persona was created, a mosaic of our reports to each other of what she appeared to communicate and our memories of the person she had once been. Slowly we gained confidence as we conducted our still somewhat one-sided conversations with her, that she was participating in a two-way relationship again. We had discovered that in order to continue having an authentic relationship with her, we needed to support her in playing her part. The quality of her experience of living over this nine years became vested in the accuracy and authenticity of our projected interpretations, mediated only by her limited feedback.

During the nine years Tory lay in a hospital bed, my career path also confronted me with many issues of interaction and relationship which paralleled this personal experience. At the time of my

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[2] As Madjar (1991:44) and Keilhofner describe it, a 'mechanistic' conception of health is one which conceptualises a physical body extrinsic to self and so available for objective measuring and assessing followed by treatment.

[3] The Glascow Outcome Scale (Jennett, Snoak, Bond and Brooks, 1981), commonly used to rate the level of disability after brain trauma, has five categories ranging from 'Good Recovery' to 'Persistent Vegetative State'. My sister would have been assigned to the lowest category not because (as the term might suggest)

sister's car accident, I had been completing my final year's study in a Bachelor of Social Work at Massey University. The course material in this degree had a broad social science base and, as a result, I began my career as a social worker in 1981 firmly convinced of the need to look at the problems of the people I worked with from both an interactive and a sociological perspective. Over the years I spent as a medical social worker this need to understand situations within a wider interactive context was constantly reinforced.

At the time of my sister's death in 1989, I became employed as a tutor in the Education Unit at Waimarie[4], the residential rehabilitation program which is the setting for this study. Here, I again encountered the creative relationship-building process my sister had experienced. In order to accommodate the effects of the brain damage, considerable adapting of and experimenting with interactional dynamics was occurring. People employed to care, in whatever capacity, eagerly shared with each other their discoveries about what interaction strategies 'worked'. The expertise and knowledge most valued related not so much to the defining of the disorders and deficits associated with the injuries, as to understanding which actions allowed the person the greatest possible quality or richness to their lived experience. I became convinced that the key to helping people who had brain injury lay in understanding the changes in their interpretation of and interaction with the world.

Having reached this conclusion, I became interested in designing a research project which centred upon interactional processes and interpersonal relationships and explored their role in the creating of new meaning and purpose after brain injury. Although current literature about rehabilitation is becoming increasingly strident about the need for a "holistic" approach (Ben Yishay, Rattok, Lakin, Piasetsky, Ross, Silver, Zide and Ezrachi, 1985; Pepping and Roueche, 1991), perhaps because of the historical reliance upon the discipline of neuropsychology, this is usually conceptualised in rather individualistic and psychological rather than interactive and sociological ways. Interactional dynamics are written of as strategies to 'manage behaviour', 'improve interpersonal skills' and encourage more 'appropriate' and 'realistic' attitudes. Realism and appropriateness, while undeniably important to a good recovery, are equally undeniably value judgements rather than fixed attributes and any goals defined in terms of them risk imposing rather than empowering.

My background in sociology and social work inclined me to believe that a more sociological approach to the problems created by head injury would point to ways of understanding the

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there was no mental activity, but instead because it was not possible to interact with her and discover whether or not there was.

process of recovery which tempered concepts such as 'appropriateness' with a greater acknowledgment of their cultural origins, negotiating the difficult territory between social expectations and the sovereignty of a self. While concepts such as *insight* and *self-awareness* have already been eagerly explored in the literature and there is a general agreement that a new sense of *identity* must be developed (Ben Yishay et al., 1985; Gordon and Hibberd 1992; Prigatano 1989b, 1992), I felt a sense of unease when such discussions all too regularly underplayed or brushed aside very real issues of interpersonal power and social expectations and the influence they played in defining and controlling the setting of recovery. Research which focused upon the socially based reconstruction of an inner self, I believed, would cast the rehabilitation staff and family in a supporting rather than a central role in the theoretical discussion and the emphasis would shift correspondingly from outer-directed treatment styles, vulnerable to the unintentional disempowering of people, to an inner-directed self-empowering which returned to the person the interpretive control over the experience of social living.

PERSPECTIVE OF THE STUDY

In the title of this thesis, one relatively new body of theory and practice, *cognitive rehabilitation*[5], is placed alongside another - that of *symbolic interactionism*. At first glance they would appear to have little in common. The first has developed from the discipline of neuropsychology and the second from sociology. However, a definition of rehabilitation which was recently proposed by LaGrow (1992:12) reveals the essentially social and interactive nature of any rehabilitation endeavour:

> **Rehabilitation may be defined as a process which seeks to limit the disability and eliminate the handicap resulting from (a) an impairment[6], or (b) an interaction between the impairment and the environment, with the goal of restoring an individual's level of participation in daily life to that realised before the onset of disability.**

Such a definition promotes a philosophy of therapeutic practice which is habilitative as much as rehabilitative, as it recognises that to continue to interact effectively it may be necessary to

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[4] The names of all places associated with this research, including the institutional setting called 'Waimarie', have been changed for reasons of confidentiality.

[5] Cognitive Rehabilitation , discussed more fully in chapter 1, is defined for the purposes of this research as "therapeutic process of increasing or improving an individual's capacity to process and use incoming information so as to allow increased functioning in everyday life" (Sohlberg and Mateer, 1989:3).

[6] The terms impairment, disability and handicap are used in this thesis (as also they are used by LaGrow) as prescribed by the World Health Organisation in 1980 (ICIDH, Geneva). The word *impairment* implies some physical loss or damage, *disability* is the limitation this impairment places upon activity and functioning, while *handicap* refers to the impact of the disability upon the person's lifestyle or life roles. However, because of the negative associations the word 'handicap' has in New Zealand, the term is avoided wherever possible.

develop new ways of looking at and dealing with the world. While it allows a distinction between rehabilitation and education and other support services, it demands that methods of evaluating outcome define success in terms of the person's own interpretive framework.

Luria (1966; 1973; 1980), a neuropsychologist, provided the underlying theoretical principles upon which current cognitive rehabilitation practice is founded. He believed that many composite processes at several different sites and levels within the brain were involved in creating even the simplest actions. The key to understanding the brain's role in human behaviour, therefore, is to recognise that it was an interacting and integrative system (Sohlberg and Mateer, 1989:11). From these beginnings, rehabilitation practitioners have developed a range of strategies aimed at reintegrating and reorganising the perceiving and thinking processes. As they became more ready to recognise the role of interaction, the literature reflected a growing concern with the nature of being and consciousness. As Sacks (1985:141-2) explains it, to address the issues raised by head injury, it appears to be necessary to break free of disciplinary boundaries:

> **... if the brain's representations are damaged or destroyed, as in the amnesias, agnosias and apraxias, their reconstitution if possible demands a double approach - an attempt to reconstruct damaged programmes and systems ... at the level of inner melodies and scenes. If we are to understand, or assist, brain-damaged patients, a "systematic" therapy and an "art" therapy is required, preferably both. ... a new and beautiful "existential" science and therapy, which can join with the systematic, to give us a comprehensive understanding and power.**

Like Sacks, I came to believe it was necessary to blend neuropsychological knowledge with other theory which recognised the central place of *meaning* to human existence and purpose. Mechanistic models of brain injury, which concentrate attention upon defining, measuring and treating disordered functions and skills, have developed an important knowledge base which no one can afford to discard. To extend our understanding, however, I believed this knowledge must now be used, not to set limits and labels which separate out 'abled' from 'disabled' or 'deficit' from 'normal', but instead to address the issues of awareness and self-awareness which confront people in this field of rehabilitation; to ask how the experience of living as a meaning-making, purposeful entity might be altered by a head injury. If one becomes less competent in perceiving and processing information, how does this affect meaning-making dynamics, and in turn, how does meaning making affect participation in rehabilitation and recovery? My theoretical perspective led me to believe there are important questions to be addressed about interpretive control and personal power. It appeared that the usual conventions and expectations made about therapy, about reintegration into a community and about learning adaptive and compensatory skills, required some careful re-examination and adaptation in the light of these concerns.

In this thesis, I argue that symbolic interactionism offers the ideal theoretical perspective for such a mission as well as providing method for the inquiry. From the time that Mead (1934) first introduced the idea of a dual inner self, many people, attracted to this interactive, processual approach to consciousness, have developed and extended the scope of symbolic interactionism until it has come to offer a comprehensive sociology of the mind, capable of explaining experience which might otherwise seem strictly mental and individual, as the product of our social arrangements. By focusing upon the experience of a self and by tracing the process of its struggle with the crisis of a head injury, I believed it would be possible to develop theory which explored relationships rather than attributes and which recognised and mapped the central role of meaning-making in recovering a valid quality to life.

In particular, from within this body of theory known as symbolic interactionism, I have drawn upon the work of Denzin (1984;1987;1987a; 1987b; 1992). Because he used this theoretical framework to explore and understand the experience of emotion, as well as that of alcoholism, he has drawn widely upon other theory of inner consciousness, as well as incorporating a range of ideas about the role of the *physical, feeling body* and the importance of *power dynamics* within relationships. In this way he has developed a broad theoretical framework which he terms "*interpretive interactionism*". Armed with this perspective, it seemed possible to enter this field of inquiry with a tool which could, in Denzin's (1992:34) words "unravel the ideological meanings that are coded into the taken-for-granted meanings that circulate in everyday life". As I examined the striving of the four men to "preserve identity" and "organise chaos" (Sacks, 1985:5), this framework offered an opportunity to identify at least something of the "ideological abuse" (Denzin, 1992:34) unknowingly or knowingly imposed both by the people themselves and by others.

A DEFINITION OF KEY IDEAS

Self as a purposeful, adaptive, meaning-creating entity, is the central focus of this study. Much of the thesis is an exploration of the levels of meaning, both personal and political, which are implicit in this word and the way in which it guides a personal relationship to the world, influencing both the defining of situations and the locus of perceived power.

Like Denzin, I have adopted the concepts suggested by Heidegger (1967) to define self. It is regarded as a moving process of *being-in-the-world* rather than a fixed entity; a *process* which is layered into an 'ontic' or taken-for-granted level and a deeper inner stream or core of ontology, that "incorporates the structures of the person's life world into a meaningful grammar of emotional expression and interpretation" (Denzin, 1984:108). This definition allows the

examination of *different modes of consciousness* and focuses attention upon the link between *awareness, language and temporality*. We know who we are only because past experience can be applied to present situations and we can mentally order and plan our lives.

This defining of ontology and world, therefore, is the inner aspect of self. Its outer expression involves a *presentation of self*. Through actions and words, a self-image is communicated and promoted, often functioning as an agent of personal power by influencing others' interpretations and achieving control over situations and people. Interaction provides the forum through which this *self-as-actor* constantly adapts itself, accommodating for the feedback of others.. The terms *role* (along with a cluster of related dramaturgical notions) and its counterpart *relationship* are used in relation to this self-as-actor, thereby maintaining a constant awareness of the reciprocal and interdependent nature of consciousness. Because role is understood as "a set of norms with the additional normative element that the individual is expected to be consistent" (Turner, 1956:317), words such as *appropriate* and *realistic*[7] can be used in this thesis without any implication that they convey an absolute value. Rather than just interpreting, the self of symbolic interactionism is constantly *negotiating* the realities it lives.

An ontological self as used in this thesis differs from similar notions of an interpreting self because of a second concept, that of the *taking of the attitude of the other*. The recognition and emphasis upon this aspect of consciousness, unique to and definitive of symbolic interactionism, identifies the essentially social and emotional nature of all interpretation. An ontology is an understanding of the world which grows from dynamic inter- and intra-personal relationships within it.

METHOD AND PURPOSE OF THE STUDY

Given the aim of this study, to examine and comment upon the interactive process of recovery from head injury, rich qualitative data was essential. Ideally this data needed to reveal both the outer observable behaviour and the inner processes which created it. With this in mind the thesis draws upon data gathered from both in-depth interviews and film. It weaves together themes from the stories of survival and struggle as narrated by the four people and their families and themes from the film of the latter stages of their story, depicting their everyday life as a resident in a rehabilitation program.

Using a style of life history collection known as the "*progressive-regressive method*" (Denzin, 1989:197) a back and forth interpretation of the 'before and after' phases of each of the four lives

[7] 'Appropriate', whenever it is used in this thesis, implies that no more precise referent can be given because the what is appropriate will depend upon the "vantage point of the person or persons formulating the role conception" (Turner, 1956:316).

was possible. This provided an overview of each life within which to place the data from the second phase of the research, a *participant observation study* carried out within the setting of a residential rehabilitation programme. Twenty hours of film of each person's everyday life was collected over a period of two months, using a form of participant observation known as 'naturalistic inquiry' (Lincoln and Guba, 1985).

According to symbolic interactionism, an individual "forges a line of conduct, by making an object of what it notes, giving it a meaning and using the meaning as a basis for directing action" (Blumer, 1969:14). Modern interactionist theory maintains the focus upon intrapersonal and interpersonal interaction to understand how our 'truths' and so our actions are fashioned through a process of ongoing negotiation of our relationship with our world. By exploring the patterns in the four lives something of this process was discerned and questions formulated to confirm and extend these understandings.

This method produced a wealth of qualitative data, so rich and thick that it often escaped simple and clear description and analysis. The complexity and intangibility of relationships was dramatically revealed and there were times during the two years of examining and reflecting upon the meanings within the data, when it only seemed possible to raise new questions, rather than offer any new answers as had been my initial intention. No simple conclusions are offered therefore and instead the findings are presented in a form designed to provoke critical reflection about current rehabilitation practices. The analytical chapters of this study have the character of a dialogue or discussion about the meaning of cognitive and perceptual disorders for the people encountering them and conclusions are offered as to what interactive styles and types of relationship are 1) effective and 2) support the recovery of an adaptive, purposeful and independent spirit. Current structures and practices within the New Zealand health system can be examined in this way according to their potential to empower or to disempower a self engaged in and/or emerging from a major existential crisis.

STRUCTURE OF THE THESIS

This thesis is divided into 14 chapters. A review of the literature about the consequences of Traumatic Brain Injury is presented in the Chapter 1 and the current state of rehabilitation theory and practice is also examined. Particular attention is paid to neuropsychological and psychological literature which defines the nature of the impairments and/or disabilities encountered by people with brain damage, describing how they alter perception, information processing and arousal and how these changes in turn can affect the personality, disturbing the level of self-awareness and

self-control. In the second part of this chapter, current rehabilitation practices are discussed, as well as the ethos and assumptions underlying the various models available.

In Chapter 2, a theoretical framework of symbolic interactionism is developed, based largely upon the work of Heidegger and Denzin but incorporating a range of related theory which explores human consciousness from the perspective of an interpreting self, acting according to continually changing beliefs and ideas. In Chapter 3, symbolic interactionism methodology is explained and the design, setting and procedure of the research is described in detail.

The life stories of the four men selected for this study are presented in chapters 4 to 7. Each chapter traces the experience of one person before and after the pivotal event of a head injury. Although some discussion occurs and some conclusions are drawn as the individual stories are told, Chapters 8 and 9 are devoted to the summary and analysis of these stories. Common themes and patterns are identified and described: firstly (Chapter 8), those which concern the inner mental experience of recovery from cognitive and perceptual distortion and secondly (Chapter 9), those which concern the person as a part of a wider picture, a person with a past identity against which he was measuring the changes wrought and who was part of a wider social network encompassing family, friends and others in the community.

Chapter 10 is a collection of 'behaviour exemplars', representative examples drawn from the filmed observations in the second phase of the research. As described by Denzin (1989:79) behaviour exemplars are "a detailed reproduction of the actual experiences, thoughts and actions of those studied" and so the writing in this chapter is in a descriptive narrative style. These behaviour exemplars are the raw data of symbolic interaction upon which the discussion of interactions and relationships contained in Chapters 11, 12 and 13 is based. These chapters develop the three major areas of inquiry concerning interactive process. The first, Chapter 11, covers the 'intra-active' processes, or the way in which disorders of awareness affect the relationship between self and world. The implications for therapeutic relationships are discussed. Chapter 12 moves on from this basis to examine the role played in recovery by the 'inner audience', that aspect of self which takes the 'perspective of the other'. The behaviour exemplars are examined as they reveal the feelings and actions of an inner moral self and some thoughts are offered as to how this should inform practice. Chapter 13 addresses the issues raised by the nature of the setting (a residential institution and rehabilitation programme) and explores the impact of the environment, both of people and objects, upon the process of recovery. In these three chapters the observations are arranged according to Denzin's (1984) typology of

"Emotion's Body" which separates into layers the blend of thought and feeling involved in action and interaction.

In the final chapter, the key findings of the study are presented. Conclusions are drawn about the meaning of these findings and suggestions are made as to how interactive practices might be adapted to encourage the recovery of independence, autonomy and purpose. Some reflections are offered concerning the research process and recommendations are offered for future research in this field.

CHAPTER 1

TRAUMATIC BRAIN INJURY: CONSEQUENCES and THE RECOVERY PROCESS

Damage to the brain can cause a wide variety of cognitive and perceptual impairments. These in turn can produce an even wider range of changes in the way people interpret and interact with their world. This chapter is divided into two parts. In the first part, a brief review of literature about damage to brain processes is provided, outlining the nature of the cognitive and perceptual disorders which can occur and the effect these may have upon the lived experience of the person with a brain injury. In the second part of this chapter, the issues for management and rehabilitation are discussed and some comments offered concerning current intervention practices.

PART 1: THE CONSEQUENCES OF TRAUMATIC BRAIN INJURY

The American National Head Injury Foundation (1985) defines brain injury as "a traumatic insult to the brain capable of producing physical, intellectual, emotional, social and vocational changes." In New Zealand, as overseas, the numbers of people who have had serious brain injuries has grown considerably. This is largely due to improvements in medical care and surgical techniques which allow people to survive despite severe damage and considerable long-term impairment. As a result, after the acute stage, increasing numbers of people are requiring intensive rehabilitation followed by ongoing support. About 170 New Zealanders are hospitalised each week and many more are concussed and have mild head injury. One in every 315 cases experience ongoing problems (Head Injury Society of New Zealand, 1994). This has lead to an increasing awareness of brain injury over the last few years and a growing concern about the seriousness and extent of the problem. The estimated cost of public hospital care alone is $25 million, while other costs, buried in the Social Welfare and Accident Rehabilitation Compensation and Insurance Corporation[8]'s more general funding systems, would considerably outstrip this figure (Head Injury Working Group Document, 1994). Internationally, head trauma is two or three times more common in males, the 15 - 29 year old age group being the most at risk (Jennett, 1990:4). More than half of the injuries result from traffic accidents.

The most consistent effect of brain injury is impairment of consciousness (Jennett, 1990) and the type and severity of injury is often assessed according to levels of consciousness, length of coma

[8] In New Zealand, this government organisation, funded by levies and usually known as 'ACC' is responsible for any costs incurred as the result of an accident.

and length of post traumatic amnesia (PTA). The Glascow Coma Scale (Teasdale and Jennett, 1974) has been found to be an effective and simple instrument to assess severity of damage in the early stages (Rimel, Jane and Bond, 1990:36) but longer term assessment has proved more problematic. Many complex factors interact to affect the eventual outcome for the victim of a head injury and several attempts have been made to devise a scale which can provide a follow up measure after a rehabilitation period. The Glascow Outcome Scale (Jennett et al., 1981) is widely used internationally at discharge (Rimel et al., 1990:15). This reveals that patients become stabilised in scores on physical, intellectual and behavioural functions after one year. This scale is very limited, however, and with only five categories from good recovery to 'persistent vegetative state', does not evaluate the more subtle cognitive and personality changes which can continue for years after the initial injury (Sohlberg and Mateer 1989:39-40). The Rancho Los Amigos Scale (See Appendix D), which does attempt to measure these aspects (Hagen and Malkmus, 1979) divides the recovery into eight hierarchical levels, but is criticised (Sohlberg and Mateer, 1989:39) for the implicit assumptions it makes as to the order in which functions are recovered, memory functions presumed always to precede abstract reasoning ability.

Ultimately, no matter how severe the initial damage and no matter how much physical and motor damage occurs, the "final common pathway after brain injury is a psychosocial one" (Pepping and Roueche, 1991:216; Akinsal and McKinley, 1974). The development and refinement of adaptive devices and compensatory strategies can continue throughout the lifespan, considerably altering the nature of the 'handicap' or the social roles and lifestyle available to the person. To examine the impact of an injury the person must be understood as a social creature and changes to interpersonal interaction need to be a central part of the rehabilitation process (Pepping and Roueche, 1991:215).

VARIABLES AFFECTING THE DAMAGE

The nature, extent and site of the damage are crucial in determining how altered the person with brain damage may become.

NATURE

One of the most decisive factors in determining the likely effect of damage is whether the injury is open or closed. *Open* injury is more likely to affect one limited area (Sohlberg and Mateer, 1989:6). The development of tomographic imaging means that these injuries can be assessed and increasingly accurate predictions made using neuro-scientific principles. In such circumstances, a form of rehabilitation which focuses upon one or two lost functional skills may be possible.

However, secondary complications such as swelling, haemorrhage and hypoxia can cause *diffuse* injury (Rimel et al., 1990) after open and focal impact and the damage will resemble that commonly found after a *closed* injury. A severe but blunt impact will generally knock the brain about within the skull, causing compression, bruising, neuronal shearing, bleeding and twisting throughout the brain. The initial damage is then often compounded by swelling, hypoxia and other secondary effects which occur in the 48 hour period immediately after the injury. A number of organic brain syndromes[9] are also associated with secondary complications and the influence of drugs prescribed for these conditions can complicate the assessing of deficits and the planning of rehabilitation (Ben Yishay and Prigatano, 1990:394). Generally when there is a diffuse injury, there will be a long period of unconsciousness (coma) and a long period of post traumatic amnesia (PTA). The Glascow Coma Scale and the associated Glascow Outcome Index have demonstrated that there are statisically significant relationships between increasing duration of coma and PTA and increasingly impaired cognitive performance (Brooks 1990:168). Most of the people in long-term rehabilitation programmes have diffuse brain injury.

Because more than half of head injuries today are the result of traffic accidents, the typical brain damage pattern is that likely to occur with high speed impact. In such circumstances secondary ischemic damage is usually widespread and many areas of the brain are involved. Regardless of the site of the impact, there are also usually contusions to the cortex in both frontal and temporal lobes and there is commonly widespread disruption or stretching of nerve fibres in the white matter of the cerebral hemispheres and the brainstem (Jennett, 1990:4)

SITE

The site of the damage may also indicate to clinicians how perceptual and cognitive functions will be impaired (Ben Yishay and Prigatano, 1990; Luria, 1963). However, a total review of all the neuropsychological literature which correlates site of lesion with nature of damage would be exhaustive and unnecessary for the purposes of this research. The following are the neuroanatomical correlates which tend to raise the more perplexing issues for rehabilitation practitioners.

The Frontal Lobes: It is widely accepted that the frontal lobes are the area of the brain which deals with the executive functions of planning and organising that are essential for dealing with unique situations and finding creative solutions in unpredictable situations (Goldstein 1952; Lezak 1987; Luria, 1966, 1973; Rosenthal, 1990; Stuss and Benson, 1986). There is a growing awareness that frontal lobe damage underlies poor performance on a number of different

[9] e.g. hallucinations, epilepsy, etc.

cognitive tests (Rosenthal and Bond, 1990:182) and as the result, the term "frontal lobe syndrome" (Bond, 1984; Brooks, 1988) is commonly used to describe characteristic patterns associated with such damage. These include impulsivity, distractability and impaired social competence in fronto-orbital lesions and apathy, perseveration, motor sequencing difficulties and a pseudo-depressed appearance with dorso-lateral lesions (Blumer and Benson, 1975). Damage to the *limbic connections* within the frontal lobes appear to cause alterations to the emotions and personality (Blumer and Benson, 1975; Sohlberg and Mateer, 1989:235).

Temporal Lobes: Some degree of language and memory disorder is typical of people with brain damage. These problems appear to be associated with damage to the temporal lobes and their limbic connections (Mishkin and Appenzeller, 1987; Lishman, 1978). Object recognition difficulties may also be linked to temporal lobe damage, although sometimes this is caused by visual processing disorders associated with damage to the parietal and occipital lobes. The hippocampus and hippocampal gyri (within the temporal lobes), appear to be involved in registering and storing new memories, while other temporal lobe structures are concerned with immediate and short-term recall. The thalamus appears to provide functions of encoding and integration of new information (Sohlberg and Mateer, 1989:189; Rosenthal and Bond, 1990:182).

Brain Stem and the Motor Cortex: Most people assume that movement is a function of muscles. However, muscles have very little to with the disabilities caused by brain damage. Brain stem damage is associated with impairment of automatic motor functions of the body, while the cortical area of the brain is more likely to affect motor problems associated with voluntary movement (Luria, 1963). Complex interaction between the three different levels of the brain, the archi, paleo and neo levels (Jackson, 1932) is involved in most motor activity including posture and balance. It is important to bear in mind that symptoms of motor damage include functions usually associated with interpersonal rather than motor skills such as dysarthria (speech impairment), posture, balance and ocular motor abnormalities (Rosenthal and Bond, 1990:182; Luria, 1987).

Occipital Lobes: The occipital lobes are involved in the perception of visual stimuli (Luria, 1987:27). Lesions here may result in pattern, form and colour discrimination difficulties From the occipital lobe, there are two distinct anatomic pathways. One to the temporal lobe for object identification, the other to the parietal lobe for spatial aspects of vision (Sohlberg and Mateer, 1989:183).

The Parietal Lobes: The parietal lobes are involved in interpreting spatial information and integrating visuomotor responses (Sohlberg and Mateer, 1989:179). Luria (1987:27) describes

the functions of the parietal and occipital lobes as together forming a block "for receiving, processing and retaining information a person derives from the external world".

Cranial Nerves: Damage to the optic nerve this can result in blindness, while damage to the oculomotor nerve controls eyelids, pupil dilation, stereoscopy and binocularity.

Limbic and Reticular System: A mass of nerve cells and fibres within the brain stem called the reticular system excites the other areas of the brain, keeping them active and alert. The limbic system, which surrounds the brain stem and lies just below the cerebrum, is also involved in more complex emotional responses. This limbic system includes the hippocampus and amygdala, the hypothalamus and parts of the thalamus (Luria, 1987:24-6; Restak, 1994)

Bilateral Duplication: The bilateral duplication of brain structure is often a significant factor in determining the effect of damage. The brain is divided into two hemispheres with connecting pathways. It is well established that damage to one side will result in motor difficulties to the opposite side (Sohlberg and Mateer, 1989). Since the 1960s, when Sperry (1968) and others began split brain experiments, it has also become accepted that the two hemispheres operate as a binary system with two functionally different information processing subsystems (Tucker, 1981:19). One hemisphere processes verbal memory and skills and the other sensory and spatial relationships and aesthetic or creative endeavours. The two sides of the brain therefore 'think' in fundamentally different ways (the left brain with words, the right brain with sensory images) and together the two halves form a partnership (Blakeslee, 1980:6-7).

Luria (1973) recognises this bilateral organisation as an important factor in understanding human thought and perception and suggests that a "doubleness" is required in understanding people (Sacks, 1985:224). He also comments that neuropsychology has been guilty of a concentration on the processes of the left hemisphere to the neglect of the right or "minor" hemisphere (Sacks, 1985:2). Although traditionally the right hemisphere was regarded as more primitive, it is becoming increasingly clear that the sensory, spatial and temporal perception it controls are essential for independent living. In fact, Sacks (1985:2) regards the right hemisphere as the more essential of the two, describing the left hemisphere as "a computer tacked on to the basic creatureal brain".

Burgess and Wood (1990a:131) recently commented that this binary nature of perception and cognition is so endemic in consciousness that any neuropsychological principles based upon 'activation' and 'deactivation' are overly simplistic. Instead, they recommended a focus upon the *modulating* and *integrating* role of the brain.

BIOLOGICAL HEALING MECHANISMS

It has long been presumed that the brain is capable of some adaptive physical responses to the trauma it has experienced (Sohlberg and Mateer, 1989:8-9). There are several biological mechanisms loosely grouped under the heading "plasticity", which complicate or assist the recovery process. Recently studies have been carried out which appear to support this idea, demonstrating in experimental situations that chemical manipulation of the brain to improve recovery may be possible in the future (Sohlberg and Mateer, 1989:10).

Although a complete review is unnecessary for this research, there are three biological healing processes which are important in understanding the experience of the four people studied.

- *Substitution:* The "hierarchical principle" (Jackson 1932; Rosner, 1970) is a theory of brain organisation which suggests higher cortical functions are duplicated at lower levels of the cortex but with less sophistication. When one area of the cortex is damaged, another level may provide a substitute.

- *Diaschisis*: Von Manakow (1914) first proposed that brain processes can undergo a temporary period of trauma or "functional shock" (Craine, 1987:87) during which there is a loss of perceptual and cognitive ability. These functions will spontaneously recover in time.

- *Biomodulation* (Kielhofner, 1985:3) or *resonance* (Moss, 1973): In more general terms, the human body and nervous system is now usually recognised as a dynamic open system with an "equifinality" (Keilhofner, 1985:8) which ensures there is more than one way to function. The brain actively responds to threat and damage, reorganising itself to minimise the disorder encountered.

It is very probable that inner brain mechanisms are spontaneously producing improvements in the person's functioning during the period of time that they are involved in rehabilitation programmes and returning to the community. What might seem a successful intervention may just have been well timed to take the credit for something biological occurring simultaneously. In reviewing the literature, this causes a constant tension about the findings produced in research.

DAMAGE TO COGNITION AND PERCEPTION

As is clear from the discussion above, cognitive and psychosocial disorders which develop as a result of brain injury, do not always neatly fit a biologically organised framework. The mechanisms involved in thinking are too complex and dynamic and damage to a specific part of the brain does not necessarily equate with a set and limited field of disability. Rehabilitation

therapists and researchers establish the type and level of impairment by assessing behaviour and task performance. As a result, the literature concerning rehabilitation usually discusses disorders which involve more than one site within the brain. 'Alexia', for example, the inability to read, may occur either because of a failure in the visual perception centres of the occipital lobe, the visual interpretation centres of the parietal lobe, or the word recognition centres of the left temporal lobe.

Because of this tendency, models of treatment and rehabilitation after brain injury, have come to rely upon neuropsychological perspective and method (Ben Yishay and Prigatano, 1990:393). Luria, a Russian neuropsychologist, provided some broad theoretical principles in 1963 which allowed neuropsychology as a science to move on from the task of isolating separate functional centres toward understanding integrated brain function. He proposed a tri-partite model of brain function: the *arousal* unit, the *sensory-input unit* and the *organisational and planning unit* (Luria, 1980). He hypothesised the heirarchical organisation of each unit into three cortical zones: the *primary* areas, which receive and send impulses to and from the periphery; the *secondary* areas, which perform information processing; and the *tertiary* areas which receive input from two or more of the secondary areas and integrate it. This model provides a useful underlying framework for understanding the nature of the disorders encountered by people with brain injury and will be used throughout the remainder of this review to organise the literature on disability and recovery.

From such a conceptual framework, it follows that recovery from brain injury should be conceptualised, not so much as the return of function to the separate areas of the brain, but rather as a process of reorganisation within the brain. Developing concepts from this theoretical presupposition, researchers and therapists in this field over the last 30 years have been inclined to concentrate upon the broad processes involved in thinking and perceiving (Sohlberg and Mateer, 1989; Ben Yishay and Prigatano, 1990; Brooks 1990, etc). As a result, literature about rehabilitation practices generally addresses broad thinking 'categories' such as those provided by Prigatano (1986b:4) who divides cognition into: *attention and concentration, initiation and goal direction, judgment and perception, learning and memory, speed of information processing* and *communication.*

What is most striking (to a symbolic interactionist) about these models of cognition is the way they blur the lines between pure information processing such as a computer might provide and aspects of mind such as 'judgement' and 'initiation' which might be regarded as falling in the domain of personality. When dealing with the nature of consciousness there is (it appears) no

way to separate out the nature of damage from the nature of the person. From the time of Goldstein (1942, 1952) and Luria (1966;1973; 1987), the overlap between what we think of as cognition and what we think of as personality has been remarked upon regularly. Those who write in this field have been challenged constantly to find ways to express the relationship between cognitive and personality changes without either conflating the two aspects or artificially separating them out to a point of absurdity. Recognising this, the perceptual and cognitive damage which occurs after brain injury is reviewed in this chapter under headings which move progressively from the more direct impact to the secondary effect of that impact upon personality and interaction. The initial three categories, the *Executive System*, *Information Processing* and *Sensory Perception*, directly concern change to cognitive processing and the second section, labelled 'Changes to Personality', discusses changes in *Self-Awareness, Communication, Social Interaction* and *Emotionality*. While still underpinned by organic change, it will be shown that the consequences of brain injury to personality and interactional patterns depend also upon both "inborn and learnt mechanisms" (Goldstein, 1952:246)[10], as well as people's unique emotional response.

EXECUTIVE SYSTEM DISORDERS

Perhaps the most significant cognitive disorders are those related to the 'executive system' of planning, organising, initiating, goal directedness, feedback interpretation and self awareness (Stuss and Benson, 1986). Often referred to in the literature as 'metacognition' or 'meta-awareness', this executive system appears to be particularly vulnerable to frontal lobe trauma. Without executive awareness a person is unlikely to make accurate judgements or estimates (Shallice and Evans, 1978) nor notice errors in performance. He or she is likely to become rigid and stereotyped in task performance and obsessive or rigid in thinking and action. In one extreme form of executive function disorder, a person may 'perseverate', or be unable to break off an activity once started. As Luria (1973:187) has pointed out, these "programming, regulating and verifying" functions are what give a person voluntary, strategic control over living. Wood (1990a), Prigatano (1991a), Cicerone and Tupper (1991) all regard the loss of this executive level of functioning as a central issue in brain injury rehabilitation.

Just how profoundly the loss of executive functions can affect lived experience after brain injury is described vividly by Luria (1987:34-5) in his classic study of Zasetsky, a war veteran with an extreme degree of loss of executive function was extreme:

> **His world remains intact, though his life is indeed pathetic: he is completely unable to form any lasting intentions, plan for the future or determine the course of his own behaviour. He can**

[10] Pepping and Roueche (1991:218) describe these as the "pre-injury assets and liabilities".

> **only respond to signals he picks up from without, but is powerless to convert these into a set of symbols to control his behaviour. And once he has no possibility of evaluating his shortcomings, he cannot correct them. He cannot even conceive of what he will do the next minute, much less the next hour or day. Hence, though his past remains intact, he is robbed of any possibility of a future and loses precisely what it is that makes a person human.**

Executive disorders underlie many of the difficulties of thinking and memory observed in people with brain injury. Any form of critical thought involves the ability to discriminate between ideas, to notice patterns and contradictions. The ability to 'timetag' experience, or to remember an intention (for which Sohlberg and Mateer (1989:157) coined the term "prospective memory") becomes severely impaired (Mateer, Sohlberg and Crinean, 1987). Remembering to take out a baking cake, or attend an appointment relies not so much upon encoding and retrieval mechanisms as upon the ability to anticipate the future. It is very hard to recover a sense of control and self-direction when this skill is lost. Without it, it becomes necessary to rely upon rigid pre-arranged time frames.

The work of Norman (1981), Reason (1977) and Shallice (1981) concerning the "supervisory attentional system" has unravelled some of the dynamic interaction between executive awareness and everyday living skills. Later, the relationship between self-monitoring and task performance will be examined further as it influences the "top down" (Gordon & Hibbard, 1992:364; Cicerone and Tupper, 1991:272) models of rehabilitation.

CHANGES TO INFORMATION PROCESSING

Whether or not they contain a metacognitive element, many thinking disorders caused by brain damage translate into general problems with learning and remembering. As a result, memory and memory strategies have been a primary focus throughout the history of brain injury rehabilitation.

The classic model of memory is a temporally based system with three stages: sensory perception, short-term and long-term memory (Sohlberg and Mateer, 1989:136). The associated mental processes are 'encoding', 'storage' and 'retrieval'. This conception has proved inadequate in brain injury research (Wickelgren, 1973) where failures to remember may also be caused by deficits in understanding, thinking, attending, judging, perceiving and language skill (Wilson, 1992). As a result of these epistemological shortcomings, memory has lost its position as a unitary cognitive function (Sohlberg and Mateer, 1989:136). Brooks (1990:165), Sohlberg and Mateer (1989) and most others who have investigated the impairments which can follow brain damage, now break down the functions once labelled memory into underlying cognitive processes. Research questions posed in this area now address components of remembering such as 'processing speed' or 'attention' and as a result, "diagnostically differentiable amnesic syndromes" have begun to emerge (Sohlberg and Mateer, 1989:136).

Transient memory disruption:

A reversible and temporary loss of memory and self-awareness is associated with the secondary complications of brain damage. This includes both 'post-traumatic amnesia' state or 'PTA' which usually occurs in the early period of arousal from coma (Sohlberg and Mateer 1989:140) and also a more general confusion and disorientation which can persevere for some time. A person with PTA is perhaps best understood as living in a constant present, unable to process information or engage meaningfully in his or her world. Typically, individuals will never remember anything of their experiences while in this state but will eventually return to more normal state of awareness. The length of PTA is regarded as a reliable measure of the severity of the damage (Jennett et al., 1981).

Permanent Memory Disruption:

Memory is often more permanently disturbed after brain injury, particularly the ability to remember new information (Lishman, 1978; Sohlberg and Mateer, 1989:141). Global amnesia, the most profound degree of permanent loss, where no new information appears to be retained at all, is relatively rare (Wilson, 1992). But characteristically, people with brain damage will score below the norm in the amount, the efficiency or the stability of memory (Sohlberg and Mateer, 1989:143).

Some degree of retrograde amnesia is usual after brain damage, but the popular view of the amnesiac as one who has forgotten all autobiographical and/or all pretrauma memory is misleading. Most people with brain damage have retained at least some memories but with gaps and uncertainties, which put them in the position of needing to piece together some of their history from what others tell them. Those who have no personal memories of a life before their accident usually need a much more intensive rehabilitation period (Sohlberg and Mateer, 1989:145).

Attentional and Orientational Deficits

Brain damage characteristically causes a loss of ability to sustain attention or concentration (Pepping and Roueche, 1991; Mckinlay, Brooks, Bond, Martinage and Marshall, 1983) and a related loss of the ability to divide attention (Gross, 1987:102). As a result, thought patterns often lack focus and direction, becoming disjointed or "phased" and "barely able to distinguish the essential from the inessential" (Luria, 1987:113).

The degree of *'arousal'*, one of Luria's (1980) three basic underlying processes of thought, has an important impact upon concentration and orientation. It might be viewed as either cause or

effect of attentional difficulties. Arousal is an "internal state of an organism with physiological (eg. pulse rate and catecholamine output) and subjective (level of alertness and feelings of excitement) manifestations" (Kielhofner, 1985:42), a physiological as much as a cognitive variable. It is very unlikely that a person who is insufficiently aroused to engage with his surroundings, will be capable of the mental manipulation necessary for more complex thought processes. Gross (1987:102) demonstrates this paradox when he suggests limitations in processing space produce a personality which is "stimulus bound, with judgement problems and impulsivity". Being easily distracted in these ways has a global effect upon lived experience, influencing not just information processing and learning, but personality and social interaction. Bray, Carlson, Humphrey, Mastrilli and Valko (1987:31) suggest that "patients with limited attentional space", when forced to concentrate upon maintaining their balance, produce fine motor acts or remember strategies for normalising muscle tone, will be less able to deal simultaneously with complex language structures". As a result, a motorically demanding communication device may reduce the person to "telegraphic" (Bray et al., 1987:31) level of communication ability. Similarly, Broadbent (1958) has demonstrated that concentration is essential to effective choice making.

Attention and concentration can be seen to have a direct link with self-directed action. Less choices will be available to the impulsive and easily distracted mind and also to the mind that does not become aroused and engage a higher level of concentration when it is required.

Speed of Information Processing

Another factor which may be a cause or an effect of cognitive disorders is the lessened speed at which information is likely to be processed. It is well established that thinking occurs at a much slower rate after a brain injury (Pepping and Roueche, 1991:229; Godfrey and Knight, 1989). This 'pace' aspect of thought can not be separated easily from issues of attention, arousal and perception, nor from notions of an overarching executive system. Van Zomoren, Bronwer and Deelman (1984), who attempted a micro analysis of issues of attention, processing speed and distractibility, eventually concluded that the "riddles of selectivity, speed and alertness" (Van Zomoren et al., 1984) were impossible to unravel. They found that success in skill performance generally depended on the level of complexity of thought required.

Dichotomous Conceptions of Cognitive Processing

Developing from the Lurian conception of the brain as interactive, there are a range of theories which regard cognitive disorders as symptomatic of an imbalance within dichotomous and modulatory mechanisms of consciousness. Disorders in thought are caused by damage to one process which causes a greater reliance upon, or a dominance of, the other. This range of theories

of cognition which are based upon dual, integrating processes will be presented together. Despite their different conceptual arrangements, considered together they provide a compelling case for regarding brain disorders as only comprehensible as they affect an 'intra-active' and dynamic process.

Conceptual versus Imaginal Processing: There has been considerable interest in the possibility of a spatial/verbal dichotomy of information processing. By implication, damage to one or the other hemisphere will alter the quality of thought and retained knowledge, causing a greater reliance upon either verbal and conceptual or non verbal and visual/sensory-motor modes. Poulos and Wilkinson (1984), for example, suggested there were two methods of storing information: "imaginal" and "associative". Associative memory progressively develops schemata, by entering new information into associative bonds, but the laying down of information into imaginal memory involves "the more wholistic recording of images" (Poulos and Wilkinson, 1984:78). Accessing a memory, therefore, may sometimes mean making a semantic association, while at other times, it may instead require an "evoking" process to occur, or an engagement with what Sacks calls the "inner melodies and scenes" (Sacks, 1985:142).

Although Milner (1970) demonstrated this theory had some validity in testing temporal lobectomy patients, research has not often revealed significant disparities (Jones, 1974), probably because the unconscious use of visual processing and metaphor in conceptual thought can not be allowed for in experimental design. However, it does seem reasonably well established that there is less integration of these two modes of processing after brain injury.

It is possible that it is this loss of integration of conceptual and imaginal thought forms which is responsible for the phenomenon of "confabulation", the term used to describe confidently expressed but patently incorrect ideation (Sohlberg and Mateer, 1989:96) which is often remarked on in the literature of brain injury. Many people with TBI will firmly maintain quite bizarre beliefs, easily contradicted by evidence. Sohlberg and Mateer (1989:96) suggest that confabulatory behaviour occurs after brain injury because the person is no longer able to monitor and self-correct the constructions and interpretations placed upon events.

Controlled and Automatic Processing: Shiffrin and Schneider (1977) have posited two fundamental processing modes: "controlled" and "automatic" (Shiffrin and Schneider, 1977:127), suggesting that automatic or habitual activities do not involve as much attention and concentration. They suggest that the more control necessary, the more demands made upon attentional ability. A brain capable of automatic processing of habitual and well learnt material may be incapable of more complex modes. Without adequate concentration the ability to develop

new skills is severely impaired, yet it may be possible for the person with brain injury to perform a well learnt task very satisfactorily.

Semantic And Episodic Memory: Tulving (1972) established that there was a difference in a normal mind in the manner of storing and retrieving *meanings* and *episodes*. Semantic memory is often retained when the memory of the particular experience (the episodic memory) which originally provided the meaning is lost. Semantic memory, Tulving suggests, is stored with no referent to the context in which it is learned, while episodes, are learned and recalled in their entirety. Craik and Lockhart (1972) have suggested a similar differentiation between 'deep' and 'shallow' learning. After a brain injury there is considerable evidence that semantic memory and the more 'deeply' learnt knowledge is likely to be retained intact, while episodic memory and shallowly learned information is far more vulnerable to disturbance and loss (Sohlberg and Mateer, 1989:149).

Procedural and Declarative Knowledge: Willingham, Nissen and Bullemer (1989:1047) developed a theory of information processing similar to that of Tulving (1972) which identifies two qualitatively different kinds of knowledge with corresponding modes of awareness: "procedural" and "declarative". Procedural knowledge governs skill performance and is "indexed by tasks in which memory is expressed implicitly by changes in performance as a result of prior experience" (Willingham, Nissen and Bullemer 1989:1047). No conscious or conceptual awareness is necessary for the applying of this form of knowledge. In contrast, declarative knowledge is conceptual in nature and "thought to support the learning and retention of facts and the recollection of prior events" (Willingham et al., 1989:1047). It has been established that many people with brain damage become confined to more procedural forms of knowledge (Cohen and Squire, 1980), with lesions of medial temporal or diencephalic structures impairing declarative but not procedural learning (Squire, 1986). Because declarative skills allow relationships to be drawn between events, objects and people, it is difficult, as Wood (1990a:7) points out, for people who lack them to retain an authentic freedom of choice.

Abstract and Concrete Thought: Goldstein (1952) suggests that after severe brain injury, people frequently became confined to a "concretic attitude" and so "..abnormally rigid, stereotyped and compulsive and abnormally bound to stimuli from without and within" (Goldstein, 1952:248). Without analysis and synthesis, thought becomes what Luria (1987:115) calls "disembodied ideas". While it may still be possible to perform habitual roles and tasks competently, such a person would be unable to deal well with novel situations, or to take self-directed and purposeful

action, being "most distracted in those situations which demand choice or a change in approach" (Goldstein, 1952:250).

Sacks (1985:163) recently revisited Goldstein's ideas about the abstract attitude and, while accepting the validity of his observations, he suggests that concretic thinking is not necessarily inferior, and may even have some advantages over the more conceptual thinking styles more valued in our culture. Both Sacks (1985:164-5) and Prigatano (1989b; 1991a) believe that it is important to understand how the quality of personality, identity and humanity can be preserved within people no longer capable of abstract thought.

Fluid and Crystallised Intelligence: These theories of interactive process demonstrate one major principle: the mutual interdependence of more static 'storage' functions of the brain and the ongoing 'processing' functions. As a result, Brooks (1990:165) suggests that the most useful dichotomy to draw is that between the 'fluid' and the 'crystallised' intelligence.

> **Deficits are maximal on measures demanding learning, perceptuomotor response and psychomotor speed. More 'crystallised, overlearned functions are relatively well preserved unless there is left hemisphere damage interfering with semantic processing. More 'fluid' aspects of function involving here and now responses to new situations are much more vulnerable. This pattern of relatively preserved crystallised and relatively damaged fluid intellectual abilities has been known for many years as a consequence of any kind of acute or chronic diffuse damage and its existence after severe head injury should be no surprise.**

It is perhaps because of this that there appears that there is a stronger relationship between ability before and after injury than the relationship between the extent of damage and the severity of the assessed deficit (Brooks, 1990:171). Since it is new input which can not be efficiently dealt with, those with more sophisticated and complex established knowledge should have a distinct advantage in their performance of cognitive functions.

SENSORY PERCEPTION AND JUDGEMENT

Another of Luria's three basic "blocks" of cognition was that of sensory input and perception. A key role of the brain is to process information from the environment to define 'what is happening'. We are dependent upon the five senses to receive this information and any of these senses may be disturbed by head injury.

A loss of ability to smell and taste is very common for head injury survivors and because it is an impairment that is invisible to others, its impact upon lived experience can be vastly underestimated. A great deal of sensory pleasure is denied a person who is unable to smell or taste. As well as contributing to the quality of lived experience, these senses also act as valuable cues which allow people to draw upon past experience and knowledge. They can both be

powerful evokers of past memories and as well, they frequently contribute to physical safety, health and hygiene by alerting people to fire, gas, rotting food etc.

The sense of touch and in particular 'cutaneous perception' can also be diminished after a head injury, making it difficult to identify an object or to be cued to wet or dry, hot or cold sensations. Again, this impairment can considerably handicap a person in the performance of everyday living tasks.

Visual Processing Disorders

Although these senses are clearly important to the quality of life, there is no doubt that it is visual perceptual disorders which have the most significant impact upon recovery after brain injury. We depend upon vision in almost every aspect of everyday functioning. Specific visual deficits common to the brain damaged person include (Zoltan, 1990:352):

- double vision;
- decreased convergence;
- blurred vision;
- abnormal oscillations of the eyes;
- visual field loss (one section of the picture seen will be distorted or missing, for example, the person will see all but the top left part of a page of writing and so make no sense of it);
- decreased oculomotor skills, causing difficulty with visual scanning, figure/ground differentiation, etc.;
- Loss of hand/eye co-ordination.

Effective vision requires the complex interplay of motor functions, perception, integration and then interpretation of visual images. Our ability to locate objects in space, for example, is assisted by a special organ in the interior part of the ears; a "vestibular" mechanism that maintains the sense of balance. Eye movements too help gauge the distance from one object to another (Luria, 1987:30). Understandably, it has not proved easy for researchers to break down these skills into component parts. Any assessment of vision is largely reliant upon people's own reports of what they see, clearly immediately limiting conclusions that can be drawn. For example, prosopagnosia (an ability to recognise familiar faces) may be associated with any one of the steps in the visual perception and interpretation sequence.

Effective visual perception clearly involves more interaction of a conscious interpreting mind than is always accounted for in rehabilitation theory and practice. As a result, as with the other forms of information processing, vision seems to be increasingly obviously damaged at levels where more complex visual processing is involved. Tasks which require rapid visual processing and a multifactorial analysis of the picture presented upon the retina will be managed less efficiently and with more errors.

Of course, ultimately, any sensory perception is inseparable from the thought which interprets and responds to it. One particular example of the dynamic nature by which sense perception is linked with interpretation is the term "confabulation" described above. It seems that perception and interpretation of sensory stimuli is not only essential to effective interaction but also determines much of the differences in behaviour patterns we think of as personality.

Proprioception

The five senses provide the brain with information about the environment outside our bodies. There is a sixth sense, however, which provides us with information about the inner physical sensation. Proprioception, which is the body's capacity to locate itself in space, is usually so taken-for-granted that there is no conscious awareness that we are monitoring our physical place in the world. Some degree of loss of this sense is common after brain damage, making it remarkably difficult for a person to control and monitor their environment. As Sacks (1985:42) points out:

> **The sixth sense, the continuous but unconscious sensory flow from the movable parts of our body, muscles, tendons, joints, by which their position and tone and motion is continually monitored and adjusted, but in a way which is hidden from us because it is automatic and unconscious.**

Agnosia, Neglect and Anosagnosia

There are a range of 'agnosias' which must also be taken in understanding the changes to the perception of the inner and outer environment after a brain injury. Agnosia is the lack of awareness or acknowledgement of a change to perception or motor control. These phenomena appear to occur particularly after a right hemisphere injury. In one manifestation, for example, that known as 'Anton's Syndrome', a person may be blind and yet insist his sight is normal. While this is rare, there are a variety of perceptual difficulties commonly called 'neglect' which cause people to fail to use visual and motor capacities which they are still in command of. The most global form of an agnosia is *anosagnosia*, a lack of, or limited awareness of one's own changed faculties which will persist even when repeatedly confronted by deficits (Babinski, 1914; Denny-Brown, 1952).

The very existence of such phenomena challenges the basic assumptions made about consciousness within a mechanistic model which sees the body as the tool of mind. Sacks, who was intrigued by this, suggested a different approach from the conventional medical model is required for the assessment and treatment of right hemisphere lesions (Sacks, 1985:3):

> **Inner difficulties and outer difficulties match each other here. It is not only difficult, it is impossible for patients with certain right-hemisphere syndromes to know their own problems, a peculiar and specific anosagnosia, as Babinski called it. And it is singularly difficult for even the most sensitive observer, to picture the inner state, the "situation" of such patients, for this is almost unimaginably remote from anything he himself has ever known. Left hemisphere syndromes, by contrast, are relatively easily imagined.**

Within the literature about agnosias and neglect, there is a recurring suggestion that they are not so much caused by the loss of function, as by the loss of integration and interaction between the functions of the right and left brain. Geschwind (1965:398) for example, suggests that agnosias are the result of a disconnection between the right and left hemisphere processing functions, the right hemisphere no longer making the information available to the left hemisphere causing a loss of ability to "introspect" (McGlynn and Schacter 1989:183) or reflect upon difficulties and disabilities which have occurred as a result of the brain damage. Similarly, Gerstmann (1942:901) suggests that one's own body is thrust "outside of central consciousness" by the brain damage. Of course, once the body has become an alien appendage in this way, there is far less accurate perceptual information available from the immediate environment and the more automatic modes of consciousness will not effectively integrate the body and mind. Schacter (1987) has demonstrated that it is possible, therefore, for 'implicit' learning to take place without conscious awareness of it.

CHANGES TO PERSONALITY

Personality change has been reported to occur in 60 - 72 percent of people who have had traumatic brain damage (Brooks and McKinlay, 1983; Wedell, Oddy and Jenkins, 1980). Generally it is these changes to personality that create the biggest problems for effective recovery and successful reintegration into family and community (Pepping and Roueche, 1991:216). Jennett et al. (1981), for example, found personality problems to be more disabling than physical impairments in 72 percent of cases.

In reviewing 22 years (1965-1987) worth of published material on the psychosocial consequences of brain damage, Pepping and Roueche (1991:233) found the following organically based changes to personality were most frequently remarked upon:

1. Loss of ability to show empathy; a tendency to become self-centred;
2. Poor social judgment; inappropriate remarks and behaviour;
3. Increased irritability and aggressiveness;.
4. Loss of the self-critical attitude;
5. Childlike or childish behaviours, silliness, euphoria;
6. Emotional lability, mood swings;

7. Moved easily to laughter or tears, or laughing and crying inappropriately;
8. Apathy, lack of concern, lack of interest;
9. Suspiciousness, paranoia and a tendency to misperceive the intention or behaviours of others;
10. Disinhibition;
11. Catastrophic reactions.

A change to personality is a change to characteristic patterns in emotion, behaviour and social interaction. As a concept, therefore, it can not be studied and understood outside the context of the pre-accident person nor outside the context of interpersonal interaction. The literature which examines personality change after head injury is discussed as it concerns *Self-awareness, Communication, Social Interaction, Behaviour* and *Emotionality*

SELF-AWARENESS

The sensory and cognitive impairments I have already described clearly prevent people with brain damage accurately defining objects and situations. I have also noted that overlaid upon this impaired judgment there may be a lessened consciousness of disability known as anosagnosia. At the level of personality change, these two levels of disorder can be seen together to deprive a person of as full a knowledge of 'self' as a presence in the world. It is not surprising that it is often difficult for people with brain damage to accept and acknowledge the personal and interpersonal problems which result from their injury.

There is some uncertainty and disagreement in the literature about the processes underlying lessened self-awareness (McGlynn and Schacter, 1989; Crosson, Barco, Velozo, Bolesta, Cooper, Werts and Brobeck, 1989) and, because of the focus of this thesis, it is important to understand this debate. Goldstein (1952) views anosagnosia as the product of "protective mechanisms"(Goldstein, 1952:257) developed in order to shield the person from an overwhelming distress. Some more recent studies support Goldstein's theory, showing optimism and denial minimise emotional distress and despair (Godfrey and Knight, 1985; Herbert and Powell, 1989) and lessened self-awareness is more likely when 'denial' has been a pre-existing personality characteristic (McGlynn and Schacter, 1989:188). It is possible that psychological defence mechanisms may act as a buffer in the early stages of coping and, as the recovery process continues, a gradually dawning insight allows a 'pacing' of recovery and adaptation. Several theorists (e.g. Crosson et al., 1989; Fleming and Strong, 1995; Roueche and Fordyce, 1983:4) suggest variations of this theme.

Whether the disorder is neurological or psychological, however, the course of successful recovery is usually characterised as the return of a more accurate self-awareness. Fleming and Strong (1995:5) and Prigatano and Schacter (1991) describe this as the gradual integration of external information with inner experience, which allows people to accept their deficits and the need to compensate for them. Although this process may continue long after other returning cognitive skills have plateaued, without sufficient self-awareness, dealing with everyday life situations will remain problematic. Prigatano (1991a) suggests that it may take from two to four years for a level of self-awareness realistic enough to support employment to return.

There is no doubt that the degree of self-awareness is strongly linked with the level of motivation as well as the ability to employ compensatory strategies. Crosson et al. (1989:47-9) have developed a model of three levels of awareness, "intellectual", "emergent" and "anticipatory ". They suggest that someone operating at the lesser *intellectual* level may only be able to recognise a cognitive deficit as it is occurring, while the more sophisticated ability to *anticipate* a problem allows a wider range of adaptive strategies to be used. From this perspective, the ability to recover adaptivity, purposefulness and independence, the ideals pursued by Wood (1990a:3), can be seen to have a strong and direct relationship with self-awareness.

Of course, how lacking in self-knowledge any person is, is a very subjective judgment. Without a conflicting definition from another, the problem of self-awareness would not exist. Truelle and Pariset (1990:82) in fact define anosagnosia as "the disparity between subjective reports of the difficulties experienced and the assessment of those surrounding them", thereby underlining the interactional nature of the perceived problem. Many researchers believe that the developing self-awareness is just as influenced by social and interpersonal experiences as by neurological factors (Bray et al., 1987; Gans, 1983; Roueche and Fordyce, 1983). Both Roueche and Fordyce (1983:6) and Bray et al. (1987) suggest that the 'catastrophic response' of family members and friends may distort their own perception, causing them to deny deficits, and so promote inaccurate ideas about the level of disability and encourage inappropriate and unrealistic goal setting.

LANGUAGE AND COMMUNICATION

Many researchers and practitioners have noted the prevalence of language disorders after brain injury[11]. The aetiology for these problems is complex. Those with a more direct neurological underpinning include speech and reading analysis, amnestic aphasia (Thomsen, 1991:297),

[11] For example, Brooks et al., (1986), Groher (1990), Levin and Grossman (1978), Lishman (1968), Thomson (1991) and Weinstein and Lyverly (1968).

agraphia and alexia (with written language) and at the level of motor disorders, dysarthria and apraxia (Pepping and Roueche 1991). The left hemisphere appears to more directly involved in disorders of word production and comprehension. Broca's area (the left hemisphere, posterior frontal damage) controls motor images of words and Wernicke's Area, (superior temporal region of left hemisphere) controls the ability to distinguish and understand speech sounds (Luria, 1987:32). The person with right hemisphere damage is more likely to experience problems with awareness and comprehension of language, as well as syndromes such as agrammatism, echolalia and stereotypy which suggest a generalised cognitive disorganisation (McGlynn and Schachter, 1989:178). Wechsler (1973), Tucker (1981) and Heilman, Scholes and Watson (1975) also all noted significant difficulties in comprehending emotional content of language and stories in people who had right hemisphere lesions. It appears that it is possible, after a TBI, to accurately comprehend the factual content of a spoken or read communication while totally misinterpreting the full message.

Some forms of language impairment may be extremely transient. Aphasia, for example, is often confined to the initial disorientation period (Luria, 1970; Groher, 1990:153). Some people may recover all but a slight loss of "smoothness" and a loss of comprehension of more complex grammatical constructions (Groher, 1990:153). Hagen's (1983) research also suggests that while most patients retain the basic phonologic, syntactical and semantic relationships in language, many lack the "logicosequential" structures necessary to make sense of them.

As soon as issues of awareness and comprehension are introduced into any discussion of language, it becomes inseparable from the more general disorders of sensory integration and information processing which have been described. Many theorists, while acknowledging there are some specific linguistic disorders with neurological correlates, feel it is more useful to study communicative disorder in this way (Groher, 1990:155; Thomsen, 1991:297).

It is not only the semantic and syntactic elements of language which are affected by brain injury, but also the *pragmatics*, or the sociolinguistic sensitivity of the person with a brain injury. A loss of speed of information processing for example, as well as being a cognitive deficit itself, has an obvious effect upon social interaction where spontaneity and the non-routine in language skills is demanded. Newton and Johnson (1985:10) suggest that in the realms of social functioning, cognitive deficits are manifested as difficulties in "following the conversation of more than one person, speaking in a crowded room, or seeing a situation from another person's viewpoint". Interpersonal communication skills such as taking turns, or being relevant and coherent regularly become problematic. Verbal expansiveness and tangentiality are common (Luria, 1987:113) as

well as talkativeness, peculiar phraseology and unusual prosody (accenting and melodic contour) (Prigatano, 1986b). It is not surprising that Godfrey, Knight, Marsh, Moroney and Bishara, (1989:181) found after brain injury people were "less interesting, less socially skilled and less likeable". As Prutting and Kirchner (1987:115) note, people are judged unfavourably when the listener must take the burden of "extrapolating meaning" (Prutting and Kirchner 1987:113).

Sometimes it is the "awkwardness, discomfort, or avoidance of interaction" with which other people *respond* to a language disorder which causes the communication breakdown (Pepping and Roueche, 1991:239). People with dysarthria, for example, are commonly perceived as "mentally retarded or drunk" (Pepping and Roueche, 1991:239). Prigatano (1986b) suggests language disorders can play a large part in bringing about social isolation and unemployment. For this reason it is very important to stress that many pragmatic language disorders are more open to change than the underlying cognitive disorders from which they develop. Improvement can also continue over a longer period. Thomsen (1991:298) suggests that it is possible to overcome expansiveness and overtalkativeness, for example, even 12 years post injury.

Finally, it is important to stress that language is not only a tool for social living, but also for an inner life. As well as being a communication system, language is "fundamental to perception and memory, thinking and behaviour" (Luria, 1987:33). The ability to 'put into words' one's own understanding and definitions may be essential to clarifying and extending ideas. As Rosenthal and Bond (1990:148) observe, communication, while not essential to biological functioning, plays a "pivotal role in determining the quality of survival".

BEHAVIOUR

Behaviour disorders are considered by many researchers and practitioners in this field to be the most significant challenge to successful recovery (e.g. Burgess and Wood, 1990; Eames, 1990). Lishman (1968) and Thomsen (1987) found 84-86 percent of those with brain injury had behavioural problems of some form.

Behaviour problems may have a direct or indirect relationship to neurological lesions. Frontal lobe syndromes, for example, can be frightening and alienating for others, particularly when there are threats of violence as in one fifth of cases (Thomsen, 1991:300). Other behavioural problems appear to stem as much from an emotional reaction to the injury or ineffective coping strategies as from the initial disorder. For example, a visual field deficit may cause behaviour changes as the person responds the altered view of his environment and yet it may be a reactive withdrawal and aggression which creates the more serious disability (Jacobs, 1990:41). Similarly, a slower

processing speed may cause stimulus overload (Gross, 1987; Goldstein, 1952) and this in turn may bring a *catastrophic reaction*, with its associated "irrational rage, an increased heart rate and breathing and, if the offending stimulus is not removed, running away, shouting, or 'not talking'" (Pepping and Roueche, 1991:235). Several practitioners have recently suggested that the catastrophic reaction is particularly destructive of reintegration into the community and the family and deserves more attention than it has been paid previously (Pepping and Roueche, 1991:235; Godfrey and Smith, 1993; Prigatano, 1987).

Pepping and Roueche (1991:219) found that brain injury tends to exacerbate or intensify preexisting behaviour difficulties. This is particularly significant because people who suffer brain damage are likely to have been part of a high risk-taking segment of the population. They may also have had ineffective decision making and coping strategies prior to their accident, which were implicated in its occurrence. Such a history of difficulty coping is likely to transfer into the rehabilitation situation.

With behavioural problems, unlike the disorders of perception and cognition, no assumption can be made that any spontaneous recovery will occur. In fact, several studies show that disturbed behaviour and emotionality increase rather than decrease in the years following the initial injury (McKinlay et al, 1981; Thomsen, 1990:61). There appears to be strong relationship, (not only in the literature but in the experiences at Waimarie), between dawning awareness and inappropriate or ineffective behaviour patterns. Self-knowledge can be a two-edged sword.

SOCIAL INTERACTION

Of course, any communicative and behaviour changes brought about by a head injury produce changes in social interaction. What is clear from even a cursory review of the literature, is that many of the changes to cognition, perception and language discussed already, have their most dramatic and obvious effect in social situations. Lezak (1987) found that as many as 90 percent of his subjects had difficulties with social contact.

Again, in examining social interaction disorders, the task of relating deficit to neurological correlate is virtually impossible. Chapman and Wolff (1959:65-7) discovered that even in those with a very slight diffuse cortex injury there was quite catastrophic loss of social skill while Godfrey et al. (1989) and Newton and Johnson (1985) found a global reduction in verbal and non-verbal communication was a common consequence of severe brain injury.

Of course, any interactive situation involves two or more parties and at least some of the difficulties people experience in social situations appear to be attributable to others' responses to

their disabilities. It appears to be particularly difficult for other interactants, even those with some knowledge of brain damage, to avoid judgmental responses in their informal interactions with people with brain injury. Gans (1983:177) points out that staff frequently fail to distinguish between the deficit and the personality and respond to a person as if he or she were "lazy or bad".

Sometimes, the problem is not so much a matter of being misunderstood, as not caring to understand others. People with brain damage, particularly frontal lobe damage, are often described as "egocentric" (cf Pepping and Roueche, 1991:233; Lynch, 1987:66). There are tacitly understood rules which guide interaction, as well as an implicit cooperative principle (Grice, 1975). The failure to follow such conventions so alters the interactive dynamic of relationships that this could alone explain the frequently observed (e.g. Thomsen, 1990:62; Thomsen, 1991:303; Oddy et al., 1985) withdrawal of former friends and disintegration of the existing social network, and difficulty making new friends. These problems are often then compounded by withdrawal and depression in response to the impoverished social life (Pepping and Roueche, 1991:234), as well as (and perhaps most significantly) a heightened dependence. Thomsen (1991:302) found 60 percent of those studied had become dependent and only 50 percent were able to return to any form of work and very few of that 50 percent managed their previous job. Similarly, Panting and Merry (1972) found that relationships with mothers survived more often than those with wives, suggesting relationships requiring equal, adult participation are most altered.

Difficulties with social interaction and social skill do not remain an individual problem. It has been well documented (cf. Lezak, 1978; Gans, 1983; Cannon, 1989) that families in this situation risk being "ruled by their weakest member" thereby becoming what Truelle and Pariset (1990:82) term the "head injured family". The very group of people most important to their recovery become progressively more stressed and negative about them. There is a characteristic loss of goodwill not only within the family network and also in those employed to care for them[12]. This deserves more attention than it has received in rehabilitation literature, being a serious issue for effective reintegration into a community. A family may even grow to hate and reject a member who has created this crisis through his or her own self-neglect or self-indulgence (Gans, 1983:178).

[12] Brooks et al, 1986; Gans, 1983; Godfrey et al., 1991; Newton and Johnson, 1985; Oddy et al., 1985; Prigatano, 1989; Weddell et al., 1980.

EMOTIONALITY

Emotional dysfunction is commonly reported by TBI patients. The most frequently mentioned emotional sequelae are dependency, depression, decreased ambition or initiative, irritability and temper outbursts, amotivation, lability, mood changes and restlessness (Lynch, 1990:65; Jacobs, 1990:38). Although the site of damage again appears to be an important determinant, any neurological underpinning is extremely difficult to clarify. Damage to the frontal lobes produces its own distinctive sets of emotional characteristics, as described earlier[13] and the limbic system, often involved with temporal/parietal injury, is also regarded as a common source of emotional disturbance, causing irritability, paranoia, suspiciousness, mistrust and overreactivity (Pepping and Roueche, 1991:235) and sudden rage (Gans, 1983:176).

There is some debate (very important in the context of this review) concerning the degree to which emotional change is a direct as opposed to an indirect consequence of brain injury. Several writers have suggested some emotional change is the effect of protective mechanisms or ego defences (e.g. Crosson 1987; Goldstein, 1952; Lynch, 1987). Hostility, belligerence, denial and rationalisation are all regarded in this way (Lynch 1987), as is a flight into "pseudohealth[14]" (Fugel-Meyer, A. and Fugel-Meyer, K., 1988:53). However, after an attempt to draw clearer theoretical distinctions, Lynch (1987:66), concludes the boundaries between primary and secondary emotional change will always be blurred. Sadness, grief, depression, hopelessness, helplessness, anxiety, fright and humiliation are all normal feeling reactions to severe injury, which may also be organically based. Similarly, dependency, decreased responsibility, social withdrawal, impatience and agitation may all be quite natural and even adaptive reactions to the stressful situations in which the person is placed during recovery.

It might be said that the change to emotionality wrought by head injury concerns modulation and balance rather than quality. Both a lack of "concern" or "affect" (Pepping and Roueche, 1991:234; Goldstein, 1952:250) and its apparent opposite, a catastrophic reaction, occur more frequently, suggesting the possibility that it is a lowered stress tolerance which is occurring (Pepping and Roueche, 1991:235). In this regard, Tucker (1981) and Bear (1982) have both offered an understanding of emotional change after brain injury which hypothesises a loss of balance between the right and left brain. Tucker (1981:20) found that "an intact right hemisphere is required for accurate interpretation of emotional stimuli", while the left hemisphere has

[13] See p. 13, "The Frontal Lobes", for a description. The sequelae of frontal lobe damage which are more distinctly emotional include including childishness, emotional lability, apathy, irritability, aggressiveness and disinhibition

important self-inhibiting functions. Bear (1982) suggests that the problem is often with the "surveillance" of right hemispheric emotionality by left hemisphere conceptualising and rationalising functions. An emotion which cannot be defined by the brain, is less likely to be controlled by it. "The two hemispheres seem to exist," Tucker (1981:21) suggests, "in some sort of reciprocally balancing dialectical relationship, each hemisphere's affective tendency opposing and complementing that of the other".

Having concluded that "cognitive functions seem dependent on the emotional ones, in a specific and perhaps revealing way", Tucker (1981:39) goes on to suggest that the concept of arousal is crucial not only to understanding emotions, but also to understanding the whole process of perception and interpretation. Prigatano (1987:4) also stresses the essential role of emotion in creating an alert mind and serving to "interrupt an ongoing behaviour for survival value". Since an alert and involved participant is essential for the success of any rehabilitation endeavour, the role of emotionality may deserve greater attention in the designing of programmes.

Whether or not emotion takes precedence over cognition in guiding rehabilitation, it is clearly playing a significant role in the recovery long after the initial arousal from coma. The highest levels of emotional distress are reported at the one, two and three year follow ups, suggesting to Godfrey and Smith (1993) and Fordyce and Roueche (1986) that increasing insight and awareness of impairment is accompanied by increased emotional dysfunction. A greater awareness of this relationship between cognition and emotion has been emerging in more recent literature as the dynamics of a-motivation, depression and low morale are examined more fully (Brook 1990; Godfrey and Knight 1987:89; Fleming and Strong, 1995).

To lose the ability to interpret one's own feeling state is clearly a profound disability with far-reaching implications. As Prigatano (1986a:47) points out, "impairment of the integration of cognitive with affective information leads to disturbances in the highest cerebral function, namely self-awareness".

SUMMARY

Across the range of literature about disorders in cognition, perception or personality after a head injury, the dynamic and interactive nature of the brain is a continual theme. The three basic components of mind Luria described, the arousal, the sensory perception and the planning and organising, can be seen as intricately linked together in a self-perpetuating loop of interpreting.

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[14] Fugel-meyer and Fugel-meyer suggested that a combination of denial and anosagnosia caused many people with brain injury to firmly believe themselves 'recovered' despite strong evidence of disability in their everyday experience.

The more social and interpersonal the aspect of experience reviewed, the more likely it will be that cognition and perception will not be an *intra-active* but an *interactive* experience, relying equally upon perceiving and interpreting the actions and words of others as in defining and interpreting one's own perspective. Because of this, the more recent the literature, the more likely there will be an acknowledgment that recovery must be examined within interactive and psychosocial contexts.

Another major theme which emerges from this review is that of the importance of self and of self-directed recovery. The changes to language and communication, to behaviour, to self-awareness and emotion when put together create a new persona, one which is usually struggling and often failing to find a viable sense of self. Recovery from this crisis requires, it seems, the integrating of thought and feeling into coherent schemes and the discovery of a personal sense of meaning and purpose.

This review suggests that a holistic approach is necessary when designing programmes. When the person with the brain injury is viewed as acting according to the meanings he or she is creating and when these meanings are understood to be strongly influenced by a social and cultural milieu, the task of therapy suddenly assumes quite different proportions. The emphasis shifts from the assessing of deficit, designing of treatment and predicting of outcomes, to the consideration of the effect of cognitive disorders in a constantly changing interactive world. Problems of emotion, social interaction and personality, often 'tacked on' as extras in rehabilitation models, can be seen as the central processes guiding and determining recovery.

PART II: COGNITIVE REHABILITATION: THE STATE OF CURRENT THEORY AND PRACTICE

The term cognitive rehabilitation refers to the "therapeutic process of increasing or improving an individual's capacity to process and use incoming information so as to allow increased functioning in everyday life" (Sohlberg and Mateer, 1989:3). Sohlberg and Mateer suggest this may involve restoring functions, teaching compensatory techniques, drug therapy and even behaviour management. As this definition implies, the intent of cognitive rehabilitation is not to improve performance on tests but to enhance the quality of everyday living. By addressing issues which relate to attention and concentration, sensory perception, planning and organising and information processing, most programmes assume they also address, (some more directly and intentionally than others), the emotional, behavioural, communicative and social interaction issues reviewed above.

In order to understand the diverse practices labelled cognitive rehabilitation today, a brief overview of its historical development is required. Luria (1973:28) provided the initial theoretical foundation when he suggested a focus upon "functions" as opposed to organic damage. He defines a function as: "the complex relationship between a constant invariant task performed by variable mechanisms bringing the process to a constant result". Defined in this way, a function can be seen to be a standardised ideal. Luria suggested that there were three separate processes involved in the recovery of functions:

1. That by rehearsal of the skills and abilities affected, a deficit may be "restored" (i.e. *restoration).*

2. That another area of the brain tissue may be able to take over a function if coaxed by constant rehearsal (i.e. *plasticity, duplication, or substitution*).

3. That the brain can compensate for disorders, covering the gap in functioning by finding ways around it (i.e. *adaptation and compensation*).

Most models in use today are underpinned by this model of functional recovery (Prigatano, 1987; Sohlberg and Mateer 1989:18; Ben Yishay and Prigatano 1990: 396) yet despite this uniform theoretical base the practice of cognitive rehabilitation varies considerably. The range might be seen as falling between the "bottom up" and the "top down" approaches (Cicerone and Tupper, 1991:272).

THE BOTTOM UP APPROACHES

The "bottom up" models might be described as those with a more mechanistic[15] approach. An assumption is made that cognitive disorders can be separated out from each other, assessed and then remediated by the carrying out of certain prescribed activities, under the supervision and direction of an 'expert' therapist.

REDUCTIONISM

The styles of therapy known as "reductionism" (Trexler, 1987) or "neurotraining" (Craine, 1987) are based upon Luria's suggestion that effective cognitive therapy must break down the complex of skills involved in any problem solving or reasoning process, into the isolated components. Retraining should then involve the careful teaching of each component in isolation, followed by whole skill rehearsal. Although these models are underpinned by a concept of an integrating brain, the course of recovery of functions is regarded as involving repetition and training in

isolated skills components in order to promote 'pairing' and 'bridging' of a damaged with an undamaged sense (Luria, 1973). The emphasis is upon deficit specific work and generalisation into real life activity is seen as a later stage in a hierarchically ordered recovery. Feedback, both verbal and electronic, as well as daily graphing of progress are regarded as tools to shape new more effective skill performance (Craine, 1987:86-97). Diller and Gordon (1981) also suggest using reinforcement, attainable short-term goals, the highlighting of success and other similar strategies to encourage participation.

Reductionism is generally regarded today as overly simplifying the tasks involved in recovery. Nevertheless, pairing and bridging (Luria, 1973) and repetitive rehearsal (Sohlberg and Mateer, 1989) have become well established practices within the context of rehabilitation programmes. Models such as Wood's 'neurobehavioural approach', although more holistic than reductionist in character, stress the importance of focusing upon the cognitive deficits and of providing copious opportunities for rehearsal and repetition of tasks before moving on to encourage their generalisation in real situations.

FUNCTIONAL MODELS

The "functional" (Cicerone and Tupper, 1991:272) orientation draws upon behaviour modification principles. Using consistent techniques, therapists 'shape' new behaviour in those ways which are least reliant upon insight and metacognitive levels of awareness. The strategies used include repetition, substitution, vanishing cues and priming[16] (Glisky and Schacter, 1987). With a group of people for whom fluid and abstract processes are less available and who are less able to control their own level of engagement and motivation, these strategies appear to offer many benefits. They tap into the procedural, concrete and crystallised forms of consciousness and knowledge which, as was shown earlier, were those less likely to be disturbed.

Bottom up models certainly appear to offer some assistance to people recovering from TBI and no one today challenges the underlying principles about mental processes upon which they are based. What is more contentious is whether or not such principles can be usefully applied to the recovery of everyday living and interactive skills. Success at building block towers in a clinical situation was once assumed to automatically transfer into everyday encounters with three dimensional objects and success in finding places on a map was assumed to develop ability to be oriented to place. In recent years there has been growing evidence to the contrary. For these methods to sustain their early dominance, proof that the leap from the specific to the general

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[15] See Footnote 2 in Introduction.

would occur is necessary, as well as proof that the simple skill relearnt could then be reincorporated into the complex interrelationship of skills being repaired or re-paired. In my own experience, many skills apparently mastered were never given a practical application after discharge and so their acquisition had little effect upon the quality of life and the level of independence in living achieved. Once a variety of reductionist programmes had been practised (chiefly in America, Great Britain and Israel) for long enough to achieve some measurable results, many respected practitioners (Ben Yishay and Prigatano 1990:397; Gross, 1987 ; etc.) in this field became convinced of the need to incorporate within their rehabilitation design techniques which assist the process of generalisation and adaptation outside the setting of therapy.

PROCESS SPECIFIC AND HIERARCHICAL MODELS

Because many people appear to experience less efficient declarative awareness after a brain injury while still managing many tasks requiring procedural awareness, the rebuilding and reintegrating of habitual subsystems[17] is often regarded as an effective focus for therapy. A programme based around reinstilling whole processes concentrates upon packaging and integrating isolated functions skills into 'units' of action. Effective habits, those which promote independent and purposeful living, are clearly invaluable for people with brain injury. They free up conscious processing space in those for whom it has become limited. Constant practice and rehearsal of adaptive habits in everyday living situations is a common focus for rehabilitation programmes, including that of Waimarie, the setting of this study.

The process specific approach assumes a hierarchical introduction of processes to be learned and, when there is no carryover, advocates training the person in the setting in which the habit will be used. Because a slower learning speed is typical of this group of people, it is assumed that many more learning trials will be necessary and one success is not regarded as indicating it is time to introduce a new process. There is a recognition that when abstraction skills have been impaired, repetition of each skill in multiple situations may be necessary (Gordon and Hibbard, 1992:364-5).

Sohlberg and Mateer (1989:22-35), propose a "process specific" approach, which allows everyday life tasks to become the focus of therapy, rather than clinical exercises. They have developed theoretically based, hierarchically organised models which concentrate initially on simple skills and progress as testing indicates, toward situations requiring complex processing and

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[16]'Priming' is the term that Glisky and Schacter use to define a style of retraining which uses prompting and cuing with partial bits of information.

[17] The habitual subsystem according to Kielhofner, (1985:32), contains within it a wealth of important unconscious knowledge built up into an inner hierarchy of subroutines, configured so that they no longer exist as separate parts. Cooking a meal, for example, involves several subroutines, each of which involves a "complex interplay of musculoskeletal, neurological and symbolic phenomena" (Keilhofner 1985:32).

reorganisation of information. They particularly stress the importance and primacy of attention and orientation suggesting an Orientation Remediation Module (ORM) should precede other cognitive rehabilitation endeavours.

Process centred frameworks for rehabilitation acknowledge the importance of working at the level of the person, pacing rehabilitation so that skills are developed to a point where people are capable of integrating into their family and community and resuming their pre-accident life. This model also takes into account the variability of each person's recovery. However, sometimes, the inner interpreting person appears to be disregarded in such behaviour shaping conceptions and the role feelings and ideas are playing in recovery is minimised.

DYNAMIC MODELS

Dynamic models are those which are the more 'client-centred'. The definition which people with TBI give to their new situation, will clearly influence the course of recovery too much to be ignored in the way that 'bottom up' and 'process specific' models might appear to do. Dynamic models (Trexler, 1987) regard the person's own engagement in the recovery as paramount. The relationship between the therapist and the client is given a greater emphasis and rehabilitation is regarded as supporting the client in achieving his or her own goals rather than imposing a rigid framework based upon clinically assessed needs. During the 1980s, these models gained momentum and began to dominate the practice and literature. As a result, there was a growing trend to acknowledge the importance of pre-trauma history and characteristic coping styles. The person's reaction to the crisis of head injury became the focus and recovery came to be seen as the recovery of a sense of control and self-directedness.

However, the more support there was for the idea of working in a therapeutic partnership, the more there was an uncertainty about the value and meaning of outcomes. Often dynamic programmes have foundered because of constant changes in direction. When learning new skills requires more effort and practice, a sustained commitment from the client is necessary. The nature of brain injury makes it unrealistic to expect a client to provide a focused direction for therapy. A person who has a lack of self-awareness, problematic emotionality, or interpersonal communication difficulties is not the ideal guiding force behind anything, let alone anything as complex as recovery from brain injury. There has been a growing acceptance over the last decade that programmes must recognise and account for the effects of a lessened self-awareness. Empowerment to follow one's own goals must be tempered sufficiently to prevent situations where the rights of others or the best interests of the person are abused.

MODELS OF ONE CENTRAL PROCESS

There are two models of cognitive rehabilitation which do not fit neatly within a 'bottom up' or 'top down' framework even although they rely upon a notion of mechanistic process. This is because they focus upon one process which supposedly mediates and regulates the interaction of emotion and cognition. This sort of conception is particularly valuable for this thesis with its central notion of a self striving for purpose, adaptivity and independence. Before continuing with a review of holistic and 'top down' approaches to rehabilitation, some attention is given to the theories of Goldstein (1952) and Gross (1987).

Goldstein (1952:245-60), based his work upon one key belief, that every human being has "an innate drive to actualise itself, or to achieve its capacity" (Goldstein 1952:246). He suggests that brain injury, because it seriously threatens this basic need, causes changes in mental processing which protect the person from too catastrophic a degree of self-knowledge. Because self-actualisation (as he defines it) has become impossible, the person has lost the sense of purpose for existence. Goldstein believes that rehabilitation situations must carefully preserve this self-deception, preventing too distressing a level of self-awareness and a resultant disabling "catastrophic condition".

Because of this belief, Goldstein recommends forms of rehabilitation which do not risk confronting people with their deficits. In particular, he suggests graded work experience should be offered to establish patterns of habit which allowed a useful and productive (if limited) life. He also suggests that rehabilitation situations should be designed to prompt a "reawakening of past impressions" (Goldstein, 1952:258-60). In terms of Willingham et al. (1989) and Poulos and Wilkinson's (1984) information processing frameworks it can be seen that Goldstein's approach encourages the development of procedural skills while discouraging the declarative appreciation of them.

Gross's model (1987) also hypothesises a relationship between thinking style and one basic change in brain processes but he centred upon the process called "*opponence*" (Gross, 1987:102; Broadbent, 1958; Solomon and Corbit, 1974). Opponence principles are based upon the general assumption that energy is created by an exafference/reafference imbalance after the removal of a stimulus (Broadbent, 1958). If a brain becomes competitive rather than integrative[18], it is unable to process and understand more complex relationships which might exist within the environment. If schemata or constructs can only be activated one after another and distraction causes their immediate 'dropping' or 'deactivation', reafference will be limited to immediate stimulus-response

reactions. Such an information processing style will be likely to decrease the concentration span and prevent the encoding of new knowledge into memory.

For Gross the problem is one of dealing with a system which is now 'closed' rather than 'open'[19] and so less able to manipulate its own level of consciousness. Unlike Goldstein, Gross believes that the solution is to open it again. He suggests that this involves 'reactivating' the arousal process in order to promote motivated engagement in living. He and others have designed exercises which demand "simultaneous information processing" (Gross, Ben Nahum and Munk, 1987:223-38) and which require that the person learn to "pay attention to the context as well as the main stimulus" in order to develop "significant residual activity" (Gross, 1987:111). Hierarchical levels are conceptualised within this process, beginning with "interference resistance training" (Gross et al., 1987:225) and at the most sophisticated level, involving "empathic dialogue coaching" (Gross et al., 1987:229-30).

Both Gross and Goldstein assume a schematic or constructivist organisation of thought within the mind with varying levels of complexity and sophistication. They both pose theoretical schemes and interventive frameworks which posit an imbalance in these thought processing systems after a head injury. While Goldstein advises a greater reliance upon the fixed, the semantic, the concrete and the procedural forms of awareness, Gross believes it is important to work toward incorporating at least some degree of the declarative, the fluid and the abstract thinking skills. As well as identifying a basic change in thought, both these men understand that this change will impact upon emotional processing[20] and the motivation the person is capable of bringing to his or her rehabilitation process.

However, neither of these men regards his clients as the master of their own destiny. They both see the role of the rehabilitation therapist as to assess the problems and then design and monitor the course of recovery. Despite their acknowledgment of the central place played by motivation, neither believes the person is capable of initiating and deciding upon the most appropriate level of stimulation. Awareness and self awareness are not seen as suitable focuses for a programme, but rather as by-products. The goal of Gross et al.'s model is to increase hope and self esteem but only as based on accurate reality testing, while Goldstein's goal is to allow the person a sense of

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[18] See Section entitled "Attentional and Orientational Deficits", p.20.

[19] These terms arise from systems theory which hypothesises a human need to achieve homeostasis. A closed system will not produce and perpetuate its own energy, while an open system will actively seek stimulation (Keilhofner, 1985:5).

[20] See Section entitled "Emotionality" p. 34, for further discussion of Goldstein and Gross's views upon emotionality and head injury.

peace. Both believe a person will perform more effectively if emotionally loaded situations are avoided, at least during the early stages of recovery.

TOP DOWN AND HOLISTIC STYLES

The models I have discussed so far can be seen to offer rehabilitation programmes which are driven by the expert therapist and imposed upon the person, however sensitively and however understandable the motive and rationale. Even the 'dynamic' approaches, although a response to the immediate needs of the person, leave the power over what sort of response is made, largely in someone else's hands. By conceptualising recovery in terms of functions and processes these approaches sometimes underplay the role of an interpreting person.

The final styles of rehabilitation therapy and those which are most closely aligned to the philosophical underpinnings of this thesis, are known as "*top down*" (Cicerone and Tupper, 1991:272) and "*holistic*" (Ben Yishay et al., 1985; Prigatano, 1986b, 1990) because of a focus upon self-awareness and self-directedness. Self, in this context, is not just another aspect requiring rehabilitation, but rather a gestalt entity upon which the many inner functions, processes, or mechanisms of mind depend. This range of models see the main task of the therapist as to support and assist the purposeful engagement of the person within the recovery, developing a level of insight and adaptive control which allows self-monitoring and self-regulating behaviour.

Top down recovery paradigms still address the same three processes of arousal, sensory integration and cognitive organisation which Luria (1973) suggests underlie cognition, but in a more integrated format, as they impact upon a characteristic identity. Wood (1990a:3) when he suggested an "*adaptive, purposeful and independent*" lifestyle should be the primary goal of any rehabilitation programme, summed up the main objectives of this range of programmes. To be purposeful requires a return of the ability to engage emotionally in and initiate meaningful action, while to be adaptive and independent requires some level of metacognitive self-awareness. It is not the goals, therefore, nor the methods for achieving them which are different from mechanistic models, but the stress placed upon the meaning-making self.

There are four goals which appear to guide more holistic and top-down rehabilitation models, *self-direction, emotional integration, identity and* finally *community re-integration*. The various ways in which this can be achieved, or the strategies of holistic method, are now discussed under these headings.

SELF-DIRECTION

Gordon and Hibberd (1992) and Cicerone and Tupper (1991) who have both recently reviewed the literature about rehabilitation, remark that there are a group of therapies which revolve around what they term "noetic" (Cicerone and Tupper, 1991:274) principles or "*insight oriented*" strategy. These models assume that people can only learn compensation strategies at the level they can accept and understand the nature of their deficits, representing degrees along a procedural/declarative[21] axis of information processing styles.

Crosson et al. (1989:50-52) have developed such a "level of awareness" model, dividing the forms of compensatory strategies into four groups, which correlate with three levels of awareness[22].

1. *Anticipatory Compensation*: When a person is able to foresee a problem occurring as a result of a disability, it allows more effective self-correction and adaptation. This is the most desirable form of compensation.

2. *Recognition compensation:* The person operating at this level is able to implement strategies once they receive an appropriate signal. This can be facilitated by a good partnership with a significant other, particularly when the use of a consistent label or signal can be arranged.

3. *Situational compensation*: Although s/he is intellectually aware s/he has a problem, a person may be unable to recognise instances spontaneously in his daily living. Strategies developed for these people need to rely upon rigid habit and so are less flexible.

4. *External compensation*: When there is very little intellectual awareness, environmental adaptations may be the only effective strategy. While many of these methods, such as a noticeboard, can be very effective, they require a stable predictable environment and so are the least open to personal manipulation and adaptive control.

As these levels demonstrate, recovery can be seen as the progression through stages from procedural to declarative levels of understanding and interpreting situations (Wood, 1990a:3-6), while accepting that for many people, the progress may stop at a lower, less efficient level. According to Cicerone and Tupper (1991:287) there are three classes of strategy which address different levels of information processing ability:

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[21] See p.23

[22] To review Crosson et al.'s (1989) levels of awareness, see "Self-Awareness", p. 28

a. *facilitative activities* which set an agenda, reinforce with accurate feedback and help the person address their feelings about therapy and develop realistic expectations of it;

b. *instrumental activities*, the didactic interactions of therapy which include elaboration, task monitoring, modeling, instruction and explanation;

c. *metacognitive activities*, those designed to increase the person's self-awareness and so promote self-regulation. They include exploration, confrontation, questioning, interpretation, replication and also formal self monitoring procedures, such as behaviour rehearsal and homework assignments.

Cicerone and Tupper (1991:287) suggest that the most important therapeutic concept for a therapist working to improve the level of awareness is Greenfield's (1984) notion of "*scaffolding*". The concept of a scaffold allows the therapist to use Vygotsky's (1962) insight that interaction and production need to occur before understanding can, or, as Piaget (1947) showed, that the cognitive processes develop from the sensory motor processes. Rather than explain and teach, the therapist's job as a scaffolder is to maintain the level of the activity at the zone of "proximal development" (Greenfield, 1984:118) where the pupil is sensitive to instruction[23]. Rehabilitation which rests upon the practice of scaffolding therefore, might be regarded as the intentional blending together again of consciousness levels which can no longer work in co-ordination with each other. This is accomplished with the help of a therapist capable of moving sensitively between facilitative, instrumental and metacognitive responses in order to foster voluntary strategic control.

When the reductionist and process specific approach is examined again in the light of this notion of therapy as 'scaffolding', it can be seen that the difference between therapeutic models is one of emphasis rather than content. While all models aim to recover processes and skills, 'top down' approaches encourage people to become empowered and future-directed by the process.

EMOTION

It is impossible to encourage self-directed awareness unless a person has at least some emotional engagement in the rehabilitation process. A person with brain damage may be cognitively capable of a better recovery, yet too passive and uninvolved to pursue it (Dickenson, 1980). Although some forms of emotional disengagement are clearly associated with limbic system and frontal lobe

[23] The region of sensitivity to instruction lies in the gap between comprehension and production (Wood, Wood and Middleton, 1978) .

injury, depression and an associated loss of impetus is practically universal (Diller and Gordon, 1981).

Fostering positive emotional energy is a theme addressed by many holistic models. Prigatano (1989a, 1991), recognising that the inner, feeling person directs the course of recovery, advocates that adapted models of group and individual psychotherapy be a central part of rehabilitation. He suggests that the failure to deal with affective states after head injury has caused many outcome failures (Prigatano, 1989b:423). He (Prigatano, 1991:6) also suggests a range of methods of tapping the less 'conscious' aspects of mind to help people clarify their own thoughts and feelings, including music, role play and fantasy. As he puts it, "it is in play that we are able to reach deeper levels of individuality, as Jung defined it, which is necessary for adult psychological development" (Prigatano 1989b:427).

Crosson (1987), Gans (1983) and Lynch (1987) have also suggested strategies which focus upon the interactive context of emotionality. They suggest specific training in giving honest feedback may be necessary for the rehabilitation staff to overcome social conventions of tact and polite pretence (Pepping and Roueche, 1991:224; Crosson, 1987:343). For the same reason, Roueche and Fordyce, (1983:4-5) suggest the family or primary social network should be intensively involved in the rehabilitation process, ensuring the person receives a consistent response from staff and family about his or her behaviour as it appears to others.

IDENTITY

The need to develop a new sense of identity is a recurring theme in the literature (Gordon and Hibberd, 1992). Because of the recognised gradual return of consciousness and function during the post acute stage of recovery (Hagen and Malkmus, 1979), researchers and practitioners have generally employed models which assume a similarly graduated recovery of identity (Gordon and Hibbard, 1992:362). Truelle and Pariset (1990) suggest that returning self-awareness impacts upon self-confidence and sometimes a period of mourning may be necessary before goal-oriented work can continue. Pepping and Roueche's (1991:242-5) review similarly characterises the path of recovery as one of "confronting the reality" of a new identity, as denial is slowly stripped away. Fugel-Meyer, A. and Fugel-Meyer, K. (1988:51-3) suggest the failure to build a realistic new self-image will result in either passive dependence or a pseudo-healthy attitude, neither of which will prove effective.

Ben Yishay et al. (1985) offer a "holistic" model of the recovery which is based upon the recovery of identity. They propose a hierarchical progression toward ego integrity, which begins with

engagement, or the focusing of attention, followed by *awareness*, or consciousness of the changes brought about by the injury. At this point in recovery, they suggest, exercises aimed at restoring skills are most effective and the person progresses from *mastery*, (the conscious and effortful performance of a new skill), to *control*, the level at which the returning skills have become habitual and attention can be focused again upon the "idea behind the act" (Ben Yishay et al., 1985:255). The last two stages of this model are *acceptance*, "that calm resignation of the fact that some things cannot be further improved upon" and *identity*, or the creation of a new re-integrated ego identity (Ben Yishay et al., 1985:255). For Ben Yishay et al. the rehabilitation setting must provide forms of therapeutic relationship which allow the person to feel a sense of partnership and meaningful commitment. They suggest this requires a climate (created by both the setting and the people) of "inspiration and persuasion" (Ben Yishay et al., 1985:256).

Prigatano (1986b) advocates a similar model of recovery as a four-step process which moves from systematic attention training to counselling sessions which are designed to improve the person's awareness of the strengths and deficits they now possess. Once there is a sufficient level of awareness, education and information giving are offered to assist the development compensatory strategies and finally, interpersonal skills.

Fugel-Meyer, A. and Fugel-Meyer, K. (1988) also recognise the central role of the reorientation of identity and have focused upon the role of coping strategies and ego-defence mechanisms at different stages in the recovery process. They suggest that in the early stages of recovery the person may be given information meant to comfort and reassure which later causes unrealistic self-understandings. Rather than hiding any facts, they suggest adequate empathy combined with the judicious feeding of information ensure a good recovery of a realistic self-concept.

As this summary of rehabilitation strategies shows, more holistic conceptual frameworks have emerged as there has been a growing recognition of the person with brain damage as a dynamic system with a need to form particular types of relationships during the recovery period. Recovery has become equated with increasing self-awareness and autonomy.

COMMUNITY AND INDEPENDENT LIVING PARADIGMS

Until now I have been discussing models and strategies for use in clinical situations or rehabilitation settings. The most powerful argument for the top-down and holistic approaches however, is that people must eventually live in communities, not institutions, and these communities will often be ignorant of their disabilities. No assumption can be made that others in a person's life will always adapt their own behaviour and expectations, allowing for the effects of

brain injury. A person who achieves rehabilitation goals in a clinical setting may fail to apply them in a family or community situation. There is some further literature which deserves reviewing therefore, because it addresses these issues of community integration from a holistic perspective, providing models to assist the process of transition from rehabilitation to independent living.

As the need for a holistic approach has been increasingly recognised, many have turned their attention to the relationships and settings which allow people to rehearse and then generalise a range of everyday living skills and social interaction skills[24]. Consistent feedback is regularly referred to as an essential element and so an inter-disciplinary[25] team is often regarded as necessary in ensuring people encounter consistent responses. A milieu-oriented programme (Ben Yishay and Prigatano, 1990) has also been suggested as an effective environment during the post-acute rehabilitation stage, allowing the regulating of responses as the person becomes progressively more aware. Considerable support appears to be necessary if a successful transition is to be made from predictable, supportive environments of treatment to more anomic community settings. A range of transitional living solutions have been devised.

Following the model proposed by Racino and Heumann (1992), "*therapeutic communities*" have been advocated by Willer and Corrigan (1994:2) who believe that recovery after brain injury is lifelong and will continue in a community if sufficient support and structure is provided. Using large houses rather than buildings with an institutional appearance, groups of eight or nine people with brain damage have managed to live together successfully and productively with the support of a small number of paid supporters. The principles of such specially adapted communities include respect for dignity, recognition of individuality, use of any available family and natural support and as little restrictiveness as is possible upon the lifestyle. Overlaid upon this, Willer and Rempel (1994) suggest the use of Wood's neurobehavioural approach to rehabilitation to provide a framework for continuing the restoring and generalising of skills and functions.

The "*Whatever it Takes Model*", devised by Willer and Corrigan (1994) to work within such therapeutic communities, makes an assumption that for community integration to succeed, considerable effort must be put into structuring the environment and the relationships which surround the person with brain injury. Ten principles provide the philosophical underpinning for this model of supported self-determination, all of which advocate the transforming of environments and communities rather than people. Quality of life is understood as a measure of

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[24] e.g. Wood's 'Neurobehavioural Approach' and Ben Yishay et al.'s (1985) 'Holistic Model' and Crosson's (1987) discussion of the treatment of interpersonal deficits.

[25] Following Crosson et al. (1989), the term "interdisciplinary" is used as opposed to multi-disciplinary because the nature of brain injury means that the members of the team need to work together upon the same goals rather than separately work upon goals which fall only within their own discipline area.

the degree to which the person is able to be engaged in "living, loving and doing" (Willer, 1996) and the role of the therapist is to circumvent any barriers to achieving this aim.

In the WIT model, living is regarded as a 'place and train' venture, with rehabilitation as an intrinsic part of real life experiences. The development of personal and family support systems is preferred over professional support services in recognition that the needs of individuals with brain injury will last a lifetime. To this end, Willer, Allen, Anthony and Cowlan (1993) have devised a self-perpetuating support system which they call "*circles of support*" which recognises that successful rehabilitation should include the establishing of a permanent support structure to ensure that the future hopes and dreams of the person can be met. In creating a circle of support, a person is provided an arena for sharing ideas and for finding creative solutions to problems.

Godfrey and Smith (1993), with a similar conception of rehabilitation as the provision of the right support at the right time, devised the *"Cognitive-behavioural Approach"*, a pilot project operating in Otago, New Zealand. People were visited in their homes regularly over a two year period from their discharge and involved in intensive education and counselling sessions addressing the problems that were encountered as they returned to work, interpersonal and leisure activities. In this way, emotional energy which might have worked against recovery and reintegration was redirected into more positive and constructive channels. Situations could be reframed as they happened, allowing the person to participate in developing solutions. The results of this research suggest such a programme allows the gains made in the early stages of rehabilitation to transfer into real life situations more effectively, while supporting and strengthening the family system.

Both these approaches, that of Willer and Corrigan (1994) and Godfrey and Smith (1993) can be seen to use an adapted form of the scaffolding concept described earlier. Although they differ in content, the general philosophy is one of providing structure or support for the person to sustain a sense of trust and security, holding the task constant and gradually withdrawing that support as the person becomes more capable of self-regulation and purposeful self-direction. When working in this area however, it is always important to acknowledge that a significant proportion of these people with brain damage will never manage without some ongoing form of support.

SUMMARY

Any review of the literature in this field of traumatic brain injury would reveal how profoundly cognitive disorders created by brain damage translate into broader disorders of personality which affect every aspect of the person's future life. This has certainly emerged in this review. This has

important implications for the practice of rehabilitation; implications which are being increasingly recognised. It is not enough to treat skill deficits in treatment settings, rehabilitation must aim to support the person as they learn to deal with daily life despite cognitive and perceptual impairment. The goal of therapy must be to find "ways to mend, bridge or circumvent the rifts in the patient's quotidian reality" (Cicerone and Tupper, 1991:289).

In order to support this process, there is a growing acknowledgment of the need to share the control over the rehabilitation process between the therapist and the client. The consciousness of the person may need to be supported by temporarily providing some awareness functions at the more declarative or conceptual and abstract levels. The degree of control accorded to each should correspond to the degree of adaptivity, purposefulness and independence the person is capable of.

The concept of a scaffold provides the best analogy of the way in which the therapy process is now envisaged. As a metaphor it suggests a role for the therapeutic process as a temporary structuring of awareness, arousal, sensory perception and organisation at a level the person is not yet capable of managing alone. In this way more procedural and concrete skills may gradually be 're-paired' with the metacognitive and fluid elements of thinking allowing the person a growing adaptive control and allowing the therapist a gradual withdrawal.

Ultimately the development of theory in this field is leading inexorably toward the conclusion that the recovery from brain damage must be conceptualised as the recovery of the ability to make sense of one's own existence and so to find meaning and purpose to direct the future. The way that a person goes about this is interpersonal and interactive. As Prigatano (1984:69) expresses it:

> **A hallmark of the live human brain that communicates with others is a search for understanding and then meaning.**

In the next chapter, phenomenological and symbolic interactionist literature which focuses upon the person as an interpreting self is examined. A range of theories is presented which explore the way in which the person communicates in this search for understanding and meaning.

CHAPTER 2

SYMBOLIC INTERACTIONISM AND AN INTERPRETING SELF: A THEORETICAL FRAMEWORK

The previous chapter reviewed literature about the range of cognitive and perceptual impairments which could result from severe brain damage and the way in which these may affect people's lives. The most significant changes were found to be the loss of interpreting skill and its parallel - the loss of social interactional skill. The chapter also reviewed the various models of rehabilitation practised and their respective notions of an ideal recovery. The most significant difference between rehabilitation paradigms was found to concern the allocation of power over interpreting and guiding the recovery process. The more recent the literature the more likely a sharing of control over definitions, decisions, processes and goals will be advocated by the author(s) as the ideal.

This shift in thinking toward a person-centred approach is not confined to the field of rehabilitation from brain injury. It reflects similar philosophical trends across the range of human service disciplines, particularly where one dominant ideology was previously imposed upon another group. A general recognition is emerging now that the only way to help another person is to encourage independence and self-direction. What is different about this field of brain injury rehabilitation, as several of the theorists reviewed recognise and stress, is the need to weigh theory about empowering and consciousness-raising against knowledge about how a loss of cognitive control affects a person's ability to manage his or her own actions. The review made it very clear that damage to the functions of arousal, perceptual integration and metacognition change the way a world is encountered, effectively altering the inner reality to which the person is relating and responding. When this created reality differs even slightly from the others in a social setting, the consequences for personal power and emotional control can be severe. If an independent and competent self is to be a realistic goal the therapeutic process must provide an extra level of interpretive support, a "scaffolding" (Greenfield, 1984; Cicerone and Tupper, 1991:288) which encourages a more effective monitoring of and adapting for others' realities, gradually being withdrawn as a renewed meaning and purpose for living emerges during recovery.

The neuropsychological tradition (and particularly the early work of Luria) has allowed this more person-centred and interactional conceptualisation of recovery to emerge, replacing earlier more mechanistic or medical orientations of deficits to be assessed and treated. Nevertheless, in New Zealand, as overseas, rehabilitation still often occurs in settings with a strongly medical character and decisions and needs are still structured within a 'diagnosis' and 'referral' mode quite hostile to

these newer understandings. To share the defining power might be an acceptable principle in theory. To accomplish it, as the preceding review demonstrates, people from medical disciplines must trade mechanistic conceptions of the body for more holistic models and begin to think in terms of the dynamics of interpersonal interaction and a sociological, rather than psychological self. Most importantly, it requires the focus to move from restoring or rehabilitating skills to recreating purpose and meaning in a vastly altered life. All the key thinkers who have explored this field of brain injury have found themselves reaching this conclusion and the literature I reviewed in the preceding chapter regularly turns to those broad and over arching theorists from earlier in the century who place human experience within a wider and more philosophical context in their writings and who explain it in terms of dynamic and interacting relationships with the world, not psychological attributes and brain chemistry. Goldstein (1952) draws upon Freud, Prigatano (1989b, 1991a) draws upon Jung (1955) and Ben Yishay et al. (1985) upon Erikson (1959). As Sacks (1985) puts it:

> **..a new and beautiful "existential" science and therapy (is required), which can join with the systematic, to give us a comprehensive understanding and power.**

The framework already exists within which this transition can be made in both the theory and the practice of rehabilitation. It has been developing over the past forty years in the school of thought and method known as symbolic interactionism and, even more particularly, as it has evolved in the work of Norman K. Denzin into "*interpretive interactionism*" (Denzin, 1992:xv-xvi).

Symbolic interactionism offers a theoretical framework which can address the essentially social nature of the problems confronting the person with brain injury while still acknowledging the role of mental and perceptual processes. With these theoretical foundations it is possible to focus upon the role played by the social relationships, interpersonal interactive styles, the physical body and (most importantly) the hidden processes of interpersonal power dynamics, in the experience of living with brain injury.

SYMBOLIC INTERACTIONISM

Symbolic interactionism, often called the "sociology of mind" (Collins, 1989; Coulter, 1979), is generally regarded as having developed from the writings of Mead.' In his lectures and his one major written work (Mead, 1934), Mead proposes a dual interacting structure to self: a knowing 'I', and a social 'me'. Behaviour is understood as the outcome of a dynamic inner process by which the beliefs of the person are weighed against and judged in relation to the perceived attitude of the 'other'. James (1890) and Cooley (1926) are early theorists with a similar approach to

understanding human behaviour and their writings, together with those of Mead, inform the work of early symbolic interactionists.

Symbolic interactionism was developed into a perspective and method distinct from others by Blumer (1969) who posits three fundamental assumptions:

- that humans act toward things on the basis of the *meanings* they have for them;
- that these meanings arise out of social interaction;
- and that they are handled and modified through an interpretive process.

While contemporary psychological and sociological theories regard interpreting as a neutral connecting factor, to symbolic interactionists, it is *the* central theme (Blumer, 1969:2). Blumer (1969:5) suggests that developing this inner meaning involved two distinct steps:

- the indicating to oneself of meaning; and
- the selection, checking, suspending, regrouping and transforming of those meanings through interpretation and negotiation.

Interaction therefore is the process which forms human conduct, not a setting for it. In taking into account the perceived or imagined perspective of the other, a human being directs and modifies his or her own conduct. In the circumstances, Blumer proposes, human research should be conducted by observing and interpreting *interaction.*

Of equal significance to the concept of interaction, is that of *symbol.* This word expresses for a symbolic interactionist the indirect nature of the link between inner meaning and the communicated and shared understandings about it. Once the essentially abstract and representative nature of communicative exchanges is understood in this way, it is possible to see that *meaning negotiation* is a key human process which allows the developing of shared meanings.

Because of these foundational assumptions, the two general terms '*objects*' and '*situations*' also have an important place in symbolic interactionism. Interaction is understood as the fluid interpreting of objects and situations through the negotiation of symbols, both verbal and non verbal. Common objects only emerge through mutual indications and negotiation. Therefore, in order to understand the actions of other people, one must identify their world of objects, while recognising that they have no fixed status. Social interaction is the forum for a dynamic interplay between definitions, thereby creating the conditions for misinterpretations, conflict, manipulative strategies and the imbalances of interpreting power. In effect, symbolic interactionists regard

language, whether verbal or non-verbal, as not just the communicator but also the building block of realities.

As well as interaction between people, symbolic interactionism recognises the importance of *'intra-action'* This concept of indicating to oneself is perhaps the most unique and important feature of symbolic interactionism (Blumer, 1969:9). Developing from Mead's notion of an inner me and I, there is an assumption that people take each other's roles in order to understand the meaning of their own acts. In this way the person's perception of social norms, values and beliefs can be seen as dynamically interacting in the creation of meanings. As Faules and Alexander (1978:44) put it:

> **A whole self is not possible without this duality of self-as-object (me) and self-as-actor (I). Further, this duality is not merely one of parallel aspects, indeed the I pushes into the me. The self is complete only when the action and the object are taken together, when, objectifying oneself, an internal dialogue is played out to establish attitudes, values, motives, reality and reasons for acting.**

Being, by implication, is a process which is never complete, as the empirical world can never be in complete agreement with the world of the self which consequently must constantly change and is as Allport (1968) put it, in the process of *becoming*. This underpinning idea of intra-action has created of symbolic interactionism a unique form of sociology which sees the human experience as an inner centred one, rather than (as with other forms of sociology) determined by social relations and structures. The 'self' and its inner workings becomes the crucial focus for any inquiry.

Since its introduction to sociology in the 1950s, symbolic interactionism has allowed the development to the interactive process by which societal norms and expectations shape an individual's reality. Those who practise social inquiry within its framework were also able to extend the boundaries of sociology into other fields. In particular, because of its concern with the inner meanings of the act to the person, it has allowed theoretical links to be drawn between sociology, psychology, psychoanalytic theory, phenomenological and hermeneutical inquiry. As a result of this eclecticism in practice, the core theory has been developed by different practitioners in a number of different directions, some strands of which are more significant than others for this review.

DRAMATURGY

The style of symbolic interactionism known as "dramaturgy" and developed by Goffman contains some distinctive theoretical principles which appear to be particularly relevant in the study of the interactions of people with brain damage. With a dramaturgical approach, everyday interpersonal

and social behaviour is examined as a "*front*" (Goffman, 1969:22) or "*impression management*" (Goffman, 1969:208), a calculated presentation of particular images or roles to others. Roles are *performed* in order to signal a coordinated set of meanings, images and ideas and promote a particular interpretation or definition of the situation. Quoting Park (1950), Goffman suggests that performances are like masks that become second nature, transforming the individual into a person with a specific character.

Goffman extends his dramaturgical metaphor into an examination of the role of the audience as well as the performer. Compressing this audience into one second party, the 'other' of Mead (1934), he recognises (as any symbolic interactionist would) that sometimes this audience is an inner self. At one extreme, people may be taken in by their own acts, while at the other, the presentation is more contrived and cynical (Goffman, 1969:15). Either way, performances are to some extent a "deceit" and as such, require some management to keep them consistent. Even minor matters such as body language, or timing should all conform and contribute to the current image, with at least no visible contradictions, an expectation termed "synecdochic responsibility" (Goffman, 1969:15-46).

There is an implicit morality therefore, in these conventions of self-presentation. We live inferentially, trusting in the stability of the others' projected images. It is often as important to the audience as to the performer that impressions are consistent and believable because until there can be a shared understanding there is no basis upon which to act. However, some aspects of our body are easier to control than others and some slippage of the person under the mask is inevitable. At such times a person can "feel shame for a well intentioned honest act because the performance went wrong," and often "...thinks his feelings can be seen, confirming a false conclusion" (Goffman, 1969:208). These feelings can cause a sense of alienation from self and a wariness toward others. According to Goffman, there are a number of social conventions of polite denial and tact to cover such occasions, and these can promote a veneer of consensus. In this way, presented images are protected from discredit and contradiction and there is a respect and fostering of skills such as presence of mind, discretion, ability to offer plausible reasons for disruption and emotional control.

Goffman is particularly intrigued by the acceptability of some forms of deceit over others. He suggests there is an implicit moral code, culturally defined, as to the acceptability of presentations and that many use this to their own, or to more general public advantage. In this way, people with dramaturgical skills become capable of promoting social change by encouraging new

definitions or valorisations (Goffman, 1969:55). This moral code about acceptable self-presentation is therefore constantly changing.

Understanding these implicit rules about deception is clearly an important social skill which allows some people more interpretive power than others. As Duncan (1968:53) expresses it, the "greater part of power is persuasion". Sometimes, for example, disruptions to front may be intentional, designed to redefine a situation (Goffman, 1969:185) or to alter the balance of interpersonal power. The creating of a scene, a quarrel or a confrontation, may manipulate an audience into becoming witnesses or supporters. Those who display such skills of "*dramaturgical circumspection*" (Goffman, 1969:194) can best exploit opportunities. Their likely reward is more powerful roles within social hierarchies. In a small and secluded community, such as the setting of this study, these theoretical ideas have important implications for interpersonal dynamics and self-concept formulation.

Teams

Goffman believes that much of the control over prevailing definitions revolves around membership of a group or team. He devotes considerable attention to team membership to describe how and why alliance within groups occurs. The members of one's own team, he explains, are those for whom less pretence is necessary. Using his dramatic metaphor, he suggests that team membership allows a person access to the quite different and more relaxing social arrangements found "*backstage*" (Goffman, 1969:86). In this backstage milieu, it is possible to communicate openly with fellow members, realigning ideas and actions and dealing openly with problems of interpersonal power dynamics. In the backstage region a person may also "try out vaunted selves" and "enter into collusive intimacies" (Goffman, 1969:181). Flirting, getting drunk, mock collusive alignments, sparring conversation, sanctioned non-serious aggression, playing games and practical jokes are all examples he gives of backstage behaviour. Being a member of a team and so experiencing a backstage environment, can be seen in this light as an essential human need. Without these relationships it would be difficult to develop, as Park (1950) would say, from an individual to a person with a particular character. After a brain injury, it would be difficult to develop the more subtle social and interpersonal skills which are part of everyday life.

It is not only important to know how to manage informal team situations, but also when to do so. There are times when a team collude to present a common front and times when they relax together and drop the pretence. Those with the poise to move from front- to backstage without confusion, are most trusted and acceptable to others in a team (Goffman, 1969:190). Those who

cannot be trusted to maintain a front and who cannot understand when a front- or backstage mode is appropriate, can not be allowed into a deception and risk the status of a "*non-person*" (Goffman, 1969:137). Servants, children and the very old are often treated as non-people, not fit to play a part and not worthy of audience status. The implication of this for people with brain damage is clear: *a loss of interpersonal skill translates in social situations into a loss of roles and a loss of team membership. Without the opportunity to belong, access to many of the arenas within which the recovery of social skills occurs is lost.* For the purposes of this study, Goffman's work offers an exciting perspective from which to examine the many interpersonal issues which emerge in a residential setting during recovery from brain damage.

Stigma

Goffman (1968) extended his theories specifically to explore the different set of dynamics and conventions which can operate when one person in an interaction had some form of visible disability which would prevent them maintaining a competent front. Such individuals, Goffman (1968:9) suggests, would often remain disqualified from the full acceptance of their society. Negative attributions made on the basis of their presentation, translate in social life into derogatory assumptions about their character and worth as a person. Any one disability may also multiply, as he noted there is a tendency to class people according to a "gestalt" of disability (Goffman, 1968:18). For example, people who are blind are shouted at as frequently as those who are deaf.

Goffman sees interaction after the acquisition of a stigma as a search for a now elusive acceptance as a person despite a stigmatising disability. He defines this acceptance as the respect and regard which the person anticipates extending and receiving because of past (pre-stigmatised) experience (Goffman, 1968:19). To achieve this, people try to hide the stigma or avoid situations where it might be revealed. This protective behaviour can cause an atmosphere of suspicion, depression, or anxiety. An uncertainty about the front they are projecting can become, in another's mind, a confusion about the status to accord. As a result, the usual scheme of interpretation for everyday events becomes undermined in social settings, where for example, a person with a disability might be thought amazing for doing something unremarkable (Goffman, 1968:26). The more confused and diverse the status indications received from others, the more difficult it becomes for a person with a stigma or disability to 'take the role of the other' in Mead's (1934) terms, or understand what the attitude of the other will be.

Goffman suggests that social convention demands a pretence of denial of the stigma within everyday interactions. This sometimes forces those with disabilities into categorisations that do

not fit them or appeal to them, but which they are unable to challenge within the conventions of politeness. When a situation occurs which forces some acknowledgment of a disability, a *"self-consciousness and other-consciousness occurs"* on both sides of the interactive exchange, *"expressed in the pathology of interaction-uneasiness"* (Goffman, 1968:30). As a result of such conventions, Goffman believes it is difficult for a person with a disability to establish a stable and invulnerable shared reality with able-bodied people. The interactive solution of pretence can cause such an imbalance in power that the inner audience becomes ashamed of the new and stigmatised self. People with acquired disabilities can begin to feel as if they are leading a double life, being one person to those who knew them before their accident and another to those relationships acquired "post stigma" (Goffman, 1968:49).

As a protection against demeaning or disempowering labelling, Goffman (1968:18) suggests people with disabilities are often drawn toward established "separate systems of honour" which allow them to remain relatively untouched by alienation from dominant modes. He was concerned that the small closed communities which once included people with disabilities, adapting to meet their needs, are disappearing (Goffman, 1968:18). People, excluded from generic groups become forced into team membership with those having similar disabilities or stigmas and this creates a situation where people can make a *"moral career"* of their disability (Goffman, 1968:45). Their similar learning experiences and similar changes in conceptions of self commit them as a group, to a similar sequence of personal adjustments. Values and roles become based around and focused upon the disability (Goffman, 1968:30-41). Having become part of a team of people all of whom have a similar disability, they become socialised into the idea of a disadvantaged career, in a protective capsule of family or neighbourhood.

The dramaturgical model offers this project a unique method of approaching the analysis of interaction after a brain injury "from without" and because of the focus upon effective interaction strategies, it is particularly valuable in addressing the research questions of this thesis. Goffman (1968:13) demonstrates that it is a language of observable *relationships*, not psychological *attributes* or medical symptoms which is needed to understand the nature of the changing of the self after the acquisition of a disability. Role interrelationships can then be seen to engender and explain action and even (to some extent) feeling states. The use of the dramatic metaphor also extends beyond role to stage and the script, as context or setting for presenting the self. From a dramaturgical perspective human interaction and communication is the means of creating shared realities from within which joint action is possible and power is understood as the relative control over their interpretation (Goffman, 1969:2). Viewing human social life as calculated performances by actors, Goffman (1969:31) demonstrates how we achieve character and

personality "*from the outside inwards*". From this dramaturgical perspective, the only way to achieve Wood's (1990a:3) ideal, of a sense of "adaptivity, purposefulness and independence" after a brain injury, would be to develop sufficient interpersonal skills to allow the person not only to understand but also to play this interactive role-negotiating game, to manage sufficient consistency and intersubjectivity to be admitted to team membership and so to influence the perspective of others to achieve their own goals.

Since Goffman wrote *The Presentation of Self in Everyday Life,* there has been considerable development of theoretical ideas about the power dynamics within social relations. There is a general acceptance within social theory of the way in which prevailing definitions limit and shape the life we lead, governing self-identity and acceptable roles. Much that has been written over the ensuing 35 years extends and builds upon these initial ideas of Goffman's, although the theoretical foundations may be based upon later post-structuralist writing. Whatever theoretical school is sourced, this way of analysing social relations makes the personal political and a politics of disability emerging from it is concerned with issues of emancipating people from oppressive inner voices. Dramaturgical-like ideas today inform the thinking of those like Munford (1995) and Haber (1994) who suggest more constructive solutions to the problems of people with disabilities will emerge when there is a better understanding of the multiple identities of women and their multiple subject positions. They suggest the normalising and universalising inner voices of the 'other' must be challenged in order to transform outer structures. To do this, Munford (1995:27) suggests, it is necessary to keep the needs of people with disabilities in the public arena so as to encourage the development of a variety of communities. In this way, a sense of belonging and team membership will be possible for people who are different and they will be able to develop greater self-respect and self-knowledge. Writers such as Munford have therefore sustained Goffman's relevance and the principles of dramaturgy can be applied appropriately in a post-structural modern world.

CONSCIOUSNESS AND SELF

The drawback of this dramaturgical model however, is the implication that people exist only in their social relations. The sociological position often seems to reduce the human being to this robotic and reactive role (Coulter, 1979:117) where, totally driven by context and norm, uniqueness and creativity have no place. For the purposes of this project this is a serious shortcoming. It is the individual's uniqueness and the role it might play in allowing him or her to transcend fate, whether a personal tragedy, or structural oppression, that is the main concern in examining recovery from brain injury.

A unique and constantly changing inner self is a central concept of symbolic interactionism. This self is regularly shown in symbolic interactionists' texts as transcending its own fate and breaking out of constraints and predeterminations of societal conditions. Because of the understanding of a self as a dynamic meaning maker acting upon constantly changing definitions of 'what is', no symbolic interactionist can ignore this inner person, nor ignore the importance of consciousness as an information processing system. To explore this cognitive aspect of meaning-making further, this review now examines constructivist theories of 'self'.

CONSTRUCTIVISM

Constructivism is a theoretical framework which relates cognitive processing to human behaviour. It fits logically between the broader and more sociological framework of symbolic interactionism and the more mechanistic and psychological conceptions of brain mechanisms analysed in the preceding chapter. Constructivism underlies a range of psychological, teaching and counselling models, all of which have as a key concept, a unit of analysis which has been called among other things, *a schema* (Piaget 1947), *a construct* (Kelly, 1955) and a *meaning structure* (Lundh, 1988). From the point of view of constructivists, the mind is a system of these meaning structures, and all mental phenomena including perception, thought, emotion, intention and recall, have explanations which relate them to the application of constructs.

Because people with brain damage have a compelling need to learn new skills and relearn old ones, constructivist learning models are very relevant to this discussion. Although they may differ in detail, these models assume three general properties are involved in all learning and change (Schuyten and Valcke, 1989:1): *epistemic conflict, self-reflection and self-regulation.* An assumption is made that a change in thinking (or in the construction placed upon reality) occurs because an awareness of a conflict emerges between a belief (or the presently activated construct) and an interpretation of reality. The only way to resolve this is to reconstruct reality by engaging in reflection.

According to constructivist principles, when people reflect they "*objectify*" (Schuyten and Valcke, 1989:5), or develop a deeper understanding of the focus of their attention by "consciously specifying their assumptions and examining them for accuracy". This objectifying process then provides the person with a basis for transforming the way reality is perceived. The transformation involves also a "*self-regulation*" (Schuyten and Valcke, 1989:5), which is the developmental restructuring of thought., through combining practical and conceptual actions. According to learning theorists such as Cobb (1987) and Schuyten and Valcke (1989:8), this regulation process bridges the mind-gap between the concrete and formal operational worlds, allowing the inner

narrative means to develop into paradigmatic ends. In this way, practical actions can restructure information processing at a higher and more abstract level, where the knowledge gained can transfer. Recalling the discussion in the previous chapter, of the loss of the abstract attitude[26] after brain injury, it can be seen that such models offer very relevant practical application in the field of cognitive rehabilitation.

What is more controversial in the field of learning theory, (and extremely significant to this research), is the extent to which this constructing process is a *creating* as opposed to a *discovering* of knowledge. These developmental transformations will obviously reflect the self-organising properties of the 'knower'. Knowledge is therefore actively constructed by the person, not passively received from the environment (Kilpatrick, 1987; Schuyten and Valcke, 1989:5). The more radical constructivists believe in the total inner construction of realities (Schuyten and Valcke, 1989:5).

Once a science of learning has opened itself to the possibility that meaning is created rather than discovered, the implications for the teacher as much as the learner are immense. An obvious implication of constructivist theory is that it is not only *situations* which are cognitively constructed but also *selves*. Consciousness can be seen as a cyclical process: the modes of interpreting the physical and social environment determined by self-understandings, which in turn determine the definitions of the environment. When a concept of self is acknowledged in this way, constructivist theory addresses not so much the rational, as the personal and emotional. Because of this, it is not only learning theory which draws heavily upon its principles, but also a range of counselling models and therapies which address the more emotional and interpersonal aspects of living. As Piaget (1947:6) explains:

> **The affective life and cognitive life are inseparable because all interaction with the environment involves both a structuration and a valuation...Thus we could not reason, even in pure mathematics, without experiencing certain feelings, and conversely no affect can exist without a minimum of understanding and discrimination.**

The "value" dimension of constructs, according to Lundh (1988:50), determines attitude and sentiment, or the "cognitive affective motivational structure which attaches a positive or negative bias" (Sherif 1980:18). It is also what Lundh (1988:50) calls the "how much" function as it determines the amount of positive or negative energy or the personal investment made. This value dimension therefore, can be seen as organising meaning structures into individually unique value hierarchies. While some values are universally held, others are cultural and yet others depend more upon individual valorisation. Mediating beliefs develop to connect meanings together coherently, providing the person with a way to link situation to self. In the previous chapter,

[26] See Chapter 1, p. 23.

issues of changes to energy and motivation were discussed as sequelae of brain injury. Now it can be seen with constructivist principles that meaning and emotion are inseparable from each other.

G.A. Kelly and Personal Construct Therapy

Kelly (1955), a psychologist, developed a 'self-talk' approach to emotional and interpersonal problems which appears particularly relevant to this discussion because it blends the notion of a cognitive construct with that of a developing self. He called this "Personal Construct Therapy" or P.C.T. Like symbolic interactionists, Kelly recognises that there is a mental dynamic by which we create as well as constrain our ideologies[27] (R. Neimeyer, 1987a:15). According to P.C.T., a person's understandings of self and other are based upon role definitions which are developed within interpersonal relationships (Kelly, 1955:860). Kelly believes that people vary in the number and flexibility of their role constructs and their social relationships are determined and structured by their ability to adapt and accommodate for the interpretations of others. The "*sociality corollary*" (Kelly, 1955:95) determines the extent that one person construes the construction processes of another and it is this aspect of the person which allows the playing of a social role.

For Kelly the self-concept is the most essential and significant of all the inner mental constructs which make up a world view. He (Kelly, 1955:909) proposes the concept of a "*core role structure*", a complex network of interrelated role constructs around which other meaning structures are arranged. Any successful new role must modify this inner core while still allowing a coherent sense of identity (R. Neimeyer, 1987b:63). To accomplish this may require a period of integration and adjustment through practice.

Of particular significance to this review is Kelly's understanding of the role of *emotion.* Emotion within this model is experience not yet mentally organised and integrated and so "often better understood merely as that which is not word-bound" (Kelly 1955:803). A state of heightened emotionality may exist for some time unresolved by satisfactory reconstruction and while in such a state a person is unable to use words effectively to rearrange his or her understanding. "The person who is anxious cannot completely verbalise his anxiety; if he could, he would no longer be anxious" (Kelly, 1955:804). Kelly believes that therapeutic practice assists the person to put into symbolic and structural form those inner feeling states which threaten effective constructive systems.

Once the link between cognition and emotion is acknowledged in this way, it can be seen that the self-awareness disorders commonly encountered after brain injury may be both cause and effect of

the equally common emotional disorders. Severe physical and cognitive disabilities can be seen to force a major reanalysis of this essential inner core of roles at the same time as putting feelings into words has become very difficult. Therapy after head injury might be characterised from a P.C.T. perspective as a matter of "*constructive alternativism*" (Kelly, 1955:3-46) which Kelly describes as using an image of an ideal personality to expand and elaborate the roles still available.

The core assumptions of PCT appear very similar to those of symbolic interactionism. Both theoretical frameworks assume that definitions are essentially interpretive, anticipatory and that as a result, human behaviour is best understood as an ongoing hypothesis-testing experiment. Both also understand the construing process as one of defining and adapting relationships and then 'elaborating' upon these definitions and integrating them into overall schemes. Kelly recognises a concept of an inner self as a "*metaphysical hard core*" (R. Neimeyer, 1987a:9) and suggests that real inner-directed change will only occur from *thought evolution*, not random adoption of ideas.

For Kelly (1955), the therapeutic relationship should be a safe testing ground, allowing the consolidating of knowledge and allowing some role experimentation with appropriate monitoring and feedback. He calls this process "*controlled elaboration*" (Kelly, 1955:584) and suggests the therapist should always ask him or her self, "have I adequately gained access to the client's core role, his deepest understanding of being maintained as a social being?" (Kelly, 1955:502). Because of this approach, the therapeutic relationship is essentially a *partnership* which furthers the investigation of new more satisfying and emotionally balanced selves, co-constructed within the joint work of the relationship.

This term 'construct', particularly as it has been extended by Kelly into the realms of selfhood, can be seen as a useful pivotal concept around which to arrange an analysis of the reconstruction of self through inter- and intra-action. It provides a simple way of understanding the underlying processes in the development of both ideal 'goals' as well as explaining the role of expectations or norms which might constrain and limit it. Most essentially, it allows an understanding of action which appreciates the jointly affective and cognitive structure to behaviour.

PHENOMENOLOGICAL THEORY

Because constructivism and symbolic interactionism both regard meaning-making as the central process of selfhood, both perspectives sometimes appear to ignore any less cognitive, mental aspect of being. Phenomenological theorists, in contrast, have a more holistic view of consciousness which recognises that human experience cannot be reduced completely to mind-

[27] By 'ideologies', I(as well as Kelly and Neimeyer) intend to suggest the ruling ideas which structure

related notions such as information processing, but must recognise the embodied nature of human experience and so the role of perception, temporality and the social environment. To incorporate more of this embodied aspect of human experience, this review turns now to a consideration of the phenomenological position of Heidegger. I have chosen to focus upon Heidegger (1967) because of his unique understanding of the relationship between mind and body, a relationship which appears particularly relevant to the problems faced by people with brain injury.

Heidegger and Being-in-the-World

Although phenomenological inquiry is concerned with the meanings underlying action, much of Heidegger's writing is a "critique of intentionality" (Dreyfus, 1991:46). He suggests human action is usually governed by unconscious processes and the key to understanding meaning is in exploring this less cognitive mode of being. In this way, as Dreyfus (1991:3) explains:

> **...he breaks with Husserl and the Cartesian tradition by substituting for epistemological questions concerning the relation of the knower and the known, ontological questions concerning what sort of beings we are and how our being is bound up with the intelligibility of the world.**

Heidegger (1967) is fascinated by the relationship between the theoretical and the technical modes of awareness and proposes that consciousness can only be understood properly when studied as one unit rather than separating out the thought from act and body from mind as many philosophers are inclined to do. While Husserl and cognitive scientists such as Kelly (1955) assume unconscious rules and belief systems are involved in even the most automatic regular actions we make, Heidegger suggests instead a mode of "being-in", which Dreyfus (1991:40-45) translates as "*inhabiting*"[28]. He shows that a traditional positivist style of thinking and disinterested methods of inquiry cannot work when the subject inhabits the object of the inquiry. Instead, all experience must be seen as intersubjective and embodied.

In order to articulate this idea of consciousness without falling into semantic traps, Heidegger (1967:78-85) invents a new, less conscious concept of being which he calls "*Dasein*" (Heidegger, 1967:f27), the German expression for "*Being-in-the-world*". He suggests that Dasein is a non-conscious and non-mental experiencing of the world from inside it and its different modes are determined by its current relationship to "*equipment*" (Heidegger, 1967:97), or the paraphernalia of the physical life-world[29]. He suggests that there are two different basic relationships possible, dependent upon the "availableness" or "occurrentness" of equipment (Heidegger, 1967:102-3;

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thought and action.

[28]"When we 'inhabit' something, it is no longer an object for us but becomes part of us and pervades our relation to other objects in the world" (Dreyfus, 1991:44).

Dreyfus, 1991:85). When manipulating something 'available' such as a doorknob in a non-deliberate manner, it has a tendency to become *"transparent"* (Heidegger, 1967:186) to us, existing only in the experience of its function. This is the "*circumspect*" mode of Dasein (Dreyfus, 1991:66) and at such times, there is an uninterrupted "in itself" (Heidegger, 1967:106) quality to consciousness. Reading a book or driving a car are two activities where equipment could be described as transparent for the skilled user. When experiencing the world in this manner, Heidegger suggests that Dasein "falls" (Heidegger, 1967:219) or is "absorbed" (Heidegger, 1967:220) into its world. According to Dreyfus (1991:85):

> **[Heidegger] describes this as a kind of "sight" which does not involve deliberate, thematic awareness... for thinking about things. Instead we find our bearings in regard to them. An extreme case is the athlete who is flowing, or playing out of his head.**

For a more contemplative mode of knowing the life world, something must interrupt this smooth flow of Dasein and Heidegger suggests that there were two ways in which this occurs, "*disturbances*" and "*signs*" (Heidegger 1967:105). A disturbance is anything which alerts or arouses, which causes the situation to be "lit up" (Heidegger, 1967:105), while a sign is not just a linguistic concept, but any "item of equipment which explicitly raises a whole into our circumspection so that together with it the character announces itself" (Heidegger, 1967:110). Both these experiences alert people, the object of attention becomes "obtrusive" (Heidegger, 1967:103) and the use of cognitive processing and reflection occurs in order to reflect upon a situation, decontextualising and recontextualising it, so as to define and perhaps reframe it, consciously altering the meaning of the life-world.

It is important for the purpose of my discussion to highlight at this stage the clear parallel between this notion of a disturbance or sign and the neuropsychological notions of arousal and engagement reviewed in the preceding chapter. As I continue with a review of Heidegger's theory, this notion of a switching between modes, the manner in which it is occasioned by outside circumstances and the way in which it is implicated in alerting an inner self, cueing more reflective and self-conscious awareness, can be seen as having a powerful relevance in this context of brain injury, allowing phenomenological theory to be used alongside the constructivist theory which appears to contradict it and allowing the interactions of the four people studied in this research to be seen as only engaging mental processes at moments of what might be called either constructive inadequacy or unavailableness and occurentness.

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[29] For the purposes of aligning the theory used in this review, this word (equipment) might be compared with the symbolic interactionists' 'objects' and 'situations'.

Extending this concept of different modes of being, Heidegger therefore understands "self" also, as having two levels, a surface everyday self and a deeper inner self (Heidegger, 1967, in Denzin, 1986:14):

> **At the ontic or surface level of a person their life is a self, which persons call their own or themselves. This self is grasped as if it were a thing, with fixed entity-like qualities. The deep or ontological level of the person, sees the self, not as a thing, but as a process which unifies the stream of thoughts and experiences of the person around a pole or point of reference.**

For Heidegger *authenticity* is the central concern of the self (Lacan, 1968:179) and to live authentically is the ideal he sees human experience striving toward and never quite managing, being only available to itself in its "thrown"[30] state (Heidegger, 1967:174). Dasein, according to Heidegger, has three modes of existing which correspond to the degree of authenticity of the relationship between the 'I' and the 'they'. The authentic (taking a stand on self), the inauthentic (everyday interpretations, using roles) and the undifferentiated (Dreyfus, 1991:31). At the ontic level, Heidegger regards human behaviour much as Goffman does, as the taken for granted and largely unquestioned performance of roles and conventions. In this mode a person may be covered up and inauthentic[31]. Ontological self, the deeper self-awareness, is also as likely to be influenced by the 'they', however. Like Mead (1934) and Goffman (1969), Heidegger sees deeper self-awareness as *intersubjective* at its roots, formed through the dynamic relationship between the inner "I" and the perceived "they".

For Heidegger, the inauthentic modes of being are not inferior and less worthy and in many ways the more real experience is the falling and throwness of blending one's self with the world. The key to understanding the ontological being is in *temporal relationships*. As Heidegger (1967:377) puts it, "temporality ... makes possible the multiple modes of Dasein's being and especially the basic possibility of authentic and inauthentic existence". In other words, it is only possible for Dasein to be aware of itself because it is capable of moving mentally forward and backward in time, regarding itself from before and anticipating itself in the future. In being absorbed in the world the anxiety which underlies the essential nature of Dasein is tranquilised (Heidegger, 1967:233), but when revealed to itself in this way Dasein is revealed as "care" (Heidegger, 1967:227) and in this state feels "uncanny" (Heidegger, 1967:233).

For Heidegger, as for symbolic interactionism, *language*, the tool of intersubjectivity, is the key to understanding self and action. Psychic reality is primarily the intersubjective world of language and inner intra-action is only a "subset" of interpersonal relations (Lacan, 1968:200). Heidegger

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[30] For the purposes of aligning Heidegger's concepts with those of symbolic interactionism, 'thrown' can be understood as similar to 'projected' or the experiencing of oneself from the perspective of the other.

identifies dichotomous modes of language which parallel his different modes of being-in-the-world. At the ontic level, language is often "gerede" or in the English equivalent, "idle talk" (Heidegger, 1967:167-8) while at a deeper and ontological level of engagement, the "rede" of reflective thought "rooted in the ontology of Dasein" (Heidegger, 1967:209) is employed. Although Heidegger toys with the notion of a non-symbolic and less conscious form of knowing, for him ontology and meaning was still reliant upon a symbolically organised scheme.

Such a conception of the relationship between language and self implies that it is necessary to look beyond the surface level to discern underlying deeper hidden truths buried within speech. This hermeneutic enterprise allows the language used by a person to reveal whether the they or I (or what degree of each) holds sway in determining action at a given moment. He uses the term "*dasein-designations*" (Heidegger, 1967 cited in Wilden 1968:181) to denote the "shifters" such as locative adverbs, which remove the person from responsibility for action in speech. By deconstructing language and understanding the use of dasein-designations, he suggests the words spoken by a person can reveal how authentic and inner-centred is an act.

Like Mead (1934), Heidegger understood that ultimately there is a nothingness to self or Dasein. "Everyone is the other and no one is himself" (Heidegger, 1967:165). He states about conscience for example, that "the call comes from me and yet from beyond me" (Heidegger, 1967:320) and suggests that sometimes "Dasein calls itself but the caller is unfamiliar to the everyday they-self; it is something like an alien voice." This call can, however, sometimes bring Dasein back from its alienation in the 'they' (Lacan, 1968:181). Having in this way established that the inner ontological self is a moral self-consciousness, a paradox of Heidegger's theory is that conscience (gewissen) can actually alienate a person from his inner self. This intrigues Heidegger and he devotes considerable attention to describing how it occurs. "Losing itself in a publicness and the idle-talk (gerede) of the they", he suggests, a self sometimes "fails to hear its own self" (Heidegger, 1967:315). In such situations, the they becomes "the voice of conscience" and an alienation occurs as this they captures the I in "the rule of the moral".

This central notion of authenticity as a goal toward which a self is directed, can be seen now as a very powerful guiding concept for brain injury rehabilitation at this point in its development. Having reached a point of acknowledging the central role played by a meaning-making, purposeful self in recovery, as well as the need to share the interpretive power, Heidegger appears to offer some important guiding ideals for rehabilitation programmes.

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[31] "Inauthenticity is a quite distinctive form of being with the world, the kind which is completely fascinated by the world and by the Dasein-with of Others in the they" (Heidegger, 1967:220).

Gadamer

Another who wrote about less-conscious consciousness is Gadamer. He developed a concept of "*play*" (Gadamer, 1975:91) as a particular *'absorbed' form of consciousness.* This concept is particularly relevant to this thesis because of its relationship to the lessened alertness and concern about others, which is a characteristic common in people with brain injury.

Gadamer regards play as an unreflective mode of being rather than a state of mind (Gadamer, 1975:94). Play fulfils its purpose only if the player loses him or herself in play and it becomes an experience changing the person experiencing it. For Gadamer, art and creative endeavour is the transformation of play into symbol or structure (Gadamer 1975:91-99). Like Heidegger (1967), he believes play takes over the consciousness of the player, controlling rather than being controlled. As a result, while playing, there is an absence of effort, goal or purpose and so by definition, the burden of taking the initiative is removed. Instead, a person draws upon knowledge by a process of imitation. He suggests that the element of knowledge in imitation is recognition and that this experience of recognition is a joyful and intrinsically rewarding one.

> **In recognition what we know emerges, as if through an illumination, from all the chance and variable circumstances that condition it and is grasped in its essence.**

Because of this quality, play creates the conditions for being centred in the present, where through constant repetition and pure self-representation, Gadamer (1975:94) suggests, the self is constantly renewed and refreshed. Recalling the discussion of declarative and procedural modes of knowledge and awareness in the previous chapter[32], Gadamer can be seen to urge that we give more importance and significance to less-conscious forms of awareness, learning and memory. In terms of this thesis, his work suggests that intervention strategies which encourage an adapted play mode may well be effective in restoring quality of life after brain injury.

Play and in particular role play, is also an important principle of symbolic interactionism. As Duncan (1968) explains, "*identification*" is its profoundest form and in identifying with another, the person can be seen to find self in the other (Duncan, 1968:119). In Mead's (1934) terms, the 'I' becomes blended with the 'me', transforming a person's relationship to the world without the need for declarative and abstract thought forms. These ideas about the creative and self-renewing aspects of a less conscious state of mind are extremely important to this review. The cognitive and neurological sciences which usually guide cognitive rehabilitation theory, can appear to regard consciousness in a hierarchical fashion and equate recovery with a return to the supposedly superior declarative and abstract qualities. If an absorbed unconscious experience is as important, or even more important to the quality of living, then to recover adaptivity, purpose and

independence, may involve the nurturing and encouraging of this less conscious experience of being.

Dreyfus and Dreyfus

Heidegger's work and thinking has influenced many more recent writers in the fields of learning theory and therapeutic relationships. For this review, the most important recent literature with a Heideggerian perspective is that produced by Denzin, Benner and Madjar as far as therapeutic processes are concerned and Dreyfus, H. and Dreyfus, S. as far as the processes by which new learning is incorporated into a person's make-up.

Dreyfus, H. and Dreyfus, S. (1986) wrote their theory of learning in order to dispel ideas that the computer could ever replace human beings. They developed a model of how new skills develop which demonstrates Heideggerian principles of different modes of awareness in action, particularly as they pertain to intuition and expertise. They suggest that there were five phases to skill building (Dreyfus, H. and Dreyfus, S., 1986: 19-30):

1. *Novice*: Context-free rules are learned with the use of information processing skills.

2. *Advanced beginner*: The rules are referenced to the situation as well as being context free. An example is the car driver able to change gear in response to engine sounds as well as to a rev. counter reading.

3. *Competence*: The person is able to plan and organise a skill performance, taking into account a constellation of factors and responding rationally.

4. *Proficiency*: The person is almost intuitive but still requires some deliberation in order to make appropriate decisions and actions. At this level problems are quickly recognised.

5. *Expertise*: At this level the person operates intuitively and there is no conscious awareness of performing. The person would be in what Heidegger (1967:186) called the transparent state. This will be sustained when things are proceeding normally but interrupted whenever it is necessary to reflect to manage adaptations or change.

What is particularly exciting about Dreyfus, H. and Dreyfus, S.'s (1986) model when applied to the field of brain injury rehabilitation, is their assertion (like Heidegger's, 1967) that learning and skills development does not necessarily begin with and depend upon reflective and metacognitive levels of awareness, but instead upon developing intuitive "*chunks*" (Dreyfus, H. and Dreyfus, S.,

[32] See Chapter 1, p. 23.

1986:33) of knowledge, for use with holistic discrimination and association styles of experiencing. They suggest that more effective learning will occur if "*deliberative rationality*" (Dreyfus, H. and Dreyfus, S., 1986:50) is developed, a form of experiencing the world in which the person tests and improves whole intuitions within real contexts rather than analysing and separating out processes. A master chess player never 'decontextualises', they point out, but rather becomes involved in a game and relies upon intuitive expectations operating beneath the level of reflective thought. They see generalisation then not as the abstract development of relationships but as a matter of frame building and frame proliferation. This is a reversal of the concrete/abstract rule (Dreyfus, H. and Dreyfus, S., 1986:35) as the person who rationalises an action is likely to be inventing reasons after the event, having performed 'thoughtlessly'. Dreyfus, H. and Dreyfus, S. in fact suggest that the conscious use of equipment will bring about some skill regression because the person forsakes 'know how' for 'know what' mental processing.

Such a conception of learning impresses upon those who accept it, the need to place less reliance upon conceptual and symbolic tools in learning and teaching and more on those which draw upon holistic and intuitive skills associated with the right brain. They point out that "..people sometimes speak of quieting the analytic mind and letting the emotional, involved holistic right brain do its work" (Dreyfus, H. and Dreyfus, S., 1986:64). Rather than a concept of metacognition, they draw upon Heidegger's notion of temporality and the way in which it makes possible the use of past experience in the seeing of a future action. They suggest "The important point is that we human beings proceed from the past into the future with our past experience always going before us organising the way the next events show up for us" (Dreyfus, H. and Dreyfus, S., 1986:88). From this perspective it can be seen that analogy, narrative and concrete experience in the world are the most effective tools for learning and teaching, because they develop and encourage holistic pattern recognition. Dreyfus, H. and Dreyfus, S. (1986:129) particularly advise the development of "*grokking*" a term they have borrowed from computer terminology which describes skill acquisition as the development of unconscious pattern recognition, so facilitating creative problem solving by the reconfiguring or rearranging of these pattern units as opposed to the slower and more clumsy referencing of analytical rules.

The discussion in the previous chapter about dichotomous thought processing styles and in particular the work of Willingham et al., (1989) about *procedural knowledge* and Shiffren and Schneider (1977) about *controlled and automatic processing styles*, can be seen now as exploring exactly this same phenomenon in human thinking and its relation to action. For a group of people for whom the more fluid, declarative and metacognitive styles of learning have become difficult, Dreyfus, H. and Dreyfus, S.'s model offers hope. They demonstrate just how these different

qualities of thought are involved together within the learning process, allowing adapted forms of learning to be designed which compensate for thinking difficulties..

THE BODY AND THE SELF

The significant difference between the phenomenological or symbolic interactionist literature and that explored in the preceding chapter about cognitive rehabilitation, is now revealed as in the manner of relating mind to self. Those from cognitive and neuropsychological disciplines are inclined to think in terms of a mind either "monitoring, regulating and verifying" (Burgess and Wood, 1990:110) the body as a quasi-supervisor, at a metacognitive, abstract or declarative level, or alternatively as a slave to habit and role at the procedural and concrete level of stimulus/response conditioning. Phenomenological and symbolic interactionist literature in contrast, regards consciousness as far less clearly dichotomous in nature, as not necessarily self-aware and as intersubjective and constantly changing in its relationship to the world.

The problem with focusing upon the process of meaning-making as symbolic interactionism has done, is that it is easy to fall into a method of thinking about human activity as mentalistic and cognitive, divorced from the sensate or physical body except as they are represented within the central nervous system. The human sciences have been accused of this neglect. In recognising 'cogito ergo sum', it seems that the development of the social sciences have encouraged, even caused this spitting off of body from mind. The physical body is, according to traditional forms of symbolic interactionism, subordinate to the social construction of the mind. As an "expressive gestural system" (Denzin, 1984:108), it operates as a physical extension of the mind, which allows the visible and audible signals necessary in the communication of meaning.

It is not surprising that this neglect of the role of physical and sensate experience has occurred in symbolic interactionism theory. It reflects a general trend which Foucault in particular traces in western industrial society, to think of the body as a machine (Foucault, 1978:139) which should be defined, organised and controlled. He suggests that the body is the product of the way we organise culture, not vice versa. In our culture at least, a consequence of this mindset has been that the most superior minds are regarded as those that suffer least from the intrusions of the body (Gatens 1992:62). Controlling and restraining the body is a major, but unacknowledged objective of western education and socialisation. A great deal of this controlling process is hidden and the justification for actions which organise arrange and discipline are so implicit within our cultural structures that they have become invisible (Munford, 1989). To become a liberating force in the life of a person with physical disabilities, it seems necessary to focus upon the body and its unrecognised or underestimated role in meaning construction. This should allow us to create

non-dualist notions of subjectivity (Gatens 1992) or consider "self of possession", in contrast to the more usual and more objective "self as a possession" (Benner, 1985:1).

Denzin (1984) proposes a reorientation of symbolic interactionism to incorporate the role of the physical body in guiding interpretation and action. Building upon the theories about emotion and feeling of Sartre (1962, 1948), Heidegger (1967) and Scheler (1973), he developed a dual 'cognitive-physical' framework for understanding human action, one which like Heidegger, recognises that being-in is an "inhabiting" (Dreyfus, 1991:45) of the object by the subject. He labels this "Emotion's Body" (Denzin, 1984:108), in recognition that our bodies are a source of feeling and are intimately involved in the interpretations and emotional appraisals we make of the world. This model provides an inverted form of symbolic interactionism; one which, instead of looking at how meanings construct realities, uses phenomenological and hermeneutic method to look at how sensation and feeling are translated into meaning. He demonstrates how such an extension of traditional symbolic interactionism into the realms of emotion and of a feeling and perceiving body, allow a clearer understanding of how different levels of emotional engagement in the world correspond to different levels of self-conscious awareness.

EMOTION'S BODY

Drawing upon Heideggerian theory of temporality and being as outlined earlier, Denzin (1984:106-8) suggests that the person has a circular relation to his body and that as an experience loops through this cycle, there are variable proportions of cognition and sensation involved in interpretation. According to the degree it is reflected upon, sensation will take on different levels of meaning. A pain, for example, when it is perceived and interpreted, moves from being a sensation to an interpreted classification of that sensation, a "disease". In this way a person reveals himself to himself through feelings. He created a model of four degrees of self-awareness in assigning meaning to experience.

1. The Sensate Body

The sensate body represents the level of experience which is not interpreted and so not expressed in any coherent way. The sensate body reacts without any intentionality or consciousness (Denzin, 1984:112) and sensation cannot be altered by the intentional feelings. ' One cannot stop the heart from beating, nor the shiver of cold, nor the pang of hunger.

At this level of the body, the mode of experience is termed "*sensible feelings*". Denzin suggests that sensible feelings are endured rather than consciously dealt with, although they may become

"routinised and symbolic". Sensible feelings may interfere with a plan or influence an action but they are not controllable by the conscious mind.

Madjar (1991), studying the experience of pain and disfigurement, provided rich examples of the impact of sudden change to the sensate body. She describes how a change in the sensible feelings of the lived body can bring about a changing sense of embodiment (Madjar, 1991:106), alienating a person from his or her self. She also describes how handing one's own body over to others and looking different or disfigured causes a feeling of having lost a former self.

However, in order for the person to act on his or her body or give it meaning, it must become a part of consciousness. It must be given to consciousness through intentional focusing upon the sensation. As soon as this occurs, the experience is no longer purely physical and sensate, as it enters the person's lived consciousness. At this level, the sensible feelings serve as a "point of reference or sounding board" (Denzin, 1984:116) and the person experiences the "phenomenological body".

2. Phenomenological Body

Drawing upon Heidegger again, Denzin suggests that when sensible feelings influence the orientation of the lived body, they begin to influence the attitude the person is currently taking to the world and at this point they become "phenomenological" rather than just sensate experience (Denzin, 1984:119). At this level, sensation has become *"feelings of the lived body"* (Denzin, 1984:118), that extension of the inner state which enters into and pervades all interactional relationships. Examples of feelings of the lived body Denzin offers include sorrow and joy. He suggests these feelings still precede thought and are not necessarily consciously acknowledged or processed.

Heidegger (1967:175) sees this embodied experience as furnishing the mood or "state of mind", which then provides the foundations for the social sharing of feelings (Scheler, 1973:338-339) and so the "peculiar value content in the lifeworld" (Scheler, 1973:339). It is pre-conscious or non-cognitive in nature and discloses Dasein to itself only "in its thrownness"(Heidegger, 1967:174). We are never free of moods, according to Heidegger (1967:175) and some, particularly the negative mood states, can intensify the covered up nature of Dasein, making one blind to self, or rather the mode of Dasein which is most authentic.

Turning again to Madjar's work, her subjects experienced their body at the phenomenological level when they experienced feelings of anger and fear at not being able to escape their situation (Madjar, 1991:122). Madjar found that such feelings could only be resolved when there was a

regaining of the sense of a *"habitual body"* (Madjar, 1991:134). This "becoming oneself again" allowed the resuming of the interrupted flow of life, a phenomenological rather than sensate or intentional quality.

3. The Body-for-the-person

The Body-for-the-person is Denzin's term for a more intentional and conscious experience of being. This is the level at which perhaps 'mind' begins to dominate 'body', or at least they are upon more equal terms in organising experience. The person, having interpreted his or her situation, adopts a specific orientation or attitude toward it and acts accordingly. The person operating as a body-for-the-person often provides for others a more coherent and sustained projection, allowing some insight into the evaluations and judgements being made of a given situation.

At this level, emotionality is experienced as *"intentional value feelings"* (Denzin, 1984:120). When attributed an intentional value feeling the inner person is given a coherence and direction. When such intentionality occurs, "all of the person, including his thoughts and feelings, become part of a single synthetic experience"(Denzin, 1984:116).

While the feelings which characterise this level are more external than the actual lived sensations and feelings, they are no less central to the reconstruction of a self. According to Denzin (1984:121), all feelings are given intentional meaning when they are reflected upon and having attributed meaning, action and behaviour is shaped in ways which express, extend or communicate these ideal and cognitively reconstructed versions of what we are experiencing. Value feelings are then part of the person's interpretive framework and ideology and exist as orientations toward the world, independent of specific interactional experiences. "We are haunted by our intentional value feelings. What we feel and express is never adequate. The ideal always eludes us. We suffer our idealised feelings in silence, yet chatter away incessantly and inwardly about the feeling and ourselves" (Denzin, 1984:123) .

Again Madjar's (1991) study offers examples which demonstrate how the intentional value feelings are an important part of a recovery of the body after injury. In terms of this intentional level of the body-for-the-person, Madjar (1991:243), found that treatment for cancer and burns could not be restricted to the treatment of a physical body. In order to deal with the trauma well, she suggests that it became necessary for her subjects to envisage and mentally adopt a new kind of future for themselves, effectively reinterpreting themselves. It was also important for them to fight to remain a person in their own mind as opposed to a patient, or victim.

The ideal outcome of constructivist styles of therapy is to ensure the body-for-the-person becomes the dominant mode of operating and the person thus feels in control of their emotional life. In terms of Heidegger's theory, the person experiencing the world in this way could be said to be approximating the authentic relationship with self and so "this makes possible the right kind of objectivity, which frees the other in his freedom for himself" (Heidegger, 1967:159).

4. The Body-for-Others

Denzin points out that although the lived body is owned by the person and although he or she alone may feel the interior sensations, this same body is also that extension of the person which denotes his or her presence in the world to others, or an "expressive gestural system" (Denzin, 1984:108). It is with this physical body that the person must manage that presentation of self which Goffman (1969) describes and as such the body is capable of being defined from the outside (Denzin, 1984:109), both by others and by the person concerned. Denzin's final level of experience of the body, at which he suggests, we experience our selves as a body-for-others (Denzin, 1984:126) expresses this quality to consciousness. In its pure form, the body-for-others is that mode of emotional experience which Heidegger described as lost to itself, when the I becomes a "they-self" so risking an inner alienation as it is captured by the "the rule of the moral" (Heidegger, 1967:312).

It is at the level of the "body-for-others" that Denzin, by using symbolic interactionism principles, most departs from more mechanistic theories of self or identity and explores in more depth the socially constructed nature of self. This notion, first developed by Mead (1934) and Cooley (1902), that an inner audience is conjured in order to appraise and direct behaviour, offers an extra dimension to understanding the concept of metacognition explored in the preceding chapter. Denzin (1984:124-8) describes the person as being subject, at this level, to the "*feelings of the self and moral person*". These feelings arise from internal self-reflection, not physical sensation and make the selfhood of the person an intentional object of consciousness. It is through such moral feelings that the person becomes joined in a shared ideological and cultural reality with others (Denzin, 1984:124-5). In taking the perspective of the other, a person becomes his or her own critic, sometimes a more harsh and cruel commentator than the others around him or her, sometimes far less so. Role and performance then, satisfy as much an inferred inner audience as a real outer one.

It is in describing this level of the body that Goffman's (1969) use of the dramatic analogy has proven so effective. Dramaturgy as method allows us to reveal something of the inner moral

person, acting in order to rationalise and justify and attempting to establish a moral career which finds acceptance and acknowledgment within the world.

In summary, Denzin demonstrates that human existence is as much emotional and feeling centred at its core as it is a product of meaning-making cognitive strategies. He provides a model of the integration of emotion and cognition which recognises Heidegger's observations about the different modes of being-in-the-world and works within it. In the preceding chapter, I noted that neuropsychological literature recognises Luria's three basic mechanisms in brain function, an arousal function, a perceptual integration function and a cognitive organising function. It can now be seen that Luria's model of human consciousness, like Denzin's, was essentially one of a feeling and interpreting self. What symbolic interactionism offers to extend this theoretical model, is an awareness the socially constructed nature of the metacognitive organising function of the mind, or in other words, an awareness of the role of the "body for others'.

EMOTION AND THE SELF

Change to one's self and the aligning of an inner ontology with a new situation in the world, clearly involve a coordination between the emotional and the cognitive streams of consciousness. As Denzin (1984:143) demonstrates, the relationship is circular, temporal and interactive.

> **In real life, thoughts interact with feelings. These cognitions are thought through the veil of feelings, just as feelings are felt and thought through the screens of cognition.**

Denzin (1984:144) suggests that the human sciences have often provided a distorted view of human experience because of a tendency to stress either the one or the other of these aspects of consciousness. It is possible that our theoretical understanding of brain injury would be better advanced, however, by focusing attention upon what it is that engages the mind in this circular process of feeling and interpreting in the first place. The third aspect of Luria's (1987:24) tripartite brain[33] is the 'arousal' function. Luria regarded arousal as the 'interruptions' which cause an emotional engaging with the world. Heidegger (1967) appears to have been describing something similar in his use of the concepts of *disturbances* and *signs*[34]. Whatever they are called, conflicts which arouse and focus a person appear to lie at the heart of emotion. As Heidegger describes from an embodied perspective and symbolic interactionism and constructivism from a more mentalistic one, interruptions to the taken for granted alert the person and engage him or her in a re-appraisal and realigning process. These are the experiences which activate that circular relationship with the body that Denzin describes.

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[33] See Chapter 1, p. 20.
[34] See Chapter 2, p. 65

Many theories have attempted to describe this sequence of interruption/arousal/reappraisal more exactly. Sartre's theory of emotion appears to offer a theoretical perspective which blends Luria's neuropsychological theory about brain processes with phenomenological and symbolic interaction theory about the processes of selfhood.

SARTRE'S THEORY OF EMOTION

Sartre (1962) suggests that emotion can only be understood as an intrinsic part of lived experience. He felt that all consciousness, whether reflective or non-reflective, contains an emotional charge of some sort and that this determines the attitude taken toward an object, or the mood felt in a situation. As he puts it, consciousness is "moved by its emotion" (Sartre, 1962:81). When the person is unable to realise their implicit emotional definitions in action, then a state of unbearable tension builds. At such times it is necessary for a "*magical transformation of the world to relieve tension*" (Sartre, 1948:48). Within this different consciousness, new connections and new ways of seeing and looking become possible. Until the world can be aligned again with the inner expectations, this emotional state will prevail, perpetuating itself and eliminating the obligation to act and deal logically with the real world.

Sartre also recognised that there are a variety of emotions such as shock, despair and panic which occur during this transformation process. Emotion in this guise may eliminate the obligation to transform the structure of the inner world. In this way, without recourse to the physiological processes, Sartre offers a phenomenological explanation for the lack of affect commonly observed after brain damage. Motivation and emotion can be seen as linked with ontological conflict while actions and communications can be understood as involving rationalisation and justification to make sense of a transforming world. By aligning world and self again, a person resolves the sense of tension. The world reframed, acquires a new value, a new negative or positive energy as a part of this transformation. Again, intentional value feelings with which to define experience, are established.

Sartre's theory demonstrates that meaning creation is dependent upon and continually influenced by emotion. Without emotion there can be no engagement of the modes of mind which foster and fashion change. Whether or not the appraisal of new information is positive or negative will be determined by the understandings of the ontological inner moral person. Ontology, it can be seen, must precede epistemology (Denzin, 1984:262). An emerging theme of both neurological and symbolic interactionist literature is this chain reaction which links emotion, sensation, cognition, motivation and so action. Disciplines which approach an analysis of human behaviour from the

opposite sides of a circle, keep finding themselves together in the middle. As Krech (1969:11) observes:

> **For this we now know and this James knew long ago. Brain events and behaviour events are not two sets of variables which can be theorised about independently. It is now an empirical finding that they must be dealt with in interrelation...If our own 15 years of brain research at Berkley have taught us anything, it is that brain chemistry and brain morphology determine behaviour but brain chemistry and brain morphology are just as clearly determined by the behaviour they determine.**

The disturbing changes in emotionality which are attributed to frontal lobe, right hemispheric and limbic system damage after brain injury, can be understood in ways which blend together the physical and the interpreted experience in a circular relationship with self. Outbursts of temper, catastrophic reaction, lack of affect, depression, anger and shock may all be the observable result of the person's response to their changed situation, an attempt to remove the affective charge from objects by withdrawing from interaction or by reframing situations in ways which allow them to continue functioning.

EMOTIONAL INTERSUBJECTIVITY

Whether the literature is neuropsychological, psychological or phenomenological, the theme of emotionality has recurred constantly in this review of theory about meaning-making. There is no doubt that it is important to understand how emotion affects the course of recovery after a brain injury.

Symbolic interactionism offers a perspective which focuses inquiry about emotional meaning-making upon our social relations. Meaning is understood as created and transformed through interpersonal interaction. What people communicate to each other is understood, not so much as cognitive constructions, but as attitudes. Common attitudes, according to Denzin (1984:130-2), do not develop through knowledge or learning, but must be felt holistically. To interpret social situations accurately, therefore, requires some awareness of how, through forms of "emotional intersubjectivity" (Denzin, 1984:133), people enter each other's world and develop shared emotional appraisals. As Merleau-Ponty (1973:45) explains:

> **We perceive the feelings of others as our own feelings. ... it is impossible to confuse in other people the redness of shame with that of anger, arousal, etc. Perception takes us a long way into the comprehension of other people.**

Sympathy, empathy, imagination, roletaking ability and introspection are all examples Denzin (1984:133) gives of emotional intersubjectivity. He explains that it can be complete or partial, erroneous or correct, suspected or pretended spurious, reciprocal or onesided. It can also be faked deliberately, or imitated (Denzin, 1984:133).

The various forms of emotional intersubjectivity which can occur in interpersonal interaction are identified and described by Denzin (1984:148-55) as follows:

1. *Feelings in Common* occur when two or more people are together acting upon a common feeling. Grief at a funeral is an example.

2. *A Fellow Feeling*: Although there is no real common feeling, a person may vicariously experience another's feelings at times.

3. *Emotional Infection*: Another's emotions can "infect" a person's stream of consciousness. Such feelings can gather momentum even without cognitive reorganisation and assimilation, through the use of imitation and repetition.

4. *Emotional Identification*: In its purest form, emotional infection can cause a total loss of a sense of self. Examples include hypnotism, infatuation and religious hysteria. People are described as "adrift in the other".

5. *Emotional Embracement*: In very close relationships, there is sometimes a weaving together of two individuals' streams of emotion.

6. *Spurious Emotionality*: There are several forms of interaction where "individuals mistake their own feelings for those of the other".

Denzin (1984:146-59) describes how each of these forms of emotionality affects the authenticity of a person's relationships, sometimes causing an alienation from an inner self and a loss of the ability to be purposeful, independent and autonomous. The forms of emotional intersubjectivity which prevail in rehabilitation settings can be seen as very influential in shaping emerging self-definitions and the developing sense of personal power. Research which traces this emotional interactional dynamic in a setting such as Waimarie, may offer new insight into which relationships and interventive strategies best foster the recovery of purposeful independence.

EMOTION WORK AND FEELING RULES

Authenticity is a key theme of the theoretical framework in this thesis. Although they may differ in many other ways, Heidegger, Sartre, Mead, Kelly, Denzin and Goffman all agree that an inner 'they' or 'other' has considerable power in defining both self and world. The degree of 'authenticity' in a person's relationship to the world is understood in this thesis, to be the degree to which the person is inner-directed as opposed to interpreting situations as a body-for-others. To address the research question and to explore how interaction may foster the development of

purpose and autonomy, it is necessary to ascertain which of these is the prevailing orientation in the film and interview data collected during this research.

Hochschild (1979:551) believes that an "*emotion management*" perspective is the most effective way of understanding this quality of authenticity. She suggests that human beings learn to fashion their inner feeling states into socially acceptable forms before expressing them. For this reason, emotions are manipulated according to internalised feeling rules which develop into an implicit part of an inner moral self. In this way she differs from Goffman who, she suggests, underestimates the level to which the inner moral self is directing action, regarding all human behaviour as the managing of impressions, or 'acting', at either a surface or deep level (Hochschild, 1979:558).

These feeling rules are "the critical set of conceptual connecting tissues by which structure and personality, real in their own right, are more precisely joined" (Hochschild, 1979:557). She suggested they are the "underside to our ideologies" (Hochschild, 1979:557) and as we adopt them, we fashion character and personality. To make a change in ideological stance means dropping old feeling rules and assuming new ones. This process is interactive and intersubjective at its core and a duty of social living. "The most generous gesture of all is the act of successful self-persuasion, of genuine feeling and frame change, a deep acting that jells, that works, that in the end is not phoney though it is none the less not a natural gift" (Hochschild, 1979:569).

Like Kelly (1955), with his notion of the self as an ever more sophisticated and integrated constellation of beliefs, Hochschild sees the person as motivated to maintain a sense of self-coherence and integrity. Social and interpersonal behaviour is managed so that it reflects this ontological inner core. Considerable psychic energy is devoted therefore, to aligning the person with the ideology, adapting both as is required. Hochschild called this process emotion work, "the act of trying to change in degree or quality, an emotion or feeling" (Hochschild, 1979:561). There are two forms of emotion work: the "evocation of a desired feeling" and the "suppression of an undesired feeling." The techniques by which this is managed as discerned by her include:

- the "*cognitive*" method, of changing images, ideas or thoughts in order to change feelings;
- the "*bodily restraining*" techniques, which attempt to change somatic or other physical symptoms;
- and the "*expressive*" strategies, of acting or role playing an emotion.

Hochschild sees cognition and interpretation as subordinate to this emotional management process, a conclusion with quite profound implications for the 'reality' of truths being constructed after a brain injury. The techniques people use to suppress their inner feelings and needs in the

interests of aligning themselves with a perceived social expectation, become the more important focus of inquiry. Like Heidegger, Hochschild sees these techniques revealed in language. For example, she notes that people talk of having "the right to feel" or discuss what they "should feel" and include in such conceptions "the proprieties of extent, the direction and the duration of feeling." (Hochschild, 1979:564). She also notes that people have expectations about feelings they will have in the future; for example, what they can realistically expect from a social occasion, allowing them to prepare themselves in advance.

Because it reveals the emotional dynamic within thought, Hochschild's (1979) work offers symbolic interactionism a methodological tool to assess something of Heideggerian authenticity. The degree of control over emotionality and the degree to which this is imposed by the body-for-the-person, as opposed to the body-for-others, can be examined within the interactive practices at Waimarie. In much the same way as Goffman's dramaturgy does for interpersonal interaction, Hochschild's emotion management perspective offers a methodology for tracing feeling.

THE SELF IN CONFLICT

Once a dimension of 'emotional integration' or 'authenticity' is accepted as a possible measure of successful recovery, a possibility emerges that particular forms of emotional disintegration and inauthenticity in interactions and relationships may be evident within (and play a significant role in thwarting) the process of recovery (or discovery) of a sense of self. There are several theorists whose work examines how a person can become caught up in a conflictual relationship with self. These offer some insight into possible pitfalls which can occur in rehabilitation settings during the process of recovery from brain damage. Foucault's (1988) "technologies of the self", Bateson's (1972) "cybernetics of self" and Denzin's (1984) "divided self", having each described self as constrained and shaped by itself, then note the self-destroying potential of this process.

TECHNOLOGIES OF THE SELF

After devoting the majority of his life's work to the ways in which people dominate and control each other, Foucault remarked "perhaps I have insisted too much on the technology of domination and power, I am more and more interested in ... the history of how an individual acts upon himself in the technology of self" (Foucault, 1988:19). He began to analyse the practices of self-knowledge and "*techniques of self-fashioning*" (Hutton, 1988:122) which have developed within cultures and the way in which a moral obligation to know oneself and to act self-consciously according to coherent principles is universally encouraged. For Foucault, our inner human nature is not a hidden reality to be found by self-analysis, but instead it is the collections of

forms we have chosen to present to the public, chosen from the "linguistic and institutional artefacts left behind by successive generations" (Hutton, 1988:127). Our only individuality then, is in the act of defining and choosing how we fashion ourselves.

This theoretical position forced Foucault to conclude that self-development is in fact a *policing process*, one by which the person is forced into ever more limited definitions of self, becoming increasingly oppressed as societal expectations are internalised (Hutton, 1988:127). In examining the experience of people with brain damage, these observations have very important implications for therapists. To assume that self-direction requires only encouragement, is to ignore the self-policing which may prevent the person fulfilling his or her own needs.

CYBERNETICS OF THE SELF

Bateson (1972) sees human existence as guided by a similar need to choose, shape and present a consistent self. He suggests that "epistemology and ontology can not be separated, ... as these are the rules by which an individual construes his experience" (Bateson, 1972:314).

Bateson uses the analogy of cybernetics. He sees the person as a system, driven to maintain a balance between self and world by aligning ontological beliefs with experience. In this way a sense of control over the world is created. This need to feel in control can cause emotional problems, however, when circumstances make a person feel he or she must demonstrate it to self or others. This creates a *"double bind"* (Bateson, 1972:331), an escalating cycle of obsessive control-seeking behaviour which destroys any inner peace or any sense of authenticity in lived experience.

DIVIDED SELF

The "divided self", was a concept originally developed by Laing (1965) and Sartre (1948) but modified by Denzin (1984) to fit with a symbolic interactionist approach to understanding experience.

In suggesting that there are two levels of feelings, those for the self and those which make the body become an object for others, Denzin (1984) opens symbolic interactionism to the possibility that a person may become emotionally divided against him or her self. Using the experience of alcoholism to explore his ideas, Denzin (1984:201-38) suggests there are people unable to reconcile the different demands of the other-centred and inner-centred self. Building upon Heidegger (1967:312) and Sartre's (1962; 1948) notions of a "they self" or "other", he describes such people as denying their own inner voices in attempting to conform to an imagined ideal.

Ultimately, such a divided existence can cause "the snapping of the circuit of selfness" (Denzin, 1984:202) and a "false self-system" (Denzin, 1984:208). This has obvious implications for understanding and explaining problematic behaviour and relationships after a brain injury and in particular it offers a different approach to issues of interpersonal power and control in the rehabilitation scene. Violence, Denzin (1984:167) describes as:

> **...situated interpersonal, emotional and cognitive activity involving symbolic interaction between two or more parties. One person's emotional and cognitive definitions of an interpersonal situation are articulated and inflicted, symbolically (verbally) and physically on another...**

Because meaning is socially constructed through the medium of the other, freeing the inner self from the conflicting voices of an other-self will not produce a more authentic person. Instead, any therapeutic endeavour (and particularly therapy after the self-alienating experience of brain injury) should support a realigning of inner and outer demands upon the person. Only then can a coherent moral self emerge.

AUTHENTICITY AND INTEGRITY

Implicit within these three theories of a self in conflict with itself, as well as within symbolic interactionism in general, is the notion that some sort of ideal balance between an inner and outer self is possible; a balance which allows a certain peace and inner integrity; or a sense of Heideggerian authenticity. This ideal can be seen now to have important implications for people working in the field of brain injury rehabilitation. It was established in the previous chapter that feelings of disintegration and alienation are common after a brain injury. Developing a new sense of *connectedness or intactness*, the logical opposite state, appears to be an appropriate goal for the therapeutic enterprise. Self-conflict threatens intactness and drives people to adapt their ontological schemes, reaching toward a renewed sense of unity and connectedness we often call 'integrity'. It may be experienced "*intrapersonally*" (as a connectedness within oneself), "*interpersonally*" within relationships which allow the self-expression, but also "*transpersonally*" as a sense of relatedness with the larger essence of world and transcendence of the limits of self (Reed, 1992:350). It is these qualities which allow a confident sense of self to develop or redevelop, providing what Sacks (1985:91) calls the "I", which he suggests must vanquish and reign over the "'it' of the cortical forces". This sense of identity must develop intersubjectively and interactively. It must achieve a sense of authenticity and it must be emotionally attuned both to self and others. The measure of how effective interactive strategies might be after brain injury, therefore, must also be the measure of how well they develop and/or maintain, this sense of inner balance.

STEPS TO RECOVERY OF AUTHENTICITY

Having adopted a conception of recovery after a brain injury as the realigning and reintegrating of a 'self', other research which uses integrity in relationships with self and other as the principle measure of recovery, assumes a particular importance in this thesis. Denzin (1987a, 1987b) focused upon this quality in studying the experience of alcoholics and revealed how a loss of control over self and consciousness caused by the mind-altering effects of drinking, created characteristic destructive patterns of relationships. He draws out six major ontological themes that he sees occurring (Denzin, 1987a:20; Denzin, 1987b:20) and the strong parallels between the experience of an alcoholic and that of a person with brain damage (and so also an altered and less controlled consciousness) is immediately revealed in his descriptions:

1. *Altered Temporality*: The person is essentially 'out of synchronisation' with fellow interactants. A slowing or speeding up of thought and emotion makes it difficult to negotiate shared realities with those who are sober.

2. *Distorted Relationships*: Competitive, negative and hostile relationships with others develop.

3. *Emotionality*: Alcohol-induced behaviour, unacceptable to the sober self, causes negative and painful self-feelings.

4. *Bad Faith*: Once this cycle of distorted emotionality and relationality has begun, a person is forced into a denial and self-deception as the only way of avoiding too painful a self-confrontation.

5. *A Loss of Self-Control*: Alcoholics use alcohol in a misguided attempt to gain, recognise and assert their power in the world in order to live an authentic existence with others, but, by its very nature, alcohol causes them to lose rather than gain control and so they enter into a competitive cycle with it (Denzin, 1987a:9-12).

6. *Self-Surrender*: When people accept their inability to control their alcoholism, the process of reframing their experience and building a new self or ontology can begin.

Denzin regards recovery as the restoring of an inner integrity. Using participant observation in a residential setting, he traced a hierarchical progression in this process (Denzin, 1987b:163). Firstly, the destructive processes by which the "old self" has lived are explored and understood. People involved in this self-examination need, Denzin feels, to "step outside their usual temporal structures" in order to reflect back and to adjust their time to fit with others. This is assisted by AA conventions which encourage story-telling and humour, as well as by the removal into a

residential community. In this way people understand the origins of their destructive relationships with self and other and so dispel the fear and guilt which caused self-deception. Eventually it is possible to "lay the past self to rest" and make a commitment to a new identity.

Because Denzin suggests that successful recovery involves a revision of six key ontological themes, he has focused particular attention upon the way in which the person participates in the recovery process. He has identified stages which correlate to the degree of authenticity in the person's relationship with the world. In the *preparatory stage* (Denzin, 1987b:163), a person is being initiated into new ways of thinking and the role is passive, listening to and imitating a new orientation to living. In the *interactional stage* (Denzin, 1987b:163), the person participates more fully in interpreting his or her lived experience. At this stage, role play and other cognitive training techniques are useful strategies for encouraging the ability to "take the attitude of the other". Finally, in the *participatory stage* (Denzin, 1987b:163), the person is well socialised into the role of the recovering alcoholic. A new way of thinking has become so integrated it is taken-for-granted. The person has acquired a sense of belonging to a subculture of recovering alcoholics with a common set of beliefs and a new ideology.

Another issue which Denzin addresses more minutely than theorists in the field of head injury do, is the potential for destructive self-understandings to arise when the philosophy underpinning rehabilitation programmes pits the body against the mind. Like Bateson (1972:333), Denzin believes it is necessary to establish a middle ground of shared emotional meanings in order to break down this dualism. Unique forms of relationship are necessary in the setting of recovery if this is to be accomplished; relationships where an emotional intersubjectivity prevails. There are quite clear parallels emerging here with recent trends in rehabilitation after brain injury. Several theorists have specifically stressed that a successful recovery will only occur when an altered self-image has been incorporated into self-perception (Truelle and Pariset, 1990; Gordon and Hibbard, 1992; Tyerman and Humphrey 1984). Even more significantly, Ben Yishay et al. (1985), Pepping and Roueche (1991) and Prigatano (1986b; 1989a; 1991a) all regard recovery as a progressive confrontation with reality which allows the paced development of more realistic conceptions of self. Ben Yishay et al.'s (1985) six phase model of engagement, awareness, control, mastery, acceptance and identity[35] in particular reflects remarkably similar ideas to those of Denzin. The more qualitative and phenomenological approach to the problem of selfhood in Denzin's work has allowed him to draw out and develop an understanding of the underlying ontological themes involved in recovery. His work effectively allows inquiry in the field of brain injury rehabilitation to move on from issues of one-dimensional 'treatment' principles, to the harnessing of the

interactional dynamics and definitions which prevail in the rehabilitation setting. In Denzin's hands, the concept of temporality, instead of being dismissed as the 'riddles of speed, selectivity and alertness' (Van Zomoren et al., 1984) might become an important aspect of the recovery process. Relationality and emotionality would become central rather than peripheral and the goal of recovery becomes but that sense of peace which comes from an integrated ontology and an acceptance of the limits of one's own power.

The key to recovery of head injury, like the key to recovery from alcoholism, may lie in the relationships that a person experiences with self and other.

SUMMARY

In this chapter a wide-ranging review of the literature concerning the nature of self and consciousness has been undertaken. These two concepts have been regarded as social and phenomenological rather than psychological phenomena and as a result, a theoretical framework has been presented which allows the lived experience of brain injury to be examined from a sociological perspective. This framework has been based largely upon the principles of symbolic interactionism, but elements of constructivism and phenomenological theory have been incorporated in order to develop the central concept, an ontological inner core of selfhood.

Following on from the discussion of brain injury in Chapter One, it was proposed that effective recovery and rehabilitation requires an understanding of self as a meaning creator and so also as a dual, dynamic and interacting process. This self was also understood as inhabiting a body and both subject and object of its sensations and feeling states. It was suggested that the 'balance' or 'integrity' of this self may become so disturbed after brain injury that it is difficult for people to make sense of their world. Alienated from shared meaning, disoriented in place and time, the person was represented as at risk of discarding any existing ontology and so cast adrift without inner resources for appraising the world.

Not only self but also consciousness was represented as multi-dimensional within the theoretical framework presented in this chapter. Different aspects of the experience of being-in-the-world were described according to sensation/cognition and sociality axes. The person was presented as inhabiting the world as a sensate being, as a phenomenological being, as a body-for-the-person and as a body-for-others. Some conclusions were reached about the meaning of recovery in the light of this wider view of lived experience as variously intentional and self-conscious, or absorbed and transparent to itself.

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[35] See Chapter 1, p. 46

The view of the person as a social being was developed with the use of 'dramaturgy', the form of symbolic interactionism which draws upon the metaphor of the stage. The person as 'actor' intentionally presenting a 'front' to an 'audience' was described. The effect of 'stigma' and 'cognitive disability' upon this experience was considered. The implicit morality of role performance was explained and it was suggested that recovery of a self as a body-for-the-person and a body-for-others involved the induction into reciprocal and socially acknowledged roles. Only in this way could the person redevelop a sense of team membership and belonging. It was suggested that something of this process of role induction might be traced by symbolic interactionist method in the residential setting of the study.

Using constructivism, the inner cognitive processes involved in healing, learning and recovery were further examined. It was established that meaning constructs, the building block of theories of cognition, are intrinsically emotional and self-oriented. As a result, it was concluded, it was not possible to separate thought processing from selfhood when developing theory about the effects of brain injury. A more complex view of the person was suggested, one which regards consciousness as a matter of relationships rather than attributes. The person was represented as mediating the different inner demands of sensate and feeling self and the moral and social self in a struggle to recover reciprocal social relationships.

Attention was then turned to understanding how different modes of experiencing the world interact and relate to each other. Emotion (as feeling combined with cognition) was proposed as the central link between self and other. It was suggested that emotion engages self and consciousness authentically or inauthentically in the recovery process. Unless there is such an engagement and participation in the rehabilitation process, it was suggested that purposeful self-direction is unlikely to return. A case was made for regarding relationships and in particular, emotional intersubjectivity within relationships, as a key to developing effective strategies to support recovery. It was suggested that effective relationships with others would allow the conflicts and challenges encountered during recovery to be transformed into energy for innovative and purposeful change. With this in mind, recovery was understood as the hierarchically ordered progression toward a sense of integrity. This quality was represented as a balanced and appropriate awareness of self and other. It was suggested that adapted forms of interaction and relationship may be necessary at earlier stages of recovery, to support the return of such a sense of integrity.

CHAPTER 3

THE DESIGN, METHODS AND THE SETTING OF THE STUDY

In the preceding chapter I discussed symbolic interactionism as a theoretical perspective from which to understand human behaviour. I suggested that its dual focus upon interpretation and interactive process offers an important theoretical framework for understanding brain injury. In this chapter, symbolic interactionism is presented as method. The research process is described and the methodological decisions which were made, whether during the planning, action and analysis phases, are explained.

THE PERSPECTIVE

Because symbolic interactionism regards meaning and interpretation as the central issue in any inquiry, the focus of this research is the interpreting person rather than the disorders and deficits caused by the injuries. Because of the recognition of the interactive nature of meaning-making, however, just as much attention has been paid to the interpretations and actions of other interactants (the therapists, the friends and the family members) as to the person with the injury. The inquiry is concerned with *process* rather than *outcome* of meaning negotiation, seeking *intersubjective* rather than subjective experience. By exploring the projecting, accommodating, adapting and corroborating processes by which ideas and beliefs were constructed in the people studied, some clearer understanding emerged as to how cognitive and perceptual deficits are converted in action into perceptions and interpretations (or misperceptions and misinterpretations) and how these in turn affect interaction. As common patterns and themes emerged in the way people interacted and negotiated effective meaning, some interactive styles could be seen to 'work' better than others, suggesting ways to support the recovery process more effectively.

It was also particularly important that the perspective adopted in this research be able to acknowledge and account for the influence of interpersonal power arrangements upon the interpretive schemes being constructed. Early forms of symbolic interactionism have been accused of ignoring the role of power, the body and gender in negotiating shared definitions. Denzin (1992:74) suggests an adapted form of symbolic interactionism, *interpretive interactionism*, which incorporates elements of post-structural and interpretivist theory, would allow the symbolic interactionist research process to "track down the ideological abuse" in a field of inquiry. These

would offer a clearer understanding of how the sovereignty of a self might be threatened or preserved by its social relations.

In considering design, therefore, my most central concern was to collect data which could reveal not just the visible actions and interactions but also the inner feeling, sensing and thinking person who underlay them. This person needed to be revealed across a range of interactive settings so that the relationship between perceptual and interpretive difficulties and lived experience could be examined. In this way, I believed, ideas would emerge about how normal interactive codes and conventions might thwart and frustrate the recovery process and so how interaction should be adapted in a rehabilitation setting.

AIMS, ASSUMPTIONS AND EXPECTATIONS

In the preceding chapter the concept of 'self' as it had developed as a central part of the philosophy of symbolic interactionism was explored and explained. Now this concept is brought into use as the central methodological tool of this research. An essential presupposition of this research was that positive resolution of the experience of brain injury is marked by the re-establishment of a sense of self, or a sense of integrity and self-awareness from which confident, self-directed action is possible. Therefore, the central aim of the research was *to explore the interactions of a group of people who have brain damage, in order to gain insight into the types of relationships with others which most assist them in maintaining and/or recovering an authentic and integrated self.*

While such an aim committed me to an exploratory and descriptive approach, it is important to note that I entered the field with a number of assumptions and expectations about what I would be likely to discover. Because any symbolic interactionist must, by definition, recognise the influence personal beliefs will have upon research findings, I make these explicit at this point. Having worked in the setting for five years, I had explored cognitive rehabilitation literature and formed opinions about learning and relearning which guided my practice as a tutor in the education unit. The most central and important of these beliefs, around which the other ideas were arranged, was that people with brain injury were unlikely to recover an effective sovereignty over their lives alone. I believed effective recovery required a very special sort of therapeutic relationship; one which provided a firm interpretive structure, guided early interpretive endeavours and which then gradually reduced the level of overt structure and instruction, fostering the return of a more independent and autonomous approach to meaning creation. I believed that such research as I planned was required therefore, in order to discover the blend of role relationships and structural arrangements which most assisted a recovery in these terms.

A second major assumption I made was of a more philosophical nature and explains also the choice of perspective. I believed that because a false dichotomy of mind and body had pervaded rehabilitation thinking, too much emphasis was being placed upon what is different about this group of people and not enough acknowledgment was made of how much is the same. The experiences of memory failure, emotional extremes, egocentricity, judgement problems etc, are not exclusive to people with brain damage. Symbolic interactionism recognises that for each of us, mental worlds are only an 'as if' or perceived reality. If the experience of living with brain injury is one of distorted perception, disempowerment, misinterpretation and misunderstanding, then it only mirrors and magnifies what is in fact a universal experience. This project does not study brain injury to discern how different from the norm these people are, but how to "circumvent the rifts" (Cicerone and Tupper, 1991:289) to capitalise upon their 'sameness'. As Sacks (1985:121) explains:

> **We consider ourselves free but actually all of us have our own distinctive mental worlds, our own inner journeyings and landscapes and these for most of us, require no clear neurological correlate. We can usually tell a man's story, relate passages and scenes from his life without bringing in any physiological and neurological considerations. Such considerations would seem, at the least, superogatory, if not frankly absurd or insulting. For we consider ourselves and rightly, "free" or at least determined by the most complex human and ethical considerations, rather than by the vicissitudes of our neural functions or nervous systems.**

The third expectation relates to my own role within the setting. As well as beginning the project with expectations and assumptions already formed, I also began with a preexisting role at Waimarie, as well as a familiarity with most of the staff and residents there. I expected to adapt that existing role, seeing the research as an opportunity to extend and then share with my clients and fellow workers, my knowledge of the impact of brain injury upon perception and cognition and so upon possible and probable futures open to them. The role of such a researcher might be described as one of "thoughtful partisanship" (Lindblom, 1987:168). By creating a forum for exploring the underlying bases of their actions and interpretations and by encouraging a reflection upon the implications for their practice, I hoped to empower the people I worked with by raising their consciousness a little. In this way, knowledge would develop out of the 'grass roots' or 'hands-on' experience, which could offer "pareto-efficient solutions" (Lindblom, 1987:168), or suggest adaptations to rehabilitation practices which better promoted the adaptivity, autonomy and self-direction of people with brain damage without massive expenditure or reorganisation of existing policy.

THE RESEARCH QUESTION

An assumption was made that, from a symbolic interactionist perspective, the recovery process could be usefully reframed as the negotiating of a new 'self'. The person from such a perspective

could be seen not as 'rehabilitating' so much as recovering an effective self-consciousness. The question this research asked, therefore, was *what interactive styles and strategies promote an adaptive, purposeful and independent self after a brain injury*? Although the word 'therapy' has frequently been used to describe such strategies to support recovery, its use has sometimes justified actions which are more accurately defined as 'interventions' or 'intrusions' into another's self-recreation so it seemed particularly important to unpack and examine the meaning of helpful interaction in this context of brain damage. Because people whose level of consciousness is altered will not be participating in social interactions in the same way, some adaptations to existing models for helping may be indicated.

Of course, the process of addressing this question began with the literature review where the notions of self, consciousness and 'meaning-making' were deconstructed. However, it seemed necessary to develop and adapt existing theory further in order to understand the particular complex interplay of power relations, cognitive and perceptual difficulties, emotions, preexisting meanings and normative expectations which might occur after brain damage. The project sought to explain, therefore, how structural, phenomenological, cognitive, linguistic and interactive processes are involved in meaning creation, feelings and action. Such a research question needed to be addressed on all three of the levels described by Allport (1942) and Runyan (1984:169) as:

1. The *individual or ideographic* level, examining characteristic patterns within a single individual;

2. The *group* level, where, by comparing the experience of the four subjects[36], some generalisations emerge which could be said to apply to people with traumatic brain injury; and

3. The *nomothetic* level: where themes are examined which appear to be universal and fundamental to humanness.

METHOD

Not only was the theoretical perspective of this project based upon the work of Denzin, but so also was the methodology[37]. Because the intent was to explore interactive practices and the way they influenced a re-developing and reintegrating self, it was necessary to design a project which

[36] Although I would prefer to avoid this word (subject) which might suggest an objective and positivist approach to the study, in this chapter it is necessary to distinguish between the four men with brain injury and all the other participants who interacted with them. The word is used to distinguish between these two groups of people involved in the project.

[37] The theoretical perspective was informed by Denzin's work on emotion (1984) and his studies of the recovering alcoholic (1987a; 1987b), while in developing the methodology, I drew upon Denzin (1986; 1987; 1989; 1992).

deconstructed the meaning-making process, looking for and examining the common patterns and themes. In this way it was proposed, some theoretical differentiation might become possible between abusive and empowering relationships. Thick, rich, phenomenological data was necessary to meet such an objective; data which triangulated observations of interactions with various interpretations of their meaning.

Because of the assumption that inner reality is a social production, constantly changing as it is negotiated, a symbolic interactionist study of brain injury also clearly required a methodological focus upon the phenomenon of consciousness. As a result there was a need to draw upon theorists who have used phenomenology as a method of inquiry. Social phenomenology seeks to understand, through studying interactions and relationships, the "circuit of selfness and self-feeling" (Denzin, 1984:278). Such research might allow a critical assessment of the explanatory power of the perspectives on consciousness and meaning creation described in the literature review, for understanding the experience of head injury.

To capture this phenomenological self within a lived world, a triangulated method was necessary. To accomplish this, a combination of two different data gathering methods was chosen, life history method and participant observation. By engaging in both forms of research over the same time period in the same setting, I believed I could provide a rich and triangulated data source. Each of these methods would also, in their own distinctive way, immerse me within the world of the four subjects as any project purporting to be symbolic interactionism must do. As Denzin (1989:71) describes it, the aim was:

> **to enter people's heads, recognising that humans engage in minded self-reflexive behaviour...that reflects their unfolding and emergent definitions of themselves and the social situations they confront...**

And (Denzin, 1992:xvi):

> **... focus on those life experiences which radically alter and shape the meanings persons give to themselves and their experiences.**

1. LIFE HISTORIES

Because interactive practices were the focus of the study, I had originally planned only to observe and comment upon interactional situations occurring after a brain injury. I did not regard the former lives of the people studied as especially significant. After discussing the design with my supervisors, however, I began to see how important it was to have some background knowledge of each person before making comments about their interactions. I realised that any aspects of their experience, no matter how clearly they seemed related to the interpretive difficulties caused

by the brain damage, could only be understood or explained when placed within the context of the whole life and its meaning, past, present and future. As Denzin (1986:15) also points out, examining a whole life history places the knowledge in a context of "historical totalisation" which can overcome the tendency of phenomenology to reduce everything to "thought, language, interaction and phenomenological structures" (Denzin, 1986:15).

For this reason I extended my original proposal to include four life histories of a type described by Sartre (1963:85-166; Denzin 1989:197) as the "progressive-regressive method" or back and forth interpretation of the "before and after" process of an epiphanic experience or "pivotal event". This method, because it allows some consideration of causality, is also known as *The Objective Life History Method* (Denzin, 1989:185). Each of the lives was analysed for internal consistency and inconsistency and some patterns and themes drawn out which explained the directions taken and the nature of the experiences (both interpersonal and intrapersonal). In this way the subjective and the objective details given to me as the researcher could be seen in relation to each other and in relation to the brain injury. As Denzin (1989:186) explains:

> **A life story is to contain within a single sweep the relevant objective details and subjective experiences of a single person's life. They are literally stories of and about the self in relation to an event or an experience.**

This thematic analysis then allowed some comparisons to be made between the four lives and eventually some general conclusions could be drawn by a process of comparing and contrasting the four life histories for commonalities and themes.

2. PARTICIPANT OBSERVATION

According to Denzin (1989:185) participant observation is "a commitment to adopt the perspective of those studied by sharing in their day-to-day experiences". Lincoln and Guba's (1985) *Naturalistic Inquiry* was selected as the particular model of participant observation to be used because it offers comprehensive methodological guidelines and also because it is closely aligned with the underpinning philosophy. Naturalistic inquiry focuses upon the negotiating process in everyday living situations while at the same time recognising that the theoretical framework must itself be regarded as an element in this negotiating process. This is particularly significant to this inquiry because of the need to remain sensitive to the possible impact of a range of different interpretive frameworks the people would have been exposed to during their recovery.

Naturalistic inquiry assumes that the sensitising concepts employed will be related to interactive causal explanations of process (Denzin 1989:70). I employed a number of sensitising concepts which might be described as separate aspects of an interacting consciousness. Believing as I did

that the human brain (and human consciousness) can only be understood as essentially integrative and interactive, I used these concepts as a hermeneutic device, to illuminate the mechanics of a disordered meaning-negotiating processes. The meanings available to the person and shared by them in their interactions, were likely to be even more 'covered up' and less a coherent expression of an inner self than the meanings being created within the normal population.

In these circumstances there were particular and unique considerations and constraints upon the sampling choices made. Before proceeding with a description of how these two methods worked in action, these choices and considerations will be examined. The first (and perhaps most significant) choice concerned setting and the second the selection of subjects and other participants.

The Setting

The central concepts and propositions in this thesis involve the dynamics of everyday intrapersonal and interpersonal interaction and it was important to observe these interactions and their consequences within a normal setting rather than create an artificial and experimental situation. This made extraordinary demands upon the setting chosen. It needed to be contained enough to allow the tracking of everyday existence without confronting unresolvable ethical dilemmas and at the same time, it had to be open enough to offer a full range of relationships without artificial manipulation. Because of the central concern with inner consciousness, these relationships needed to be explored in some depth and this meant that all the interactants, not just the four subjects, needed to be available for follow-up interviews about their interactions.

Waimarie was a 66 bed residential institution five miles out of a small rural town which operated a rehabilitation programme for up to 20 people with traumatic brain injury. This programme had been incorporated into a group of buildings which had been home, since early childhood, to a dwindling number of people with severe physical disability caused by spina bifida, cerebral palsy and muscular dystrophy. These two groups now co-existed a little uneasily at times. In their different behaviour, they often revealed the contrasts between those accustomed to disability and institutional living and those for whom both were strange new situations which needed to be resolved. There were facilities at Waimarie, shared by both groups, which offered a range of opportunities for both informal and formal social interaction. These facilities included an indoor heated swimming pool, a dining room, a chapel, an aviary, extensive gardens and a large hall. A bar and a canteen opened for short periods outside the timetabled programme hours. There was also a sheltered workshop, an education unit, an activities centre, a physiotherapy department, an

occupational therapy department and a main office/reception, all of which operated only between 9.00am and 4.00 pm on week days.

While it might seem at first that institutional life cannot provide a window to everyday normal existence, this was perhaps the only environment within which the methodological imperatives mentioned above could be managed. Many of the constraints upon generalisability that might be assumed could also be dismissed upon a closer examination. This is largely because Waimarie, perhaps as a result of the introduction of a rehabilitation programme but also because of the personalities who lived or worked there, appeared to have transformed itself in many small ways from a conventional 'institution' with limited and structured role relationships and a hierarchical ordering of power, to a microcosm of a close-knit but diverse community. Relations at Waimarie could not be categorised simply according to any existing model of total institutions or formal settings. While the behaviour of the people who lived and worked there was sometimes constrained and organised by formally defined roles and functions, the full range of relationships could be found both among the residents' interrelationships and also between staff and residents. Hochschild's (1973) description of an "unexpected community"[38] appears to apply to Waimarie. The boundaries between staff, residents and their family members blended, with roles and relationships more typical of family and friends. This produced what van Manen (1990:102) calls an "at homeness", a space experience which has "something to do with the fundamental sense of our being". As a result, the study was able to capture the person in relaxed unselfconscious moments as well as in the more formal and self-conscious relationships of treatment.

Waimarie did, of course, have many of the features of a formal treatment facility as identified by Goffman (1961b) and Denzin (1987b). In particular, temporal rhythms and space arrangements differed from the New Zealand lifestyle norm. Many of the facilities described above, for example, were locked and unavailable to the residents outside weekday work hours and so a vast area of the building they lived in became long, ghostly hallways with locked doors during late afternoons, evenings and weekends. Such necessities as the structuring of time into shifts for the staff and timetables between 9.00am and 4.00pm for those on a rehabilitation programme, also produced an environment where "outside time appeared to stop" and the residents found "that [their] time had become someone else's." (Denzin 1987b:55). However, although Waimarie certainly was "incompatible with many of the basic patterns of life in society at large" (Smith,

[38] Hochschild (1973) in her book "The Unexpected Community", explored the complex relationships and networks which had developed in an old peoples' home. She discovered a closeknit community, complete with its own norms, roles and expectations had developed and she identified primary, secondary, reciprocal, complementary, formal and informal relationships.

1970:45)[39] most of these differences were adaptations necessary to compensate for disability rather than designed to regiment the residents to make life easier for the staff.

Some of the residents were able to manage daily living tasks independently despite their disabilities. Because of this, two different types of living arrangement were provided: supported flats, where a group of two to four residents lived together a few yards from the main building and Terehi, a 20 bed unit within the main building, arranged around a U-shaped passage with doors at each end, where each resident had a small private bedroom cubicle but shared bathroom facilities, lounge and kitchen[40]. In the flats, the residents had considerably more independence. They did their own cooking, cleaning and washing with limited support from domestic and occupational therapy staff. This allowed them more privacy and independence than the Terehi House dwellers. Outside programme hours they were more often left to their own devices.

In Terehi house, the nursing staff had responsibility for the residents' physical wellbeing and daily care routine and the environment was considerably more 'institutional' despite the many efforts made by individual staff to humanise it. The people it was there to serve had needs which produced this sort of atmosphere and which frustrated attempts to overcome it. Many of the floors were covered with linoleum, even the lounge and all the doors were extra wide sliding doors which accommodated wheelchairs easily. Many of the residents of Terehi had unusual, specially adapted chairs, some looking more like tilted beds on wheels. As a result, living areas, passageways and bathrooms all had to have large expanses of empty floor to accommodate them, giving the space a barren and uninviting appearance. Individual personalities were given more expression in the tiny bedroom cubicles, where personal televisions, videorecorders, photos, soft toys, posters, and stereo systems were all jammed together in the small amount of space not filled by the standard bed, wardrobe, basin and dressing table supplied.

The nature of the social environment in Terehi House was also restricted more by the impact of brain injury than by the clinical nature of the setting. About one third of the residents were unable to speak at all, while of those who could speak many made only bizarre remarks which showed their confusion and disorientation. Many of the residents too, were unable to wheel themselves about, whether for physical or cognitive reasons and these people tended to be placed in front of the TV in the lounge, if not due anywhere else and as a result the lounge area was often full of

[39] Smith (1970) regarded this description as one of several defining characteristics of a total institution.
[40] Terehi was one of three such 20 bed units. Taikau and Ruahina, the other two units, housed the long-term residents with physical disabilities. Although the two groups shared the occupational therapy, physiotherapy, education and social work services, their residences were separate and a different pool of nursing staff were assigned to care for them. Because of this, Taikau and Ruahina did not feature in the research project at all although their inhabitants frequently did.

impassive faces staring dully at a television screen. Efforts to make the environment more warm, inviting and conducive to social interaction were restricted by practical considerations to pictures on the walls and the occasional pot plant, bookcase and magazine.

Of course, the rehabilitation ethos which drove Waimarie also structured many of the relationships within it, suggesting findings might not generalise to other interpersonal situations. However, because the aim was to examine the relationships of recovery and to examine the efficacy of adapted interaction styles, this was an advantage rather than a disadvantage. Not only did Waimarie offer the opportunity to observe the impact of formal treatment relationships upon the meanings, actions and interactions of staff and residents during recovery, but it also supported a focus upon the central theme, transition. In each of the life histories and in many of the interactions, elements of the three stages described by Turner (1969, cited in Epston and White 1990:7) as the "rites of passage": "separation", "liminal" (or betwixt and between) and "reincorporation" were apparent[41].

It is possible that Waimarie also offered the research what Lofland (1980) called "perspective by incongruity" not achievable in a community setting. As they adapted to perceptual and cognitive disorders, the residents at Waimarie constantly challenged others to examine what was usually taken-for-granted in social practices. Because of the nature of their disabilities, there were frequent occasions to observe people (with and without brain damage) dealing with social and moral dilemmas caused by "disruptions to front" (Goffman, 1969:185). The abnormal came to seem normal among people who were variously unable to move or speak, unable to remember who or where they were from moment to moment, or who looked strange and unusual or, initially seeming 'normal', behaved in such uninhibited or eccentric ways that others felt unable to predict what they would do next.

The setting also made it possible to overcome some of the normal ethical dilemmas which could impede this type of study. Its semi-closed nature meant that staff, residents, family and regular visitors could become accustomed to the presence of the camera. They could be informed in advance of the research project and having obtained their consent (and even enthusiastic commitment in many cases), it was possible to follow the four people about throughout a normal day, often leaving cameras running in both formal clinical areas and informal residential and social areas without committing any ethical offences. It was also possible to seek out all the people involved in key behaviour exemplars and interview them later.

[41] Although "Rites of Passage" was a concept originally developed by Turner (1969), it has been popularised in Australia and New Zealand by White and Epston (1990) and for this reason, both references are cited.

The Use of Film

The second design choice was the method of recording. I adapted the pure form of naturalistic inquiry when I chose to use a video camera to record the experiences as I observed them. Although it is hard to be 'naturalistic' with a videocamera in hand, the type of thick description I needed was only possible, I believed, using such a tool. Film allowed the playing and replaying of the same scene, a huge advantage for this form of research because the full range of symbolic gestures involved in communication were too vast and changed too rapidly to be captured and noted simultaneously in the first encounter. Note taking would only allow the most immediately obvious aspects to emerge and audiotape would not record the non-verbal communications involved in interaction. With film, I believed that small representative samples of interaction could be bracketed, cut loose and explored in depth at the psychological, dramaturgical and phenomenological levels essential to addressing the research questions at the intense and detailed levels necessary.

The Participants[42]

Because of the nature of the inquiry, the film and interview data collected needed to be particularly thick, rich and descriptive so that it could be triangulated for internal validity. For this reason the number of subjects was limited to four. As each person's story is told in depth in chapters 4 to 8, only a brief summary will be offered here.

1. **Rob Johnson**: A 24 year old Maori[43] man, Rob worked in an "access" training course at the time of his injury eight years earlier and lived with his parents, two older brothers and two younger sisters. Before his accident he had been a talented rugby player and boxer. Rob was very severely physically affected by his injury having the use of only one arm (and that had a pronounced tremor) and although he could 'walk' slowly with a walking frame, he was usually reliant upon a motor-chair. He had, in the past, lived in the transitional living flats but because he had become depressed there he had been relocated in Terehi House. He was very near to discharge at the time of the research. His parents, **Piri** and **Fraser Johnson** lived five hours drive away and visited only irregularly. They were not closely involved in the day to day rehabilitation process, therefore, but were involved at the time of the research in plans to alter their house in preparation for his return home.

[42] Readers are advised that in accord with ethical considerations, the identity of all persons involved in this study has been protected with the use of fictional names.
[43] The indigenous people of New Zealand.

2. **Mark White**: A young man of 19 years, Mark was about to commence university study at the time he fell off a roof fifteen months earlier. Mark was living with his parents, **Juliet** and **Daniel White** and a younger brother **Simon**, at Porterton, one and a half hours away. He also had been a talented rugby player before his accident, but now had been advised not to play contact sport again. Despite a slight weakness to his left side, Mark had no obvious visible physical disability. At the time of the research he had just moved into a transitional living flat and was staying there for five days a week, returning home to Porterton by train every Friday afternoon to spend the weekends with his family and friends.

3. **Max Kavanagh**: A 52 year old carpenter, Max was living with his second wife **Prue Kavanagh** at the time of his accident two years earlier. He had been a fit and active 'outdoor' man with an independent personality up until his fall from a ladder, but was now virtually immobile, reliant upon a motor chair and confused and disoriented. He was regarded as too dependent to manage in the flats and so was staying in Terehi House. Because Prue was living five hours away, where she had a full time job, she was not heavily involved in his daily programme at the time of the research although she was using considerable energy at the time battling with outside agencies to arrange a placement back in Limmerton.

4. **Bryce Lawson**: A 20 year old dairy farm worker, Bryce was employed in a live-in situation on a farm prior to his accident, but spent his weekends with friends in a nearby city, Wimberley, where he had been brought up and where his parents still lived. Although he had left school without qualifications he had done well in a dairy farm cadet course, passing second in his class and had, at the time of his injury intended embarking upon another year of polytechnic study to complete a manager's certificate. Although he lived quite near **Bob** his father, **Pat**, his stepmother and **Alice**, his mother, he saw very little of his family and by the end of the research period, it became evident that **Stella**, his fiancee, a solo mother in Wimberley, would play a more significant role in his future life. There was very little physical and motor disability evident as the result of Bryce's injuries which were caused by a car accident, but it was becoming evident that he would have ongoing problems with memory, with visual perception and with situations requiring some social judgement.

SELECTION PROCESS

Selecting The Four Subjects

Because I was interested in brain damage as a 'pivotal event' or life changing experience, it was important to select people whose brain injury was grave enough to be regarded in this way. I

confined my choice therefore to those with a 'very severe' injury (according to the Glascow Outcome scale) or levels IV to VII on the Los Amigos Cognitive Scale (Hagan & Malkmus 1979, See Appendix D). Because the design also called for the charting of a life interrupted by brain injury but now resumed, the amount of time which had passed since the accident was another important variable. Eight years had passed since Rob Johnson's accident when he was 16, while for the other three, the experience of living with brain injury was still relatively new, Max having two years, Mark fifteen months and Bryce only eight months.

The more diverse these four people were on sociological (class, gender, race, educational level etc) and reported personality (sociability, independence, beliefs, values, skills and roles etc) parameters, the more confident I could be that similar problematic patterns in their perception and thinking were related to their brain injury. In this respect the subjects showed many differences which are summarised above, as well as some similarities. Two, for example, happened to be extremely talented sportsmen before their accident and three were under twenty at the time. All were male and none of the four was particularly known for intellectual or sedentary pursuits. Although they appeared to offer a wide cross section from the general population in some ways, in other ways the sample was skewed. The outdoors-oriented young male, although over-represented, does reflect the group most at risk of severe brain injury[44]. As a consequence the experience of these four men would be more typical than a sample group with a more balanced weighting of personal attributes.

In order for the aims of the research to be practically achievable, there were some further restrictions placed upon the possible choices and in particular, upon the degree and nature of the disability caused by the brain injury. Many of the residents of Waimarie were unable to move or speak. Although these problems were minimised as far as possible with compensatory devices, I decided that the four people I chose needed to be independently mobile so that what movements they made could be seen as purposeful and able to speak so that it was possible to conduct life history interviews with them and to film their conversations.

Finally, in order to minimise the influence of interpersonal relationship styles upon the data gathered, I only approached people who had been at Waimarie for at least two months. This lessened the risk of initial engagement behaviour distorting the interaction. Waimarie was familiar (as far as any environment could be in the particular circumstances of memory deficits) and interactions were less self conscious and formal than would be found in a strange new

[44] See Chapter 1, p. 11.

environment. Any psychological or behavioural variants could be assumed as more attributable to the interactive and 'intra-active' processes of that historical moment.

Once the residents at Waimarie became aware of the nature of the research, several were excited and eager about being filmed and interviewed. Rob, the first subject, was one of these. Because he enjoyed attention and coped well with the teasing which was the inevitable lot of the first person to be filmed and because he fitted the criteria I had laid down, he seemed an appropriate first candidate for the study. I did not consider the selection of the second subject until I had nearly finished the second cycle of filming with Rob. Because the design meant three months was devoted to each subject, it would have been impossible to do otherwise. The time each resident spent in the rehabilitation programme varied tremendously and some of the people recovered independence dramatically fast, requiring constant revision of goals and discharge plans. As each three month period drew to a close, therefore, I began to look around for the next person. Of course, this had an added advantage. After watching others being filmed and, in two of the three cases, already having been filmed themselves, the putative subjects were in a much better position to understand what they would be agreeing to. Seeing it in action also made it seem more attractive to them. In fact, after the research had been in progress for a few weeks, I had such a pool of voluntary subjects that there would have been no need to look further afield. However, because I wished to ensure my sample was as representative as possible, I approached both Max and Bryce in preference to volunteers that were available at the time. Bryce was immediately happy to be involved. Although it would not have occurred to Max to offer to be a subject, (since he very rarely initiated any interaction), when I approached him I did so well aware that he had been comfortable about being filmed in group situations where Mark was present.

Selecting The Other Participants

There were two sorts of other participants in this research. Firstly, the family members of the four subjects who were interviewed as part of the process of collecting the life history and secondly, the people at Waimarie whose interactions and relationships with the four subjects were observed and recorded on film. Because I involved the people at Waimarie in the research before I approached the subjects and their families, I will begin by describing this group.

Because I wished to collect film of the whole range of interactions the four subjects experienced during the two months I filmed them, anyone in the setting of Waimarie was a potential participant. This included other residents and their family members and friends (if they happened to visit during a filming period), nurses, nurse aides, kitchen hands, cleaners, occupational therapists and their aides, social workers, physiotherapists, tutors, a visiting psychologist and a

recreation coordinator. Altogether, just over 100 staff members and 55 residents were initially approached to obtain their informed consent and later as the research proceeded over the period of 14 months, the consent process was repeated 35 further times to account for new arrivals and casual visitors. For most of these people, their participation involved nothing more than sometimes noticing a camera in the distance. A smaller number were occasionally aware that the activity they were involved in was being filmed, although the camera was always trained upon the area around one of the four key subjects. A smaller number again were involved in the filmed segments selected as 'behaviour exemplars' and when this happened, their actions were described as a part of a total scene. Even at this stage however, the involvement of many remained minimal as they were not interviewed unless their role was considered to influence the subjects in some way. Eventually 24 people were interviewed as other interactants in the filmed observations, including three nurses (**Hilda, Olwyn** and **Jackie**), three nurse aides (**Winston, Ginny** and **Marie**), the recreation coordinator (**Don**), two occupational therapists (**Jill** and **Esther**), two of their aides (**Del** and **Diane**), three education tutors (**Linda, Trudy** and **Dierdre**), a social worker (**Philippa**) and a physiotherapist (**Joan**), five residents (**Nadine, Betsy, Rosemary, Phillip, Sid** and **Mark**[45]) and three people from the community, one a work place supervisor (**Carolyn**) and two ex-residents visiting Waimarie who had ongoing friendships with the subjects and other residents (**Graeme** and **Wayne**). Of these 24 people, eight staff members, (**Trudy, Linda, Philippa, Don**, **Jill, Joan, Diane** and **Esther**) and two residents (**Sid** and **Nadine**) were interviewed upon several occasions because they were present in more than one of the behaviour exemplars. It is significant that six of these staff members were all professionally qualified with a more defined and planned role in the rehabilitation process, suggesting that this position had allowed them to play a more intensive role in the recovery process. The seventh was an occupational therapy aide whose duties kept her alongside Rob for long periods. The other staff member to appear in several behaviour exemplars appeared to do so partly because of the nature of his job, (running informal recreational activities where a great deal of interesting social interaction occurred), but also perhaps because as an energetic and sociable young man he was something of a minority among the staff and a minority toward which the subject group (also largely young men) was particularly drawn.

Of the residents interviewed more than once, one was a flatmate of Bryce's, so thrust by his situation into his company, while the other was a young woman that Rob Johnson enjoyed teasing.

[45]Mark White, a subject, was also interviewed as an other participant during the research.

THE ETHICAL PROCEDURE

A proposal was first submitted to the Massey University Human Research Ethics Committee and their approval obtained after some adaptations to the consent process to further safeguard the subjects and participants. I then approached the Waimarie Clinical Team, (comprising Medical Director, Charge Physiotherapist, Charge Occupational Therapist, Health Services Manager, Tutor, Social Worker and the two charge nurses). After a discussion with them explaining the nature of the research and what it would demand of the residents and staff, they offered their approval and support. The adapted proposal was then submitted to the Crown Health Enterprise Ethics[46] Committee along with a letter from the Medical Director noting that the staff knew of and supported the project. This C.H.E. committee also requested some minor changes to the consent procedure, but eventually allowed it to proceed .

OBTAINING CONSENT FROM THE 'OTHER PARTICIPANTS'

In the week following receipt of this second letter of approval I arranged to speak to everyone living and working at Waimarie. By asking to attend regularly scheduled meetings, I was able to speak to the majority of staff including the cleaners, kitchen hands, orderlies, nurses, nurse aides, occupational therapists and their aides, the recreation officer, the Education Unit tutors and a tutorial assistant. Because they did not hold a regular meeting I arranged to talk to the residents in three groups, one session in each lounge of the three 'houses' (Tuakau, Terehi and Ruahine) which housed the living quarters.

In these meetings I explained the purpose of the research and, no matter what the person's role or position and however unlikely they were to appear in the filmed interactions, they were all fully informed of the steps taken to ensure confidentiality and of the possible outcomes, methodology, their role, the researcher's role, the potential uses of the information gained, the ownership of information and the feedback which they had a right to expect from the process. It was made clear that written informed consent was a condition of involvement of every participant, however minimal the eventual involvement in filmed interaction and that if they refused to sign the form, I would be obliged to switch off the camera while they were present. I stressed that no one should feel guilty if they preferred not to participate. Because only ten hours of film was required within a seven day period, I pointed out that there would be plenty of opportunities to collect film even if I was obliged to switch off regularly throughout the week.

[46] Crown Health Enterprises are in future referred to as 'C.H.E.'s

Apart from these eight more formal meetings, smaller numbers of people, not so easily grouped together, such as the office staff, the physiotherapist and her aide and those residents or staff who missed the meetings, were approached during the day and a time arranged when I could discuss the project and have them sign the form in the presence of a witness. Over the first week, 25 further consents were obtained in this way. At all these meetings very few issues or objections were raised by either staff or residents. The prospect of being filmed did not appear to worry most of them and many were openly enthusiastic and eager. The prevailing impression was one of bewilderment that it was necessary to obtain consent from the whole Waimarie community at all, before being able to carry out this project. As I went painstakingly through their rights and my obligations with them, however, some became disconcerted as they realised that they was agreeing to something more serious and intrusive than the proposal initially sounded. The possibility occurred to them that their own practices might be the focus of criticism and there were some suspicious or defensive remarks made as a result. After some reassurance about ethical safeguards however, most of these people were pleased and intrigued at the prospect of being in the film and several remarked that they welcomed the opportunity to explore some of the dilemmas of working with this subject group. There were only three people who eventually refused to sign, one an elderly and confused resident who believed he might lose his savings if he put his signature on any official looking piece of paper and two orderlies, who were concerned that they might find the filming process intrusive.

Of course, one of the three resident houses which I spoke to at this time was Terehi, the living quarters of the group from whom I would later need to select my four subjects. Over the time of the research the numbers of residents in Terehi varied between 12 and 18, but at the time of my initial approach there were 12 residents and, as was usual for Terehi, several of their family members also[47]. I spoke only to a small number of these people in that initial meeting, preferring to approach as many as possible individually (but in the presence of family or staff members), following up this initial explanation with a letter home or a telephone call to their next of kin whenever staff were unsure whether or not the person could make an informed decision alone (see Appendix A and B for relevant consent forms and information sheets). I was acutely conscious when asking for the consent of this group, that some of them might later become my subjects and even if they did not, they were likely to be more intensely involved as the filming would occur in their residence. I was also aware that the normal processes for obtaining consent assumed that people would remember or understand information they had been given accurately, that they would see the implications of their decisions, or they would be aware of their right to

refuse. None of these assumptions could be made when a person had severe brain damage. Not only were they less able to make an informed judgement, they were also less able to communicate their concerns or pose a question because of their physical and communicative disabilities. Although I had the required signatures, therefore, I worked upon the assumption that informed consent as an ongoing process. Participants were regularly asked if they understood what was involved and if they wished to withdraw. I would demonstrate the use of the video camera regularly, holding it up to their eyes if they wished and encouraging them to see what and how I was filming. Whenever I filmed in an area where other residents were present, I made sure that they were aware of the camera, remembered its purpose and had no objections to being filmed at that moment. All the staff were also encouraged to intervene at any point if they felt that the filming process might be intrusive. Because of their obligations to their clients, the qualified professionals in particular were assured that their continued positive opinion was essential.

After obtaining the consent of everyone at Waimarie, it was still necessary to inform the residents' families. Although it was important to me that residents be given the opportunity to make decisions themselves (whenever they were considered legally capable), their families had a right to learn first hand about this project. If they were to hear stories of videotaping from others, it was possible that they would feel concerned and even distressed unless the design, intentions and safeguards had been fully explained A standard letter (See Appendix C) was therefore sent to all family members that had not already been approached as legal guardians, setting out these details for their consideration. It was made clear to them that any concerns they had would be addressed seriously and the research would not proceed if there was any serious issue left unresolved. There was no formal response from family to this letter at all, only occasional informal and supporting comments made over the following months when these family members visited and, seeing the camera, remembered receiving the letter.

OBTAINING CONSENT FROM THE SUBJECTS AND THEIR FAMILIES

It was only at this point, when everyone in the Waimarie environment and in the network surrounding it had been made aware of the research, that I was ready to proceed with selecting the first subject. Rob Johnson was one of several people in Terehi eager to be selected as a subject. He told me so at the time of the meeting described above and then reminded me of it on several later occasions. According to the consent process agreed upon with the two ethics committees, however, the family had to be present when I obtained informed consent of the four subjects and so nothing could be formally signed until Rob and I had travelled to his parents'

[47] Although family members usually stayed in the separate flats provided for them, they used the lounge area

home in Camberton, five hours away, to conduct the first interview. Because I knew that Rob was willing to participate, I was able to make arrangements for this meeting, to discuss the implications over the telephone with family members and be reasonably confident that a formal written agreement could be arrived at later.

The families of the four subjects included three sets of parents, one set divorced and living separately and one second wife. These people had already been informed about the research at the time that their family member became a participant and so when the step was made for each to become a subject, the information needed was not the general background to the research, nor the filming process, but rather the requirements that would be placed upon them in the collecting of the life history. All the family members approached generously offered their support and time to this putting together this life history document, although two had some reservations. Prue Kavanagh was concerned that she was unable to accurately tell the story of Max's earlier life for him, while Alice Lawson was concerned that I would want to write the story of her own marriage breakdown. Both agreed to proceed after some discussion and in the case of Alice Lawson, after agreeing to leave out some of the detail of Bryce's early life story.

OTHER ETHICAL ISSUES

Because the study was conducted in an institutional setting, the ethical concerns of the research were superimposed upon existing ethical standards. The staff at Waimarie considered themselves responsible for their clients' safety, confidentiality and informed consent in any issues regarding treatment. It was necessary, therefore, to establish some guidelines to deal with potential conflict between the two sets of ethical requirements. It was agreed that:

1. Staff would always act in the interests of subjects, residents and other participants, placing the needs of the research second.

2. The researcher would drop the observer status and intervene if anyone in a setting was at risk of immediate physical harm.

3. The researcher would inform senior staff or take any other appropriate action to ensure any harmful or unethical practices observed during filming were stopped.

4. Staff members would intervene in the research if, at any given moment, they believed it was harmful to subjects or other residents.

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extensively during the day and so needed to be included in the informed consent procedure.

As it happened, none of these considerations became an issue during the research. However, in discussing them at the outset, staff were made more aware of their own rights and because of their protective attitudes toward many of their less assertive clients, I feel that this process was very important to them. Without this sense of power over the process, some staff may have felt unease about potential conflicts between the needs of the research and those of their profession.

In general, therefore, all the participants, including subjects and their families, were made aware throughout the research process, that the most important considerations were that no one could be harmed by the research, that no one felt any implied coercion and that no connection should appear to exist between the provision of a service by Waimarie and participation in this research.

THE RESEARCH IN ACTION

(I) LIFE HISTORY

For the purposes of this project, a biographical record had several advantages over a more autobiographical account. Memory and interpretive difficulties made the subjects sometimes very vague and confused about their own past and susceptible to factual errors. Each of the four people had large 'gaps' in their memories and the family members I interviewed could only fill some of these gaps and even then, only from their own particular perspective. Piecing together what had happened over that time required some detective work and such 'pieced together' data risked becoming meaningless without rigorous triangulation which allowed all the available memories, facts and ideas to be placed alongside and understood in relation to each other.

I discovered, particularly in exploring Max and Bryce's past lives, that the meaning of events in a person's life could be very elusive when the subject was no longer capable of explaining it. It could not be established just from known facts about the events, but required some conjecture and deduction on the part of everyone else involved. I could and did, for example, draw upon a variety of sources including the case notes, the memories of family members, friends and the staff involved in their rehabilitation, any relevant filmed data from the research process, as well as any diaries, photo albums, scrap books etc which were available. In this way a comprehensive picture of the four people both before and after their accident slowly emerged.

There was also in describing the 'after' phase of each life history, a constant need to be aware of the difference in the subjective lived reality caused by damage to the brain. In each case, the description of life since the accident was, as a result, extensive and intensive, needing to deconstruct the experiences in order to grasp their essence and so explain the course of recovery in a way which enlightened and which also revealed the continuity as well as the discontinuity in

each story, showing the influence of others which surrounded each person, as well as the influence of the various spatial environments they had inhabited since emerging from coma.

For each of the four subjects, two audio-taped interviews of approximately two hours each were sufficient to produce a broad general picture. These were transcribed and a copy given to the person, with some explanation of what they had said, allowing them to confirm or contradict their earlier remarks which all four had by then, largely forgotten. Although a semi-structured schedule was used to guide the interview initially (see appendix E), in each case, these meetings quickly lost any formal structure and became a free flowing discussion roughly based upon their past and present experience, but sometimes diverted into issues concerning Waimarie and, (particularly with Max), requests for information about their own progress and about future plans being made for them. All four of the people found the questions I asked difficult and although none were threatened or distressed by their inability to answer, they frequently turned for help and confirming evidence to their own photos and written documentation which they appeared to believe was more reliable than their own memory.

Armed with the knowledge from the interview with their family member, I next discussed the life story with other family members. The purpose of these interviews was to allow the subjects' closest family to provide their own accounts of their life and experience both before and after the brain injury and describe how they saw it as having changed the life of the subject. Each of these family interviews required me to travel some distance. In all but Bob and Alice Lawson's case one main interview per family of between two and three hours was sufficient to cover the ground. In the Lawson case, both parents chose to be interviewed alone and so I made two separate journeys to Wimberley on two different days, spending two and a half hours with each parent. Using creative interviewing (Douglas 1985) techniques and as often as possible confining my own role to summarising, reflecting back, clarifying, etc, the interviews were conducted so as to resemble, as closely as possible, an informal conversation. Although I carried an interview schedule with me therefore, it was more in the manner of a checklist (see Appendix E).

In each case, a transcription of these interviews was made and sent to the family members within two weeks. After allowing time for them to read through the transcripts, I would then ring them and in each case further discussion occurred to clarify areas of confusion and to cover any extra questions which had occurred to me as I typed up the transcript. This second telephoned interview was not tape recorded but written notes were made.

The information collected was then subjected to what Denzin (1989:192) describes as "careful readings and interpretations in looking for orderly patterns". An analytic abstraction was

produced which included some initial generalisations between the four stories upon issues such as structural processes, relevance of theories and the individual differences which suggested causal interrelationships.

As well as being "phenomenological-interpretive", these life histories could be described as using "critical" method (Denzin, 1986:14) in that they sought to lay bare the impact of power relations upon the actions and understandings of the person. As Denzin (1986:9) pointed out, "politically, the study of every life demands an analysis of power at the most meaningful personal level". For a symbolic interactionist, power is control over definitions and so the study of power is the study of the domination of some understandings over others and the examination of how this affects individual lives. The traumatic brain damage was regarded as the turning point in personal power relationships with the world (Goffman, 1968:53) and the person's emerging self-understandings were understood as a compound of inner definitions and socially constructed understandings.

Disadvantages of the life history method

There were several disadvantages created by the use of the life history method with this particular group of subjects. All of these issues were borne in mind during the writing of the life histories and allowances and qualifications made wherever necessary.

1. When people are asked to tell someone else their story, there is a tendency to objectify and externalise what was in fact very personal and 'felt' experience. Although hopefully the climate of the interview minimised this tendency, there were times when I found it difficult to know how the person had felt at the time and how this had influenced the interpretations made and the actions taken.

2. Similarly, there is a tendency to believe, when telling a story, that every action and thought has an underlying intentionality. In fact many actions are only understandable as less conscious, habitual and taken for granted. All the people involved not only the subjects, to some extent "reauthored" (White & Epstein, 1990:38) as they went, ascribing meaning which was never present during the original action.

3. Life history collection assumes (and places upon the written product) a linear model of living, while the phenomenological perspective adopted by this research project understands meanings to be the result of a much more complex interpretive process. Particularly in describing the 'after' experience, this caused a tension in the format of the life history, which sometimes lost its linearity in my need to explain the role of interactional and intra-actional processes.

4. Life history also assumes that the meaning of narratives can be extracted by analysis while in fact symbolic interactionists would have to agree that analysis creates the meanings imputed to the texts and that such preoccupations with theory can place the researcher's interpretations over those of the subject. Denzin suggests that there will always be a tension on this point (Denzin, 1989:196). I was surprised at how hard it was to overcome or minimise this problem. Perhaps because of the nature of the difficulties my four subjects were encountering, I was constantly in a position of having to analyse 'what had happened' from disparate interview data. I felt very uncomfortable about this and triangulated findings about causal relations as much as possible. I also fed back the written documents, asking for any comments and in particular asking that interviewees inform me if they felt I had misinterpreted what they had said.

I discovered, however, that people were surprisingly accepting of another person analysing them and their experience in this way. I received remarkably little contradictory or corrective feedback throughout the course of the research and what I was offered tended to refer to small detail rather than overarching interpretive schemes, or conjecture about probable dynamics. In fact this discovery, of how ready most people were to except interpretive schemes imposed by others, was one of the most unsettling to emerge from the research and it caused me to look again at the nature of the setting and to regard the medically oriented framework as being more disempowering than I had originally supposed. While this passive acceptance certainly made it easier to proceed with the research, it left me more aware than ever of how important it was to scrupulously follow the ethical constraints placed upon me by the University and the Crown Health Enterprise Ethics Committees. It seemed that unless circumstances raised the human consciousness about the risks involved in intruding upon another's private world, there was very little consciousness of it.

Perhaps this style of research, which reduces a life so, is only acceptable when the design is balanced by participant observation methodology, ensuring the capturing of actual lived experience can be placed alongside and considered with, the data produced.

(2) PARTICIPANT OBSERVATION

In the proposal to the two ethics committees the method of collecting videotape was described in this way:

> **(I) A maximum of 10 hours filming per month for a period of two months. This filming will be carried out by the researcher between 9.00am and 8.00 pm over a period of seven consecutive days each month, not exceeding four hours on any one day. ..**

Eventually, 80 hours of film were collected, 20 hours focused upon each subject in turn. Each month would begin with a period of seven days during which I would collect 10 hours of film and the following three weeks would be devoted to transcribing and to interviews which related to that 10 hours. Of course, 10 hours, although a large quantity of film, was still only a small proportion of the total possible time available for participant observation over the span of a week. Such a design allowed considerable flexibility to the person operating the camera, but posed the risk of selective observation and the skewing of the content of the film. The filming choices I made were not arbitrary, however, but guided by a "representational map" (Denzin 1989:88) built during the five years I had spent at Waimarie. On the first day of each new monthly cycle any two to three hours of film taken during any moment of the day was equally acceptable. As the week progressed however, I would monitor the nature of the film so that the eventual ten hour sample would provide a working picture of typical interactions over a normal week. Mapping, usually the preliminary stage of naturalistic inquiry when entering an unknown field, was superfluous in this situation where I could already make judgements about the range of possible interactions and the most likely times and places to encounter them. The periods of observation were deliberately chosen toward the end of the filming week to ensure that as wide a range of interactions as possible was observed not only those with professional staff, but with support staff, families and with other residents at Waimarie. Where possible I planned also to film during peak interactional times (Denzin 1989:88) allowing the collection strategies to be as economic of time as possible.

In this setting it was relatively easy to rely upon such a map. The interaction patterns were more fixed and constant than they would have been in an open community. Because of the structure there was almost a guarantee that during the seven days the four subjects would encounter professional people, support staff, peers, family and outside visitors. Each of the eight ten hour data sets therefore contained many different types of social encounters. This included timetabled sessions where there were definite therapeutic goals, interactions in the supported flats, the front office, the lounge of Terehi house, the dining hall and even the passageways. Although the majority of film was collected during the weekdays, there was some time in the evenings and early mornings as well as weekends.

There was some initial uneasiness about being filmed from Mark but surprisingly little from the other three[48]. For all four, awareness of the camera appeared to come and go and Max often seemed to forget its existence entirely. The only times that Rob asked me to switch off were when he was eating. Because of difficulty controlling his hand, this was sometimes a clumsy and

[48] There were several possible reasons why there was such an observed lack of concern and these have been explored later in Chapter 12, p. 478, the Self-Awareness and the Use of Film.

messy business and when he felt self-conscious, his control over a fork tended to get worse. Mark frequently asked me to stop filming because the presence of a silent observer was suddenly oppressive, but neither Max nor Bryce ever showed any desire to curtail filming despite my frequent reminders that they could ask me to switch off the video camera.

Although none was made particularly uneasy by the presence of the camera, in all of them except Max it clearly influenced their behaviour sometimes. They seemed to enjoy performing for it, particularly during the more informal encounters when it was easier to 'hold the floor', or when supposedly alone and it became harder to pretend I was not present. I had expected such an effect, but in similar studies (Cicourel 1981:93) it was found that after an initial period, this 'staging' disappeared and "judgements about the persons in the situation, their feelings, attitudes, relationships and intentions can therefore be made without serious qualification" (Denzin, 1985:81). I found instead an erratic oscillation between self-consciousness and unconsciousness continuing throughout each filming cycle except Max's. Because of the nature of the research question, this appeared to be a theoretical rather than methodological issue and as such is examined further in Chapter 12.

Most of the other participants in the filming process good naturedly ignored the camera, offering only a quick grin to acknowledge they knew of its existence, before 'carrying on' regardless. I have no doubt, however, that some reactive effect was occurring. Several people actively encouraged me to film something, becoming the "collaborators, informants and catalytic agents" which Whyte (1984:66-7) also observed in his participant observation[49]. This eagerness did not appear to influence the nature of the film markedly, but perhaps it increased the number of occasions when the residents were given attention and increased the intensity of the climate. Because my intention was to capture "events, candidly filmed, as they unfold in their natural settings" (Denzin, 1985:80) where participants "seemingly do not know they are being filmed", I adapted my methods of filming to compensate for this effect. I began to arrange the filming situations so that the camera while not 'hidden' was in the least intrusive position in the room and whenever the person was alone or in a one to one situation I would quietly leave the room and wait nearby, so as to alert anyone who might be entering that area of the presence of the camera. It was remarkable how much these small adaptations removed the feeling of being filmed and the film collected at such times was noticeably less staged.

[49] There is a good example of this in one of the behaviour specimens (p. 395) where Ginny, a nurse aid decides to ask Max "Do you know where you are?" and later told me she "was trying to get some good film" for me.

The staging effect, however, was not an entirely negative outcome of the method. Because of the particular theoretical interest in the person's awareness of another's perspective and because of the use of dramaturgical analysis, film of self-conscious performances offered an intriguing body of data which offered insight into the competence of the projecting process. Two of the behaviour exemplars were in fact selected specifically because of their ability to reveal more about self-conscious performing and its affect upon interpersonal interaction[50].

There were several logistic issues which also arose over the first week of filming. Those concerning the recharging of batteries and the replacing of tapes were partially resolved but caused ongoing problems. Both batteries and tapes ran for only forty-five minutes and I found that it was best to synchronise the replacement process to reduce the number of intrusions and frustrating gaps caused by the failure of the one or the other in the middle of an important interaction (eg "Going to Limmerton" p. 391). Another issue was the use of a tripod, which, while it ensured a more stable picture, made it difficult to move quickly to cover an unexpected interaction or a sudden departure. Eventually I discovered a combination of hand-held filming during more mobile and informal moments and a fixed position for a formal timetabled session worked best and I made these decisions continually as the day progressed. Often the tripod would be left at the other end of Waimarie when I wanted it again and I would find myself running through passage ways to retrieve bits of equipment needed again but discarded earlier in a hurry.

Each night I ran through that day's videotapes and transferred them to a normal sized, 180 minute VHS tape. Each of the eight cycles of film eventually fitted onto four of these, giving me 32 video tapes to process. All my notes were indexed with counter numbers and initials which referred to these 180 minute tapes, not the smaller camera tapes, which were reused for each new cycle. Because the counter number from the smaller tapes was recorded on the screen as well, these numbers were used to pinpoint an exact moment in the film.

Packaging

Each week of filming was followed by a period of a week during which the ten hours of film underwent a "packaging" the method suggested by Schatzman and Strauss (1973:99-100) for recording and systematising data by dividing it into observational, methodological and theoretical notes. Because the videocamera provided the most complete possible record of the interactions, this packaging did not attempt to record the content in any depth, merely using rough outlines. I

[50] e.g. "Being Filmed" (MW Cycle One, No. 1), p.372 and "Before the Polytech Students' Visit", p.396 (BL Cycle One, No. 2).

would rule paper into three columns, jotting the tape counter number and time regularly in the left column, along with any relevant theoretical notes in the form usually of theme headings such as 'Emotional Intersubjectivity' or 'Scaffolding'. I developed a habit of using capitals and underlining, asterisks and even exclamation marks to call particular attention to those theoretical notes I felt were most central to my thesis. I also regularly noted the current physical location within the Waimarie complex in this margin so that when flicking through the notes later I could trace the course of the day more easily.

The middle column I used for observational notes or alternatively for the building of "primary frameworks". Goffman (1974:21-39) suggests that these interpretive schemes begin the process of attributing meaning or definition to a situation or event. Denzin (1989:21) calls the concepts involved in this level of analysing "first order constructs" and Coulter (1979:21) "common sense knowledge". The key focus in this column was the person's own probable or apparent understanding and intentionality. This column contained comments about non-verbal behaviour and what it might signify (e.g. "Head goes down, ashamed?") and sometimes also tentative hypotheses to be kept in mind. I would write, for example, "seems particularly nervous at the moment, could it be because waiting for a phone call from Philippa?". These notes did not have the certainty of the theoretical notes but formed the basis of my own analysing.

The right hand column contained a running commentary of the action and words used in the film, sometimes in the form of rough notes just to prompt memory of a scene, while at other times becoming verbatim dialogue transcription when it seemed particularly significant. It took some experimenting to find the right mix of recording and relying on the film in producing this transcript column. Obviously the videotape itself was such rich, thick data that to attempt to translate it totally into words was absurd, yet to continually rerun film I found was remarkably time consuming. How much transcription was necessary ultimately depended upon the type of activity recorded. Observation of a person playing a game required relating of symbolic communication gesture to the course of the game for example, while conversation might require some careful linking of subtle interpersonal cues and actual words. As a result the amount of film covered by a single page varied considerably from two minutes for an intense conversation in Mark White's to 45 minutes of Max watching television.

The methodological notes were much less frequent and did not require their own column. They were usually explanations for a disturbance to the filming process, or directions to myself to guide future filming choices. I would normally print them in capitals at the top of the page, or if they related to a definite moment during the filming, I would draw lines across the page and put the

note between them. An example would be when I noted that film in an area was inaudible because of noise interference or that a camera had been switched off for some moments while I obtained informed consent from a visitor.

Initially I had assumed that I would be able to divide these film notes up into the clearly separate sampling units which Goffman (1961a:8) called an "encounter", a "focused interaction", or "situated activity". I found, however, that except for some brief encounters in the passageways, the lived experience of the four people did not fit neatly into ten minute segments and the packaging eventually produced one long stream of interaction lasting 45 pages on average, with lines drawn to break these up only where filming stopped and started again.

In each cycle, regularities accumulated quickly in the types of interactions experienced and it was relatively simple to see themes and characteristic patterns which could be used as naturalistic indicators. In the same way it was possible to select for further attention, moments which seemed deviant or irregular. At this point, the research could and did proceed with the selection of behaviour exemplars.

The Behaviour Exemplars

Naturalistic inquiry requires that between 5 and 10 percent of the packaged data should be bracketed, "cut loose" and analysed in more depth as a "behaviour specimen[51]", defined by Denzin (1989:79-85) as follows:

> **.. a detailed reproduction of the actual experiences, thoughts and actions of those studied. They are by nature therefore dramaturgical ... The interactants and their relationship with each other will be noted, then their utterances and non verbal gestures will be recorded in sequence, the unintelligible followed by the letters tr (translation). The form of the encounters (hostile, intimate etc), the imputed thoughts and motives are all included within the record. The whole interaction is timed and dated and significant social objects and rules of conduct remarked upon. The record endeavours to separate out the interactional participant and the interactional analyst.**

The behaviour exemplars I used, although they followed Denzin's (1989) written format as described here, were considerably longer than the examples from his own work, *On Understanding Emotion* (Denzin, 1984). This adaptation seemed necessary in order to discern the sequential order and interrelationships of probable thought and feeling processes and in order to understand how the dynamics might have been influenced by the unusual perceptual and cognitive processing. As a result the eventual 'detailed reproductions' required up to five typewritten pages and at the completion of all eight cycles of film, I had accumulated 95 pages of behaviour

[51] Hereafter, I have substituted the word 'exemplar' for 'specimen' in order to lessen the unfortunately dehumanising and objectifying connotations which this word can have, particularly when used in this context of cognitive disabilities.

exemplars, 10 for each subject. These excerpts differed in duration from 2 minutes to 45 minutes with an average length of 13 minutes. Altogether they involved 550 minutes of filmed interaction which was just slightly more than the '5 to 10 percent' of the total film required by the design.

Once selected, these exemplars alone formed the basis of further analytical endeavours and so it was important to ensure they were truly representative. In line with naturalistic sampling strategies, selection was based upon the ability of segments of film to depict recurring themes and patterns, as well as their ability to reveal behavioural influences in action. Also important however, was the 'observability' of the phenomena regarded as present in the film. While clearly the research hoped to explore below the surface level of interaction, it was preferable when working with film to begin with actions, transactions and expressions which offered evidence about what was occurring and to work from there inwards through the process of interviewing and analysing rather than beginning with a piece of film where the participants' actions communicated little. The greater the public nature of the act, therefore, the greater the validity that could be assumed from the filmed specimen. When a large degree of imputing of motives or intentions (i.e. understanding and intentionality) was necessary in order for the interaction to convey any meaning a segment was regarded as a less suitable specimen.

In writing these behaviour exemplars some imputing was, of course, essential. This is implicit within the definition Denzin gave and was a necessary step in the linking of an interacting and a phenomenological self. Inner feeling, negotiating, adapting and accommodating processes will not necessarily produce any clear observable phenomena and so I found some "poetising" (van Manen,1984:2) was necessary to evoke a feeling for the intra-active qualities in the reader's mind. In doing so, there was a risk that I imposed my own, alien interpretation upon a situation, especially in the more ambiguous scenes where two observers might have interpreted what happened in quite different ways. However, as Blumer (1969:179) says in justification of such method:

> **It may be argued that the designation of an act as being respectful, hateful, aggressive etc, is actually an inference and so is not properly a part of the observation. That it is an inference, is I think, unquestionable, but in many instances it is an inference that is fused immediately into the observation itself. This is true of every act of observation; even the designation of a physical act is in the nature of a judgement or inference. The only question is whether the inference will stand up in the face of a test. The observation of a physical act can be so validated because it can be brought inside a time-space framework. Similarly the observation will hold up if observers have the same grasp of the situation and attach the same meanings. The incident is immediately fused into the immediate observation. All that is important is that the inference can be validated.**

Whether or not it is regarded as a necessary evil, some interpretation is clearly unavoidable when using such a methodological tool and in order to sustain a sense of validity, I was as rigorous as possible in describing minutely the actions both verbal and non-verbal, that occurred. In this way

alternative interpretations could be drawn by readers from the same data set. For this reason in particular, it was important as Denzin (1989:80) suggested, that indicators based on private acts (thoughts, dreams, fantasies, imputed intentions) never exceeded the number of indicators based on public acts and this rule was followed throughout the selection process.

Some of the behaviour exemplars are presented to the reader in full in Chapter 8 of the thesis. Others are presented only in summary form.

Interviews with the Participants in the Behaviour exemplars

Symbolic interactionists are interested in how people's understandings of their situation influence and guide their actions. Therefore, after each week spent packaging a ten-hour cycle of film, at the same time as the selected behaviour exemplars were being transcribed and undergoing a preliminary analysis, the subjects and other participants were approached and asked to view these behaviour exemplars and offer their own readings of what was happening[52]. The purpose of the interviews was to gather the variety of interpretations influencing the action and to gauge the opinions of participants about the outcomes of their interactions. By involving them in the interpretive process in this way, it was also possible to build in some protection against the sort of bias I described above in imputing motives unilaterally.

These interviews required a climate of open and frank discussion, where people felt free to share their own ideas without any feeling of obligation to frame their answers to suit my theoretical framework. As Douglas (1985:15) points out, interviewing is itself an instance of ongoing interaction and so subject to all the usual influences of rules, dynamics and talk conventions. I attempted to create an accepting environment with the use of open ended questions and a manner which conveyed that there was no 'right' answers. In the manner described by Easterday, Papademas, Schorr and Valentine (1977:66), I also adopted a role of an "acceptable incompetent", so allowing interviewees to feel what they said would be respected while they would not be laying themselves open to overly critical judgment.

According to Gadamer (1975) and to van Manen (1990:98), the ideal interview transforms the interviewee into a "co-investigator" and concentrates the focus upon the text, thereby avoiding the potential distortions of unequal power relationships. It was easier to maintain such a relationship with some interactants than with others. Predictably, because of their brain injuries, the four subjects found it most difficult to explain their actions in terms of underlying thoughts. Without videotaped interaction to observe, such a backward reflection would probably have been

beyond all of them. Even with the support of the film, they still needed a great deal of negotiative conversation to engage them in authentic interpretation and only managed well when the questions allowed them to describe what they could clearly see was occurring. Often, when a confused silence prevailed, it was necessary to offer tentative interpretations and to ask them to consider these, clearly risking imposing interpretations rather than drawing them out. Such interview material needed to be used with care and perhaps provided more insight into the nature of interactive process after brain injury than it did into the lived meaning of the filmed interaction.

The interviews with staff conducting formal therapeutic sessions revealed considerably more certainty about underlying motives and causative interrelationships. They were often able to articulate very clearly how and why they were fashioning their interactions to account for difficulties that they sensed or observed. Many staff clearly found this opportunity to reflect upon their practices extremely rewarding and commented upon how useful the film was as an educational tool in their own professional development. This comment was made as frequently by unqualified aide staff as by those with qualifications. These interviews were sometimes extremely long and revealing, offering a secondary source of qualitative data to assist the interpreting of the behaviour exemplars. Transcribing these tapes, supplying the participants with a copy and confirming that they were happy with the content of the interview, therefore consumed a considerable amount of the remaining week in each month, leaving only a few days to make some preliminary analysis of the findings before beginning the next cycle of filming.

This cycle of one week of observation to three weeks of interviewing, interpretation and triangulation of the perspectives of all involved was repeated over a second month for each subject, allowing some temporal grounding and the tracking of progress which might occur over a limited period. With Rob and Max the two sets of film did not show any particular differences, while with Mark and Bryce there was a noticeable change in their attitude toward recovery. In both cases the theme of increasing independence and resentment of the constraints placed upon them becoming pronounced in the second set. This was significant to the analysis of the findings for several reasons, but in general terms it might be said that the second month separated out the authentic themes of recovery from any more transitory influences, such as occurred in Bryce's second week when he suddenly became obsessed with a plan to become a mechanic, a plan which he discarded shortly afterward.

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[52] See appendix F for the question framework used to construct interview questions for this phase of the research.

ISSUES OF VALIDITY

No matter how naturalistic the nature of the inquiry, the research process itself must influence the findings to some extent. In the case of this study, this influence was predicted before entering the field and some consideration was given to minimising the effect. Fears that the process may have invalidated the conclusions can plague research of this sort and so these issues are addressed separately.

1. RELATIONSHIPS

This type of research relies heavily upon the forming of trusting relationships which encourage the sharing of ideas. As I explained earlier, I already had a role and some established relationships within the setting, but these underwent considerable change during the 13 month period of data collection as the research process gave me a more detailed understanding of undercurrents and interrelationships in the setting. This could have worked against the validity of the findings as perceived personal obligations might have caused me to temper my comments or drop some lines of enquiry and interpretation. However, I generally found people were eager to engage in critical reflection and, as they did not seem threatened by my questions and interest, I soon relaxed and adopted a relationship of co-investigation which most people appeared to enjoy. It is possible, however, that my concern to monitor and adapt for any slight changes that occurred in others' attitudes was causing me to be more careful than usual about how I spoke with people and what I said and chose not to say. Goffman (1961) warns that the sort of embarrassment which accompanies a sense of being exposed to a researcher may cause so much volatility that there is a total break down of shared understanding and I was particularly anxious to avoid such a situation because I intended to continue working at Waimarie after the research was completed.

The enactment of gender could also, in theory, have influenced my relationships with the subjects as they were all of the opposite sex. However, my age and marital status[53] appeared to minimise this risk and it was never apparent during the months I spent closely associated with each in turn. It was not so much gender as the degree of rapport (Denzin, 1989:118) which appeared to be a decisive factor in my relationship with the other participants. The degree to which I shared a common language and frame of reference may well have influenced the richness and depth of the data in some interviews. It was noticeable that interviews with my immediate colleagues in the education unit were longer and more intense than others.

[53] At 41 years, married, with three young children, sexuality was not likely to be a major issue between Mark, Bryce, Rob and I as they were all young and single and Max at 52, regarded himself as a settled married man.

Denzin (1989:116) also warns that normative rules of conduct within a setting may filter through and influence the structure of interviews, distorting the responses given to questions. The hierarchical system of role relationships at Waimarie and the division between staff and residents may have influenced the nature of responses. "The local context of social interaction plays a central role in the way language is used to convey power, deference, agreement, disagreement, social status differences and the like" (Cicourel, 1981:90). However, these issues were an implicit part of the thesis and the very fact that the field of inquiry contained many complex relationships made it more rather than less suitable for this particular study.

2. A VIDEOTAPE RECORD

The act of making an observation, particularly with the use of a video camera, actually creates attitudes and behaviours. Behaviour may be deliberately monitored so that only certain selves are presented (Denzin, 1989:117) or participants may be inclined to act in a "messageful" fashion (Denzin, 1985:81). Visual sociology cannot be regarded as capturing an objective reality, but should instead be seen as a "trace, or a picture of something that has been" (Denzin 1985:79) which may trick those who view it into believing that they are seeing 'truths' when in fact they are seeing what the person holding the camera focused upon. One face is followed while another slips from the frame, one person is viewed in close up while the other interactant wrings their hands in distress and goes unobserved.

In this research, however, the camera was used purely as a recording method and what was filmed was constrained by preordained rules to ensure the sample was representative of everyday interaction. This should have minimised the extent to which the filmed data distorted the reality of the person's experience. Of course, the film record was never expected to stand alone anyway. Any conclusions drawn from it were triangulated by interview data and interviews were held with all those who appeared to play a significant role in an interaction.

Even if there was still some room for doubt about the validity of filmed observation, there were just too many advantages to reject it as an option. The record it provided was far more complete than any other data source, providing as it did both the verbal and the non verbal experience of the four men. In addition, it could be viewed repeatedly, not only by the researcher, but also by all the participants. Interactants, even those with memory difficulties, were able to explain the interplay between perception, feeling and action and reveal how they interpreted others' actions simply because they were able to observe and reflect upon their own and others bodies as fields of expression. As Denzin (1984:140) explains:

> **Bodies are treated as fields of expression of their emotional experiences. On the basis of such emotional evidence, the other's joy, fear, shame, anger or embarrassment can be perceived in his voice, his facial expressions, his gestures and his language.**

Although film could not reveal the deeper structures of meaning, therefore, inferences could be drawn which could be triangulated later during the interview process. In this way the interactants were all able to contribute to the research as experts in their own interaction, simply because as Merleau Ponty (1973:45) points out:

> **We perceive the feelings of others not only their expression, we perceive them with the same certitude as our own feelings ...it is impossible to confuse in other people the redness of shame with that of anger, arousal, etc. Perception takes us a long way in to the comprehension of other people.**

Because emotional intersubjectivity was a key theme in this research, to draw upon this aspect of the participants' experience was essential.

3. THE EFFECT OF REFLECTION UPON INTERACTION

The subjects and those who interacted with them were asked to reflect self-consciously upon their actions and interactions, both filmed and remembered. They were asked to discuss the effect that their various actions had upon a situation and relate their underlying intentions and motivations. Engaging in such reflection clearly affected all those involved, whether staff, residents or family members. As it proceeded, the research raised people's awareness of interaction and its role in recovery. No doubt such an awareness influenced the staff and this may have distorted the findings. However, being assessed, supervised, trained, educated and in general terms, reflecting upon practice was the norm within Waimarie. The camera and the research interviews represented only another of many layers of observation and critical reflection.

4. OTHER INDEPENDENT VARIABLES

Participant observation, life history and film all rank high on all dimensions in Campbell's (Denzin, 1989:28, Table 1-1) treatment of external and internal validity. However they are regarded as "poor" at control of rival factors (Denzin 1989:31). Control of independent variables is, of course, impossible in this study, as it would be impossible in any study of human consciousness. Because of this, it was sometimes difficult to narrow down the causal relationships. There will always be an element of ambiguity about the factors responsible for change in interpretive schemes and ontology, however and this is a universal dilemma for human research which recognises people as meaning-making. I accepted before I started that a person will always evade total definition by another and regarded this as a cause for celebration rather than frustration. I was merely concerned to provide plausible explanations about interpretation and negotiation and to explore possible effects of cognitive and perceptual disorders. Ultimately,

whether or not others accept such findings is likely to depend upon how well they reflect, explain and confirm their own experience of consciousness and interaction rather than because they satisfy any objective measure of validity

ANALYSIS

Two separate reports emerged from the two forms of research; a life history report and an interactional one, each designed to complement the other so that together they could provide a comprehensive view of the lived experience of four people with brain injury. The following sequence charts the steps which the body of data passed through as it was systematised and analysed.

1. Collecting and systematising the life history material and writing a report which related each life to relevant theory.
2. Filming and packaging of the participant observation film and selecting the behaviour exemplars.
3. Interviewing participants to discover the variety of meanings influencing observed action and describing the interactive process in the light of both this knowledge and the theoretical framework.
4. Repeating these steps (one to six) for each of the four subjects.
5. Comparing and contrasting of the four life histories and identifying of common patterns and themes.
6. Comparing and contrasting of the four sets of analyses of the behaviour exemplars and identifying common patterns and themes.

A theme or pattern, the guiding principle of the systematisation process, was regarded as a "motif, formula or device which occurs frequently - embodied and dramatised in the evolving meanings and imagery" (van Manen 1990:78).

A MULTI-LEVEL STYLE OF ANALYSIS

At the risk of oversimplifying, it might be said that the most distinctive feature of symbolic interactionist research is the assumption of a dual structure to selfhood. For the purposes of analysing data about inner consciousness, however, I found it necessary to blend Mead's (1935) notion of an 'I' and a 'me', with Heidegger's concept of an ontic and ontological level to self, which may be defined as follows (Heidegger, 1967 cited in Denzin, 1986:14):

> **At the ontic or surface level of a person their life is a self, which persons call their own or themselves. This self is grasped as if it were a thing, with fixed entity-like qualities. The deep or ontological level of the person, sees the self, not as a thing, but as a process which unifies the stream of thoughts and experiences of the person around a pole or point of reference.**

The analysis of the videotape and the life history interviews was directed to discover these dual themes: the actor who in a variety of situations and roles, attempts to present a coherent image to the world and the inner feeling self manipulating actions and understandings to maintain a sense of connectedness and integrity. At the ontic level, a dramaturgical (Goffman 1969; 1968) style of analysis focused attention upon the nature and function of the roles being adopted. In line with symbolic interactionism, the subjects' and other interactants' actions and behaviour were interpreted as temporisations, manoeuvres, negotiations or justifications designed to maintain a consistency of ontic presentation. The ontological level of course, was the more difficult to account for adequately with this very special group of people. To explore an inner consciousness required a combination of phenomenological and constructivist theory. In line with the theoretical framework developed in the literature review, the frameworks and concepts of Kelly (1955), Gross (1987) and Goldstein (1952) were drawn upon to guide constructivist analysis, while those of Denzin (1984, 1987a, 1987b, 1986), Heidegger (1967), Gadamer (1975) and Sartre (1948), guided notions developed of the phenomenological lived experience. In particular, Denzin's (1984) theoretical framework of "emotion's body", which acknowledges the role of a physical, feeling body in interaction was relied upon. Because brain damage was the focus, such a framework, which allowed some separation out of the different levels of bodily consciousness or awareness was necessary in order to maintain control of extremely complex and interdependent data.

A separate but related issue for this research was the two levels of structural influences upon the developing self. At the first level each person's subjective "life-world" (Schutz and Luckman, 1973) influenced the meaning they attributed to events, causing some of the diversity in the interpretations placed upon the same life story or piece of film. Given the research question, it was important to regard any structural understandings, no matter how unusual and unrealistic, as "real in their consequences because they [were] being defined as real" (Thomas, 1928:571-2). At the second level, however, meanings were clearly structured and influenced by both the institutional arrangements of roles and relationships at Waimarie, as well as the wider social structure. There were two varieties of questions used in the interviews, therefore, to ensure both levels of structural influence were discerned. At the first order level, by asking 'how' questions, the research developed descriptions of a person's subjective experience of his or her social relations, while at the second level, by asking 'why', more abstract and sociological understandings of structure were uncovered (Denzin, 1986:15).

Causal explanations given by interviewees, whether staff or residents, were carefully examined to discern the influence of these structural understandings so that the impact of cognitive and

perceptual disorders could be understood in a wider context of social relations. In this way, by combining principles from interaction theory and causal-interpretive analysis, the invisible dynamics of social relations became more visible (Denzin, 1989:33).

HERMENEUTICS

Both these second levels of more covered up experience, the ontological and structural, required a hermeneutic analysis. As Heidegger (1977:86) explains it:

> **The methodological meaning of phenomenological description is interpretation, or hermeneutics which is the work of interpretation.**

Hermeneutics and interpretivism both shift the enquiry from behaviour to the intrinsic meaning structures underlying it. This empowers individuals by helping them understand why the conditions under which they operate are frustrating and "the sort of action that is required if the sources of these frustrations are to be eliminated" (Carr and Kemmis 1983:131). Denzin (1984:254-5) suggests that the following steps are involved in such an analysis:

- uncovering and describing the understandings that the people approached the situation with;
- displaying the "after-interpretations of the act";
- showing how the features of social structures might be shaping and modifying the experience;
- fitting this knowledge into an "interpreted totality" (Denzin 1984:8) which should display the interactions as they fit within their structures.

The process of hermeneutic interpretation was at first linguistic and descriptive, as the sequential acts that made up a behaviour exemplar were pieced together. It then became an interpretive process, a social psychological endeavour, where possible inner meanings of the acts were postulated. As the data passed through these processes, the role of the feeling, interpreting person remained the central focus and what was studied was "persons and their moments, not moments and their men"(Goffman, 1967:3).

INTERACTING THEMES

A self which is adaptive and purposeful must, by definition, be a self which is capable of sustaining a range of meaningful reciprocal relationships with others. In community settings, it would be difficult to follow through the development or reestablishing of such relationships during a recovery period. Spontaneity is an essential and perhaps even a defining characteristic of interpersonal relationships. In the setting of Waimarie, however, the two month period each subject was filmed was sufficient to observe the development and change within a number of different relationships (primary, secondary, reciprocal and complementary) and to develop a

greater insight into the impact that cognitive and perceptual problems had upon the negotiating of shared realities.

An important goal of the film analysis was to lay bare the processes which supported or thwarted the attempts of the four men to build mutually satisfying relationships. The interview questions were designed to ensure that the other participants would explore their own relationships with the four subjects. I originally assumed that any responses would be confined to the particular behaviour exemplar observed, but soon discovered that when it came to discussing relationships, people ignored any such artificially imposed limitations. All those I interviewed (but especially the professional staff) tended to call upon their past experiences with the person and their own theoretical and philosophical frameworks, as well as regularly fleshing out the observed interaction by describing the sequence of events which preceded and succeeded it. As a result, the interviews were a richer source of reflective insight than originally envisaged, but they created a body of data which it was difficult to organise into separate themes. All the interviewees showed a tendency to broaden an instant into something typical or something a-typical and to reframe situations so that they reflected a personal or professional issue. By the completion of the first cycle of filming I had realised that any format and concepts I used to discuss my findings needed to be as interactive and interlinked as the nature of the data. Eventually, broad theme areas emerged but these were interconnected sensitising concepts as opposed to rigid categories and because of their entwined nature, it was often difficult to apply second order and theoretical concepts appropriately or confidently. An example is the theme of 'waiting'. There were large amounts of film where each of the four men 'just sat'. Usually these times occurred when there was a gap in a timetable and sometimes when the person was told that 'something would happen soon'. When I packaged film of this sort, I initially made observational notes along the lines of unassertive body language, lack of frustration or irritation and as a theoretical note, I initially wrote simply 'altered temporality' and 'institutionalisation' in capitals with question marks. However, when I interviewed people about these waiting periods, I discovered that there were several other explanatory themes emerging, some of which suggested quite opposing interpretations. As a result, the themes and concepts which seemed applicable multiplied. The use of the passive voice seemed implicated, for example[54], suggesting the use of "dasein designations" " (Heidegger, 1967 cited in Wilden 1968:181) to control people and yet the slower pace of information processing, may equally have created this passivity. Having wrestled with multiplying themes in this way, it became clear that it would be necessary, not only to isolate and define interactive dynamics in Goffman's sense, but to link them convincingly to the intra-active

dynamics. This created a complex interlinking framework of key findings which confirmed Goffman's (1968:13) assertion that understanding human behaviour requires the study of *relationships,* not *attributes.*

CONCEPTS

This focus upon the relationships as opposed to the attributes of recovery provided a novel approach to many current issues in the field of brain injury rehabilitation. Perhaps the most novel aspect of the research was the concepts I employed to discuss disordered brain processes. Recovery was understood as the building of effective and authentic ontological schemes. While this might immediately make sense to someone with knowledge of phenomenological and symbolic interactionist research styles, it was very important that I made any findings just as accessible and credible to people from other theoretical disciplines. To accomplish this, I made use of some established neuropsychological and psychological terms describing interactive processes, consciousness and self and linked these concepts with their apparent counterparts from the fields of phenomenological and sociological knowledge. By constantly juxtaposing concepts from different disciplinary perspectives in this way, I hoped to demonstrate how a symbolic interactionist perspective, with concepts which focused upon the dynamics of meaning-making, could provide more insight into the lived experience of cognitive and perceptual disorders.

The symbolic interactionist concepts which were particularly important were *self, role, symbol* and *negotiation. Ontology, authenticity, transparency, disturbance* and *manipulation* were central concepts drawn from phenomenological theory, while *arousal, integration, cognition* and *perception* were drawn from a neuropsychological knowledge base. *Scaffolding, shaping, modelling* and *prompting* were employed from the field of learning theory. In line with the research question and the stated aims and assumptions of this research, all these concepts were applied to examine how interactive strategies promoted or prevented *adaptivity, purpose* and *independence*, the three qualities which suggested an authentic and integrated self.

Good symbolic interactionist research should always explore the nature of links or interactions between concepts rather than attempting to measure and quantify them. For this reason the concepts used were treated as "key linkages" and "substantive and logical levers" (Strauss and Schatzman, 1973:111) with which to explain situations and, in recognising human experience as emergent process, constant distinctions were made between sensitising and definitive concepts

[54] eg "The van will be arriving soon." "You will be collected this afternoon", "the concert has been arranged" etc.

(Bulmer, 1984:243-4) so recognising instances where problems have been caused by defining and understanding process with the use of static constructs.

PROCESS

Bearing in mind these concerns with the multiple levels of inquiry and remembering that the focus was emergent process not static deficit, the analysis phase of this project can be seen as directed toward the discovery of the "abductive insight which makes apparent what was previously taken for granted" (Denzin 1989:101). Analysis is essentially an intuitive process and has been called "primitive and unmanageable in any rational sense" (Miles, 1983:127). Any symbolic interactionist recognises the risks of imposing an interpretive framework upon any human experience and yet as Miles (1983:113) has pointed out, it is essential to impose some such framework. What was essential to the process of analysis in this case was to systematically compare the data with the theory in order to develop explanations which satisfied each.

A variety of different analytical processes occurred therefore, at different stages in the generation, testing and refining of hypotheses. Accordingly, the analytic process could be variously described as:

- inductive, developing "grounded theory" (Glaser and Strauss, 1976);
- deductive, confirming some of the theoretical positions established in the literature review;
- "analytic induction", eliminating negative cases in a cyclical fashion (Lindesmith, 1947);
- "retroduction", the term Bulmer (1984:247) gave the process of comparing data and theory simultaneously in the creation of insight.

In writing down my findings, I have used a discursive format, attempting to provide the reader with as much opportunity as possible to examine the steps of reasoning which were taken in reaching the conclusions drawn. For this reason too, copious verbatim extracts were taken from interview transcripts and I regularly incorporated small extracts from the behaviour exemplars in the text of the discussions.

SUMMARY

This research was designed to be a phenomenological, interactive and interpretive inquiry, the aim being to critically examine the relationships occurring during recovery from brain injury and consider which styles of interaction were most effective and empowering for the subject group. The methods were chosen to provide thick, rich data about inner intra-active processes, which could be considered alongside more observable incidents of interaction.

Because of the nature of the research question and because of the cognitive and perceptual difficulties of the subject group, considerable triangulation was built into the design so that 'what was happening' could be defined the broadest possible sense. Life histories were first collected to place the experience of head injury into the context of a life and the four subjects were then filmed as they lived their daily life in a residential rehabilitation programme. The film collected included formal one-to-one therapy sessions, group situations and informal interaction in the living areas, dining room and passageways etc. The four people (and also those with whom they interacted) were then shown selected excerpts from this film and interviewed about what was happening.

Using phenomenological description and qualitative interviewing, some insights were gained into how people resolve the problem of continuing to interact with their world when it is difficult for them to make sense of it and interpret it and how other people (as an audience, or as fellow members of a group), tend to respond to them. Some common themes and patterns were identified and conclusions drawn as to how other people's interventions affect the process of recovery. In order to accomplish this, it was important for me to maintain a position as a "simultaneous insider/outsider in a position to generate creative insight" (Lofland, 1971:97) and conduct a style of analysis which encompassed first and second order levels of structural understanding as well as ontic and ontological levels of self.

Ultimately, the study was designed to "offer more than a sociological description of role relationships. The goal [was] to find out the wisdom, frustration, puzzles, dilemmas and knowledge embedded in practice" (Benner, 1985:12). In the next chapter, the first of four 'before and after' life histories is presented as the first step toward this goal.

CHAPTER 4

ROB JOHNSON'S STORY

THE ACCIDENT

Rob Johnson was celebrating on the night of his accident. It was the end of a Salvation Army 'PEP' course[55] that he had been attending in Camberton, his home town. The people taking the course were all young and single and had become good friends. The supervisor had organised a barbecue for them, at a lakeside recreation area near Camberton.

Rob's father felt that what happened next was the result of an unfortunate error of judgement by this supervisor, in providing alcohol and then leaving the group celebrating alone.

> **FRASER JOHNSON (Rob's father): They were going to come back and pick them up. He came in to do something in town or something and left them out there ... all the workers there but they left them to it and, there was no one there looking after them - they had booze and were smoking drugs and things like that -**

Rob, only 16 years old, did not have the experience or the maturity to handle this sort of situation. Along with several of the party, he was soon drunk or 'high' or some combination of both. In their intoxicated state, it seemed a good idea to pile onto a 'ute[56]' (some in the cab and others including Rob, on the trailer) and tear around the grassy area beside the lake:

> **FRASER: He got on the back of the ute with his friend - a girl - driving and he had a girlfriend with him on the back and they must have had an argument or something and he came off the back of the ute - the girl that was driving was a European girl, she was doing, or she said she was doing, about 70 -80 ks an hour when he fell off -**

Rob hit the ground hard, head first and his life was suddenly and abruptly transformed.

CHILDHOOD

Rob grew up as the middle child of five in a closeknit Maori family. He had two older brothers and two younger sisters. His father worked as a truck driver for the local County Council and his mother had a cleaning job in a nearby boarding school. When he began school the family was renting a house in the country, but soon afterwards they moved into town. The house they moved into was on his grandmother's land in Camberton and as well as being right next door to her on one side, on the other they were neighbours of Rob's uncle and his family. From then on he was

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[55] These courses, funded by the Government at the time, were for young people who needed extra skill training to become more 'employable'. This particular course had been running for twelve weeks.

[56] a 'ute' is a New Zealand colloquial term for a motor vehicle which has an enclosed cab for driver and one passenger, and an open tray at the rear for carrying freight rather than people.

part of a close community of relations and friends, always in and out of each other's houses and sharing each other's cares and triumphs.

If you asked anyone who had known him during his childhood, the first thing they would mention about Rob was his sporting ability. Coming from a family full of keen sports people, Rob appeared to have the most outstanding talent of them all. His father spoke of these skills as being so good they were possible future career options. The children in his family were close in age and so Rob had two older brothers to practise his boxing and rugby with. Perhaps because of this he shone at both at a remarkably early age. At thirteen, he was the first Camberton person selected for the Junior Provincial Representative Rugby team for thirteen years, as well as being the youngest player in the side and then later at fifteen, he was the runner-up to his brother as provincial boxing champion.

Rob was extremely proud of these feats and treasured the photos and other memorabilia from those days. When he told me about these triumphs it became clear that he was proud not so much for himself, but perhaps mostly because of the thrill he gave his whole family and community:

> **ROB: ...they've even got a photo of me at school, in the hall!**

For the whole extended family, sport was extremely important. Although, with five children, money was often tight, there was always enough for the boys to take up any sporting opportunities.

> **FRASER: We went to all the championship tournaments....We were going all around the country and stayed in motels.... We always made sure we had enough for our sport because of the love of it.**

Perhaps because everyone in the family was equally committed to sport, the family lifestyle could revolve around these competitive activities without it causing any friction. Rob and his brothers and sisters always got on well with their parents and were never in any sort of conflict with police or other authority figures. He was not a paragon of virtue, however. His mother remembered Rob fondly as the most mischievous of her children:

> **PIRI JOHNSON (Rob's Mother): He used to be a rough! I'd buy him shoes and then he'd wear his old ones and then he would have long pants dragging on the ground and he would walk with them on, oh and he had long hair and - real scruffy! Yes, he was always the mischief one of the family.**

His father remembered him being the laziest:

> **FRASER: Rob was the only one that wouldn't train hard. He would try to find a way out of it all the time!**

Both parents also particularly mentioned the special relationship Rob had with young children. There were several smaller cousins about as well as his younger sister and he always had time for them. As a result he was the object of some hero worship, particularly for his younger sister, Maryan:

> **FRASER: She used to look up to him because he used to come home and she liked his dancing, he was quite a good dancer you know. Yeah, he used to do a lot of Bop and rock and roll and that and she used to be quite rapt in the whole thing. See, to her, he was about the favourite.**

Rob's own memories of childhood were very pleasant, if a little vague. Although he would first mention the importance and thrill of his sport, alongside it and just as important, he would have placed the memories of belonging to a close and loving family. He also remembered particularly the importance of his grandmother:

> **ROB: She was right into her Maoritanga[57] eh? and like, talked Maori and the kids, children, they really latched on to her and she really spoils them eh -"Hey a lolly, go to nanny..." - even visitors - like "where's your visitors Rob? - give them a cup of tea - heres your friends, come inside, go and make a cup of tea - go and make some bread and a cup of tea!" And I go "Nah, nah, nah - they're all right Nan." "Go and make some tea- go and make something." "Nah, No, they're all right we had a feed" - "Nah, ah rubbish - rubbish - some bread, butter in the cupboard, have a cup of tea.", "Okay then Nan, okay." Then, .. "Hey boys, go and catch up with the wood and start the fire...". "Okay" I'd go and go and chop wood..."**

When it came to school, however, Rob's memories were not quite so positive. School was something he had to do but would rather have avoided. He regarded himself as "dumb", and when he was put in the work experience class at College, he clearly believed this proved it. His parents agreed that for Rob school was never a great success:

> **FRASER: He only went to school because he wanted to play rugby on the Saturday or something like that. He couldn't get on with his teachers.**

There was considerable evidence to suggest, however, that he was quite capable of learning when he wished to. His basic literacy and numeracy skills appear to have been perfectly adequate and he managed to memorise his road code quickly, getting his licence at fifteen, the first of his peers. His parents were tolerant of his negative attitude to school work, being sure that he would be perfectly competent in learning any necessary skills when he found his niche.

> **PIRI: If he would have put his mind to it he could have been okay... He was certainly capable of doing things that he wanted.**

At fifteen, Rob left school and moved to another uncle's place in Limmerton, a nearby city, so that he could attend a work experience course. From then until the time of his accident a year and a half later, he kept himself occupied in courses or short-term jobs, not really directed toward a career, but enjoying himself. Neither he nor his family saw any need to plan ahead, regarding him as still young. His money was spent on his sport and his girlfriends and as soon as possible, upon buying himself a car.

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[57] The Maori expression for Maori culture or Maori ways of doing things.

Rob clearly had a very active social lifestyle at the time of his accident. His friendships seem to have developed both from his sporting contacts and his job courses. There was as a result, a large crowd of young people he knew and mixed with. Among them several had been girlfriends, but there was one special girl, Gina, with whom he had had a steady relationship for some time. When he told me the story of their meeting, he demonstrated that he had, at that time, a confidence with girls that eludes many teenage boys:

> **ROB: She was a netballer - I met her playing softball against her school - her school come and they want the talent, the best guys in the school to play softball - and there were thirteen of these guys - I got to play and I was pitching and I pitch a ball and hit her on the side and then I went "You all right, you all right?" She said, "Yeah." "I'm sorry [I said]- well - you can take a free run - you can run for free - hows that?" - Afterwards, I go up; "You fellas talking?" She goes, "You go up to Benny's? the Space parlour?" I go, "Yeah." She goes, "I meet you there after school -"**

His fondness for Gina was clearly evident in his talk of her. By the time of his accident, their relationship was a long-standing one of shared interests rather than an adolescent's tentative experiment with the opposite sex.

Another characteristic of Rob that everyone laughingly agreed to, was that he was very accident prone. While the term 'accident' might suggest co-incidence, or events over which he had no power, the pattern of the accidents he had suggests a person sometimes a little reckless, overconfident of his own physical strength and ability[58].

> **PIRI: He's been hurt more times than any of the others put together.**
> **FRASER: Yes, hes had back trouble, neck trouble and been electrocuted—**
> **DS[59]: How did all these accidents happen ?**
> **FRASER: Most of them were through rugby, but one was at the Camberton primary there where he was sitting on a rail, I suppose he was acting the goat and he come off and put his neck out or his back out... Yeah, so everyone in the hospital or the ambulance all knew him because they had taken him to hospital that many times!**

The young man who was celebrating at the lake that night had a special place in the hearts of all his extended family, as well as being admired and respected by a wide circle of friends. In his sixteen years of life he had shown the potential of becoming an admirable adult.

THE FIRST DAYS AFTER THE ACCIDENT

When his parents first arrived at the hospital, they were told to expect their son to die, probably within the hour. This shattered Fraser and Piri, who had arrived thinking this was just another of Rob's many accidents. Frantically, they rang other family and quickly word spread. Soon his family and friends were all gathered around his bed in the Intensive Therapy Unit, or "ITU" as it is called.

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[58] this profile (of a risk-taking and physically-oriented person) suggests that Rob was susceptible to head injury as noted in the literature review. See Chapter 1, p. 11

[59] The initials DS are used throughout this thesis to signify the researcher and writer, Deborah Sutherland.

Rob's accident occurred in 1986, the earliest of the four accidents described in this study. It is interesting to note that then, Limmerton Hospital placed no limits upon family presence[60]. The parents remember they were encouraged to stay with him as much as possible, in whatever numbers they wished. They took full advantage of this arrangement:

> **DS: And did you sort of go in shifts, did you?**
> **FRASER: Yeah. In ITU[61] while he was still unconscious there.**
> **PIRI: They said to talk to him, play tapes to him and squeeze his hand, give him a pinch or two.**
> **DS: And you did?**
> **FRASER: Yeah, we did, we spoke to him all the time.**

Piri and Fraser remember that they censored the subjects they talked to Rob about as he lay unconscious, making their talk to this precious son about only the positive and happy things. The emotional distress, the terror and fear of death, was carefully hidden.

> **DS: What did you talk about? Do you remember?**
> **FRASER: Just things that he used to like. If there was a rugby match on the score of the rugby match and the team that was playing. ... Yeah. We used to talk like that to him, but as though he was away. I know he was there with us but not, you know -**
> **DS: Not emotional?**
> **FRASER: Yeah, we never spoke of the emotional things.**

It sounded, from the family's description of the first days after Rob's accident, as though Limmerton Hospital was soon inundated with huge numbers of family and friends who wanted to "be there" for Rob. When told about this later, Rob was very proud of the fuss made of him.

> **ROB: Yeah. All my relations came up to the hospital - all the ward was just full of my relations they reckon. And next minute they reckon, "Yes Rob, you were the most popular, popular of all the patients we have ever had they reckon - little kids running round eh, ... too much - gee I really feel good... .**

For the family, the support of close family and friends was very important at this time. Both parents felt that they could not have found the emotional support they needed from someone employed by the hospital for that purpose.

> **FRASER: It was only our family - her [Piri's] family and my family who were always with us - that took a lot of the weight off our shoulders. I think if we didn't have them, we wouldn't have been able to cope. ...Brothers, sisters, my mother, she was still alive then and my older sisters and my aunties and her sisters and her cousins and her aunties.**
> **PIRI: They were all there.**
> **FRASER: Yeah, they were all there.**

The hospital arranged for them to stay in the Nurses Home and as a small community they supported each other during the early days of Rob's deep unconsciousness. Although Fraser and Piri had no strong religious persuasion, in this time of crisis they turned to Maori healing methods which used faith and prayer. Fraser's mother, who was a committed and active member of the Ratana church, was able to provide guidance in these ways of healing and clearly this gave all the

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[60] In later stories and particularly that of Bryce Lawson, it was apparent that Limmerton Hospital limited the numbers of visitors, explaining to families that too much excitement and stimulation might be harmful.

family considerable peace of mind and emotional support. Of particular significance was one small glass object which assumed a great importance in the minds of the family. The medical staff clearly accepted the importance of this glass object for the family.

> **FRASER: We use to say a few words over it you know and it helps. I didn't really have anything at the time and Mum had this little glass thing. And she carried that with her wherever she went and blessed herself with it and, she gave me that to put in Rob's hand while he was unconscious. And said, "tell the nurses and Doctors not to take that out of his hand while he was unconscious, no matter what." So I told them that and they left it there with him.**

To this day, the family believe Rob would have died were it not for this glass object. Even the fact that it broke after the first few days was regarded as an auspicious omen:

> **DS: Did you feel any change when Rob had this with him?**
> **FRASER: Oh yes defmitely. Well they only gave him an hour to live -**
> **PIRI: Defmitely.**
> **FRASER: Look at him now! And it was through that glass that he had from mum because when he came out of it and they moved him out on a ward, that glass just fell off and broke into little pieces....I was really upset when it broke, thought I'll have to pluck up courage to tell my mother that her thing had broken and she said, No that's all right, its done its work.**
> **Ds: That was sort of a sign?**
> **FRASER: Yeah, that it had broken.**
> **DS: Now its up to Rob?**
> **FRASER: Yeah exactly.**

And so the first days passed without Rob dying and then gradually he began to "wake up". The family then had to become accustomed to seeing this once healthy and strong young man as totally helpless and dependent:

> **PIRI: He was a lot like a baby.**
> **FRASER: I think a new born baby was better!**

Rob's state can not really be described at this stage of his recovery, as consciousness. He was in a state known as "Post Traumatic Amnesia" or PTA[62]. PTA can confuse families because although they appear to be awake or alert, people's behaviour shows no evidence of thinking ability or information processing at all. It requires a suspension of all the normal assumptions we make about the awake state. While some broad awareness of who he was returning to him, he was extremely confused and disoriented about where he was, why he was there and how long he had been there for. His day-to-day existence was not becoming a part of him as he lived it because he was not able to make sense of his experience.

As well as being unable to process information, Rob seemed unable to behave appropriately. This caused some initial embarrassment for his family:

> **FRASER: We used to laugh about it. Well, I didn't really at first, I was quite concerned with him. It was when he just come out of his coma - the nurses beside him, you know, his hands**

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[61] ITU is a commonly understood abbreviation of "Intensive Therapy Unit", the ward in New Zealand hospitals to which people in a coma are admitted. In ITU a person's physical condition is constantly monitored with a range of technological equipment and there is a one to one nurse/patient ratio.

[62] See Chapter 1, p. 20

used to wander you know, used to go up their dresses and everything you know (laugh) and ah, they used to talk to him - "Hey Rob, don't do that!", But he used to always go back up ...

This out of character, socially or sexually disinhibited behaviour is common[63]. So is the sense of embarrassment and bewilderment about it which family feel. Linge (nd:1)[64] equates this state with regression:

At this time, my wife thinks that I had regressed emotionally to almost an infant state, wanting to touch her and the nurses, wanting to hold on to her hand and becoming agitated if she had to go for even a moment.

The medical staff would have had previous encounters with this loss of inhibition and were probably less surprised or offended than the family imagined. And yet some judgments about who Rob 'was' were very probably made at this stage and he began to acquire a character, and a rather 'naughty' reputation, something which in retrospect rather pleased him.

The duration of this period of PTA is often regarded as being a reliable measure of the severity of injury and the likely long term outcome (Jennett et al., 1981). Rob's PTA lasted six weeks, enough to have him classified as very severely injured. During this time, he could not have remembered what he had done two minutes ago, let alone yesterday and his behaviour was therefore confused and 'blank'. When he emerged from this state, Rob suddenly became aware of himself and others again.

PIRI: All of a sudden he just got better.
DS: He suddenly just like that went back to being Rob?
PIRI: Yes.

His mind may have been under his control again at this stage, but his body certainly wasn't. Apart from his right arm, which had some very shaky and awkward movement, Rob seemed to be unable to control his body at all. No one would yet offer any firm predictions about the implications for the future, but it was becoming clear that in the short-term, anyway, Rob was going to have to cope with a profound level of physical disability.

FRASER: Yeah well, he couldn't even sit up. He couldn't eat or anything, they used to put a piece of bread with a bit of marmite on it and stick it in his mouth and he used to just suck away at it until it was gone.

He was moved to the rehabilitation unit of the hospital. It was at this stage in telling their story, that Rob's parents began to report feelings of dissatisfaction with Limmerton Hospital. The Rehabilitation Unit was not really geared for young males with head injuries. It seemed, sometimes, that they did not really know what to do with him.

FRASER: No - they didn't really do any good for him there eh?... it was all elderly people there and all they did was just let him roam around and give them their meals and that's it - they had his physio there but that's all they had.

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[63] See Chapter 1, p.28.
[64] Linge (nd) is a psychologist who wrote material for workshops based upon his own experience with head injury.

Although it was clear he would have to concentrate and work hard to master everyday living skills again, Rob was so vague, disoriented and confused it seemed he could not relearn even who and where he was. His cognitive needs made him out of step with the other clients of the Rehabilitation Unit and because no speedy return to mobility occurred, the hospital staff appear to have changed their working definition of him around this time. What problems he still had became reclassified as longer-term disabilities rather than immediate rehabilitation issues and the talk changed from recovery to adaptations and community facilities.

As the hospital began to talk to them about discharge, Fraser and Piri Johnson became increasingly concerned about the lack of mobility and independence. He was clearly totally dependent upon others for all his daily needs, yet both parents worked during the day and needed to continue working to meet the family's financial needs. They could see that their son was not ready to be left on his own. The hospital assured them that they would make arrangements for all his needs to be met from home and for rehabilitation to continue on an outpatient basis. Four months after his accident he was discharged home.

SIX MONTHS AT HOME

At first, Rob and his family felt capable of making this new arrangement work. Although a little nervous, they were all feeling positive and hopeful about the future. They saw Rob's continuing physical and cognitive disabilities as temporary. With the promised support, they thought they could manage until he had completed the rest of the recovery process and become fully independent again.

The hospital did, as it had promised, put in place some arrangements for Rob's ongoing rehabilitation. The trouble was with the quality of those arrangements. Firstly, his day was to be organised for him. During week days he would be attending "Accomplishment House[65]", a sheltered workshop. Soon they came to realise however, that Rob and "Accomplishment House" were not going to get along together well.

> **PIRI: That was - he was just there - and put pegs in a plastic bag and all that stuff.**
> **FRASER: There was nobody with like head injuries there - it was all intellectually handicapped people.**

Rob's family didn't blame him when he stopped going.

> **ROB: Everybody was mad there - it was supposed to be like a job, but everyone that was there was...it's not like a job. Just do that all day!**

[65]This Pseudonym was selected because of its similarity in implied meaning to the real name. I felt it was important to preserve the meaning of this name because of the irony in its use and because of the slight air of patronising which it conveys.

Secondly, the hospital arranged outpatient treatment but only in the form of physiotherapy, no support for his problems with memory and information processing was made available. Since the family also defined his problems as purely physical, no one challenged this arrangement. The family members, (not surprisingly, considering the high value they placed upon physique and fitness) had high expectations of the physiotherapy process and were eager to support and encourage any efforts to get him walking and moving freely again. However, the hospital staff had assumed a commitment of time and transport which the family were incapable of managing.

> **PIRI: I was taking him to Limmerton Hospital for physio and it got hard for me - because Fraser was working, I couldn't drive, you know, and these others were coming here and picking him up and taking him down there and he went to shelters, you know sheltered employment and they wouldn't let the van come here to pick him up. I had to do that.**

Although the Johnsons attempted to sort out these logistical problems, arrangements continued to fall through, people who were supposed to look into the situation somehow never got back to them and they were left with a vague feeling that the hospital found them a nuisance. Gradually, over the months, the family became disillusioned with the service they were being offered. They felt cheated, that Rob deserved more from the health system than to be dumped back home in the early stages of his recovery. They wanted the best for him and instead, medical people seemed to expect them to make do with anything, so long as it kept him occupied and did not involve using too many of their limited resources.

> **FRASER: Yeah, nobody seemed to know what - seemed to want to help us here. The doctors soon as he was well enough to come home they said, "You can take him home."**
> **DS: and you were saying basically, "You should do more"?**
> **FRASER: Yeah, we just couldn't get no support from anybody up here.**

After six months of this struggle to get by, Rob's parents had had enough. Rob was doing virtually nothing for himself and spent most of his time sitting in his chair unstimulated and lonely. Piri was determined not to be fobbed off again when she approached the hospital again and asked for someone to review their situation:

> **PIRI: I was going around the bend so I took him back to Ward 22 and that's when Michelle Hunter got hold of him.**

This time, Rob was referred to a social worker who took the family's needs more seriously. She was shocked to see how little Rob was doing with his day and how little progress had been made in the six months since he left hospital. She arranged for him to be readmitted to the rehabilitation ward and called for some new reports, saying she believed it was important to reassess the whole situation and "restart" the rehabilitation process in his case.

The new assessment did not turn up many surprises. Everyone quickly reached agreement that the home placement had been inadequate, that he was not (and had never been), independent enough to cope in the situation into which he had been discharged six months earlier. With the

benefit of hindsight, it seemed a further period of rehabilitation in a residential setting would have been preferable and should be considered again. The nearest residential centre for rehabilitation was Waimarie, five hours drive away. This was a huge distance to a family like Rob's, where both parents worked all week and the sporting activities of the other children were the central focus of the weekend. To drive down to visit regularly was clearly going to be almost impossible and yet there seemed to be no alternative. Piri and Fraser felt unable to refuse. An application to Waimarie was made and it was arranged that Rob move there, with the specific goals of increasing his level of independence in daily living routines so that his family could manage at home.

FROM REHABILITATION TO RESIGNATION

It was 1989 when Rob Johnson first moved to Waimarie, five years before the time this study was conducted. During the period of the research however, the staff still regarded themselves as working upon this same task of rehabilitation. Although Waimarie's role is to offer a 'slow stream program', five years seemed a very long time to be spent still accomplishing this original goal of maximising independence. In fact, there was much in Rob's daily life to suggest that aggressive addressing of his disabilities had been forgotten long before. It appeared that Waimarie was no longer so much the agent of Rob's rehabilitation as it was his home. Slowly but surely, living in a rehabilitation programme become a particular way of life. It is interesting and perhaps instructive to reflect further upon how this situation eventuated by tracing the story of his transition from rehabilitation to resignation.

WALKING

For the Johnson family and Rob, 'walking' summed up the principle goal and even perhaps the full meaning of recovery at the time of his admission to Waimarie. Because of this they focused upon any talk about walking, perhaps hearing what they wanted to hear more than what was indicated to them. This caused a number of accumulating misinterpretations and confusions to occur over the years which followed. When, soon after Rob's arrival, the doctor at Waimarie suggested an operation to lengthen tendons might assist mobility in his ankle joint, the family believed that this was an operation "to make him walk again". They were delighted, even though they believed the doctor warned them not to expect a total recovery:

> **FRASER: So that is his goal, this, he wants to walk again and ah, there's a doctor down there that said he could he might be able to, 99 percent, you know. It won't be 100 percent.**

Unfortunately their polite reticence and the distance from Waimarie meant that this misunderstanding remained uncorrected. As the years passed without this miracle operation

happening which would return 99 percent of his walking ability, they felt frustrated and powerless that their son was being denied his chance to walk. The medical system must have seemed incredibly heartless from their perspective:

> **FRASER: Yes, but the Doctor said he could go and have surgery and we've given our consent on it but that's, how many years ago now?... Well there was going to be a 99 percent chance - Even that is better than no percent at all.**
> **DS: That he could walk?**
> **FRASER: Yeah, I'd like to see him get up and walk.**

When I discussed their ideas about the operation with them, it became clear that considerable effort had been made to explain clearly what was involved and the confusion was solely in the meaning of the word "walking". Unfortunately, this was very much the key word in this particular issue.

> **DS: Do you know, did you understand what the operation was going to do?**
> **FRASER: Yes, they were going to operate on his achilles heel because his foot always went to the side and they were going to cut the muscle there somewhere and lengthen it so that he could put his foot down properly on the ground.**
> **DS: Right, is it sort of contracting up?**
> **FRASER: Yeah and they said that there was a 99 percent chance he would walk then.**

To the physiotherapists involved with Rob at that time, a useful level of walking was no longer attainable. Rob was already able to walk a short distance with the support of a walking frame or something similar. The operation would[66] slightly improve the mobility of his ankle joint, allowing him to roll on his foot more smoothly during the walking process. The damage to his motor control, however, had been very profound. Any moving of his legs was a huge effort involving considerable concentration and he had very little ability to balance and manipulate his body. A more mobile ankle joint was not going to affect this and could never, therefore cause any dramatic change in walking. It appears that when the family and the medical people talked to each other about walking, they misunderstood each other mainly because to the family the word 'walking' implied a fully functional normal walk, while to medical staff it implied any approximation of the process of balancing on two feet and moving forward, even if with the aid of some support[67].

Of course, while they were waiting for an operation the family did not think about the future for Rob, believing that walking was the key to recovery. They felt some disappointment with

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[66] This operation did improve the mobility of the ankle joint when it was performed shortly after the research was completed. It appeared that the long delay had been caused because the operation was always regarded as offering only a slight improvement in Rob's walking ability and so it had not been given a high priority by medical personnel.

[67] A transcript of this section of my interview with Rob's family was made available to the clinical team and subsequently, the purpose of the operation and the realistic expectations were explained more fully to them.

Waimarie for not concentrating more aggressively upon it with Rob. When asked to describe his conception of the perfect rehabilitation programme, Rob's father responded:

> **FRASER: If I had the money, I've always said this, I would have sent him off to somewhere where he'll get that kind of treatment you know, to get him back on his feet. I've heard over in Australia, or in America there, where the head injury patients are gone through, had these operations and all that and now they are walking around today.**

HOUSE ALTERATIONS

The second major misunderstanding about the role of Waimarie occurred later during the five year stay and was also related to this confusion about the meaning of the word 'walking'. This concerned the organising of house alterations.

The social worker arranged several meetings with the family at which the future was discussed and an occupational therapy report had made it clear at the time of these discussions that if Rob was to return home, it would be necessary to alter the family home. Extensions would be needed to provide him with his own living space and the house would need to be adapted for a motorised wheelchair, with special facilities to make showering and transferring himself more easily accomplished. The family agreed to these suggestions and followed instructions to set in place the ACC process necessary to have such alterations carried out. This process required quite complex arrangements, including hiring an architect, calling for quotes and filling in appropriate forms with the proper authorities. Each official body seemed to require pieces of paper from the other official bodies and the whole matter assumed huge and tangled dimensions, putting it beyond the scope of any one person. A great deal of complicated correspondence crossed back and forward between Waimarie, the Johnsons and all these agencies, sometimes leaving everyone under differing impressions as to who was responsible for the next step. Months would go by with everyone comfortably assuming that something was being done only to discover that it was not.

These ongoing confusions meant that for months at a time no progress would be made on the alterations. The staff at Waimarie began to wonder whether Fraser and Piri were feeling so nervous of having Rob home that they were resisting the attempts being made to place him back there. They knew that there were problems at home at the time of his admission and Piri had been frank in stating from the outset that she would not be happy to have him back home unless there was more commitment and support from the health system. There was now developing, among some of the staff who had spoken with them, a feeling that the family believed a setting such as Waimarie offered more than they would be able to and that it was not in Rob's interests for them to actively encourage his return to home. It was possible they felt that some of the delays were the result of a passive resistance on the part of the family.

Back in 1989, the short-term rehabilitation programme was only just beginning to be developed at Waimarie. Most of the residents Rob interacted with had been living there for years. It is possible that this encouraged him to think of himself as settled. Gradually, he developed a contented dependency upon the regular meals and the caring service provided by staff. There was a growing danger that it was institutionalisation rather than rehabilitation that Rob was going to receive from Waimarie. The family's passivity and feelings of powerlessness in the face of large bureaucratic institutions appeared to foster this trend.

SHIFTING SCHEMES

When he first arrived at Waimarie, Rob and his family believed that he was there because he needed to complete an interrupted rehabilitation regime. In their understanding, this process would fully restore, if not the Rob of pre-accident days, something a great deal closer to it than he had yet managed. They believed that in the not too distant future, perhaps a few months, he would walk unaided out of the doors of Waimarie and resume an independent life, no longer a burden to his family even if no longer capable of amazing sporting achievements. Initially of course, the staff would not have been in a position to pronounce with any certainty at all concerning the reality of such a goal. They would have needed time to assess for themselves what was realistic in terms of expectations of recovery. Time passed and they gradually discarded absolute recovery goals, replacing them with notions of adapting and compensating for his various disabilities.

There appeared to be a time lag at this point, however, in the communicating of this new interpretive scheme to the family. With the hindsight possible at the time of this research project, it was clear that this new interpretation of 'qualified independence' was never clearly established between the Waimarie staff and the family. While the family still waited for his returned independence, the staff worked with Rob to achieve more minor adaptations to his life, coaching him to manage as much as possible on his own within a supported style of living arrangement. Being aware that his care had become too much for the family at the time of his admission, they began to give priority to what was originally the secondary role, the provision of a comfortable living situation. The more that Rob was regarded as 'in care' rather than 'in rehabilitation', the less urgent became the goal to place him back at home.

This lack of fit and failure to clarify the different definitions of staff, client and family in a rehabilitation programme is very common (Bray et al., 1987:33; Gans, 1983). This is understandable as while the process of recovery is continuing it is often difficult to predict exactly what level of ability or disability could be accomplished. As well as this uncertainty, there was the

complication caused by underlying emotions. The family may well have misinterpreted situations because of their own denial and feelings of guilt, while staff may have glossed over or minimised remarks they made about Rob's disability to avoid distressing and angering the family.

These differences would not have been significant in a situation where the client, as the central player in the drama, was able to make sense of his or her experience and develop effective insight about his or her own problems. However Rob, like many people recovering from a head injury, had become more dependent upon others to interpret his situation. He appeared to be unable to set others' conflicting ideas alongside each other mentally and integrate them into something more coherent. When confronted by opposing interpretive schemes, he retreated into a powerless confusion. He became increasingly prepared to accept and adopt any available idea or belief others expressed about him. This habit, well entrenched at the time of the research, was having a profound impact upon the quality of his life, an impact potentially more disempowering and disabling than any mere physical disability could cause. It was clearly extremely important that those doing his interpreting for him frame his situation in ways which allowed him to take realistic and effective action. As Pepping and Roueche (1991:245) point out:

> **The capacity of patient and family to strike a reasonable and fair balance between remaining strengths and weaknesses in multiple areas impacting quality of life seems critical. In fact of central importance is the concept of "coping" which means similarity in perspectives, acceptance of reality without intense emotional response and realistic planning..**

Instead of a "reasonable and fair balance", Rob had been offered only confusions and misconceptions. These played a major role in creating his new lifestyle. Rather than knowing himself and his needs, he fearfully suspected the worst and then avoided facing the implications. At the time of the research he was passively waiting for others to tell him where and how to live next.

BECOMING A RESIDENT AT WAIMARIE

And so it was that, in February 1994, nearly five years after his admission, Rob had come to be a part of Waimarie. In his own mind he was not a client any more. Rather, he had come to regard it as home. Being a very sociable sort of person, he had developed easy relationships with many of the staff and other residents, the sort of friendships which involved light-hearted teasing. He seemed to have accepted that such a setting was necessary for his survival or happiness.

Although he always seemed content he was usually submissive and passive in his response to staff. Although he joked with them, he was very careful never to give offence and was anxious to appear cooperative and willing. He appeared to regard himself as at Waimarie on sufferance

without any real right and some of his acquiescence was the result of a slight fear that to challenge the status quo was to risk losing his home:

> **ROB: "Why am I there?" they [might] say [if I protest about something], "why am I there?" - they don't want to work with me - "why am I there?" - then everyone would be picking on me because I'm not wanted I'm not wanted.**

It is interesting because of the particular themes of this research project, to consider more carefully the apparent satisfaction Rob and his family felt with Waimarie as a surrogate home; a satisfaction so complete as to make him prepared to make these sort of concessions to freedom of speech. It might at first seem unlikely that he would become so settled, so at home in such an environment. His Maori cultural heritage, it could be assumed by many, would incline him and his parents to the belief that the *whanau*[68] or family was a more appropriate place for healing to occur.

Certainly the lifestyle of an institution (one would have thought), would feel particularly alien and different to Rob who left behind a very warm, caring community of family, all within a few doors of each other and quite obviously (from my visit and Rob's stories) all continually in and out of each other's houses and sharing each other's lives. Instead of finding Waimarie sterile and cold as conventional wisdom tells us institutions are however, Rob appeared to have found what he called his "second home". Because of its history and because of the many residents for whom Waimarie had always been home, the roles and relationships he experienced were more typical of family and friends than staff and patient. Perhaps because his childhood gave Rob experience at living in a group situation, this made it easier for him to find and tap into the elements of Waimarie which I described earlier as "unexpected community[69]". Among the staff and residents, he appeared to have found replacements for some of the relationships he had in his own family and community: parent figures, sibling figures, mentors, peers and team mates were all available to him in the person of staff or fellow residents. These relationships were far richer and more emotional than the treatment or fellow patient relationships from which they developed, giving Rob more latitude with some and less with others, than the formal institutional arrangement would have dictated. One of the cleaners for example, a Maori woman much the age of his mother, enjoyed having a secret cigarette with him when she should have been working. This progressed into Rob teaching her how to play the games on his computer and offering her the use of it when she wished. The sense of ownership and of being able to give and the experience of teaching something valuable to

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[68] *whanau* is the Maori word for the family. It is important to understand that for Maori people, the family is not only the immediate nuclear group, but includes aunts, uncles, cousins, grandparents, nieces, nephews etc.

[69] Hochschild (1973) in her book "The Unexpected Community", explored the complex relationships and networks which had developed in an old peoples' home. She discovered a closeknit community, complete with its own norms, roles and expectations had developed and she identified primary, secondary, reciprocal, complementary, formal and informal relationships.

someone else, were all extremely rewarding extra dimensions to Rob's life at the time, allowing him to experience far more than the restricted role of resident would seem to offer him.

A TYPICAL DAY

Rob lived in Terehi House, the head injury rehabilitation unit within Waimarie. He had a small bedroom about three by six metres in size, which he had decorated with large posters of Bob Marley and a 'bikie' in full leather regalia as well as several photos of his past rugby and boxing teams. A high quality stereo system and a small television had been added to the standard furniture provided. He could just get around this room in his motor chair, but this required considerable manoeuvring skills. There were showers and toilet just opposite his room and the communal lounge four metres down the passage.

Rob rose quite early, dressing without needing any prompting or assistance. This habit was appreciated by the nurses who had to help many of the residents to rouse themselves and begin the day, but by now it was taken for granted that he would be independent and he would generally be ignored. Although he might have made a passing comment or two to others in Terehi house, socially his day really began with breakfast in the common dining room, sitting always at the same table with the same people. The resident he made the most effort to be with and talk with at such times, Charlie, generally sat opposite him. This man, a middle-aged former farm worker, was also in a motor chair but otherwise would seem less affected by his head injury than many of the residents. He was a heavy smoker and when Rob and he met, they would often both light up and quietly smoke a cigarette together.

The official rehabilitation programme ran between 9.00 a.m. and 3.00 p.m and during this time Rob's day was artificially divided up into half hour 'slots' with a different activity assigned to each. It was Rob's responsibility to keep track of the time and to ensure he moved from one department to another. Each day Rob had the day's timetable attached to his chair. It was made of cardboard, written in bright felt tip pen and then laminated. A typical day would have something like 'physiotherapy' scheduled for nine o'clock. This might have involved a swim in the heated pool with flotation aids. The aide who supported him, like everyone else at Waimarie, had become fond of Rob and he would no doubt have been chatting to her, teasing her and being teased, as well as calling out at any passers-by to watch him. Of course, changing in and out of togs[70] took considerably longer than it would have for an able bodied person and by the time he had dressed it would have been nearly ten o'clock and Rob would steer himself straight to the main dining room for the ritual of the morning tea.

Most of the residents would be already congregated in the diningroom by 10.00 a.m., waiting for the clattering arrival of the large stainless steel trolley. Two large silver urns were on the top and cups, mugs and special drinking vessels underneath. Those, like Rob, who were able to manage the drinking for themselves, were expected to wheel themselves up to a table and wait until someone served them. Usually if he saw someone smoking in the side passage where the floor ashtrays were, he would motor over there and pull out his cigarettes, postponing a drink until this ritual has been completed; with only one useful arm, it was necessary to take such pleasures one at a time.

Morning tea for Rob was an attempt at socialising that often went awry. Mug in hand, he looked around for someone to speak to but often found no eye to catch and if he ventured an opening comment to another resident, one he could rely upon to respond in a reasonably predictable manner, there was very little chance his low and slurred voice would be heard and understood in the clatter and noise. He did not attempt to chat with nursing staff at this time, because their bustling actions made it clear that they were too busy to stop for him, although many of them made a teasing one liner as they passed, leaving him frustrated at his inability to say anything clever back[71].

Morning tea was always allowed a full half hour on everybody's programme; until 10.30 a.m. Rob did not really need this long, he would usually drink his milo within the first two or three minutes. If he still had not managed to strike up a conversation, he would go over to the stereo set up in a corner of the hall, with sofa and armchairs arranged creating a music corner. He would turn on the radio, or a tape of Bob Marley or Eric Clapton if he had one and then sit and listen. Every few minutes, he would inspect his programme to remind himself of what was to happen at 10.30 am.

It was at such idle moments that a staff member might see him and remind him of something he had forgotten to do. Typically these forgotten tasks were the "smaller things" which did not take up as much as the half hour and so have not been written in his programme, but they usually made him run late. For example, putting dirty clothes in the washing machine and switching it on, taking pills set out beside his place in the dining room, or making a phone call. He would usually dutifully wheel himself off to carry out the forgotten chore, even if it meant being late for the next timetabled activity.

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[70] The New Zealand expression for a swimsuit.

[71] It is possible that a number of the quick teasing remarks thrown out to Rob by staff were a reactive effect of the filming process. Often these remarks related to the camera. It may be that normally he would have been more ignored than he was during the periods of my observations, but it appears that the staff saw him as someone who enjoyed this sort of light bantering.

When no one distracted him however, Rob would generally follow his written programme. Most mornings at 10.30 a.m. he was due at a group session. Because his programme said Education Unit, Rob would steer himself towards the main classroom. Even after three months of habitual attendance of the group, he still did not remember to go to the right place for the morning group meetings. Fortunately, he always went past the open door and in passing, noticed the other members already there with Linda, the tutor. There would then be a two second delay as he processed this and, about ten feet further down the corridor, his brakes would go on and he would turn back to the room. He would enter with an "excuse me" and then try to pick up what was happening.

The various disabilities meant that the interaction within the Education Group at Waimarie was slower, as well as being more contrived than other groups of its nature. The tutor needed to ensure those using communicators, alphabet boards and makaton had a chance to contribute, that those who were deaf understood and those who were totally physically immobile were comfortable and engaged if not involved. While interaction between the group members was encouraged, it had to be controlled carefully because some residents were easily upset or angered and found it difficult to control their emotion and behaviour while others were so passive and withdrawn that they needed to be coaxed into making even the smallest input.

After his group session, Rob might have had another commitment, perhaps with the social worker to talk about his house alteration arrangements, perhaps to remove his washing from the machine and put it in the drier. After this it would be time for him to head for the transitional living flats to prepare his lunch. His chair's top speed was slow and he liked to stop and chat along the way and so it might have taken him five or ten minutes to make this journey down the long passageways, past the front office, through the automatic front sliding doors, to the left and along a curving concrete path to the building the flats were in. He would prepare his lunch with the support of an occupational therapy aide and then eat it alone at a dining table in the living area using a specially adapted fork-knife which allowed him to eat (very slowly) one handed. After lunch he washed up, a chore he loathed and as always when there is a gap in his programme, he would then probably light up a cigarette.

Two afternoons a week Rob went shopping in the local town, riding with other residents in the Waimarie van. All those who lived in the flats were expected to buy their groceries each week with support from the occupational therapy staff. The other trip, on Thursday, his time in town was his own. Anyone who wished might put their name on the 'town list' and provided they were waiting at the van's special exit/entry point at 1.00pm they would be taken into town and picked

up again at 3.00 p.m. Rob always went to town on Thursdays. He enjoyed the contact with retailers and town people and particularly the cafeteria he always stopped in for fish and chips. The manager and he shared an interest in computer games and would often chat about them while he was there. Most residents would average a trip a month or so, but Rob would never miss any opportunity to get out and mix with other people. On other afternoons, Rob would probably spend some time in the computer room, some time in physiotherapy unit and perhaps some time with occupational therapy aides who were helping him with daily living skills. He also spent considerable time with the Maori group, which involved several of the nursing staff and occupational therapy aides and which met to learn songs, listen to guest speakers, or watch videos, followed by a morning or afternoon tea party. At 4.00 pm when the programme ended for the day and his time was his own, he would generally go around to the computer room and boot up a game of Tetris, or cards. Whenever it was open[72] he would go to the bar and socialise with other residents and the occupational therapy staff who manned it.

The evening meal was due at 5.00 pm and Rob and the other residents usually gravitated toward the dining room 15 minutes or so before this time and sat around, waiting and smoking. Rob might be reading a TV Times, perhaps reading out the day's 'stars' for someone else. The meal was quickly eaten and the long evening until around 9.00 pm (when he would go to bed) was spent either in front of the TV in the Terehi lounge or the computer screen in the empty, half lit classroom. It was possible to chat to only one or two other residents in the lounge, because some preferred to watch their own TV or listen to their own music alone in their bedrooms and others were unable to speak. Perhaps a nurse aide sitting in the lounge might also strike up a conversation. In the computer room, however, he was likely to be alone.

LIVING WITH ALTERED COGNITION

The use of the before and after approach in describing Rob's history allowed a distinction between those themes which have continued through and beyond the accident and those which only became a part of his lived experience after the accident. The 'after' themes by implication may be related in some way to the disabilities acquired as a result of his brain injury. Because this study focuses upon the meaning-making and interpreting process and its impact upon the newly developing self, it is particularly important to understand how the cognitive and perceptual disabilities influenced the changes in lived experience and the emerging ontology. For this reason in this section, the various aspects of Rob's cognitive and perceptual disability are explored and some suggestion made as to how they altered his symbolic interaction.

[72] The bar opened three times a week on Tuesday, Thursday and Saturday afternoons.

MEMORY AND INFORMATION PROCESSING

Like many people who have had a severe brain injury, Rob regarded himself and was regarded by others as having suffered 'memory problems' as a consequence of his accident. In exploring his typical experience at Waimarie, many occasions were revealed when these memory difficulties had a broader impact upon his lifestyle. Most of these problems with storing and retrieving information appropriately however, had developed from much broader changes in cognition and perception. This discussion will therefore explore the separate aspects involved in Rob's loss of effective memory skills.

Memory Gaps and Confabulation[73]

It seemed logical at first to assume that Rob could only offer second-hand information about the period during which he was in a coma and also about the period immediately preceding the coma. Because his brain injury was severe, I assumed that he would have considerable loss of memory about events in the weeks or months preceding the injury as retrograde memory loss is commonly associated with severe head injury (Jennett, 1990; Gregg, 1994). I was startled, therefore, when during the initial stages of our first interview, Rob calmly described the events of the night of his accident as if from memory:

> **ROB: It was the rugby club break up - I was on the back of a ute. I wanted to take a leak. I stand up then I fell back over the back and crashed.**
> **DS: You remember going to the party, the break up?**
> **ROB: yeah.**
> **DS: you remember the break up night?**
> **ROB: Yeah it was good - I got a prize I think.**

It was not until later, in interviews with his family that I was able to establish that Rob's accident was nothing to do with the Rugby Club; that he was in fact, recalling a totally different occasion. Believing that he was talking about the night of his accident, I questioned him further only to discover that his memory was a curious mixture of facts he had been given and imaginative detail added from his own memory store, creating an 'as if' reality, within which he could picture this event and understand his own actions.

> **DS: Do you remember getting the prize?**
> **ROB: Nah.**
> **DS: No?**
> **ROB: I think I did - maybe my brother told me.**
> **DS: Anyway that's how you ended up on the back of the ute, trying to take a leak.**
> **ROB: It was the drink [*laugh*] too much drink - makes me think I can jump off the truck.**
> **DS: You tried to jump off the back of the truck to take a leak?**
> **ROB: Yeah.**

As he told the stories, he sometimes revealed that a creative blending process was going on, building memories out of his knowledge of the people and events involved and of his beliefs about

his probable behaviour. When I was asking this family about the early days after his accident when he was still in ITU for example, he casually chipped in and told them:

ROB: You usually used to go on as if I was the same.

One example of how this process influenced his actions was his understanding of the new and different relationship he had with his younger sister Maryan. Before his accident, Maryan had clearly looked up to this successful older brother and Rob, who enjoyed children, seemed happy to bask in her admiration. After his accident, Rob was unable to enjoy Maryan's company, hurting her feelings constantly with criticism or rejection. Rob was as bewildered about this change in his relationship as his family and he had turned to this story creation process in his attempt to develop an explanatory scheme which fitted his picture of himself. Unfortunately in the process he denied Maryan's own feelings and evidence of her actions which contradicted his beliefs:

ROB: She probably said something to me I don't know, when I was unconscious, probably said the wrong thing. Things I didn't like.
DS: Do you think she felt hurt that you didn't like it, what she said?
ROB: I felt hurt. She was saying something I didn't like.
DS: How do you know that if you were unconscious?
ROB: I feel it. I heard something I didn't like?
DS: So you believe that when you were unconscious you got a feeling about how people were with you?
ROB: Yes.

He might, of course, have remembered moments from this time of coma. However, whether or not he was really remembering eventually became less important to Rob's story than how these beliefs were influencing his interpretive scheme. However much they were based upon real episodic memories, the stories were clearly created to support semantic memory. Later, when I had experienced more interviews with Rob, it became clear that filling gaps in this way was essential to his understanding of the new person he had become. In this time of transition, created memories acted to connect his past and present, allowing a future to be developed. In this way, he was able to rebuild a coherent picture of his history. Although it might sometimes have disregarded facts and details about the actual events, it allowed those same events to have an active role in his identity again. Sometimes when challenged, he was even able to acknowledge that the memories reported were in fact "what I think happened", without losing his conviction in their essential truth. This 'colouring in' technique appeared in this way, to help him make sense of his life and give it back some of the continuity lost.

Memory and Habit

As is apparent in the story of a typical day, Rob had a number of regular small 'housekeeping' duties which he was expected to perform. The staff found, however, that very little was

[73] Confabulation, explained more fully in Chapter 1, p. 22, implies fabricated or imagined memory.

accomplished automatically. He generally needed to be reminded to carry out all his tasks, even those he repeated daily. He would constantly forget to do his washing, put it in the drier or fold it away. He would put something in the oven and forget all about it. Grocery items were not replaced when they ran out and dishes were never washed or the kitchen tidied until he had been reminded several times.

This might suggest that Rob's cognitive difficulties would have prevented him managing an independent life. Certainly, the staff assigned to help him master everyday living skills had begun to believe that without a structured institutional setting and staff to remind him what to do, he would not manage to take reasonable care of himself. However, it is equally possible that the problem was one of failing to engage his personal interest and commitment in learning these regular routines. The contrast between his ability with 'daily living tasks' and social skills was marked. He did not fail to use any of the social and recreational opportunities which presented themselves and revealed an ability to independently arrange many small and simple pleasures for himself. He would light up a cigarette, take out a tape and put it in the stereo, catch the van into town, motor around to the bar at opening time and have a drink, or seek out a friend and strike up a conversation. He was quite capable of establishing a habit and maintaining a routine provided he enjoyed the activity and chose to do it. Once engaged in an activity he enjoyed, any other obligation was forgotten. Perhaps as Gross (1987:102) suggests, he was restricted in the number of ideas which he could hold in his mind simultaneously and he responded to this by becoming absorbed in what he enjoyed and ignoring what he regarded as a chore. He divided his time into bigger blocks and if there was nothing in the gaps between these blocks to interrupt and disturb him, the smaller details and obligations of a day slipped away from him. Without a metacognitive level of awareness, he was released from the constraints of declarative awareness and prospective memory[74] and revelled in the pleasures of the present.

Memory and a more Closed System

In the literature review, I noted that several theorists had come to regard the damaged brain as a less 'open' system[75]. Perseveration and obsessive, rigid thinking are often mentioned as a concern. When Goldstein observed that many of his patients were "stereotyped and lacking in depth" (Goldstein, 1952:248), he could have been describing Rob, as could Gross (1987:102) when he developed his theory of a loss of "opponence". Activities like Tetris[76] which for others soon palled, kept him absorbed for hours. He appeared content with a lifestyle which others

[74] See Chapter 1, p. 18
[75] See Chapter 1, p. 42

would have found monotonous and showed little inclination to challenge himself, or seek out the new and appeared content to live at a lower level of arousal than others do.

A changed relationship between being and time, was a more accurate description of this change than any description which involved memory. As a result of becoming a more closed system, Rob lived in the present, memories and plans (or past and future) receding to the back of his mind while repetitive activities engaged and held his attention. Because his mind did not monitor and analyse what he was doing upon a metacognitive plane, he did not seem to become habituated and so seek out further stimulation by searching his memory and his environment for something else to do. As a result, he reacted rather than initiated, responded rather than planned. Any control over his life was limited to the choices he could discern moment by moment.

CONTROL AND POWER

These distortions in temporality and thinking styles altered the nature of Rob's life in a number of ways, the most obvious and important of which was the sense of self-directedness and autonomy. As I commented in the literature review, this theme of self-direction and the types of therapeutic relationship which support it have begun to dominate the literature in this field. Unless people are given some control and choice, they cannot be said to participate authentically in their own recovery.

Temporality and The Level of Awareness

Control and choice both require more future-directedness than Rob was showing. Crosson et al. (1989:48-9) would have described him as operating at an "intellectual" rather than an "emergent", or an "anticipatory" level of awareness and because of this any interaction needed to be highly structured if he was to contribute equally. Because he needed someone else to create and maintain this structure, it was difficult for him to feel a real sense of ownership and participation in the activities arranged for him during the day. Without any underlying abstract pattern or theme recognition, it was difficult for him to grasp the "idea behind the act" (Ben Yishay et al., 1985:255). As a result, his sense of accomplishment was limited to any immediate, concrete result of effort; the poster, the crossword, the right answer or the cooked lunch. It was impossible for him to grasp the concept of a skill mastered, or feel a sense of increasing competence and independence.

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[76] A computer game involving shape manipulation which Rob played frequently and at which he had become very proficient.

An example of this was his management of his timetable. Rob originally carried a weekly timetable but was incapable of remembering which day it was and continually followed the programme for the wrong day. To overcome this problem, five separate daily programmes were made up and left at the front office. Each morning, Rob was expected to call at the front office and swap one day's timetable for the next. This timetable arrangement, at the time of the research, was proving to be as ineffective as the weekly schedule because he frequently forgot to make the exchange and followed the timetable for the previous day. Without temporal flexibility and abstract thought processes, Rob needed such a strategy as the written timetable. What might seem to others to demand compliance and limit autonomy, in fact provided him with the means of a sense of self-direction. Provided he understood that the timetable was open to negotiation and change, it could be seen as providing him with a concrete form of remembering the "idea behind the act".

Control and Interpersonal Skills

Control and power appear at first to be individualistic qualities, denoting some sort of personal strength. The reality is of course, as symbolic interactionism acknowledges, they are essentially interactive or interpersonal skills. To symbolic interactionists (Goffman, 1969:2), power is the relative influence over the definition of the situation. To achieve personal power by implication, requires good skills in interpersonal situations and what Goffman (1969:44) called the "ability to discern the wider meaning of a situation from the minor cues provided."

It is these very skills however, which are most likely to be severely impaired by a severe brain damage. As Pepping and Roueche, (1991:237) recently remarked:

> **To a large extent our sense of value and connection is determined through interpersonal experiences with others. Through these experiences we develop a sense of what is appropriate and inappropriate and learn to both expect and appreciate certain interactional patterns in others. In addition to our highly refined competencies in this area, we possess remarkable sensitivity to even subtle alterations in the stability of these interactional patterns. It is difficult to conceive of a more potentially devastating source of disruption to this process than the effect of brain injury.**

Rob, now less able to keep up with all the elements of a conversation, or pick up on the more subtle nonverbal cues of interaction, took longer to perceive, process and interpret what was happening. Because of this, he was often put in a position where he lost "expressive control" (Goffman, 1969:44) and was forced to play a more passive role in setting the scene. While he still had considerable interpersonal skill, Rob clearly did not have the same level of sensitivity to subtle alterations and this would certainly have had an impact upon the roles available to him in social situations.

Rob acknowledged these difficulties himself and had managed to adapt his social style somewhat so as to mimic the circumspection[77] which was now beyond him.

> **I say the things I am going to say first inside my head and I think them out so I don't say something that will be wrong.**

He had become so practised at this skill that he often managed the appearance of spontaneity to those who did not know him well. Although this method worked well in the initial stages, as a conversation progressed, it was not easy for him to respond quickly and select suitable rejoinders from his rehearsed repertoire. Misunderstandings and misinterpretations occurred more frequently the more spontaneity the interactional situation demanded. Without interactive fluidity, Rob appeared to have settled for an anxious deference and to have learned to fear causing offence more than he feared losing personal power.

Control and Defining Situations

It was not so much this loss of fluid perceptual skill which caused the greatest change in Rob's interactive functioning but his response to it. Because he appeared to recognise his own difficulties, he was learning to approach all situations with a wariness about the impressions he was creating. Because he was so concerned to avoid making a negative impression or humiliating himself by revealing a misunderstanding he avoided any attempt to influence the shared definition of the situation. A person who constantly apologises for their interpretation of what is happening and discards it when even the slightest of challenges is made of it, does not inspire much respect in a fellow conversationalist, nor are his ideas and beliefs likely to be given much credence. Any idea or piece of knowledge Rob might have possessed was likely to be rejected without serious consideration. Thus, with his co-operation, other people unknowingly overrode his thoughts and beliefs and began to assume that he wished to have situation defined for him.

In fact, quite apart from being unwilling to express an idea, there were times when it seemed that Rob did not form an independent idea at all. The most striking feature of the interviews with Rob was his hesitancy to express any personal belief about his situation. Whatever the issue, no matter how well he knew his ground, he deferred to the opinion of others. Often what seemed at first to be a memory lapse or a contradictory remark, was in fact an attempt to say what he believed his fellow interactant wanted to hear, rather than express what was in his own mind.

> **ROB: I feel better, I rather do what what's her name feels. Do that better than what I feel.**

According to symbolic interactionism, 'taking the role of the other' is a part of anyone's interpreting process. What is important is not that it occurs, but how it affects one's ontological

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[77] See Chapter 2 p. 56 for an explanation of the meaning of this term within dramaturgical analysis.

understandings. Rob's hesitant, guilty manner and his frequent apologies suggested that, for him, the other had assumed too much prominence over the inner person.

Control and Physical Dependence

As these remarks demonstrate, Rob had become a person who deferred to others partly from habit, but also out of a sense of fear. While some of this fear appeared to spring from his loss of interpretive independence, the loss of physical independence was also implicated. This young man, once six foot tall, now interacted with others from a wheelchair. He could only use one arm freely and even that shook whenever he concentrated. Face-to-face contact forced him to look up and others to look down. The psychological effect upon a sense of power was immense, especially so since his physical power had once been central to his identity. Together with the impact of the cognitive change, these physical disabilities caused the loss of a feeling of personal power and the gradual development of a sense of "learned helplessness" (Bray et al., 1987:65).

Control and Inaudibility

Quite apart from the interpretive and physical difficulties, Rob's sense of personal control was limited also by his overly quiet voice. As Mirenda and Iacano (1990:5) point out, people with a disability often suffer a loss of power because the manner by which they communicate is easier to ignore than others. Artificial speech producers, alphabet boards and makaton signs are obvious examples, but even in a case such as Rob where the difficulty and change seemed relatively minor, the effect on interaction can be major. His slurred and very quiet voice made much of what he said very difficult to follow and as a result people made assumptions about what he said and responded to these assumptions. He generally accepted such changes in the direction of his conversation without demur, responding as if this had in fact been his meaning.

> **ROB: The new Rob. Ah - doesn't really like sport now cos he can't do that - those physical things.**
> **DS: [*having misheard Rob's remark*] So you can do some sporting activities?**
> **ROB: Yeah [*silence*].**

This pattern of being misunderstood was very common during his day and caused a diminishing power in the direction and tenor of his conversations. Over time such experiences were likely to have discouraged any attempts he made to maintain an equal role, if for no other reason than the sheer effort involved. In order for therapeutic intervention to be truly empowering and in order for it to offer any real sense of fellowship or partnership, the setting must allow him to be heard clearly. Interaction which negotiates control rather than imposing it, requires a real and equal participation from both parties.

SELF-RECONSTRUCTION

I concluded after reviewing the literature that an essential and intrinsic part of recovery from brain injury is the construction of a new self-image; one that is compatible with the new limitations brought about by the disability and one which allows the person to take self-directed and purposeful action. Rob had not managed this at the time of the study. Heidegger (1967:312-5) would have said that Rob was listening to the "they-self" and Denzin (1984:201-38) would have described him as a "divided self[78]". It is very important to understand how the encounter with brain injury had affected his ability to create a self-concept and how his experience at Waimarie was influencing this process.

LOST ROLES

Physical power was once a central part of what Kelly (1955:909) would have called Rob's core role structure. When the validity of the core role structure is cast in doubt a person may withdraw, feeling guilty. In such situations, the person is at their most vulnerable to the control of others (R. Neimeyer, 1987b:67). These themes could be seen clearly in Rob's experience:

> **ROB: Then they tell me, Rob you did this, Rob you did that - Rob you were good at that you were good at this.**
> **DS: That hurts, hearing that?**
> **ROB: Yeah, cos I can't show anyone now.**
> **DS; Doesn't that feel good, that you did?**
> **ROB: Yeah - it feels good that I was good at sport and everything. Yeah, I feel good but I can't prove that I was and you mix with the guys and "he's lying, ah, he's lying". I'm the kind of fella that can *show* you that I was good at something-but now I can't. I can't show them anything.**
> **DS: Do you think that you're still that person now?**
> **ROB: Nah....In some ways yes, in some ways no.**
> **DS: You're proud of that other Rob that you used to be.**
> **ROB: Yeah.**
> **DS: How about this Rob now?**
> **ROB: This new Rob is trying to find a new Rob - going on a new trip. I can't fit. But the old Rob, he was all right with his sports and that.**

Because his previous identity was so tied in with sporting achievements and a physical appearance of power and strength, the need to find a satisfactory new self-image was especially important for Rob. There was evidence that the beginnings of a less physically dominated self-concept were emerging. Rob and his family had begun talking about a different sort of lifestyle for the future:

> **ROB: - perhaps I could find a club to join and be a speaker, a coach, or give them some advice or something.**

Some new directions were emerging. He felt he would enjoy teaching and leading younger people and children. He had bought a computer and was discovering a variety of sedentary recreational activities. He had also experimented with activities such as darts, drawing and

[78] See Chapter 2, p. 81 for a discussion of theoretical understandings of self-alienation.

carving. These were the seeds of new roles only however. Until he had returned to his community it was difficult to know whether or not these interests would provide him with new purpose and direction.

SEQUENTIAL THINKING AND A NEW SELF

The tendency to think in a sequential and relational way, as well as the slower pace of processing, limited and defined the strategies available to Rob as he went about ontological reconstruction. There was a certain rigidity which gave a black and white absoluteness to his interpretations of his life and relationships and there was a concreteness to his categorisations.

Goldstein (1952) suggested that without an abstract attitude, a person loses his essential humanity. Because he saw them as confined to the immediate moment, he believed his patients were unable to self-actualise. Rob appeared to overcome the limitations of this thinking style very neatly, however, by the use of story-telling. The rhythm and dramatic style of his stories were as powerful as the words. Together the rhythm and story appeared to create vivid word pictures for him. Two examples of this were quoted earlier, when he described his relationship with his grandmother and with his girlfriend. In the following excerpt he described the relationship he had with his friends before his accident and in the process, felt again the experience of being the person he was before his accident.

> **ROB: I like being on my own, eh. Not treading on anyone else's toes - that's how I was - the mates I thought I had, they didn't know me the way I am - they don't come to me now but when I had my car, every day every day it was- they ring me up - "Rob Rob, what you doing?" "I'm going to rugby, you fellas down town, can bugger round town." "Why?" "'Cos it isn't safe for passengers eh?" "Oh year, okay - we'll go in your car." I go, "Hey you got some money for petrol just send the boys off - we'll see - send the boys off with about five bucks" - go, "Okay see you fellas in about an hour's time - I'll pick you up - make sure you carry something." They go okay "Yeah." I go, "Money first, pay, pay, my car don't run on fresh air !"**

Although sometimes his stories contradicted themselves and lacked coherence, the atmosphere and character of a scene was usually vividly brought to life. Rob was not just reliving but re-creating and modifying the meanings of incidents in his life through this sort of rehearsal and acting out. Because at the same time he was trying them out on others, he could reassess his experiences and even take into account something of the attitude of the other. As Poulos and Wilkinson (1984:78) put it, imaginal memory "evokes" and in evoking, a much more vivid and lasting impression of the past remained for the future.

This evocation appeared to work as a compensatory technique for Rob; one which had the potential to balance memory deficits and slower processing speeds with images and feelings. Not fully aware what he thought as he started to speak, by the end of the above excerpt, Rob was in a much stronger position to understand his relationship with his friends and the significance of

having a car when you are only sixteen. As a bonus, he could re-experience something from his life that was a pleasure for him. At least in his case, it seems important to encourage such self-interpreting strategies. Rob believed himself that 'picturing' had become the best way for him to think effectively. He believed that when he expressed himself well it was because he had drawn on visual imagery:

> **DS: You are finding different ways perhaps to communicate?**
> **ROB: In pictures. Pictures is the way I talk to people. You know? Sharing it , or - a question.**

Rob's use of story and picturing in these excerpts is very reminiscent of the recovering alcoholics studied by Denzin (1987a; 1987b). Story-telling was found to be a remarkably effective tool, actively encouraged by the AA programme in order to help people see patterns in their lives. For Denzin (1987b:197) it is a "...learning to listen, to recognise the self as a double structure of experience, the immediate living of the moment and the turning back upon oneself to reflect and objectify experience, so becoming a second self in the context of stories in order to re-centre self."

INSTITUTIONAL LIFE AS A LIMINAL STAGE

This discussion of the role of story-telling reveals that for Rob, as for many people with brain injury, being 'different' in the manner of their interactions and relationships may have been an essential step in learning to develop a new self. It seemed that Rob's recovery involved a progression through "separation", "liminal" (or betwixt and between) and "reincorporation" (Turner 1969 in White and Epston, 1990:7) stages. Many of the people at Waimarie were in a transition state; while they were learning new roles, habits and skills, more energy was also being given in their talk and thought to self-fashioning than would be appropriate in social interaction in the wider community. In Rob's case, the liminal state appeared to be giving way to the stage of reincorporation, perhaps partially because of the imminence of discharge.

Denzin (1987a, 1987b), in considering the alcoholic, felt an institution could play a unique role in accomplishing these processes of altering self-image. He suggests a person who has lost a sense of surety about his self-presentations needed the "languages of treatment in order to step outside himself and adopt a new interpretive framework" (Denzin, 1987b:42). Admittedly, any parallel between alcoholism and brain injury must be treated with caution. However, there are some striking similarities between Denzin's observations of the difficulties alcoholics encountered in finding a new identity and the problems which appeared to be facing Rob. A new mode of selfhood needed to be found in both cases, one which could deal with life within the mainstream of our culture while the standard images of that culture were unavailable and even destructive to them (Denzin 1987b). A new interpretive framework which functioned within this mode of self

was also necessary, one which allowed experience to be interpreted and understood without necessitating self-denigration.

TOUCH AND SEXUALITY

Although it functioned reasonably adequately as a surrogate home, institutional life had some important disadvantages for Rob. Perhaps the most obvious during our conversations was the loss of sexual and non-sexual love relationships and the loss of physical contact in his interaction with other people.

Touch at Waimarie, as more generally in New Zealand communities, is surrounded by conventions which inhibit and limit it. The private family home traditionally is the place where these conventions are relaxed, when a much higher level of touch is acceptable. Family members will hug each other without imputing anything more, or without any suspicion of an ulterior motive. Living in Waimarie deprived Rob of loving touch. This sometimes left him feeling isolated and alienated. Although nurses and therapists touched him many times in the course of a day, their contact was more impersonal.

This loss was one of the most difficult for Rob to manage and accept. Already his accident had demanded of him that he experience his body in a vastly different way and accept its inability to perform, now it appeared he must accept other people's denial of him as a physical being. Rather than resign himself to this change, Rob looked around him for anyone who might be prepared to develop a more physical but still non-sexual relationship with him and tentatively reached out a hand to many of the women staff and residents. When his initial approach was not discouraged, he would be encouraged to move progressively closer. Unfortunately, these interactions were often misunderstood and he was frequently the subject of a sharp rejection, as well as causing worried team meetings, referrals to the social worker and discussions about the most appropriate response.

Quite apart from his need to be touched, Rob, a 24 year old single man, had a desire for sex. Perhaps partially because of this sort of response from others when he touched them, but clearly also because of his own beliefs about disability and sexuality, Rob appeared to believe that he was no longer attractive to women.

> **ROB: Girls don't think of me that way any more. They look over my head now I am in the chair.**

Rob obviously found it difficult to deal with this need. There appeared to be no "feeling rules" (Hochschild, 1979:557) to cover such situations. Touch was becoming inseparable from sex and his sexuality and he was therefore at risk of regarding both his sexual feelings and his wish to be

touched and hugged as shameful. Considerable "emotion work" (Hochschild, 1979:557) was clearly expended in this area during the time he was at Waimarie, but he was still finding it difficult to satisfactorily resolve this problem, which seemed as much a societal as a personal issue. Until a need for physical contact and sexual relationships can be more openly acknowledged within the general population and until conventions are established which allow a more honest and straightforward physical access to each other, it is unlikely that people with disabilities will find easy solutions to this sort of need. In the meantime, any interactions which draw attention to our physical presence and physical needs, will continue to contain an undercurrent of the fear and threat of being assaulted or invaded.

While family as a setting provided a physical intimacy which an institution could not match (because of its nature and its role in raising children from dependence to independence), there were some areas where the home setting seemed inappropriate for Rob. However strong the family bonds, there are topics about which parents and children may never speak to each other with ease. For Fraser and Piri Johnson, the thought of their son as a sexual being was surprising:

> **PIRI: No, we never even thought of it that way.**
> **FRASER: No. I don't know we didn't even think about that.**
> **ROB: We didn't actually talk about it - they didn't know I know how to do it even!**

When the accident happened, Rob had been a 16 year old boy. Now at 24 he was to return home in a wheelchair, living in a self-contained flat admittedly, but still in his mind 'at home'. Although he was quite comfortable with this idea, it appeared to an objective observer, that it might later become difficult for him to step outside the role of a dependent son. The family as a system would need to adapt its understanding of Rob sufficiently to accommodate the needs of a disabled man rather than a boy, a man who, had it not been for his accident, would probably have left home and shrugged off their authority. The parents' love for their son was woven with images of protection and caring accentuated by his disabilities, which might later frustrate and limit Rob's future. The father's comments in particular reflect how much the parents had mentally adapted their role to account for the needs of physical dependence.

> **FRASER: My relationship is very close to Rob, I think Piri has too but I'm inclined to get really really close to him you know, I never leave him very long and I suppose I bath him and things like that and try to keep him tidy.**
> **DS: and you feel okay about that, bathing him?**
> **FRASER: Yes, I do that, no problem at all. I suppose his bathing, is more like a baby and things like that (laugh) - ah - I didn't think I was going to bath him again at his age!**

A man such as Rob would never normally be bathed by his father. With effort and proper facilities, it should still have been possible for him to take care of his own physical bodily needs. Yet the perception that both parents had of their relationship with Rob was one of loving and caring for him and Rob felt a sense of belonging, security and self-esteem largely because of this.

After a head injury, a parent to child relationship appears to be easier to reestablish than an adult to adult bond. Panting and Merry (1972) showed that mothers adapted better than wives to a head injury in a man and Thomsen's (1990:61) research also suggests that dependency relationships "work" best. A family group contains more than one dyadic relationship, however and when Piri and Fraser were thrust into a parenting role for an adult son who came in the middle of a large family, this changed the structure of the family relationships in a more global way. Once a parenting relationship has been reestablished in an adult family in this way, its influence upon the rehabilitation process may be more complex than it appears at first. It seemed possible that the father's role as a caring mentor could become a positive and important new relationship after Rob's discharge.

Power relationships and emotionality are obviously intimately connected with the way each individual resolves this conflict between inner self and outer pressures in order to find a place in the world again. As he recovered, Rob may have called upon various spurious forms of emotional intersubjectivity (Denzin, 1984:133) which left him overly reliant upon a "they-self" (Heidegger, 1967:312) and "adrift in the other" (Denzin, 1984:151). Hopefully, with appropriate interpretive guidance from others, he would eventually arrive at a more independent emotional authenticity.

THE FAMILY AND SELF-RECONSTRUCTION

Compared to many of the people at Waimarie, Rob was regarded as having experienced very little change to his personality. It was often repeated to me that he is "still the same Rob" and despite acknowledging some cognitive problems, the family seemed to believe that the only important issues for rehabilitation were physical ones.

> **FRASER: Yeah well his memory is very very bad now, but I understand that it's normal for a head injury patient.**
> **DS: It's not an important thing to you - his ability to think and understand and remember?**
> **FRASER: Yeah, it is a concern to me really.**
> **DS: As important as the physical?**
> **FRASER: ...Aah, not really...**

A more objective observer may have assumed that Rob's memory difficulties would have a massive impact upon his relationships. I was assured by his family, however, that he "remembered the important things". He still knew the names of his nephews, nieces, uncles and old friends and he still enjoyed the same jokes and pastimes. Any problems he had with other practical tasks of living, planning and organisation were a minor nuisance rather than an identity transformation. These comments revealed how this family (and I suspect many other families of people with a head injury) were focused upon the emotional inner person rather than his perceiving and thinking abilities and there was no strong connection between these two aspects of being. It was taken for granted that Rob's inner self was inviolate from the damage to his brain.

Similarly, other families at Waimarie managed to regard people in a vegetative state as just as intact as an entity or person as they had been before. Love, or perhaps more accurately the more authentic forms of "emotional intersubjectivity" (Denzin, 1984:129-59) did not appear to require perceptual, information processing and interpersonal skills. This finding reinforces the importance of involving people with lifelong primary relationships with the client in any rehabilitation process. They may have the key to retaining and recovering authenticity as a person. With the participation and commitment of at least one person who already knows and loves the person, rehabilitation programmes may become more effective in fostering continuity, coherence and purpose in the life still to be lived.

MUSIC

It became clear as Rob's story was told how important it was for him to find new ways to value himself if he was to maintain hope for a future with a satisfactory quality of life. However, as Prigatano (1989b) points out most of the images and symbols of success in the modern world come from our love, work and play. All three of these areas are likely to be severely affected by brain damage. Because of this, people such as Rob have to overcome quite major obstacles in their battle to face the future optimistically but realistically. For Rob, as for many at Waimarie, music appeared to have an important role in achieving this.

Prigatano (1991a:7) suggests that songs played repeatedly are one of the best projective techniques after head injury. They can help both subject and therapist to understand the life being experienced. They also commonly contain powerful symbols which when explored, capture and articulate feelings beneath the surface of conscious awareness. In drawing out the experience of the song, a person may clarify thoughts, reintegrating them more effectively with feelings. Bob Marley and reggae summed up thoughts Rob could not express. The lyrics gave him hopeful messages of a somewhat fatalistic but soothing nature. Many of Marley's songs appear to concern struggle and the overcoming of it, but as much as this message was important, it appeared that it was the nature of the delivery which was the real reason reggae was so powerful. The rhythmic, almost hypnotic beat and the repetition of a small number of words embued simple statements with a powerful, persuasive meaning. Like the story-telling technique described earlier, these songs gave Rob a concrete way of understanding the abstract and an almost physical way of resolving the spiritual and emotional conflicts in his life. Like a ritualistic chant or a prayer learnt by heart, these songs had the power of a spell over his life. The song most important to Rob consisted of a few lines repeated continually with a strong melody and beat which clung to his mind long after it had stopped playing:

Rise up this morning, smile with the rising sun. Three little birds by my doorstep singing,

sweet songs of melodies pure and true, bringing this is my message to you-ou-ou,
Baby, don't worry, about a thing, cos every little thing, is gonna be all right,(repeated twice)

Rob had discovered a powerful way to deal at a concrete level with emotional and spiritual needs most often dealt with at a much more abstract and complex level of cognitive processing. The effect was a sense of calm and security. Prigatano (1989b:4) suggests new "practical and personal symbols of a meaningful existence need to be introduced to the patient". Through the medium of music, Rob introduced himself to meaning and hope at the same time as he provided himself with a profoundly satisfying and soothing sensory experience.

SOCIAL NETWORKS

When Rob left Waimarie, he assumed that there would be the same wide group of family and friends available to him as had been there before his accident. Neither he nor his family had examined this assumption in any depth and yet already their conversation suggested the reality might not live up to the ideal.

FRASER: He is very friendly. He had heaps of mates. Most of them are still asking about him too.
DS: (To Rob) And do you still keep in touch when you are home?
FRASER: I usually give them a call and they come over, but - a lot of them now they joining the fire brigade and things like that and they haven't got the time but they always send their regards and that.
DS: So perhaps you're losing touch a bit with Rob's old friends?
FRASER: Yeah. I suppose life's just got to go on they can't just sit down and mope about it.

Waimarie may have been partially responsible for this situation, but the research available on social interaction suggests that the loss of social networks is an almost universal experience (Thomsen, 1990:59). What is likely is that Waimarie had insulated Rob and his family from this consequence, so that it had not become the issue it would be when he returned home to stay. The family believed that Rob would be able to find a place in the group of family friends and relations and enjoy socialising as part of the family.

FRASER: When he was back here, we used to take him with us to darts and he used to sit and watch us and have a social drink and our friends got on well with him they used to take him round, you know and it felt really good.

Although this concept of a social outing may differ radically from the sort enjoyed by the 'old Rob', this family more than most had a chance of making the transformation work. They had the type of generation-bridging network more common to Maori culture which might have provided him with new roles and relationships as well as managing effective adaptations of existing ones. To return successfully into his community, a concerted and prolonged effort on the part of all his extended family and friends seemed essential.

SUMMARY

The story of Rob at first seemed a straightforward one to tell; a modern tragedy repeated throughout New Zealand with horrifying regularity. A sixteen year old boy goes out to a party with his workmates one night, drinks too much and is involved in a near fatal vehicle accident. His family and friends, filled with fear of his dying, wait beside his unconscious body for six weeks, then rejoice when he regains consciousness. Gradually, however, the elation fades and the sadness and pain of loss set in as they and he learn to come to terms with a number of disabilities which seem to have shattered his life and changed his future forever.

A sporting hero already at sixteen, it was soon evident that his sporting career, the primary part of his identity was a thing of the past. Rob and his family came to terms with this loss but still centred their hopes upon him walking again. The story as told by Rob and his family, is one of frustrations with services and people who tried to meet his needs within a system which had few if any appropriate services.

It became apparent as the story was told that the traditional forms of intervention, which relied upon a model of assessing and treating disorders and deficits, ignored the powerful role being played by interpretation in the recovery process. As a result of his accident, Rob was shown to be less able to manage his own independent judgment of his situation and so he had come to depend more heavily upon the attitudes and opinions of others. Inevitably, there was some major differences and inconsistencies in the views and priorities of the staff, the family and the other agencies involved, leaving him with a confusing array of alternative perspectives to take upon his rehabilitation and future. In the circumstances, Rob appeared to became more anxious to attract approval and avoid criticism. When unable to understand how he fitted into his post-accident world, Rob experienced the sort of emotional danger Kelly (1955:95) describes of losing the ability to anticipate and control his future.

Much of Rob's story could be described in terms of symbolic interactionist theory, as the slow negotiating through interaction, of a new, now powerless and ineffective self-image. He was becoming so anxious about acceptance that he deferred constantly to others. This habit had become so extreme that he was denying himself the right to any control and power in living his life. This was not a conscious message which others were giving him, but rather his interpretive response to his everyday living at Waimarie.

The change in his relationships was not only disturbing his sense of personal power and worth, it was also making it very difficult for Rob to construct a workable concept of self. A common

theme of the symbolic interactionism and phenomenological theories discussed in the literature review is that "ontology precedes epistemology" (Denzin, 1984:262) or in other words, that beliefs and values develop around a sense of self. While Rob was still in the process of redeveloping a secure ontology, he was in a liminal state and so very vulnerable to others' interpretive frameworks. Unless the rehabilitation process empowered him to define his own world again he risked becoming divided against himself in his efforts to satisfy the conflicting demands of his life.

Interpretation and ontology construction as concepts suggest just the abstract, conceptual and fluid forms of information processing which had become most difficult for Rob. Giving him back the control over interpreting himself was clearly not something which could easily be accomplished. Goldstein (1952) regards people who have lost the more abstract levels of awareness as confined permanently to a stereotyped and impoverished quality of future life. Although elements of Rob's story demonstrated how real the risk of a robotic and externally controlled lifestyle is, there was also evidence of the power of the human spirit to overcome such cognitive limitations. Rob had found several more concrete and sensory ways to restore a sense of self, the most notable of which were role rehearsal, music and story-telling.

A concept of the person as a meaning-creator, who acts according to his or her understandings would have suggested quite different directions for rehabilitation, directions which would have involved more negotiation of shared understandings so that there was a sense of shared purpose. In order for Rob to use these more concrete methods of integrating his experience however, it seemed that there was a need for him to experience especially adapted forms of interpretive support and structure at least during a "liminal"(White and Epston, 1990:7; Turner, 1969) period of his recovery. Concepts such as *persuasion and inspiration* (Ben Yishay et al., 1985:256) *mentorship* and *interpretive guidance* become an important and necessary part of relationships. In the absence of an effective dual inner self, Rob required specially adapted relationships to ensure that he was involved in and empowered by his own recovery.

Consciousness therefore, is inseparable as a concept from that of self. The level of awareness at which Rob was operating appeared to have a profound effect upon the level of autonomy, purposefulness and adaptivity he was capable of attaining. Much of the literature I reviewed assumes dichotomies within thought processing styles. While many of these conceptualisations are useful as heuristic tools, Rob's story demonstrates that levels of awareness include many more than two dimensions. The symbolic interactionist notion of a dual inner self which interprets the world as it interacts with it offers a more dynamic model of mind; one which suggests it is the

relationships the person has rather than the treatment they are given which have the most powerful impact upon recovery.

CHAPTER 5

MARK WHITE'S STORY

THE ACCIDENT

On 14 January 1993, Mark White was cleaning out the guttering of a two-storey building. He was only 17, a student on a holiday job, yet he worked alongside the other men without any additional supervision, as an equal. He had always been expected to handle whatever they did, responsibly and independently. That was the way he was.

This morning however, nobody knew quite why, he climbed onto the roof. Perhaps he had managed to finish cleaning his side of the guttering and planned to help out on the other side. A workmate cleaning the other side of the building heard a crash and looked over the ridge to see a gaping hole. Mark, a solid 6ft 2in, had walked straight onto a fibrolite skylight and crashed through to the floor, eight metres below.

MARK BEFORE

Mark was the older of two boys and lived with his parents, a company manager and a primary teacher, in the city of Porterton. Before this accident his life was full of potential. He was about to enrol in the first year of a resource management degree. A commitment to environmental issues had been a central theme in his life since high school, where he had been involved in many conservation projects through the integrated studies (university extension) unit. University, rather than being a new direction, would extend and build upon these interests.

His sporting career was full of equal promise and excellence. He was a fit young man who enjoyed canoeing, hunting, climbing and tramping. His greatest love was his rugby and he had been in his school's first fifteen as well as being a provincial representative for several years. He also excelled at tennis, swimming, cross country running, field athletics (in particular, shotput and discus) and basketball.

When I asked his parents to describe their early memories of him, his size was the first thing to occur to them. He was extremely tall.

> **JULIET WHITE (Mark's mother): He grew very fast when he was 11 or 12 -inches over half his friends.... He was very gangly because of it and he had knobbly knees and kept falling over and knocking things over...**

The young Mark, already 6ft 1in at twelve years, managed to overcome any awkwardness and even capitalise on his height. Being identified as a leader early in his life, he was given a range of opportunities.

> **JULIET: He gained a lot of experience with different sorts of things, like, he learnt how to use a video camera and he was called on to video the school stage productions and those sort of things, so he developed in a lot of ways.**

Daniel White, Mark's father, remembers Mark not so much for his exaggerated tallness, as for his inconsistency.

> **DANIEL: Inconsistency would just about sum him up actually ... He had a lot of ability when he really tried...**

Believing that sporting activities motivated him most effectively, Daniel encouraged Mark to develop his physical strength and skills. He saw the discipline of a milk run and the demands of sporting activities as the key factors in his development from a gangly thin boy into the muscled, well-proportioned athlete he was at the time of his accident.

Socially, Mark was always extremely comfortable and assured. In fact, according to his parents, people always had come first in his life. He was a sensitive and caring friend, having many long-lasting friendships among girls as well as boys, teachers as well as peers and among the many members of the extended family and their friends from other generations.

> **JULIET: Yes. He has always been and still is, a very social person - people are very important to him and he has always liked to interact with other people and have other people around....he has always had good groups of friends all the way through.**

This sociability was not a reliance or dependence upon friends. When making the transition from intermediate to high school, Mark was confident enough to choose a coeducational school although all his friends were going to the two available single sex schools. This school offered him more opportunities to further his interests in outdoor education and conservation and he was self-assured enough to know that he would manage in an initially alien environment.

> **DANIEL: The attraction at Camden was because it has Integrated studies - and computers - IBM - research projects.**
> **JULIET: That is what he wanted, that is what he was really interested in -**

His parents were delighted with his choice. It must have been very satisfying to have a child so sure of his direction and motivated at only twelve, going on thirteen. His father spoke of this young Mark with remembered pride and respect and added that for he and his wife Juliet, Camden had one other advantage which Mark, at his age, had not really considered:

> **DANIEL: I went to Boys High - an all male school, 1200 boys - there are 3 males in this family and one woman, male cousins - no females and at least at Camden, he would have some contact with girls and that was what he didn't have in our family.**
> **DS: Was it any feeling that he didn't cope with girls, with relationships with girls?**
> **DANIEL and JULIET: (laughing) No, the opposite!**

By the time he was finished high school there was no doubt in anyone's mind - Mark was a mature, responsible adult. He was no longer regarded by his parents as a child in any sense. They acknowledged him as an equal and had for some time. In fact they were surprised when the Labour Department, thinking of him as a 17 year old, assumed he was still immature and should not have been left unsupervised to carry out the gutter cleaning task:

> **JULIET: He was thought of as a man - and he had an adult physique. He was given responsibility at school, with the rugby captain, he was on the ball committee that organised the school ball, he was one guy and three girls and he was house captain...**

For his mother, he was a companion, caring and sensitive and with a good sense of humour. For his father he was a fellow worker, fellow family member, a sportsman, a friend.

> **JULIET: - and he had a lot of fun. As far as I was concerned he was a very sensitive boy, he was very tuned into my emotions and friends' emotions, caring, I mean, just the night before he had his accident, Daniel was away and Mark was lounging all over the floor and when he did he just took up the whole floor stretched out - and I was doing the dishes and his uncle came in and said, "You great big hulk, what are you doing down there while your mother is doing the dishes!" and really gave him a hard time, but.. Mark had cooked tea for both of us, he was cooking several times a week-"**

Mark's record of achievements supported the parents' description of someone who stood out and excelled. He had been selected so many times to lead, to represent or to take on extra responsibilities. He became deputy head boy of a college, voted in by both his peers and teachers. Whether in sport, socially or academically, it seemed that Mark had always stood out from the crowd. Like his height, everything he did was a bit bigger and a bit better. Whenever life had offered him a challenge, no matter what sphere, nine times out of ten he had gone out there and not just met it, but totally mastered it. At the time he stepped up on to that roof, no young man's future could have seemed brighter.

THE FIRST DAYS AFTER

As Mark's parents described the first few days after the accident, the horror and fear come clearly through their words. Juliet was initially alone, Daniel was away working in another city, Simon (Mark's younger brother) was camping with friends, two hours away. She sat in the waiting room of ITU (The Intensive Therapy Unit), reminding herself of the positive signs, determined to hold on to her hope, determined not to think of the terrifying possibilities of death, or severe brain damage. She knew a little about severe head injury, she had often taken blood from similar accident victims in her years working as a laboratory technician.

> **JULIET: - When I first saw him, the machinery didn't daunt me and the hospital didn't daunt me. I had been warned by the army nurse that came with him. She said "I am sorry to give you such bad news, but he has got a head injury". I still didn't feel "Oh no." I could see he was deeply unconscious and bleeding out of his nose, but what I looked for was blood in his ears and the inturned arms and his arms were straight and there was no blood in his ears and I thought, "There is hope." And I just clung to that and I just gave him a kiss and sort of hung on to that and I just knew there was hope from then on.**

Looking back, Juliet can see now that she was in a state of shock. The hospital was like a place out of time for her and it allowed her to remain in this stunned and numb state, not really feeling. She sat alone, in the waiting room.

> **JULIET: You see, it takes them so long to set up all the tubes and things and you are shunted out and so it was sitting in that waiting room and that is why she said to me "Are you sure you don't want anyone?" I actually felt quite strong and in control, but, as soon as you leave the environment, you actually crack up. I came away and had a shower and it was convulsive crying and you just don't know what to do. You feel so helpless -**

Daniel arrived at the hospital at 8.00 p.m. that night. He had put off the drive back to Porterton during the first hours because Juliet would not be able to phone him if anything happened. After his arrival they settled into the pattern which dominated the next few days; one of pendulum swings from fear to euphoria as the vague news they were given by medical staff sometimes seemed positive and sometimes confronted them with their unspoken fear.

The most dramatic pendulum swing they were put through happened on the fourth day. By then they were beginning to acclimatise to this strange half-life and both felt a drive to know and understand more about Mark's situation. This coincided with Mark's taking a turn for the worse. As is often the case with brain injury, after an initial period of trauma, the brain begins to swell as a response to the injury. This swelling can endanger life more than the damage to the brain tissue, as well as causing further diffuse damage as it crushes and blocks off oxygen to vulnerable areas which may until then have been unscathed. The medical staff, having been mildly encouraging but largely noncommittal for four days, suddenly introduced the possibility of death.

> **DANIEL:... on the fourth day they got hold of us and said the swelling is getting worse, prepare yourself for death! Which, after four days of his heart rate coming down and everything going perfectly, was a bit hard to take.**
> **JULIET: We really hadn't faced death until then. We thought it would be a recovery and we didn't know what sort of a recovery and we were very realistic with head injury - mainly from my work we knew what the possibilities might be, but we had never faced the possibility of losing him until that day -that was devastating - we just crumbled.**

He recovered from this crisis, but it seemed to have left its mark upon the family. For his parents, after this day, to have him alive was no longer taken for granted. They had started to face the thought of his death and so, when he recovered, it was perhaps a little, as if he had returned from the dead. This feeling of gratitude for his life, may have become important over the next few months when it became clear that the road back to recovery would not be smooth. Mark remembers his mother particularly, as grateful just to have him alive. As he has no memories until two months after the time of this crisis, it seems that at least to some extent, the events of these early weeks were dominated by this theme of 'at least he is alive'.

THE HEALTH AND WELFARE SERVICES

The drama of that time is interwoven in the Whites' minds with intense feelings toward the professional staff; of frustration and anger about some and of gratitude towards and dependence upon others.

> **JULIET: - It was a Sri Lankan Doctor and he had no diagrams. I am a very visual person and I need books, diagrams and I said to him, "haven't you got anything you can show us what is happening - in the brain - that this has happened?" And he didn't and it was stilted English, but, our Susan -**
> **DANIEL: The charge nurse -**
> **JULIET: Yes, she was excellent and she was quite devastated too, I would think. And then it was terrible, because we were with him watching the machinery and it becomes so intense, you know, every heart beat, the fact that his temperature was putting more stress on the brain and - it was the swelling down at the brain stem that was the problem if it got too much it was just going to kill him and that was it - it wasn't that he was massively haemorrhaging or anything it was just the swelling - it kept on swelling - it was terrible.**

It appeared from their stories, that those with the right or responsibility to make decisions about Mark did not always recognise the needs of the family, nor did their behaviour always inspire confidence. The inadequate handling of their feelings on this fourth day perhaps marked the time from which the Whites felt a need to monitor and understand every detail of Mark's injury. They had not, like many families, felt intimidated by the knowledge and expertise of officials and professionals and never assumed that these people would make the correct decisions alone. Each new person became obliged to earn their respect.

Their caution was shown to be justified. Over the ensuing months, they were often confronted by other people's incompetence or by the absurdity of regulations which were inappropriate for dealing with a head injury:

> **JULIET: I have a file this big of letters that I have written and the correspondence that has come backwards and forwards is just huge. I mean we got furious about some things.**
> **DANIEL: Well, like, they kept him in a surgical ward.**
> **JULIET: Even before that, they didn't fill out the ACC form correctly and when I went to ACC five weeks after his accident, it hadn't even been registered and the Doctor had only filled it out for that day instead of for the next six weeks and then when we went to try and get ACC, well, "Why hadn't we heard from them?" He had not been registered - they had lost the form!**

They developed the habit of getting photocopies of everything, of trusting no one. Nevertheless, they believed Mark was disadvantaged because of inadequacies of the system.

> **JULIET: First we went to the broker that is in town-and she said "Right. Your next step is to go to Social Welfare and see if you can get an invalid's or sickness benefit." And then we got all the data - it is incredible the data you have to get together - and we applied and they said, "well, had you applied within a week of the accident, you would be entitled to a specific amount from the date of the accident." And we said, "well how could we, when we didn't even know, when ACC hadn't written to us and told us!"**

As well as these personal frustrations with the system, they were beginning to feel a very real and sincere concern for other people who did not have their skills. Some of their personal troubles with the system, they began to see as important political issues which needed confronting.

JULIET: But we got so confused ourselves with all these agencies and unless you are fairly articulate with language and letters and things - there are people who aren't - and they just don't get their entitlement you know!

Perhaps the most frustrating aspect of the bureaucratic illogic was the assumption that Mark should be responsible for his decisions despite the nature of his injury.

DANIEL: And they kept writing to Mark and telling him to get his stuff together on the accident! He was in hospital! - there was no way he could! ... he had to do all that sort of thing and he didn't even know what his signature looked like! Juliet kept saying, "what about the people who don't know how to deal with it, don't have someone."

Mark continued to be totally uninterested in the forms and procedures necessary for him to receive any entitlement well after his discharge from hospital and up until the time of the research. Although the Whites managed his affairs for him, letters continued to be sent to Mark personally, causing them to resent the implication that they were somehow stripping Mark of a right to self-determination which he had voluntarily abdicated.

AFTER THE CRISIS

From January to March, the family watched as Mark emerged from the coma. Consciousness did not return immediately but instead Mark experienced the restless twilight world of Post Traumatic Amnesia, or PTA[79], where he was disoriented, hostile, not speaking and blank faced. Although he was still really unconscious he became physically stable and so after three weeks in ITU, he was moved to a surgical ward. The immediate fears for his life disappeared, to be replaced by concerns for what sort of recovery he would make. For his mother the blankness in his face was particularly distressing.

JULIET: ...to us, he was such a smiling happy person and to just suddenly have this bland face with no expression in the eyes, no smile, was just so hard to take. ..

Mark still had no idea who he was and no coherence or meaning in his actions. Because of this he was totally incapable of any sort of relationship with his mother or anyone else at this stage and could not be trusted to keep himself or others safe. This restless, agitated state of PTA continued throughout the four weeks in the surgical ward as he returned to full mobility which made him very difficult for the hospital staff to manage. He seemed to need to roam and pace and became frustrated and hostile if this was thwarted and yet he was not conscious enough to observe even the simplest of social rules. He walked in on other patients or wandered miles away from the hospital. The extended family found themselves taking on the very necessary but exhausting role of just 'being with' Mark for ten to twelve hours a day to watch over him as the process of waking up mentally followed on after this earlier waking up physically.

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[79] See Chapter 1, p. 20.

JULIET: And, once we had got him further down the track and we realised that he could read and could track with his eyes and things and then we got speech -

It is not always easy to tell when this PTA has ended. Sometimes, like after concussion, a person will suddenly emerge into full consciousness and behave and think again much as they did before the accident. Mark, however, experienced a gradually diminishing confusion and disorientation. For his parents and for Mark himself, the most significant turning point which marked his 'real' return to awareness was a smile. It was four days before his mother's birthday and Mark had just been told that he would be going home for the weekend.

MARK: Do you know what I gave Mum for her birthday last year?
DS: No.
MARK: A smile!
DS: A smile?
MARK: And she said, "this is the best birthday present ever!"
DS: This is when you came out of your coma?
MARK: In March - I had my accident in January, so, in March I was in Rehab.
DS: So it was a couple of months later in rehab that you smiled for the first time.
MARK: Yes. And Mum was there. And I was stoked.

If PTA is, as Jennett et al. (1981) presume, a reliable measure of the severity of injury and the likely long term outcome, then Mark's future was not looking good at this stage. His PTA lasted 18 weeks, enough to have him classified as very severely injured. He might have made the first step toward becoming the old Mark when he smiled but it soon dawned upon his family that he had very limited self-awareness. His memory of the past was gravely affected and without this past experience to guide him, he had no way back to being 'Mark' and no foundations upon which to build a new self.

DANIEL: He doesn't remember anything about school - that he had actually left school.
JULIET: It was just the most amazing experience. Like - this year, Simon is doing environmental studies and Mark did too and he has just canoed the Wanganui River you see, from Taumaranui down to Pipiriki and, Mark did that trip too and he can't remember any of it. And yet I know I picked him up from the trip and he came out of the river dripping wet because they had all dunked each other and he was grinning from ear to ear and he said "Mum, that is the most awesome thing I have ever done!" you know? And to be there, to have experienced that and for him not to remember it now is just heartbreaking- and he has climbed to the top of Mt Taranaki, he has traversed Mt Tongariro, he has -

The process of offering him back his memory began with photos. Juliet White brought photos to the hospital and surrounded his bed with them, so that any possible trigger was exposed to him. She then took photos, day after day, mapping his progress through ITU and the Rehab Unit, smiling staff, friends and family, weekends at home building up his strength, surrounded by friends and family, playing games, going out with old school friends. These photos initially were attempts at triggers and reminders. Later, when they became aware that he was not remembering from day to day during the period of PTA, the photographic record keeping was extended to become a way of 'filling in the gaps' for him, helping to orient him and allow him to develop an awareness of who he was.

Because the photos seemed so effective, others were included in the collection. Photos from his past, of his seventh form common room, the balls he had been to, the friends and good times. Soon Mark had his 'bible', his collection of photos which documented his past, the days after the accident that he had lost and the days since which recorded his recovery. They had developed into a comprehensive visual history for him; three photo albums that told him who he was. They have become so important a part of his identity that he will always ask anyone with whom he hopes to make friends to look through them.

It soon became clear to Mark's parents that the hospital system did not really fit the needs of a young man recovering from a severe head injury. It was designed for people with physical and medical illness, not cognitive problems and certainly not cognitive problems combined with an active restless young body. They could see that unless they challenged the system upon his behalf, his cognitive recovery would be allowed to slow and stagnate just when it was most necessary to help him. In the surgical ward, designed for people who lay in bed, no one was actively addressing his intellectual and emotional needs, no one was offering him any comprehensive sort of programme to assist his recovery. The hospital's attitude appeared to be that this step should wait until he became less confused and easier to manage.

However, the Whites were not happy to put this off any longer. They were confident that their concerns deserved a hearing. The medical crisis was over, the personal crisis, the identity crisis, was just beginning and they believed it was they and not the hospital, who were the experts upon Mark's personal life and identity. They were prepared, therefore, to assert themselves and insist upon changes that they felt were necessary to maximise his chances of recovery. In fact, many of their comments suggested they had come to see themselves as directing his recovery at this time. This use of 'I' and 'we' in regard to decisions, instead of the common amorphous 'they' was typical.

> **JULIET: I guess because I am a teacher, I think of it that way. I have to take him through his whole human development again. But I mean right from his coma on and even just getting back his physical power, we had to teach him to stand and we had to teach him to walk, so developmentally, he was having to leap along more or less a continuum ...**

And when they were not happy with the environment of the surgical ward they had no hesitation in agitating for his right to a more appropriate type of treatment.

> **....we agitated to get him into rehab because we just felt that was what he needed...**

Because of their determination, they managed to convince the head of the Rehabilitation Unit to accept him there despite the continuing PTA. Normally, the unit did not cater for people until they were sufficiently aware to manage without constant supervision. While the extended family had accepted responsibility for providing such supervision in ITU and the ward, after seven weeks

of ten to twelve hours each day 'on duty', they all needed to return their own lives to some semblance of order. At this stage, the head of the Rehabilitation Unit offered to set up a unique arrangement just for Mark. He was transferred to the unit and allowed to participate in a rehabilitation programme, but with his own caregivers, employed by the unit between 7.00 a.m. and 9.00 p.m., just to supervise and manage him. The family now only needed to take responsibility for the gap in the middle of the day between shifts.

This scheme had some initial teething problems however. The first five or six potential caregivers trialed, found it difficult to understand how to relate to Mark and there must have been moments when everybody wondered if the right decision had been made:

> **JULIET:... and they were actually scared of him. He could get very pushy, abusive and highly mobile to the extent they couldn't turn him back. He walked home, four and a half kilometres, on quite a number of occasions in fit's of fury, or a denial that he needed rehabilitation at all!**

Eventually two young men were appointed who not only could manage him, but who also managed to form a 'quasi' peer relationship with him. The family were excited to see how well these relationships worked for Mark.

> **JULIET: Probably his happiest times were with Johnie - that was the school friend who became a care giver. Mark was out with him, so mobile and not able to orient himself at all and, really, this was the ideal for him. And also when Regan looked after him. Two guys, the two caregivers, you know they would play baskets with him and they'd go 10 pin bowling, they'd do things together and he really enjoyed that...**

Sadly however, they did not have the power to dictate what services would be provided for Mark. While they could see that this combined 'carer and rehabilitation' arrangement was the ideal, the number of hours allotted to him dropped as he became more aware and the rehabilitation unit, geared for physical rather than mental disability, for the elderly rather than strong young men, was running out of useful experiences to offer him. He was only being offered one and a half hours a day of structured rehabilitation programme now and most of the activities offered were indoor and sedentary.:

> **DANIEL: Well we are keen on sport and wanting to build him up-he lost so much weight - got down to a thin stick - so we thought walking was a good exercise to make him move those arms and legs about -**
> **JULIET: I think that in the beginning, we thought we were having more success at home than they were there and that to have him at home with the support of OT and physio would have been ideal**

Mark was discharged from hospital on 17 December 1993. He became an outpatient of the unit. The Whites then employed Regan, one of his caregivers, for eight hours a day to help them to manage at home. For them, Mark had not yet 'recovered'. They felt that he still needed intensive rehabilitation, both physical and cognitive, but around them there seemed to be nothing designed for his problems. They believed that he would only respond and continue to improve if he was given continual challenges and they were ready to fight for his recovery alongside him, but

recognised that they could not do it on their own. They needed the support of a suitable structured programme. He was beginning to stagnate in Porterton and they were determined not to accept that. They began to look about for some more comprehensive programme for him and Waimarie's name came up. The family were thrown into a terrible dilemma.

> **JULIET: I mean, our first reaction was you know -"I don't want him to go to an institution." I mean from all of us. Simon said, we said, the Grandparents felt that. And we *forced* ourselves to go up and look at it and it was a cold day, there wasn't much happening and we were just full of dread -**

Their instinctive revulsion for an institution for Mark, however, had to be counterbalanced by the powerful arguments in its favour. Although it was by no means ideal, it offered him a full day's structured programme and it offered the family a chance of returning to a more normal lifestyle, of recovering a sense of balance. For so long, their lives had been centred around and constantly focused upon Mark's needs. They decided that, provided Mark returned for weekends, they would arrange for him to become a resident at Waimarie. They believed that with Waimarie's help, they would be able to provide Mark with the stimulation and structure he appeared to need to support the most effective and complete recovery he was capable of. At the end of February 1994, Mark arrived at Waimarie.

THE 'AFTER' MARK

Until shortly before the time of the research, it was difficult to make definite statements about how Mark had been altered as a result of his injury, because of the rapid changes he experienced as he emerged from unconsciousness. Although he was still recovering, at this point in his story, some interactive and intra-active themes related to his new identity were emerging.

IDENTITY

Many of Daniel and Juliet White's concerns at this time, as well as those of staff at Waimarie, might be summarised as involving the theme of Mark's future identity. Everyone agreed that he did not have any authentic sense of self. He did not initiate much that was purposeful or goal-oriented and people were feeling he had lost the drive to know and to develop which once he had taken for granted. Because these characteristics had once been so central to the person he was, he remained alienated from his former personality. There were several themes emerging in his story, which related to this lack of fit between the before and after Mark.

Performing

Comments made by those around him at Waimarie, suggested that a new inauthenticity was appearing in Mark's interactions. His life was in danger of becoming one long and stressful role

play for which he has an inadequate script. In trying to please his parents, the rehabilitation staff and his family, he was watching for clues as to how to present himself rather than looking inside himself for direction. His only motivation appeared to be to get approval for this performance. His only pleasure appeared to be from acting a part well, or from acknowledgment of his effort in the attempt. This inauthenticity was given away by little details, particularly the moments he regarded himself as 'off stage'.

> **JULIET: And, he is not really, I mean, he is living in that flat but he is not really *initiating*. He hasn't actually initiated any activity which shows that he has explored the flat in any way. We have talked to him about his washing and where he gets his clothes dry and that sort of thing and we will say there is actually a clothes horse. And he will say "Oh is there?" and we will have to take him down and show him. You know, he hasn't actually wandered around and pulled open drawers or cupboards or discovered anything about the flat that people haven't told him.**
> **DS: They are not really things you teach people to do are they?**
> **JULIET: No but Mark doesn't think to do them. Normally he would have been, I mean before his accident he was extremely inquisitive and always trying to find out things, or ask things.**

Perhaps his parents saw these details more clearly than others because of their closeness to him and their ability to compare the 'before' and 'after' versions.

> **JULIET: No. and I think he really is floating. He doesn't know where he fits into the family any more - you know he was just saying that he doesn't really feel that he fits into Waimarie. The thing with rehab is that there are so many other more disabled around him that he feels not quite right there - but he doesn't feel quite right here either - and - he doesn't fit in with his friends any more either and neither with his brother and, so, I think he really does feel quite lost and alone.**

Although Mark wanted to belong and wanted to demonstrate that he could still achieve, the structure of a rehabilitation programme did not seem to offer him anything he could feel a sense of pride in. Success at Waimarie could not compare with the achievements of his former existence, nor could it even compare with the more physical and clear cut rehabilitation progress of the rehabilitation unit. The cognitive improvement and the interpersonal and social successes he achieved at Waimarie appeared to have little transferability as an achievement measure in the outside world. While attending Waimarie, Mark's social interaction opportunities were hardly ideal:

> **JULIET: He is such a people person that he would get involved with the people, - and here [at Porterton Hospital Rehabilitation Unit] he took that role - because he was mobile he helped hand out the meal trays - he used to tell us so and so could walk in the gym today and he was so excited - "You should have seen it Mum!" and he was really excited and "we celebrated" and that sort of thing and he took so much more interest in the people and how they were progressing.. whereas, at Waimarie he is not interested in the others there ...and it is a withdrawal, he is not really thinking of them or feeling for them the way he did up here.**

Mark's problems were no longer physical, but had more to do with relationships. As time passed, he appeared to lose his existing relationships and fail to establish meaningful new ones.

Projection and Perspective

Not surprisingly, much of Mark's interest and attention was absorbed by the issue of how well he would recover. The most constant theme in his talk was about 'trying'. He believed it was the vital ingredient in his recovery and was distressed that he found it so difficult. He felt a great deal of guilt about the effort and energy his parents had given him and believed that he should 'try for their sake'. Unfortunately, the trying theory was proving difficult in practice. He would try intensely for half an hour and then proudly display his effort. But the therapists, after the first week of gauging his level of ability, then wanted to continually raise their expectations of him as he reached a goal. Success for them signalled the time to move onwards to a new challenge. He became frustrated that there seemed little recognition for the half hour of effort and too much concentration upon the next half hour. Frequently he became hostile and defensive, refusing to participate.

Noone, parents or staff, wanted to see Mark trapped in this vicious cycle of effort and failure, but their actions and the structure of the programme may have been perpetuating it. He was very dependent upon his projected impression of the 'perspective of the other' in making decisions as to how to act. Because all those around him defined him in terms of a brain injury it must have seemed to him that he used to be interesting because of a variety of skills, abilities and personality characteristics, but now he was interesting because of how these have been affected by brain damage. As a result, he became intensely interested in the head injury rather than the underlying person. His actions were directed toward creating an image of a 'good rehabilitatee'. It must have been confusing to know how to play this dual role of the person 'I once was, that I can no longer remember' and 'the person I have become because of my accident'. His need to adopt this role may alone account from many of the observed problems.

This excessive self-consciousness and deference for the attitude of others may also have been responsible for the way he appraised himself in a comparative way. The 'old Mark' was placed alongside the 'new Mark' as a standard or benchmark. He recounted stories about himself with a peculiar mixture of awe and dread. Awe at how good he 'used' to be and dread, that he will never be this person again. Awe at how he used to impress everyone (particularly his parents) by succeeding at every challenge he took on and dread, that in this rehabilitation challenge he has met his match at last.

Trying

Rehabilitation then, had become identified by him as a new challenge. He clearly took pride in his demonstrated ability to rise to challenges. The delight with which he described his achievements

in rugby was intensified by the pride his parents had felt. He talked at length about the support which his father gave to him as a rugby player accompanying the school team to Australia "just to watch me!". Similarly he talked of his mother's devotion to him, of how she gave up her job for two months to be there for him during this early recovery period, of how she painstakingly collected and organised the photo albums for him, writing a description beside each one so that they told his story.

As he told these stories he revealed a sense of obligation to work hard at his rehabilitation that he had built in his mind. It was as if he believed that if he worked harder, concentrated longer, he could learn to be this other person again. Whenever he failed to win approval, respect or friendship at Waimarie, therefore, he blamed himself. The only reasons he could offer related to some lack of effort on his part.

To those who lived and worked with him, however, he was at times trying too hard to act out some sort of role. His constant need to work for attention and approval could become irritating. He did not seem to know how to relax or how to be alone, because, perhaps, he did not know how to 'be himself'. When I suggested to him that he was even talking of recreational activities as 'work' he looked bewildered. He did not seem capable of 'play' as an absorbed consciousness, or of the "transparency" (Heidegger, 1967:186) of dasein in its everydayness. Instead, a restless watching and performing for others determined his days.

His parents found this restless energy very disconcerting at first. They had been prepared, during his period of unconsciousness, to find him drowsy and unmotivated in the early days. Instead they were confronted with 6ft 2in of restless energy, prowling, pacing, invading their body space, unable to let them alone. Mrs White told stories of being followed around the house by this large 'toddler', who constantly demanded attention. She found the experience of living with this oppressive and exhausting and it was clear that anyone else living alone in a house with him would too. Waimarie, with its extensive grounds and buildings and a large number of people, provided an environment where no one person bore the stress of his company alone.

Imitating

As well as looking for guidance about himself in others' responses to him, Mark also sometimes watched people in order to imitate them. Without memory of his former life, it was difficult for him to construct his own 'scripts' to rebuild an appropriate identity and so instead he imitated those he saw as being like the 'old Mark'. Simon, his brother, was the most obvious model when he was at home and the Whites described him as carefully following this role model:

JULIET: Yes, well we just notice that if Simon was reading the paper Mark would grab a paper and look like he was reading it- or if Simon was watching TV he would. Just like a child would. Like a child who imitates a parent's behaviour, Mark will watch everything that Simon is doing and if Simon is doing it he reckons it is okay so he starts doing it too.

The trouble with this strategy at Waimarie was that many of the available role models among the residents were behaving in bizarre and unusual ways as a result of their head injuries, while the other role models, the staff, were behaving in clinical, treatment-oriented roles. To copy others' actions at Waimarie was therefore fraught with problems and unlikely to be successful or impress anyone. His parents had a similar problem with their parenting roles. They found that, because of their need to be his 'coach' and 'prompt', it was difficult to model peer relationships before him. Because of their insight into this, they were quite consciously organising Mark's environment when he was at home during the weekends. They arranged situations so that he was exposed to roles which he could appropriately copy, asking Simon to invite his friends around and arranging social occasions for him with his former friends. This was something Waimarie could not do and also, something which many families would not have the strength and internal cohesiveness to attempt.

This strategy clearly placed some stress upon all three of the other family members. Simon, because he was obliged to manipulate his own social life and recreational activities to make them double as 'therapy' for Mark and Juliet and Daniel because they seemed to be looking at their family and friends as 'resources' for Mark and their home as his stage, or training ground. There was in this transition of home into therapy centre, the recipe for considerable tension. The space which these three needed for relaxing was acquiring some of the contrived and objectifying qualities of a clinical workplace.

Imagining

The awe Mark had for the 'old Mark' was based largely upon what he had been told by other people. He could not remember his life before his accident very clearly and what memories he had appeared to be 'flashes', or 'glimpses' almost as if at another person's experience. This retrograde memory loss had several drawbacks which both contributed to and were compounded by, the 'role-playing' approach to living discussed above.

Firstly, it meant that his notions about who he was were comprised largely of descriptive detail of faces, names and actions as opposed to emotional content. Whenever I asked him how he felt about something which had occurred back then, he would respond with something which was more narrative than feeling, doing so triumphantly as if waiting for approval for remembering. When he thought about and talked of his previous life, both his self-description and his narrative

was presented as something 'learnt' or thought, rather than something experienced and felt. It is possible that this apparent loss of emotional memory was related to the site of his injury. Mark's right brain must have received the more serious damage because it is his left side of his body which was physically affected. A reliance upon more conceptual and analytical thinking processes may have restricted his recall to memories with a verbal rather than a visual quality. A memory is not personal or meaningful unless it has an emotional, visual, or perceptual component. It cannot "evoke" (Poulos and Wilkinson, 1984:78) in a "wholistic" sense rather than just process information as a "tacked on computer" (Sacks, 1985:2) would.

Although Mark's memories and thoughts were not devoid of the emotional, visual or perceptual, he seemed to be having difficulty integrating those memories with their narrative counterparts. As his memory was returning, it was as fragments of episodes from his past, often cued by visual memory aids such as photos, but sometimes occurring at random and without him appearing to consciously conjure them. He was not sure of the source and the location in time and place of these memories and did not feel he could rely on them.

> **MARK: I was - I remember this I was with Greg and we were on the last hole, and I did this big drive. It went about say, 50 metres.**
> **DS: And you remember that?**
> **MARK: Yes... Either I am making it up, or I believe it - I am not sure.**
> **DS: But you are not sure if it is or not, it might be something you imagined?**
> **MARK: Maybe they hit it - maybe it was other people. I remember being on the golf course, when I hit it hard... This one is real, I know it is real - deep down. It just came to me actually -**

Mark appeared sometimes as here to be almost 'conjuring up' and actively creating memory images rather than just passively receiving them. His description of what was happening on some occasions sounded like 'hallucinations', out of his control and frightening for him.

> **MARK: - Like when I am sitting on a bus and I see people with my eyes which scares me. In 1993 December the 1st - it would have been just on the night - I turned around like this and got a view of my cat - I turned the light on and it is a white cat. I just looked at it and it disappeared**
> **DS: Right. So sometimes you see things that are not there.**
> **MARK: Yes. It is just in my imagination.**

This 'image conjuring' strategy was obviously not totally under Mark's control and perhaps therefore potentially as destructive as it was constructive as a strategy for recalling the past, but fantasy and image did appear to play an important role in the recapturing of memories. Zasetsky (Luria, 1987:97) in *The Man with a Shattered World*, mentioned a similar phenomenon:

> **If I happen to be sitting, or just doing nothing, I'll suddenly see images, visions, or pictures of my childhood: the shore of the Don where I liked to swim when I was a child, the cathedral in Epifan', the talk some friends and I gave at a club meetings. These visions have helped me become aware of my past again, though only small fragments of it.**

Because these images were visual, perceptual and emotional, they had no location in time, they were "glimpses", which were as Mark explained it "like a fly flying through one ear and out the

other." Under these circumstances their meaning was not always clear and as Zasetsky (Luria 1987:97) found, they were not easily controlled:

> **But, he could not summon them at will, a problem that was particularly difficult in the early stages...**

It would not have been useful to regard these illusive images as 'fact' or 'memory'. While real memories may well often be summoned first as fleeting images, Mark's preaccident memory was too impoverished to act as a counteracting force and if he relied too heavily upon such a strategy for recovering his past, he was in danger of being labelled 'confabulatory'[80]. To allow him to practice evoking the past without slipping into fantasy, he appeared to require an environment and people who could provide him with some objective fact to help him learn to distinguish between reality and fantasy.

RELATIONSHIPS AND INTERACTIONS

When Mark's parents tried so hard to remind him who he was with photos and with their talk, they were essentially teaching him what his own relationships had been so that he could interact with his world again. They focused upon this even when the medical staff were more concerned with physical and neurological issues, seeing his cognitive recovery as central to his consciousness. As they worked with him in those early days they developed some interesting strategies which had an impact upon their relationship with him. It seemed important to understand these dynamics in order to understand Mark's story.

Perhaps it was their early use of photos which led the Whites to believe that the key to recovery was finding the cues which prompted him to connect present lived experience with his existing knowledge. They learned to fashion their own responses so that they organised and labelled his experience in this way, almost providing a running commentary of explanation at times. This interpreting support appeared to be an effective way to assist him in integrating new experiences as well as helping him to understand what action or behaviour was expected of him. Using this technique, they reinforced and clarified for him each weekend, what had happened at Waimarie during that week. With the written timetable as a prompt, they would help him go over and integrate his experiences, reflecting upon how they might be helping him, reassuring about how far he had come and giving his life a sense of order, continuity and hope.

> **DANIEL: Because, initially, he would remember nothing. We would say, "What did you do this week?" and he would say "nothing"... "Where did you go?" and "Who did you talk to?" (imitates Mark shrugging blankly). And then, well, we thought that he just had no memory. But it is like going to a filing cabinet and saying, okay, where is my file and you don't know, but if the label is back on, you can find it. And if he has got cues - like "Your timetable says that**

[80] See Chapter 1, p. 22.

you went to this - " "Oh, yeah -" and then it is like a waterfall! And so, we use his timetable as a cue to whatever he does during the day- and often, it triggers things off.

As the Whites discovered, this cueing was a powerful tool but it required that the prompter understood the person as a whole person, not a 'case'. It was necessary for them to understand how the events of his day may have been linked with his past experience and probable future and also to understand his personality well enough to guess what went wrong in situations they did not observe, so that they could guide him to understand this better himself. The structure of a total institution with its impersonal relationships, division into clinical roles with each team member treating a different part of Mark and its hierarchical structure of power, would actively have worked against the development of such relationships. However, many of the staff at Waimarie had managed to overcome these obstacles of structure and environment and had built up sufficient background knowledge of Mark as a person to continue a similar cueing and prompting process during the week.

The Waimarie environment also developed its own more formal methods to help Mark organise and label his day effectively; largely the written programme he carried with him, but also whiteboards in his kitchen area and a notebook system so that he and others could record particular events. Nevertheless, it is probable that Mark, expected largely to be responsible for himself in moving around a large institution to follow his programme, was constantly thrust into situations where he had to guess what was appropriate without the level of cueing he would have received at home. The stress of deciding what he should do at such times, sometimes appeared to overwhelm him and, as will be seen later in discussing the film exemplars, this sometimes resulted in his opting out completely from organised activities.

Tangential thinking

One interactive difficulty Mark experienced was his inability to stay focused upon a coherent central theme. Sometimes it seemed that there was no logic or order in his conversation at all. His talk would become peppered with irrelevancies and he appeared to respond to whatever immediate association occurred in his head rather than monitoring any themes in the talk he was engaged in. This was understandably bewildering and irritating for fellow interactants who quickly discarded attempts to explore issues in any depth.

Luria (1987:113) comments upon this tendency in his own patients, explaining that the "law of strength"[81] which usually operates upon ideas can be disrupted by head injury.

...Strong and weak stimuli register with the same intensity, arouse equally strong responses and leave just as permanent traces. Think of the strange associations that unexpectedly occur when

[81] See Chapter 1, p. 20.

> **you are falling asleep; your thoughts are confused and you can readily become disturbed by things that appear trifling during the day. A cortical condition such as this, but pathologically induced, is what Pavlov termed a "damped" or "phased" condition. In this state the cortex functions far less precisely and is barely able to distinguish the essential from the inessential.**

Without a law of strength, Mark's thoughts and conversational gambits were less governed by themes and they lacked a sense of direction. However, he appeared to have some "intellectual awareness" (Crosson et al., 1989:47) of this change and to be attempting to control the impression of oddness it created. He watched carefully and attempted to self-correct when he saw bewilderment or frustration appear. This habit may have helped him to compensate for the tangential logic but unfortunately, it appeared to make it difficult for him to move on from watchful participation to an easy and relaxed conversation. Until he was more in "control" or more focused upon "the idea behind the act" (Ben Yishay et al., 1985:255) he was more likely to take a passive and responding role in interactions than to grasp the initiative.

Intellectual awareness can be seen in this context to promote a loss of confidence at the same time as it improves awareness. To have an awareness of a difficulty without the concurrent ability to compensate for it effectively, meant for Mark at least, the development of a sense of insecurity and of an over anxious intensity.

Egocentricity

Of course, there were many times when the tangents he took led Mark's conversations back to his favourite subject: himself. Egocentricity is regularly mentioned in the literature as a consequence of head injury[82]. Commentary about this trait can appear rather judgemental as it is often discussed as an unfortunate sort of personality defect which has emerged, rather than as a thinking pattern which fulfils some need for the person. Such an approach may have caused practitioners to ignore the function it serves in recovery.

The symbolic interactionism approach offers an alternative way of looking at what was happening to Mark at the times when he appeared to be egocentric. Mark found it confusing always to be imitating, trying to work out from others' actions how he should respond. He wanted to behave as the old Mark would have, yet this took so much effort and was not often successful. He did not understand the new person he had become any better than the person he had been. Part of him was 'looking on' or as Mead (1934) would say, 'taking the attitude of the other' in order to try to learn who he was. By initiating conversations about himself and by changing the subject always back to himself, he maintained an environment which helped him to achieve this task of finding

[82] See Chapter 1, p. 33.

out who he was in a before and after comparative analysis that worked toward the re-placing of his identity.

This process was not always as pleasurable for him as the term egocentricity suggests. Indeed, throughout our interviews, I noticed that he often abruptly changed the subject because he touched memories that were frightening and distressing, often things he could not yet explain. Sometimes he would embark on a story he had heard and suddenly realise he had no deeper or thematic comprehension of what he was telling. This clearly had an unsettling effect upon him, causing him to pull back from a topic and turn his attention to something more pleasant and concrete. His photo albums appeared to be functioning as a compensatory strategy at these times, allowing him to return the conversation to a concrete and visual level where he could be confident that he would have sufficient cues.

Purpose and Direction

A loss of initiative and self-direction also coloured Mark's interactions and relationships, suggesting he had some degree of 'frontal lobe syndrome'[83]. Like most of the people who came to Waimarie, Mark's initial injury was complicated by the secondary effects of crushing and heat which caused bruising and trauma over the whole brain. As a result he appears to have suffered some frontal lobe damage and some loss of what Goldstein termed the abstract attitude. Luria (1987:35) suggests that with this combination of deficits, the person is

> **.. powerless to convert these into a set of symbols to control his behaviour. And since he has no possibility of evaluating his shortcomings, he cannot correct them...**

Mark's behaviour would certainly not have suggested a loss of symbolising ability, but it did suggest some inability to recognise and identify internal feelings appropriately. His understandings of situations were often so divergent from those of others that his behaviour appeared bizarre and he was unable to "evaluate his shortcomings" in any coherent way. Without effective self-knowledge, he had been robbed of a sense of self-oriented purpose and direction and had become confined to a limited reacting to the immediate moment.

For Luria, the implications of a loss of frontal lobe activity were profound. He concluded his discussion of frontal lobe injury by suggesting that the person in fact loses "all that which makes him human" (Luria, 1987:35) For this reason, all the small attempts which Mark made to initiate, to plan and organise for himself, no matter how small, had a greater importance than it might seem. With support and encouragement for his self-directed actions, he was slowly learning to take charge of his future again.

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[83]See Chapter 1. P. 13.

EMOTIONALITY

Everyone who knew Mark before and after his accident would have agreed that his emotions were profoundly altered by his injury. This was one of the most difficult aspects for family and friends to deal with. During the eighteen weeks of PTA, the loss of an emotional relationship was particularly striking and distressing for this family because he had always been so caring and sensitive in his interpersonal interaction. There was, as a consequence, a general sense of alienation and an inability for friends and family to understand how to relate to him. The return of the smile was therefore seen by those closest to him as a major turning point, signalling to his mother in particular, that the old Mark was not lost, but temporarily absent. Because of the importance of emotionality to the rebuilding of a self, exactly how this relationship can become disturbed by damage and how the process of recovering an authentic emotionality occurs is particularly important to this study.

Damage to the frontal lobe, according to Burgess and Wood (1991:111), is responsible for a "shallow affect, euphoria, poor insight, diminished social awareness and a bland unconcern for social rules." These characteristics were certainly evident in Mark's interactions at this time. Emotional change caused by damage to the limbic system typically caused behaviour described as "restless, hostile, intolerant, with violent mood swings" (Pepping and Roueche, 1991:235). This description appeared just as relevant to Mark. As already discussed in relation to imagery, however, Mark received more damage to the right brain, as is evidenced by the physical motor weaknesses which affected the left side of his body. The right side of the brain is considered by many (e.g. Schwartz, 1975; Tucker 1981, etc) to manage emotional processes and there is abundant evidence that people with right sided brain damage also exhibit similar symptoms to Mark. Gardner (1974) described a person who had the right hemisphere removed as thinking in a machine-like way, being unable to integrate thought and feeling. Although there was something reminiscent of Mark in this description, he did still appear to be feeling and feeling very strongly but had become less able to process what he felt.

There were, therefore, three aspects of brain function which appeared to have been altered by his injuries, all of which were implicated in emotionality. It was not as useful to identify neuroanatomical correlates for Mark's problems as it was to recognise the essentially interactive and integrative nature of brain function and particularly when dealing with emotional function. Mark comments about his feeling confusions suggest just such a loss of integration:

MARK: It's horrible really, it is like I am an alien...

From this perspective it became clear that how Mark's experience of raw feeling had changed was not the issue, but rather how his difficulty relating thought to feeling affected his intra-action, interaction and social relationships. Hochschild's (1979) theory of socially acquired "emotion work and feeling rules" which discipline and shape emotional feeling and expression and fashion the person into a "moral self" (Denzin, 1984:124-8), offer a more useful approach to understanding Mark's emotionality than any literature about brain tissue could do.

From this symbolic interactionist perspective, Mark's social behaviour often suggested that many of his problems were created by a failure to control and discipline the sometimes overwhelming and unmanageable feelings which gripped him. This failure to cast his feeling in socially acceptable formats in order to express them, thrust him into a vicious cycle of failure, where he could see that he was unable to feel what he believed he 'should' feel and unable to adapt his feeling rules to suit his changed situation.

He appeared to have developed some strategies with which to accomplish this 'emotion work' and one of the most obvious was his tendency to imitate others' emotional attitudes. He would regularly adopt the feelings of others both at Waimarie and at home, or at least appeared to be guided in what to feel by closely watching the reactions of people around him. His family encouraged this copying tendency, believing that even if it sometimes made him appear odd, it also allowed him to develop his own emotional expression. They saw this as a necessary stage in relearning to feel appropriately.

Another strategy he used in this intermediate period, was to use sensory means to control and temper his emotional tone. He had become adept at soothing and calming himself in a number of sensory ways.

> **JULIET: And he says that the swings are relaxing - and I can see, you know, they are very therapeutic - that sort of action and if he gets angry that is what he says, I go and swing on the swings and I can think -but, - it just looks so strange this great big hulk on a swing! ...**

And...

> **JULIET: He would love to get hold of the cat ...if we can get her on to his lap, he goes all gooey - he strokes the cat and he really just gets rid of all of those emotions and I think he just loves her and wish she would go and sleep on his bed like she used to...**

This reliance upon the concrete is perhaps not surprising. The limitations upon Mark's emotional control were clearly related to limitations in his level of self-awareness. He appeared to be operating at an "intellectual level of awareness" (Crosson et al., 1989:47) of his different emotionality at the time of the study. It is possible that anticipatory awareness, which would have increased his sense of control, required a more abstract thinking ability than he was yet capable of. During our interview he talked constantly of being frightened but was often very vague about

why. When pressed to talk about this and similar emotional feelings, his explanations often drew upon very physical concepts rather than abstract or relational terms. He would say that feelings 'hurt' him, that he felt 'pain in my heart'. It was possible that this concrete level of understanding feeling limited his ability to express his feelings towards those he cared about in interpersonal relationships.

Goldstein (1952:247) suggested that people "confined to the concrete attitude" in this way would experience catastrophic reactions whenever they were thrust into situations which demanded too much of their interpretive powers and which threatened their self-actualisation. This certainly appeared to describe Mark's behaviour whenever confronted with his uncontrollable emotions.

> **DANIEL: He just goes and goes and goes.**
> **JULIET: - He doesn't even seem to hear us -we ask him to stop and he just keeps going.**
> **DANIEL: He seems to whip himself up- and he just ran out here [***indicating sliding door into back garden***] and he was just sitting there and he going like this [***imitates Mark panting and distressed***[it was only because he fainted or ran out of air that he had stopped!**

When he did appear to manage a more appropriate emotional tone, it was usually because he was provided with cues as to how he should appraise a situation. Having learnt how important it was to manipulate Mark's mood for him in this way, the Whites managed to develop relationships with him which avoided tapping into irrational fears at the same time as they helped him maintain at least an intellectual awareness of his difficulties. It was frustrating for them to watch others with less understanding fail to do this and so in effect accentuate his problems with emotional control.

> **DANIEL: So, at Waimarie that very first week I was there with Mark, I offered to give him a race in the swimming pool and he said, "No no, you'll beat me" and so I said "Okay, I'll give you a head start, you go two metres up" and he was off, full length, overarm and he actually did eight lengths, racing like that and now, he is useless..**
> **JULIET: He won't even do overarm and he has got this sort of helplessness that has developed. He has got to have a sort of floating collar on his neck, in case he drowns and, we just feel it is the way it has been handled - you know - that, he can actually swim, but he just is lacking confidence and he just needs that support, that trust, to actually give him the courage to have a go. ..**

The family believed that the change in Mark's emotionality was gradually disappearing as he learned to feel again. He was showing an increasing ability to love, to care and to consider others. Although earlier, this may have occurred because of neurological healing, later it appeared that the path of emotional recovery was a psychosocial one and involved him learning how to express and comprehend emotion appropriately again in much the way Hochschild described. It seemed that to live a more effective life, to have equal relationships with others again, he needed help to reformulate his "feeling rules" (Hochschild, 1979:564). If ontology precedes epistemology, personal meaning schemes must precede any authentic emotional understanding of the outside social world.

Humour

This relearning of how to feel and how to experience emotion even affected Mark's ability to understand and relate to humour.

> **JULIET: ...And once we had got him further down the track and we realised that he could read and could track with his eyes and things and then we got speech and he was reading Garfield and I would say, "Is it funny?" and he would sort of look at me and say "What is funny?"- He says "Is this funny?" (Imitates Mark holding out an imaginary Garfield book) and, it says "Tee, hee, Hee" and that is how he laughed. So, if we said anything funny he would go "Tee hee hee" and that was his substitution -**

A sense of humour is not something which can be reapplied through imitation and role play. This lack which still existed in Mark, perhaps more than anything else, demonstrated the way that his conceptual and perceptual problems affected his interpersonal exchanges. Humour often requires that we manipulate or play with conceptions and perceptions, creating absurdities by reorganising words. Mark demonstrated continually that he was unable to recognise the more subtle forms of humour and so his more informal and light hearted interpersonal behaviour was frequently out of step with others.

Zasetsky, (Luria 1987:116) showed an unusual and revealing insight here into his own shortcomings regarding humour.

> **I was sitting in an auditorium once, listening to some stories and a performance by some visiting artists. While the narrator was talking, the whole audience began to laugh. Seeing everyone else laugh, I did too, though I didn't understand a thing the man had said and only had some real reason for laughing when an actor imitating a drunk began to stagger and fall.**

The drunk staggering and falling was about the level at which Mark's humour stood at the time of this research. Like Zasetsky, he appeared to recognise his lack and to respond to it by imitating others in order to conceal it. But it was much more difficult to imitate feeling than behaviour and much less satisfactory. His laughter at Waimarie was usually a response to some action of another person's which he saw as ridiculous or absurd in some way. Although he genuinely believed that he was 'laughing with' people, this sort of slapstick styled humour had the effect of making him appear to jeer at other people, or to guffaw inanely. The effect was to suggest that although he could laugh at, he could not yet understand how to laugh with[84]. One way to monitor Mark's return to full consciousness, therefore, may have been to monitor his response to jokes, watching for a return of appreciation of the more subtle forms of reality manipulation.

[84] this appears to be an area where Mark was making a rapid recovery and it was becoming less accurate to describe him in this way as I wrote. However, his idea of what was humorous still frequently jarred with others.

Insight vs "Outsight"

Earlier, I remarked upon Mark's difficulty in balancing his own self-concept with his projection of the 'perspective of the other' toward him. I suggested this was making it difficult for him to reformulate an identity. This lack of fit between the projected other and the inner person was also making it difficult for him to establish authentic emotional intersubjectivity. During his recovery Mark was constantly drawing quite unusual and incorrect inferences about other people's meanings and their motives. As the following remarks demonstrate, the problem was often caused by a loss of ability to empathise with others' feelings, coupled with a concretic approach to understanding.

> **DS: So it was a couple of months later in rehab that you smiled for the first time.**
> **MARK: Yes. And Mum was there. And I was stoked.**
> **DS: Why do you think that was so important to your mother?**
> **MARK: Because I had movement in my face back - because when I was first in hospital, I couldn't move my eyes, couldn't hear, -**

It was clearly very difficult for Mark to 'put himself in the role of the other'. Apart from not really understanding what motivated people, he had very little idea of how he appeared to others and therefore, how others felt about him. This awareness of others' perspective is sometimes called insight. It is not really an insight into oneself however, so much as it is an 'outsight' or rather, an objective meta-awareness of how one is presenting or appearing during social interaction. Thinking about what others might think of him may have been quite threatening and distressing at this time.

> **DS: Okay and if I said "What's Mark White like?" -What would you say?**
> **MARK: I am a pain.**

Whenever he was confronted with the differences between how he used to be and how he was now, Mark had two main explanatory schemes: either the difference was caused by his brain injury (which he regarded as still healing and so probably temporary) or it resulted from his lack of effort. When it came to the area of social skills however, neither explanatory scheme was really satisfactory and Mark was left with a confused notion that his social failures and his lost friendships were somehow caused by a lack of effort, when in fact they reflected a quite different type of loss, one he could no longer comprehend.

Sadly, when it comes to his interpersonal skills, this notion of trying was often very dysfunctional for him. He was over eager in his approach in many social situations, seeking constant approval and reassurance from others and seeming to need their confirmation of every little detail of his existence. Conversely, his idea of what was appropriate was limited to a few general 'principles'. For example, he believed that it was socially appropriate to be friendly and polite, to initiate conversations, to take an interest in the other person and to share his own ideas. All

unremarkable and acceptable opinions, these seemed a good basis from which to act. However, when asked to convert these principles to descriptions of actual behaviour within a situation the results were sometimes bizarre.

> **DS: How about if you met someone your age, that didn't know you before your accident and he was just meeting you at a party or something... how do you think you would come across to them?**
> **MARK: Well, say I was dancing, I would go over and ask him, "Excuse me, but do you mind if I ask you something?" and if he says "Not at all" I would ask him a favour or something and if he can come around I would - do you know what I could do?**
> **DS: What's that?**
> **MARK: Baked beans!**

His attempts to show concern and interest in others usually appeared as inauthentic and forced as this excerpt suggests they might and could even cause offence. Perhaps this was more likely to occur when he attempted to copy his peers in an easy 'teasing' style of interacting, but without sufficient skill at managing the subtle tone differences of teasing. The subtlety, the light touch involved in teasing was difficult for him to imitate. This inability had devastating effects for him. On one occasion, for example, a close friend became so irritated that he made his feelings clear to Mark:

> **MARK: I can't even talk about it - there was something I did and someone which was, you know, I felt like he was putting me down and that hurts. But he wasn't.**
> **DS: What was he saying?**
> **MARK: I don't remember, but you know, when I fed back to Greg how it came out - I put my hand out and said "I want us to be friends" and he shook my hand and now we are friends again!**
> **DS: But you can't remember what it was that you did that nearly stuffed up this friendship?**
> **MARK: I think I put him down too. I think I put him down, more than he put me down.**

In fact, Mark and Greg were not 'friends again' at all. Mark had taken this polite initial response of Greg's literally. Unlike his parents, he did not appear to have realised that since this incident Greg had disappeared out of his life. He was beginning to suspect, however, that his manner of interacting with his friends was inappropriate, but felt powerless to change. It seemed that the limitation to an intellectual level of awareness and concrete level of understanding again prevented the appropriate use of compensatory strategies (Crosson et al., 1989:46-9) in spontaneous situations where no rehearsal and preparation was possible. To be aware enough to recognise a problem without sufficient cognitive skill to control it must have been extremely distressing. Many people with brain injury appear to be caught in this gap between understanding and ability and self-knowledge in such situations can create an intense self-hatred or shame. Zasetsky (Luria, 1987:100) showed this sort of insight in this remark he makes of himself:

> **-no matter what circumstances I'm in, I'm always aware of these defects in my memory and in my ability to speak or think. I sense just how abnormal I am when I talk to people; I'm aware of that idiotic smile on my face, that silly nervous laugh I have and my constant habit of saying "yes, yes" while someone is talking to me. And when I begin to talk, I start to laugh in some stupid, peculiar way for no reason at all.**

In such circumstances, it seemed the more positive times in Mark's recovery process were those which allowed him to place his failures in the context of a recovery continuum; to see himself from the perspective of others as someone with interpersonal problems which were typical of brain damage and an expected part of the recovery process. In this way he was able to accept some losses and yet still hope for more skill in the future. His 'outsight' had effectively become better aligned with his 'insight'.

Godfrey and Smith (1993) recommend that therapists help people with brain injury understand their problems by "normalising"[85] them. Perhaps the most important effect of the normalising strategy for Mark, was that it allowed him to relax and drop his level of other-consciousness. Intense self-consciousness was not an effective mode for interpersonal interactions as it is difficult to be spontaneous and authentic when constantly measuring and appraising oneself. Eventually it would be essential that he managed to regulate his social interaction unconsciously, in the way Dreyfus, H. and Dreyfus, S. (1986:129) describe as an intuitive "grokking[86]". Until he learnt to replace self-conscious trying with "deliberative rationality" (Dreyfus, H. and Dreyfus, S., 1986:50) he could not interact in the absorbed "transparency" (Heidegger, 1967:186) of "play" (Gadamer, 1975:95) and so would have difficulty with authentic emotional intersubjectivity.

THE FAMILY'S ROLE

Truelle and Pariset (1990:82) write of the "head injured family". This expression recognises the inevitable disturbance to the whole family system and dynamics which commonly occurs after a severe head injury. Even in cases where recovery verges on the miraculous, the experience of centring so much emotion upon one family member is likely to alter and distort relationships. There is no doubt, that this family made Mark the centre of concern for a time. The way they recounted their story since January 1993 made that clear. Juliet White, for example, gave up her job for two months so that she could sit beside Mark, while Daniel White was quite obviously there beside her as often as he could be.

As the months went by, Daniel White returned to his normal work routine which involved long periods away from home. His wife's attention was still given fully to one son. Many fathers and other siblings would have become disengaged in this situation, but the Whites appear to have avoided this and they felt the ordeal had strengthened and united them, not only with each other, but with the wider extended family. Certainly the manner in which they dealt with hospitals, ACC and medical and rehabilitation professionals suggested a united front.

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[85] By which they mean pointing out that experiences which distressed them were in fact a normal consequence of brain injury, something which could have been expected to occur (Godfrey and Smith, 1993).

Mark's parents believed, however, that some aspects of coping with a son with a brain injury had caused (and continued to cause) tension and disagreement between them. Because both could recognise the danger and because they relied upon each other for emotional support, they were able to resolve differences of approach or opinion in dealing with Mark, or to acknowledge their differences without destroying their relationship. Because of this ability, Mark had two actively involved parent figures during his recovery who were able to reflect upon his needs together. This thoughtful partnership often allowed the family to reflect together upon behavioural problems, often finding unique and creative strategies to deal with them. The following example demonstrates how effective and useful such a problem solving strategy has been to them both in keeping themselves sane and finding ways around Mark's cognitive difficulties:

> **DANIEL: ...things like, when we would go for a walk. For months he always walked behind us, like he was a dog and we could never get him to move up beside us. We would slow down and he would slow down and if we sped up he would speed up, so it wasn't the fact that we were walking too fast. It is very difficult to talk to someone who is always back there!**
> **JULIET: We asked him to come up and he wouldn't.**
> **DANIEL: Eventually we worked out that he didn't know where we were going to go.**
> **JULIET: If he was up front with us he would have to decide when we got to the corner whether to go left or right and he didn't know which one and so he followed us - it took a long time to work out what it was!**
> **DANIEL: When we go for a walk now we will say well, where shall we walk and he will decide, you know he might say well let's go down by the river and then, he knows where he is going -**

Again, the constant use of 'we' throughout this excerpt is typical. This couple appeared to think about Mark's problems and resolve them as a couple. But there were two sons in the family and Simon, 16 now and 15 at the time of the accident, was the family member as yet unconsidered in this discussion. He was, of course, likely to have experienced a major change in his relationships with his parents as well as the more obvious change in the relationship with his brother. The Whites felt some concern for Simon and believed that Mark's accident had had a serious impact upon his life. They did not feel that his needs were neglected, but rather that he felt awkward and uncomfortable with Mark and because of this, had become disengaged from his family. They felt he was aware of his importance, was not feeling alienated from them and knew that it has been his choice to avoid involvement, which they had respected and acknowledged.

They saw Simon's biggest difficulty as being the complete role reversal with his brother. From a respected older brother adviser and friend, Mark had become the younger brother, unsure of himself, seeking approval and affirmation from him.

> **JULIET: Simon had got past the stage of being annoying and had actually got to the stage of having girlfriends and that sort of thing and they would chat for hours and they would play music, talking about girls, everything they had got and they had a really nice relationship in that way as well and it was sort of at that stage where Mark was there to back him up.**
> **DANIEL: And then, after the accident, there was a role reversal.**

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[86] See p. 70 for a description of this term.

JULIET: ...and Simon doesn't want to be looked up to by Mark, he hates being the role model - he has lost his own role model and he just doesn't want to be a role model for Mark... we just notice that if Simon was reading the paper Mark would grab a paper and look like he was reading it - or if Simon was watching TV...

This new younger brother that Simon had acquired was not always seeking his approval either. His resentment of his changed position it seemed, had caused Mark to subtly attack and challenge Simon.

JULIET: ...and there has just been so much aggro through the recovery, I guess Mark was feeling that Simon was doing things that physically he couldn't do, socially he wasn't allowed to do and so as soon as he got out of our hearing it was subtle put downs to Simon all the time, putting him down, til in the end Simon just shut his bedroom door and that was it.

These types of interactions are characteristic of brothers and not necessarily harmful. Yet Simon did not give himself the right to respond honestly to Mark. The role change has been too abrupt and he was confused by how to deal with this new relationship. He was tending to avoid situations and close in upon himself emotionally. The parents, aware how distressing this must be for him, felt powerless to interfere.

JULIET: Oh, he (Simon) has exploded a few times but hasn't really dealt with his feelings. He has been to the psychologist a few times and I think he should have been more frequently but he just said he doesn't have much faith in that sort of thing.
DANIEL: And he is involved in something almost every morning and he is out with his friends and often he will stay over night, or he sleeps in until lunchtime - Sunday morning he will have to work in the afternoon or -that sort of a thing.

At the same time as they felt concerned for Simon however, they had other motives for wanting to re-involve him in the nuclear family. They were aware that in some ways, Simon had more to offer Mark than they had, or even than all the professional and clinical staff had. He could offer him both a role model and a peer relationship and in an unobtrusive way, within the protective environment of the family.

DANIEL: ...and we say to Simon. "If possible, sort of have your mates around here so that Mark can join in a game you know, kick around a ball or whatever..", it really worries us that Mark is having no contact with young people now - we find that he is better amongst his peers - when he is with them his behaviour rises appropriately but if it is left with just us it will deteriorate.

Sadly, their insight about Mark and their determination to maximise his chances put them both in this invidious position of perhaps exploiting one son to serve the interests of the other. They quieted their fears about this by seeing it as a temporary measure and one which maintained the relationship between the brothers.

At the beginning of his stay at Waimarie, the Whites seemed uncertain about the role Waimarie was (or should have been) playing in Mark's and their lives. They were equally unsure about the most appropriate role for themselves. They wanted to continue in the role of the principal carer and decision-maker in Mark's life and because he returned home during weekends, this appeared possible. However, Mrs White often found it frustrating to attempt to direct and organise his daily

programme from a distance. She would become frustrated by the frequent communication breakdowns which were an inevitable result of the distance and Mark's role as messenger and self-reporter. Despite these frustrations and despite some differences of opinion over the decisions that were being made on his behalf, the Whites felt at the time of the research that the decision to apply to Waimarie had been the right one in the circumstances and they appeared to regard the problems created by the joint care arrangement as either resolvable or as differences they could live with.

SOCIAL NETWORK AND RELATIONSHIPS

Because he had a strong social and extended family network, it was relatively easy for Simon to meet his emotional and support needs elsewhere. In contrast, Mark's strong social network collapsed inwards until there was only the family and a few girlfriends remaining.

The trouble was that Mark was no longer (at least for the moment) the 'same person'. It was difficult for friends, re-encountering him, to know how to deal with this person who made odd remarks, who invaded their body space, was over eager, over anxious in his forays into conversations, who made overly personal, or inappropriate comments. Many of his friends at the time of his accident had just finished the seventh form at school and were moving into a new life of university, polytechnic, teachers' college or a job. Life must have been full of many new challenges. It was not surprising that many of them turned away from Mark when he began to show himself as different. As could be expected, the boys were deserting him even faster than the girls:

> **DANIEL: The boys, we don't see them any more. The girls are still writing, ringing, asking to take him out -**

This pattern of the break down of the social network is typical after a head injury (Thomsen, 1990:62; Thomsen, 1991:303). There is evidence that it is also more usual for women than men to remain involved with the person, but that this involvement being less reciprocal, would more accurately be described as care than friendship (Panting and Merry, 1972). It is becoming a concern to clinicians and theorists alike, who are beginning to recognise how often it is this loss of social skill that is the prime reason for a failure to return to a previous life even after a supposedly successful rehabilitation process[87]. Mark attempted to pinpoint some of the moments when a friendship was lost, believing that it was an isolated moment, a chance remark, but his parents understood how much Mark's brain injury had altered his personality so that, for his friends, he had become a stranger.

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[87]See Chapter 1, p.32.

JULIET: And, we had to tell him, I mean every time that we actually went out, he would say hello to every person that we met and if we - we sort of said "Mark, you don't say hello to strangers and he would get angry with us, [Saying], "I am just trying to be friendly..."

The Whites responded to this oddness by attempting to 'coach' him into more appropriate styles of interacting. They attempted to be honest and open with him, explaining as far as it was possible to explain social convention, why the behaviour was inappropriate and what should be done or said instead. They sometimes felt absurd as they did this. They were forced into explaining the unexplainable, the taken for granted and they laughed as they recounted some of the more bizarre incidents.

DANIEL: ...and so then we learnt that if we could actually prepare him before we went out walking "and Mark when we are out walking what do you have to remember to do?". "Not to say hello to people that I don't know", he would sort of say it reluctantly and "What do I have to do this for?", but we could actually go for a walk then and not be interacting with every single person that we met! ... and he eventually takes it on board - it takes quite a few weeks and a number of repetitions but he does take it on board and his behaviour is definitely improving and far more appropriate...

Their love for Mark thrust them into taking this role as coach or prompt, but sadly, this alienated him to some extent from them. In becoming his prompt, they found that they sacrificed something of the role they used to have, the companionship which both parents remembered so fondly, the easy joking friendship which had grown as he changed from boy to man.

JULIET: We always get the aggro because our initial remarks are interpreted as criticism which we were really intending to be helpful and it doesn't matter which way we phrase it or how we say it, he sees it as a criticism...

Because they had fashioned the home environment to give him practice at social interaction, the Whites had become like stage managers in their own house when he was at home. It was hard to be the prompt off stage at the same time as playing an authentic role. Their own need to have a place within which to be 'at home' was not always understood and valued sufficiently by them. As van Manen (1990:101-2) has pointed out, home is "where you can be who you are". Mark did not know how to be at home. The Whites were in danger of sacrificing their own at homeness to their drive to help Mark's recovery.

JULIET: Yes it is and I guess that is what we find, you know - when do we actually relax and - when is our time together and our normal interactions because even if we have a normal conversation he is there and interrupting and wanting to take part all the time and if we have friends visiting I can't have any conversations with him there all the time.
DANIEL: He is sort of like, an only child at the moment - living with parents and only ever associating with other adults. You know how those sort of children can be - they are more adult than children their own age -because when he is at home he is with us.

One of the frustrating things for the Whites was that at first Mark did not appear to be different. Although this might seem an advantage, it actually caused people in the wider social network around Mark not to be alerted, not to recognise a need to adapt their own behaviour, or to accept some oddness in his manner of interacting.

DANIEL: We took him out as soon as possible - trying to lead a normal life and you would take him to watch, say .. Simon playing football, or to watch his old friends and, the teachers would see him and say "We didn't expect him to be so good, we thought he was totally -" and there he was just walking across the park as normal as could be so they would look at him for 30 seconds and say "Isn't he marvellous!" That is what they wanted to see.

The family were forced to watch as Mark 'exposed himself' to friends and family and to see it gradually dawn on people that he was different and then watch their careful withdrawal:

JULIET: There was one incident with his cousin Anthony who is 21 and they were sitting on the couch together and Mark does, he gets closer and closer and he is talking away and Anthony felt quite uncomfortable about it and so what did he do he just turned around and put his hand up like this you see *[imitates Anthony, swivelling upon the sofa so that knee and elbow made a barrier between him and the other end of the sofa]* **so that Mark had to keep his distance. He had worked out a strategy without telling Mark anything or having to actually get him to keep his distance.**
DS: How did Mark respond to that? - Or did he respond to that?
JULIET: No. I don't think that he notices other people's body language at all.

The Whites had resigned themselves to some changes. They appeared to accept and understand that he was not able to be sensitive and caring toward others at the moment. To accept this in their son was very painful and they both clung to the hope that it was a temporary stage in his recovery that they were witnessing. They believed it was their task to preserve the friendships he had before so that they were still there for him should he recover enough to reclaim them for himself. With this intent, they developed what seemed quite collusive relationships with some friends and parents of friends in order to plan strategies to improve Mark's insight and social skills. They described conversations which sound almost like reporting back or debriefing sessions.

They must sometimes have felt considerable discomfort at placing themselves in this position. They were not the sort of parents who would have interfered unnecessarily in the normal course of a teenage son's life. Their relationship with Simon was demonstrably a relaxed, accepting and liberal one which he and his friends appeared to enjoy. They attempted to maintain this sense of equality, believing that Mark responded best to relationships which offered him camaraderie.

JULIET: It is the same with this caregiver that we had, I mean- he had no skills at all -he is a plumber! but he had a really nice manner with Mark, I mean, he took so much flak, day after day - but, they still did things together and they still enjoyed each other's company and he managed to get Mark to do things that others couldn't do, you know. It is relationships and the way it is handled...

They had come to believe that although Mark needed support with interpreting situations and still required considerable supervision to keep him safe, he needed this support to be offered in ways that allowed him a sense of equality and participation. By offering him opportunities to share the power over his recovery and his future, they hoped to encourage him to seek out and use opportunities independently and to begin again to initiate, to think and act for himself. It had become clear to them that before he could manage this alone he would need an intermediate

period where he could rely upon consistent guidance and honest feedback with genuine, equal and emotionally intersubjective relationships.

> **JULIET: Yes. And eventually for him to take over -**
> **DANIEL: We would like him to think that he has made the decision-**
> **JULIET: I see it as getting him involved enough, so that he is then going to take on that motivation for himself. You know, he is enjoying it enough to want to do it again, rather than feel -**
> **JULIET: rather than he just says no, or no I can't do that - and won't even try and, we just say, "Yes you can, come on then, we are going". It is like the orienteering, he says, "I am never ever going orienteering again" and the neighbour comes over and rings the bell and says "Mark, I am going over to Wanganui today, orienteering, do you want to come over?" and, "Yes - Please!" New person, new relationship, he is off.**

The early discovery the Whites had, that Mark could be manipulated into doing things when the approach was right, has led them to develop a range of tactics for keeping him busy and involved. They came to realise (perhaps firstly through the positive experience of the two male carers) that it was the *type of relationship* that he developed which was the most important factor in success. The most successful relationships were those which converted any activity into a shared one, so that he had no sense of being 'treated', but felt himself to be involved in a shared pleasure. It was frustrating for them to watch as other people, without this level of insight into their son's motivation and feelings, inadvertently set him up to fail, or to become negative and reluctant when with the right approach, he would have become enthusiastically involved in the activity and sailed through it successfully.

> **JULIET: Absolutely - yes - and he responds so much better to that and it is like that with basketball - he will go, "no no I don't want to play" and we will say "oh, come on, you get in there and bounce the ball around -" and, he is joining in no time and he is getting the physical exercise, the activity which we feel that he needs.**

AUTONOMY AND INDEPENDENCE

This issue of relationships is strongly linked to a further issue: that of autonomy. Wood (1990a:3-4) suggests rehabilitation after traumatic brain injury should encourage the person to resume at least some sense of control and feel capable of "making a choice from a repertoire of responses and so keeping the notion of freedom and choice." Autonomy and independence, power and control, are such positive and attractive concepts. It is not as simple as it sounds in the field of head injury however and it is also very common to find a great deal of disagreement between family members and staff at Waimarie as to the level of independence a person could safely be allowed. A lack of motivation and an inability to comprehend his situation in any appropriate way, meant that autonomy, or choice and control, could become dangerous and destructive ideals for Mark to pursue.

The Whites recognised that it was to encourage independence and self-motivated behaviour that Waimarie was putting Mark in situations where he might not cope. He had been moved into one

of the independent living flats and was expected to operate there very much as an adult would in the community. He would in this way be confronted with a variety of interpersonal experiences and relationships and be expected to make decisions and solve problems alone. The Whites were very nervous about this. They were concerned that Mark's misplaced self-confidence had fooled the staff, that they believed he was capable of daily living tasks which were actually quite beyond him. They were in a difficult position in this regard, as their protective feelings for him conflicted with their determination to 'push' him.

> **JULIET: No he will be all right. But it is hard not to worry because he is still really vulnerable and yet we know that their aims and Waimarie and ours as well, are for independence but to us we actually have to be giving him the skills and you know the problem solving - which we find that he just doesn't have, you know, anticipating what could happen in this situation -**

Although they recognised his need to practise in real situations, they were acutely aware of all the possible pitfalls and, as parents will, they had run through all the possible 'what ifs' imagining consequences which perhaps had not occurred to staff.

> **JULIET: Mmm. The night that he was away until nine o'clock he was out by himself but he says, "I came home under the lights on the footpath Mum and I was safe." He still didn't anticipate that walking alone, he was vulnerable- he never, it just didn't worry him.**
> **DS: But would he really have been in any danger?**
> **DANIEL: The point of that is that if he sees somebody on the footpath, they would be like a magnet and he would walk toward them -**
> **JULIET: He would say hello -**
> **DANIEL: - and on the bridle path there are a lot of women and if suddenly this very large person comes toward them like that they will scream and start running and if that happened and she ran away, he would probably chase her to see why she was screaming not realising that he was the problem -and.. well, you can see the sort of problem!**

Another reason it was difficult to offer Mark independence was the unpredictable nature of his behaviour. He would manage to appear and behave in sensible and normal ways for long periods of time, but for the Whites, the occasions when he lapsed into irrational unpredictable behaviour were a serious concern. They believed that to plan a lifestyle for him which ignored this tendency was unrealistic:

> **JULIET: It is the inconsistency that we just find so difficult, that we just can't predict anything, you can't plan anything, it is just so inconsistent -**

As a result, at the same time as they were attempting to encourage independence, they were trying to protect him from situations where failure might have dangerous and destructive effects. This ongoing ambivalence was a major theme for the family at the time of the research. More than anything else, it perhaps threatened the strength and effectiveness of the family as the primary therapeutic agents at this point. The problem was that Mark resented the change in roles. He was perceptive enough to see that he was treated differently and he was responding to this altered attitude with rebellious and aggressive challenges. This, his reaction to the situation within which he found himself was not necessarily anything to do with brain damage at all. As Berne (1964)

could demonstrate with his method of transactional analysis, when we encounter a 'parent' approach, most of us will respond as a child would.

> **JULIET: Yes. Just things like we don't mind him going out walking, all we say to him is all you have to do is just tell us and he doesn't, he just goes and he says, "Why do I have to do that- you are just checking up on me!" and we say "But we expect it from Simon" and Sally [a close family friend] says "But I expect my boys to tell me Mark, whenever they are going out, you know - in case you don't come back we know where to start looking!" But he still feels that we are checking up on him or treating him like a child.**

Although the rational 'adult' Mark might have understood why he should mention it when he went out, the 'child' Mark was very quick to dominate his interactions at this point. It took considerable effort from the Whites to find the way to handle situations such as this one without setting up Mark to become challenging and aggressive.

SUPPORTING SOMEONE WHO IS IN THE PROCESS OF "BECOMING"

The Whites adapted their own relationship with him early on, probably when he was still unable to speak for himself. They learnt to understand his situation by initially almost "getting inside his head" in order to understand what was happening. Then, they felt able to guide him, teach him again, fill in the gaps, understand the problem from his perspective. Not surprisingly, it is difficult to let go when you have entered into such an intense relationship. They knew more than anyone at Waimarie how much he needed some added structure during the process of recovery. They knew how insecure he could be, particularly when thrust into situations where he was frightened of being exposed, or where he was not sure what he was supposed to think or do.

> **JULIET: He is a clock watcher and he likes structure. He feels a lot more secure with that. But you know, it is becoming more flexible and like, we would never about five months ago let him go off on his own like he is doing now but we know now that he knows this patch, that the neighbours all know him now and know the situation and we feel a lot more secure in letting him go and giving him that autonomy. There was a time and, we still feel it is most of the time actually, that he needs supervision and you know that has been one of the frustrations actually that he is able but he still needs constant supervision. ... he is just so easily distracted. If you just send him out to the dairy, he might meet someone who invites him in for a cup of tea and he won't remember that he was supposed to be going to the dairy and that we were waiting for the milk back home and worrying about where he is. It is those sorts of things...**

However, it was clear that they were learning to think in terms of process and change when they considered Mark and his needs. They talked of "becoming" and "more" or "less", rather than in static certainties. Their conversation reflected back constantly to remind themselves how far he had come. They still hoped that he might one day take up the tertiary study he was about to embark on, but saw it as a long term goal, feeling they would be satisfied if in the more immediate future he managed some more manual or concrete occupation.

It was difficult enough to grasp what he 'was' at any given moment without also simultaneously maintaining an awareness of how he was changing each day. They recognised that it was

important that they did not hold up his recovery because of their fears, but they also recognised how long this process was taking and that the nature of recovery and rehabilitation after a brain injury was very different from recovery after physical injury or disease. To assist Mark they developed a new way of being alongside him as he changed. They accepted that he would continue to need such compensatory strategies from them for a long time and perhaps forever, but that they needed to change their manner of relating to him without losing hope, without giving up on his behalf, the chance to become, if he could, that other Mark again.

> **DANIEL: You slowly realise. You think, when he was out - most people's attitude was that in a year it would all be over and he would carry on with his life and then when he was in rehabilitation it became two years and now that the rehabilitation stage is over, it has become five years and you start to think well will he still be recovering in 10 and 15 years.**
> **DS: It's not really "recovering" any more is it?**
> **JULIET: Yes. I think it is perhaps developing more strategies and you know, coping better.**
> **DANIEL: But initially we thought that by now - you know first he is sitting up and now he is walking and in a year it was quite possible - . And then, when he didn't make the progress that you hoped -**

Clearly from their remarks, the family now understood his recovery as a slow progression through stages. They spoke of the progress almost as a journey they were on, but a journey where, for every three steps forward, there were two steps back to deal with. The swinging pendulum, the alternate despair and delight of those early days had never really gone away, but slowly they felt more in control of the future. They had come to see that their role was to ensure that there is a supportive caring network within which he could work through the moments he was confronted with the profound changes to his identity and relationships.

> **JULIET: Well, it varies, I think - often it will come, he will become quite lucid about it - after a major argument, or if he has had a major let down I'm thinking particularly of when his friend Jane went up with him, you know, orienteering and she said that he had grumbled and moaned and found it difficult the whole way - back to his flat and he was really depressed, really down, but she said it was interesting the way he handled it. He just kept saying "I wish I hadn't had my accident, I wish I was like I was before, I would have been able to fly over those fences, I would have been able to run but I didn't want to do that.." And she said he was comparing himself with what he used to be like, but then he got out his photo albums and he showed Jane all the way through from Intensive Care and he actually talked himself out, because he could see his own improvement in those photos and she said that then they had a game of cards and he was quite happy in the finish - it is sort of usually at times like that that he will sort of realise what he can't do.**

Supporting someone who was still recovering from a brain injury, they had come to see, meant helping him or her become aware of self-change. The growth of insight was inseparable from and essential to progress and yet it often resulted in cruel and destructive confrontations. To turn despair and distress into a realistic and purposeful new perspective required a very special sort of relationship with those closest to the person.

PERSONAL EXPERIENCE VS EXPERTISE

In recognising the importance of their close relationship to Mark the Whites were sometimes caught in a terrible bind. They searched for experts who could understand him better than they could yet no-one could possibly measure up. They had by then had such a wealth of experience with Mark both before and after his accident. They monitored every tiny change, every small moment of progress. They recorded every triumph and failure and no one else understood the possible underlying causes for behaviour quite as well. Having known him intimately before his accident, they could quickly distinguish between what had become different purely as a result of brain damage and what behaviour might have its roots in his response to experience. Accordingly no one else could possibly describe his behaviour, or predict his probable reaction to something quite so accurately.

This experiential knowledge made them experts in this one case. They had intuitive knowledge of Mark, but they did not have sufficient theoretical knowledge to know how to convert their 'feelings' about him into explanations which fitted the clinical picture of Mark and his injury. Because of this, they could not rely upon being respected and accepted if they attempted to offer this knowledge to professionals.

The professional staff were in a similar dilemma. They might be bewildered by Mark's behaviour but did not feel that they could draw too heavily upon the family's offered knowledge. It was very possible that any remarks made by the family were influenced by their own unresolved emotional distress, their picture of the premorbid person, their denial or misunderstandings of the nature of brain damage and a myriad of other possible interfering interpersonal dynamics. They had a moral responsibility to make their own assessment, drawing most heavily upon the feelings and ideas of their immediate client.

What was clear was that therapeutic staff approached their relationship with the person as a job, however much they might feel committed to it and they approached the family members as people who could support or hinder them in the carrying out of their job. For the family members, however, the involvement with this person was life long and very emotional. They might identify so strongly with the injured person that a comment about that person was taken personally, as an insult. It must seem to professional people in these situations, that it is necessary to feel one's way to avoid the pitfalls of disturbing displays of emotion.

Pepping and Roueche (1991) suggest that insight and interpersonal difficulties of the sort described here in Mark's case, make the type of relationship which therapists are forming

exceptionally important to rehabilitation after brain injury. They suggest that there is a need for "long term therapeutic relationships, carefully developed over a period of years, with very frank discussions of the differences in opinion and respect for the patient's needs and outlook" (Pepping and Roueche, 1991:234). After a year and a half of "therapeutic relationships", the Whites had encountered a large number of occupational therapists, physiotherapists, speech language therapists, doctors, nurses and specialists. It was possible (but not likely), that one or two of these relationships might have lasted long enough to provide continued support and guidance for a year or two yet. They alone, however, had been there beside Mark right through all his experience since the accident. Only they could have the sort of perspective that came from this long-term continuous involvement in the process of his recovery.

This knowledge put them in the difficult position, especially when they could see shortcomings in the treatment programme Mark was offered.

> **JULIET: Yes. And this is what has been so hard with the rehab thing because OT is geared to weaving and that sort of thing and he is just not into that at all and never has been and never will and they promised us when he went into rehab that they were going to get him into outdoor things and they never did - they never had the expertise, or the personnel to offer him the rehab that we felt would really get him on side.**

Sometimes, the shortcomings related to people rather than programmes and diplomacy became important.

> **DANIEL: I would say all the staff - all the physios and occupational therapists have been girls, except for one - and the speech therapist and, they all come Juliet's version size wise - 5 ft 3, 5ft 4 or that -and you go over there and the OTs are a few years older than him - -the physiotherapist, she would be nearer my age - the only males are the male nurse aids -**

They must have felt acutely aware how much power these 'young girls' had over their and Mark's life at that time and negotiations on Mark's behalf had to be a careful manoeuvring through potential mine fields of giving offence.

Sometimes, the staff's comments seem to be thoughtless and show their lack of any real awareness of living full time with brain injury.

> **JULIET: Yes and it's, I guess when it's a one off with other people they can just laugh it off, but when you live with it day after day after day, it's- I think that is really what you find with all those who have to work with him. The nursing staff even started to take that kind of view, - when he was in rehab and quite consistently pushy and abusive, we believe and the speech therapist would come up with you know "You must treat him just like normal and be consistent" and I would say "It's all very well for you don't have to live with him, you know, you don't have him 24 hours a day -you have him for half an hour one day - you can have these theories on how to treat him, how to speak to him but, -"**

Throughout Mark's recovery, they were forced to deal with multi-disciplinary teams. A team is very difficult to communicate with. It sometimes presents a united front, yet sometimes it breaks down into individuals with different points of view and conflicts with each other, professional jealousies etc. In order to assure themselves that they are maximising Mark's chances, the Whites

had to try carefully to co-ordinate with such teams and, once Mark was at Waimarie, much of this co-ordination had to be managed by phone, or letter, allowing no opportunity for clarification and for negotiation about each other's attitudes. This is a very difficult task. It is not surprising that many families withdraw and disengage from the more intensive involvement in the daily programme and planning they had become used to when their family member was closer. The Whites appeared to be learning to do this, to let go a bit and trust others to make the decisions they have been used to making themselves.

THE FUTURE

At the time of the research, Mark was still at Waimarie. He had been a resident there for four months and become settled and familiar with the environment. He saw himself as staying at Waimarie to complete the process of recovery from his accident and regarded himself at that time as nearly ready to leave and resume normal life.

The future then, was about to begin. The Whites still held on to their hope of more recovery of cognitive and interpersonal skills. They felt they could still see the results of their efforts. They believed that they could still influence his future, maximise his chances. This theme ran strongly through all their thoughts and actions. To them, Mark was still on his way back to them and they were waiting. They were prepared to wait for much longer than they had already before they stopped trying, although they accepted that the recovery curve was tapering off:

> **DANIEL: Even when he didn't make the recovery that you hoped, we were still very full of hope - all of them were very steep graphs to start off with and then they tapered off and, of course, any time you asked anybody, they all would say, "well it takes time.." It was always time til if we heard any more of these remarks about time, you know, "time is a great healer..!"**
>
> **JULIET: We also now appreciate the uniqueness of head injury that there are no general patterns and that every sort of head injury is quite unique and you can't predict what it is going to be like - and also we would certainly concede with Mark that there are periods of great progression and then there is regression and you have got to do it again. But we sort of feel that he is progressing and that gives us a lot of hope and so we keep pushing - he keeps responding and we are going to keep pushing and he is going to keep responding and expecting more and more of him and we just feel that we just want to achieve what is the best possible recovery for him.**

Helping Mark recover had been a central task for this family for some time. Although no one could tell them when their task would be completed, they hoped that one day they would be able to reflect back on this time and feel proud. Mark's future might never be what it once could have been. There would no doubt be more sadness, more loss for he and his family to confront. Nevertheless, the story of Mark, his accident and his family's response, is one of people working together and creatively resolving problems by adapting their relationships to respond to Mark's changing needs.

CHAPTER 6

MAX KAVANAGH'S STORY

THE ACCIDENT

In June 1992, Max Kavanagh fell off a ladder and severely damaged his brain. That moment dramatically changed his life and yet he would never be able to remember it. In fact, after that moment, he would never remember anything that happened to him very accurately again.

His wife Prue remembered, however, very well:

> **PRUE: It happened on Queen's Birthday. The 1st of June, 1992. It was about half past two in the afternoon. My daughter and I were in the lounge, talking. He had been up there all day painting and sanding - he had gone right up to the very top. We heard a crash and I knew that he had come off the ladder. I just knew - it was that sort of noise..**

As she told the story, you could tell she had already done so many times before. She told it with the sort of precision that came from repetition and from answering the questions of a variety of people, both friends and medical professionals.

> **...We were probably out there within five seconds and he was lying on the concrete.... The little girl next door actually saw him fall ..."**

Prue was fairly sure that Max would never just "fall" from a ladder. He had been up and down them all his life. She believed that he had fainted and dropped from it to the ground. The scanty facts she managed to draw together support this view.

> **...and she said he fell with his arms by his sides. He had obviously passed out, he must have. There was no way he would have done the damage he did otherwise. He might have broken a wrist or something when he hit the ground but would have grabbed the garage roof - he was right next to that. He was right next to a tree, he could have grabbed that ...**

Sometimes her narrating style also reflected the questioning process she put herself through at the time, wondering if she might have prevented it, or perhaps, trying to explain why it should have happened.

> **...Oh, there was a lot of things you could think of afterwards, which are not a lot of help.... but he probably wasn't very well at lunch time when he came in., but we had some visitors for lunch and so I think I probably didn't take as much notice as I would have if it had just been the two of us. He was just quiet, but then, he was often quiet when we had visitors ...**

Like most sudden crises, each player at the time knew only their own part in the drama and later pieced together the whole story, sharing what they knew and adding the medical facts they discovered.

> **... Kirsty [her daughter] rang an ambulance immediately. The lady next door is a nurse and she tried she tried to help but he wouldn't keep still. He was struggling to get up and he was making horrible noises....it went on for a long time...**

It was not until a year later that Prue realised it was a seizure she was witnessing. During this extended seizure, Max's brain was probably starved of oxygen and the damage received in the initial fall was compounded. The family and neighbours were powerless, bewildered witnesses of that frightening struggle as they waited for the ambulance. When it came, Max was quickly rushed to the hospital where he was admitted to the Intensive Therapy Unit (ITU).

MAX BEFORE THE ACCIDENT

Max's early life story could not be as easily confirmed as those of the three younger men, Rob, Mark and Bryce. His parents had died, his brother was out of touch and the people from his childhood had long scattered and moved on. The details given here were internally consistent in their regular retelling by Max and they also fitted in broad terms, with what could be confirmed and added by his brother and wife[88].

Max was the younger, by ten years, of two brothers. He grew up on a dairy farm not far from Ashton, a town of about 6,000 people in the North Island. He went to a small primary school in the country and then on to Ashton College, which he left as soon as he could, while still in the fourth form. He was always an "outdoor" boy, enjoying sport and physical challenges a great deal more than the work inside the classroom.

Max's memories[89] of his school days were pleasant ones. As he spoke of them, he built a picture of a quiet young boy who saw himself as an outdoor type, who preferred to be doing physical things, working with his hands, rather than reading and writing and more intellectual pursuits. Labelling himself and limiting his options in this way caused him no concern at the time and in retrospect, still seemed satisfactory and accurate. Prue confirmed this and explained that as soon as he could, Max left school to work on the family farm. This decision appeared to have been 'drifted into' rather than thought through carefully and, not surprisingly, it did not work out well. As Prue explained:

> **PRUE: He hated it so much and there were a lot of rows from what I can understand, because his father would never pay him for working on it....**

Max was quite frank about his unhappy relationship with his father. He described a picture of a family life and childhood that was not easy and although he loved his mother, the household was quite obviously dominated by an alcoholic father and must have been a rather barren and lonely

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[88] Prue's knowledge of this time was, of course, 'second hand'. However, she felt confident that most of the information Max gave was accurate, even if the names and places were confused. They were in essence, the same stories she had heard from him before his accident and fitted with what she remembered as being established fact.

[89] Later, in discussing Max's memory difficulties, more attention will be given to the nature and quality of these childhood memories.

place to grow up. Although for a while he was happy to drift, after two years working for his father he decided to leave the farm. Prue told the story of what happened next.

> **PRUE: Max decided that he had had enough of it and he decided he wanted to go to town. And so his father bought a house in town, for the family, but shifted Max into it while he sold the farm because he said if the boys weren't going to work on the farm then there was no point in keeping it so he would sell it... so Max went to town, I think he was there on his own for about eighteen months - and then his father sold the farm and his parents shifted into it as well. Then, he did an apprenticeship for his building, when he shifted into Ashton, into that house, he became apprenticed to a local carpenter...**

Max had found his niche. He loved the carpentry trade and stayed with it, becoming qualified and going into partnership. He was a hard worker and a meticulous, exacting craftsman who took pride in his work. Many of the stories and comments he made during my interviews with him showed what simple pleasure and pride he took in these skill and how much he enjoyed the sometimes lonely long hours in a workshop, or up on scaffolding.

But life for Max was not just his work. Until he was 26, he obviously enjoyed an active and carefree bachelor life in Ashton, spending his spare time with the other young single men of the town looking for fun and excitement:

> **PRUE: With 'the guys'. Yes. And I think their weekend's entertainment was to buy beer and drive to Te Katai[90] for a hamburger and ..**

After experiencing his father's drinking problem, Max only ever drank a glass or two. He seems to have preferred physical activities to social occasions anyway and much of his socialising was an intrinsic part of his sport. He was competitive by nature and obviously enjoyed a challenge and so he achieved a high level of competence in many different sports and outdoor activities. His most impressive sporting achievements were in roller skating where he won national level competitions. He also spent a great deal of time with his mother during this period of bachelor life, joining in the activities she and her friends enjoyed such as board games and bowls. Perhaps it is these experiences which gave him his easy relaxed deference for other people, particularly older people.

At 26, Max married a local girl called Catherine. He probably didn't have much option at the time. She was pregnant and in New Zealand in the late 1960s any young man whose girlfriend became pregnant would have been expected to marry her. He seems to have accepted the situation happily enough, however, but without really understanding the commitments he would need to make to become a good husband or father. Prue recalled conversations with Max about this time in his life and suggested this was probably why the marriage failed:

> **PRUE: She was the only girl friend he had ever had - I think he was 26 when they got married. He was a farm boy and he was pretty immature really. They got married, they had two children, I think that, like I said, Max was hard working and work came first and he worked a**

[90] A nearby town.

12 hour day, seven days a week and he would never be at home, it was down to the working mans' club, or perhaps he would play bowls...

His wife clearly saw very little of him during these final days in Ashton when his first son was growing into toddlerhood and a new baby was born. In 1971 they moved north to the nearest large city: Limmerton. Prue believed this happened because there was more work for builders there. By then, he and Catherine had two very small children, boys of one and three years. It was not an easy time for Catherine. Max was heavily involved in his work and sports clubs and Prue thought he probably didn't realise that his wife was unhappy.

PRUE:...They bought a house over in Fairston [a suburb of Limmerton] and Catherine must have been very fed up with him at that stage, because he was never around to help her with the kids. And he told me this himself too. She found herself another man and left. That is how it happened. Which really I think devastated him for a long time. I don't think he ever talked about it to anybody. It was one of those things. It was to do with the squash club where he belonged too. She met somebody else at the squash club where she had gone with him and of course everyone at the squash club knew about it apart from him. It was that sort of scenario.
....

It is possible that the break up of this marriage was a time when Max realised he should have worked harder at being a good husband and father and at building a good relationship. It is unlikely that he reached this conclusion immediately when the pain and hurt was fresh. But by the time he told the story to Prue a few years later, he seemed to have accepted that Catherine was not to blame, despite the fact that she left him for another man. She took the boys with her and Max's life returned to the pattern of work, casual socialising and sport. He saw his sons when he wanted to and his relationship with Catherine was reasonably amicable. He was settled, if a little lonely. By the time he and Prue met each other and began living together in 1979, he, like her, was a busy and independent person and it suited them both to have an easy and unpossessive companion. This arrangement developed slowly and calmly into a relationship strong and secure enough for them to have built a house together in 1980, yet more peaceful than passionate perhaps and more giving than demanding emotionally. They were married in 1982, but only after they had lived together for some time and developed an easy going relationship which was much more compatible with Max's nature than his first marriage had been.

PRUE: He wanted to get married. I really couldn't have cared less, I had already been married once and so it didn't mean a lot to me. But, it did to him. So we got married in 1982.

The four children from their previous marriages were almost exactly the same age. In fact, Prue's daughter and Max's older son were born on the same day. They all soon accepted each other and became good friends, although Max's sons continued to live with their mother and only visited. Max had a little more trouble adjusting to being a stepfather, however, and Prue found herself having to deal with confrontations between her new husband and her son. Nick was seven at the time they started living together and more boisterous and demanding than Max believed he should be.

PRUE: Max is quiet and reserved and as far as he was concerned, children should be brought up to be seen and not heard - he brought up his own sons in that way.

The relationship with Kirsty, her daughter, who was 11 at the time, appears to have gone more smoothly. Max obviously managed to overcome these early difficulties, as the years they shared together are remembered by Prue as generally peaceful and happy. As the children grew up and moved on to establish their own lives, he developed easy adult friendships with all of them while never really being especially close to any of them.

MAX AT THE TIME OF THE ACCIDENT

Max was about to turn 50 when he had his accident. His second marriage was ten years old. From his stories and from Prue's description, he had become just the sort of person everyone would like to have living next door. A good neighbour, friend or workmate, he was on casual easy terms with a wide range of people, always ready to pitch in and do his bit for a friend or a community concern. He was also a quiet and private person, however and not many who knew him were allowed to share his deeper worries and concerns. Friends were for light hearted fun, practical jokes, a game of squash, or a weekend with boats and waterskis. The more intense emotional feelings and thoughts he kept to himself, not always even sharing them with Prue.

The four children had all grown up and left home by the time of his accident and he and Prue lived alone in the second house they had built together two years after their marriage. This house, which Prue now lived in alone, was a modern, two-storeyed building in a quiet residential suburb. As two mature people they had managed to create a marriage relationship which allowed them to lead their own lives and yet offered each a loving companion.

It was not only in terms of his personal life that Max was settled and happy. His working career too, had reached a point where he was content to sit back and relax the pace a little, recognising that he was growing older. He had been a self employed carpenter all his working life and obviously the life had suited him. Shortly before his accident, however, he had taken a salaried job for the first time. Prue explained how time and age had changed his priorities.

PRUE: ... he had been in partnership all his life, he had built for himself for the whole time. The year before his accident, we just decided that it was getting too hard for him digging footings and doing all the heavy work that builders have to do on houses... at the Waipata Herald there is a maintenance carpenter and years before he had said, "one day, when I am ready to retire, I will do that - it will be a really good job." And it came up and he decided to take it. It was not a lot of money, considerably less than what I was earning. But we decided that it was time for him, at 50, to watch himself, he had back problems, all builders do and so he took it.....

The decision was soon proved to have been the right one.

PRUE: For the first time in his life he had an 8 to 4 job. For the first time in his life he had friends and people around to work with - he loved that because most building jobs are very

insular... yes it was good. He had lots of other things that he did at the weekend. He was always out doing renovation work for people. So, his income wasn't lower than mine, it was probably well above mine. But he worked really hard to do it. He really loved it.

Max was remembered fondly by his workmates from the Herald. He was obviously an easy person to work with and he could be a lot of fun as well.

PRUE: He liked pranks and jokes. And that is what the guys at work remember most about him is his really wacky sense of humour. He was always having someone on at work. Doing horrid things, like sticking the hose through the toilet window if he knew someone was in there or nailing somebody's lunch to the wall of the workshop. You know, he used to do things like that.

He wasn't like that with Prue, however. Their marriage was a quiet, steady partnership where each respected the other's differences. There was no attempt on either side at any sort of manipulative 'games playing'. While they were different in the skills they brought to the marriage, they were able to pool their experiences well as they demonstrated in successfully building two houses together. On each occasion they would plan together with Max the practical design expert and Prue adding the aesthetic touch.

Max and Prue, on that day in June were two contented people. They knew where they were going and what they wanted from their lives. More than most couples perhaps, their lives were set into a pattern which would have taken them happily into a settled old age together.

THE FIRST DAYS AFTER THE ACCIDENT

At first, in those early days just after the accident Prue was told that Max was probably going to die. Her memory of that time was hazy. Numbed and shocked, she waited, sitting with him as often as she was allowed.

PRUE: I didn't stay there the whole time because it was very hard to stay there. They kicked you out every two hours so that they could turn him over and suction him and all those things that they do to him...

She was trying to deal with personal agony and anxiety in a very public setting. The crisis stripped her of control over her own life as much as Max's. Unsure of what was coming next, she was hesitant about expressing grief or distress when Max, the person at the centre of the drama, was still alive and could 'wake up' and return to her at any moment. Similarly, she did not want to invade others' feelings, or say the 'wrong thing'.

PRUE: The lounge up there was always full of families. So in the beginning I think I stayed there. For the first few days. But after that I used to go up there four or five times a day .... I would go up there and when I was kicked out after two hours, I would come home because it used to take them an hour or more to do what they had to do before they would let you back in, so I would do that for weeks...

Life began to revolve around the ITU unit and around those two hour periods of time. Prue spoke mainly in the first person as she recalled those early days and this gave her narrative a

strong sense of her isolation from the ordinary world, where people were continuing with their everyday life. There was throughout her tale a feeling of being essentially alone and struggling against this awful disaster without Max's support, coping with the busy and intimidating medical setting.

> **PRUE: I used to sit there and watch the, what is it called? ICP monitor isn't it? The intracranial pressure. They had a bolt stuck in his head to monitor it and I used to monitor that all day and as it turned out it didn't mean a damn thing anyway but I used to watch that all day -**

Interestingly, Max's own sons and brother faded out of the scene during these early days. It was as if those who were there at this time primarily to support Prue still found their presence purposeful, but those who were there primarily to support Max drifted away when he did not quickly recover consciousness. This later meant that Prue and her family and friends were the only people who were there for Max during the process of his rehabilitation. She did have considerable support from this personal network however and found their presence very comforting, but perhaps because of their status as primarily 'her' rather than 'his' friends and family, there was less sense of their direct involvement in a drama which was so central and overwhelming to her.

> **My daughter was pretty good, but she had two children to look after as well, two little ones. My parents were there -**

At this stage, Prue did not think logically about what was happening to Max. She said she did not even begin to consider the immediate future in any rational way, but sat blankly waiting. Looking back, she believed that, despite being told to expect death, she was in fact (in as much as she had any conscious thoughts about her situation), sitting and waiting for Max to wake up and come back to her whole and untouched. It seems that her mind refused to accept that this could be an ending.

> **PRUE: No. I didn't work out what it was going to mean because nobody said it was going to mean anything. They just said he was extremely ill at the time -**

The family, like most families put in this sort of position, had become a passive audience in the drama assuming that the medical team understood the situation, knew what to expect. They depended upon these people, trusting them to keep them informed, relying unquestioningly upon their judgment. With their knowledge, their drugs and their equipment they alone seemed to have the necessary power to "bring him back". When she recalled those days, Prue painted a picture of a person who was more naive, more prepared to trust, than the woman who looked back later.

> **DS: What did they tell you about the intracranial pressure then? Did they explain it at all?**
> **PRUE: Oh they just said that if it reaches 30 then he is in trouble. But, then we found out there was a young boy in the next bed and his read 90 most of the time! and it was just so they could check it and see if it changed... Max's used to go up and down every time they turned him over and in the end they said it was faulty and it wasn't working properly and so they took it out -**

Prue remembered that she asked to see the consultant of the Intensive Therapy Unit one day. He showed her the brain scan and pointed out the damage. To Prue this conversation was meaningless. She looked at the blurry images and felt totally lost. In retrospect she felt angry for that person she was. She believed that this consultant should have offered her some initial preparation, some gentle education about Max's probable (even if it was just a "possible") future. Instead, the staff appeared to believe that they should wait until they could speak with more certainty. Later, she angrily remembered the conversations she had had with medical staff and the lack of knowledge she had gained from them:

> **PRUE: Nobody ever said what the damage would cause and it would have been so easy for them to do that. I didn't know the questions to ask and they said they would answer any question you asked them but you don't know what to ask, I had never been in that situation before!**

Like most family members in her position, Prue yearned for a clear and definite diagnosis, so that she knew what she would have to come to terms with. When the staff were unable to answer her questions with certainties, she was left in a state of confusion and powerless waiting.

The staff would have become aware with the slow dawning of Max's consciousness, that the damage was probably very severe, causing a permanent change in his personality and behaviour. They would also have known as he began to emerge from the coma, that he was entering a period of disorientation and confusion called "post traumatic amnesia" or PTA[91] which typically follows the arousal from a deep coma. Yet Prue could not remember that the staff ever gave her any clear statements about Max's situation during this time. She admitted it might be that in her distressed state of mind she did not take in the information she was given, but in her recollections, they appeared to be concentrating entirely upon the "physical needs", such as naso-gastric tubes and tracheotomy and maintaining normal body temperature. It was as if the issue of cognitive damage was secondary, less important, at least for the moment.

Saillant (1990) talks of the "problem of information", suggesting that leaving much of the real situation unsaid is a tactic which the medical personnel use in order to maintain morale and hope. Unfortunately, as time progressed without any substantial improvement in Max's consciousness or cognitive awareness, Prue' experience was one of alienation rather than hope as described by Saillant (1990:99):

> **The gap between discourse and experience widened ... Maintaining morale and hope became more and more a contradictory task. Social and emotional isolation deepened.**

[91] See Chapter 1, p. 20.

AFTER THE CRISIS STAGE

Over the space of the five weeks after his accident, Max progressed through the hospital system from ITU, to 'Post Op', to a general ward as his physical condition improved. Decisions appear to have been made purely because and when the medical needs changed without much consideration or attention being paid to the cognitive damage.

> **PRUE: They shifted him to Ward 2 because he wasn't breathing well and perspired so much his bed was soaked, so that was that body temperature thing I was telling you about. It was really bad then. He couldn't drink a lot either because he choked - it was automatic reflex - he choked on everything ... and then I think he got well enough for him to be shifted again ...and they moved him on after two weeks... they must have decided it wasn't the right place for him...**

The problem of damaged consciousness was sometimes difficult to ignore however For instance, the removal of the tracheotomy was made vastly more complex than it should have been by the confusion and agitation of post traumatic amnesia:

> **PRUE: they couldn't take it out because he used to panic when they tried. So in the end they did it while he was asleep and he woke up breathing normally without knowing that it had gone...**

Despite the very understandable feelings Prue had that the staff ignored or avoided the issue of Max's consciousness, dealing only with medical certainties, some attempts to prepare her and to help them adjust to the head injury appear to have occurred at this time. Occupational therapy staff, for example, suggested that Prue should keep a diary for Max, so that when he emerged from the coma, he could be helped to understand what had happened. Unfortunately, this well meant suggestion later became a bitter joke for Prue when Max never recovered enough to make use of their plans.

> **PRUE: One day he will be able to read about it, they said. That is why we did it. We told everyone who came to visit him to leave a note in the book, he couldn't talk to them, but leave him a note and he would read it. But he has never been able to understand it because he doesn't know anybody that is in it - all these people are friends that he had at the time of his accident... he just doesn't remember them at all...**

Sometimes too, the staff's ideas of what Max might need to see for himself in the future, touched raw nerves in Prue:

> **They also suggested that we take photographs of him too. But I couldn't stand to do that because they told me he was going to die and I didn't want photographs of him looking like that ... his whole head - he was just black - his whole face, a great black mess...**

After two and a half years, Prue needed to refer to this diary kept so religiously for Max to remember the detail of the months that he spent in hospital. The day he took his first step, the day he ate his first meal - these were all recorded faithfully for him. As she wrote those words all that time ago, it seemed to Prue that they were the visible signs of progress but as each day passed it began to occur to her that there was to be no magical 'waking up', no moment to write down and treasure when he returned from unconsciousness.

In the first days after his accident, Max, like many patients, was given morphine to keep him still because agitation and stimulation are considered to cause additional swelling and damage in the traumatised brain. For the family however, this practice had the unfortunate affect of giving even more control to the medical team. It meant that the family could not sit and wait for him to recover consciousness and there was even less chance of them being able to make a difference with their own presence by the bed.

PRUE: They told me that they had had to give him lots of morphine while he was in intensive care. They said he needed lots more than most people to keep him under. I don't know why. I used to talk to him a lot, but I never knew if he was awake or not -

When Max failed to regain consciousness in those first days, Prue was never sure whether or not this was because of the morphine. When he seemed disoriented and confused she believed that this might have been caused by the drug rather than the damage. Nevertheless, as each day went by it slowly dawned upon her that although he was now not likely to die, he was also not likely to recover quickly.

PRUE: I know we all just wanted him to wake up - just waited for it to happen, but when it did happen it was so gradual that it was you know... and then, we were never really quite sure if he was really awake or not, or even hearing what we were saying -

Prue could not ignore the changes in Max's consciousness and cognition any longer. For her this aspect of his injury was fast becoming central. It was becoming clear that he had lost a large slice of his memories. In fact, the memory of all the years that he had lived in Limmerton (and so all the years he had spent with her) was completely gone. Twelve years of his life were effectively wiped out. As far as he was concerned he was in his thirties and he lived in Ashton. This timewarp was probably more distressing for Prue than it was for him at first.

PRUE: After his accident, all he ever used to talk about was Ashton. There appeared to be no other memory there at all except Ashton. And even now if you ask him if he wants to go home he usually says that he is going home to Ashton.

The problem for Prue was that she and her family and all the friends visiting him in the hospital were people he had come to know only after he left Ashton and moved to Limmerton. Now he didn't recognise any of them and he seemed incapable of relearning who they were. He looked vainly for the friends from Ashton, most of them long dispersed and out of touch. It must have been a frightening world full of strangers who insisted upon treating him as husband or friend and until a visit from his brother, Prue was too bewildered to help him.

PRUE: I used to write down all these names that used to come out all the time and I had never heard of them, yet they were so regular. And then one day his brother did actually visit and I showed him all these names, I got the book out. And he was able to clarify who they were - they were all people that he knew and they were all from Ashton. The people that he worked with - worked for - his friends - his neighbours, a lot were neighbours -

But as time went on and it became clear that the twelve years would not easily return intact, it must have become a great deal more disturbing and distressing to have this man whose accident

had turned her world upside down, look at her with indifference as he talked about people and places she had never heard of.

While she was dealing with these emotional difficulties, Max was moved from 'Post Op' to a general ward. In this ward, there was far less intense nursing and Prue found herself participating more in caring for him. This gave them more time together and perhaps gave her back some of her sense of control over decisions and plans. She became involved in his early rehabilitation and noted in the diary the meals he was managing to eat, the progressively longer "walks" he managed with a walking frame, the day he managed a standing transfer etc. With the encouragement of the occupational therapist she began to coax him into writing (or rather copying) a few simple words, learning his address, remembering a few details, practising a few daily living skills. As she worked with him in this way, it must have become clear to her that there would be no instant return of her Max and that there were all sorts of unforeseen difficulties to rehabilitation when the person concerned had cognitive damage.

The hours spent up at the hospital were hours out of her own recreation and home life, however, and juggling her time between work and hospital was taking its toll. There was virtually no time left to think, and looking back, Prue believed that she really just "existed" over this time, mechanically going through the motions without the time to work through in her mind, the larger issue of her and Max's future. She remembered the six month period of hospitalisation as also a time during which his friends gradually fell away, visiting less and less as it became clear no quick recovery was in sight, until she was left with the support of a small nucleus of her own friends and her family. By the time he was discharged from hospital in December, it must have seemed a relief, simplifying her life and ending the long stretch of going to and fro, trying to keep up with the events at the hospital at the same time as she was trying to settle back into some semblance of normal life.

As the hospital began to talk of discharge she began to realise that soon she would be expected to take charge of his care and rehabilitation herself. This would be no small task as Max was as helpless and dependent as a small child. He needed to be fed, walked and dressed. Yet unlike a child, he was large, heavy and unpredictable in temperament. The hospital told her about Waimarie, suggesting a referral there to assess his further rehabilitation needs and she agreed to an application being made. They then seemed to regard their role as over. As there would be a delay before Waimarie would take him, they suggested an initial period at home and she began to plan for his arrival.

Looking back, she could see that it all seemed such a temporary and make shift situation at the time. She did not think deeply about rearranging her own life and assumed that she could continue working and use the ACC home help allowance to provide a carer during these hours. She assumed arrangements would be made for some sort of rehabilitation process during these working hours and saw herself as just taking over in the evening to provide him with a meal and help him to get ready for bed. While he was still in hospital it seemed a manageable plan, but later, looking back, she could see that it was doomed from the start. The eighteen month period that Max spent living at home gradually became a nightmare of tiredness and stress punctuated by crises.

AT HOME

At first, the return home appeared to be working reasonably well. Despite their lack of real knowledge of the task before them Prue and her family had prepared for the discharge as best they could. A carer was arranged and her son Nick moved back home to help her. With a supportive daughter, friends and parents, at first it seemed that the placement at home was working well. A fairly predictable pattern was established:

> **PRUE: He was always in bed in the afternoon and I would get him up and we would have a cup of tea and try and talk about what he had been doing during the day and I would get tea on and have tea and he would want to watch a bit of TV. He always wanted to go sit over there after he had had tea. Like immediately up from the table and over there. And I would do the dishes, do the housework, do the washing, do all the other things that I needed to do. At 8 o'clock he would always want to go to bed -**

This calm routine, however, was doing nothing to improve Max's longer term prospects. He had slipped into a passive inert role when it is quite clear that what he urgently needed was people and stimulation and an intensive rehabilitation programme, to deal with the massive deficits, both physical and cognitive/behavioural, which remained. Both she and the carer could see this gradual slide into inertia happening but were powerless to stop it.

> **PRUE: There wasn't a lot of places he could go, there was no therapy out there for him, no treatment anywhere. We tried bowls and they didn't want him because he was too disabled for them to handle. There was basically nothing in Limmerton for people with head injury. And so he would be here all day. They [the carers she employed] would take him for drives, take him shopping, they would try and think of things to do, but there is not a lot you can do. You know, just take him for walks to the lake.**

When Max was discharged he was ready to leave a medical setting, but he was still a long way from being an independent person again. It didn't take long for Prue to realise she needed help and support, yet with each day that passed, the old Max, his life and his friends, slipped further away as he became more and more dependent upon her. The plans she had made before he left hospital were obviously not going to work for long. She had made them without a full awareness of the reality of living with a person with severe brain damage and without the benefit of effective

information. Yet she had really had little option anyway. The hospital staff believed that their role was over. They took no responsibility for the cognitive and behavioural changes that remained and did not regard themselves as the appropriate people to deal with this type of rehabilitation. Astoundingly, ACC would not pick up the reins the hospital had dropped. They would not assume responsibility for the costs of further rehabilitation if she arranged it herself, because they had defined Max as now requiring what they politely called 'maintenance'. She discovered that by applying such a label to her husband, they were able to absolve themselves of any further part in his future:

> **PRUE: Well, ACC wouldn't even give him physiotherapy. I mean he needs physio every day. They told me that he was entitled to six for the rest of his life - six physiotherapy appointments for the rest of his life! That they were "not in the business of maintenance" were their words.**

As she was beginning to discover all these difficulties a bed for a six week assessment period became available at Waimarie. In March 1993, three months after his discharge from hospital, Max and Prue made the five hour trip south, and after seeing he was settled in, Prue returned to Limmerton without him.

THE FIRST STAY AT WAIMARIE

This assessment period went reasonably smoothly, yet although a placement for further rehabilitation was offered, Prue made the decision to turn it down. The file at Waimarie states:

> **Admitted March 1993. Discharged after assessment period because his wife felt that she would prefer to continue to provide for his needs at home.**

It was clear from the notes made by staff at Waimarie that Max was showing a wide range of cognitive, behavioural and communicative problems. The reports of the various staff all suggested that further rehabilitation and treatment would be useful for him and while Prue had no quarrel with the content of these reports they told her nothing she did not know from her three months' of experience at home. She could also see that Waimarie had facilities that Max needed. Yet, when she weighed this against her concern about him being so far away from family and friends it did not seem appropriate to go ahead with the placement.

Although this decision was made after careful reflection and in full knowledge of the likely consequences for herself, she was strongly influenced by her belief that she was dealing with a temporary phase in Max's recovery.

> **I thought that he would go to Waimarie and probably be half way right when he came home.**

She looked at what interventions were being offered from this perspective and believed that she should be able to find some similar alternative in Limmerton. She knew that this would not be easy but felt that she had to "give it a go".

Prue at the time was really too busy with her double life to analyse more deeply than this. This decision was one of many she was forced to make. There was no slower stream cognitive and behavioural rehabilitation facility in Limmerton, and Waimarie was five hours drive away. The thought of having him so far away was abhorrent, but there seemed no 'emotionally possible' alternative.

THE RETURN HOME

And so Max made the journey back to Limmerton. Although now she knew the rehabilitation was going to be a much bigger and more stressful task, Prue decided to continue with the make shift arrangements that had been set up for her upon the original discharge from hospital. In particular, she continued to use the precious home help hours while she was out at work. Once she had made this choice she was left with no time for herself. The daily routine may have seemed manageable but as it stretched to weeks and months and as the routine was punctuated by the crises which were bound to occur and did, the strain began to tell. She became an exhausted automaton, too tired to deal with the multitude of problems, the series of crises that confronted her. She was ultimately coping alone at these times, her busy life making it almost impossible for her to talk over her situation with the people closest to her.

> **PRUE: The kids have got enough to cope with without you unloading on them as well and, mostly I didn't have the opportunity to do that. I was here with him.**

The ACC refused to offer any further attendant care hours, eight hours being regarded as the maximum that should be necessary. It was apparently assumed that Prue had an obligation to take on a caring role after work and in the early days she accepted this obligation. It was only when it dawned upon her that there was no agency there for her in the crises, no matter how extreme and frightening these were, that she began to resent the system. No one seemed to understand just how difficult he could be. What could be casually referred to as 'agitation and confusion' in a hospital setting, became a frightening unpredictability in a private home. His behaviour was often irrational and aggressive, particularly in the mornings, when his mind appeared to be clearer and he seemed to have more insight into the severity of his disabilities.

> **PRUE: Those were the times when I had the most problems with him not liking what he was. And, he would get angry. I would put his slippers and dressing gown on so he could come downstairs for breakfast and he would usually get bolshy somewhere in the middle of it. And oh, he punched me a couple of times because I hadn't put his slippers on properly or something. You know, just little things. And then he would get up and he would still be bolshy - and his arms go up and -**

As the months passed, Prue felt that she had no option but to battle on, and even then, if there had been any form of support for her, anywhere she could turn when the situation became desperate, she might have been able to make the arrangement work. She certainly had a

commitment that no employed carer would have managed to sustain. But there was no agency in Limmerton that could provide any form of back up. She was sometimes amazed and incredulous about the situations she found herself facing alone. She could not believe that the 'system' could really leave her to manage in the sorts of circumstances she confronted throughout that next fifteen months:

> **PRUE: I never felt unsafe, but I did feel that I shouldn't have had to cope with quite a few of the incidents that happened but I didn't know where to get help anyway. That is something I have talked about with other people is that they need a 24 hour help line in Limmerton so that when you are in a position like that there is someone there to help..**

She didn't ever blame Max for his strange and difficult behaviour. She knew he would never have hit anyone, no matter what the provocation, before his accident. In fact, for her, the most disturbing thing about his totally transformed personality was imagining how he must be feeling about it inside his own confused mind. She was quite sure that that part of him who was still her "old Max", was observing these events with horror and despair. She believed the periods when he had flashes of insight and awareness were overwhelming for him; that he could not accept the great changes in ability both mental and physical.

> **He would hate to be like he is now. He was one of the few people that I could say if he ever had the choice to 'turn off' something that that is what he would have wanted. He just couldn't stand it - he couldn't stand his mother even repeating herself. He said to me once, "If I ever get to sound like her put me out in the paddock and shoot me." It has often occurred to me. If I had known the extent of the way he was going to be especially last year, when he was such a screaming violent mess. Yeah.**

At this stage however, she still believed that she was dealing with a temporary stage in his recovery, something that they had to 'get through' together. Her heart ached for him and she looked around for solutions that would allow her to carry on trying to help him at home. As well as taking on the role of carer for this man who was once her lover she also tried to offer him some emotional support.

> **PRUE: He often tells me he is stupid as well. I feel terrible for him because he is not stupid.**
> **DS: How do you tend to respond to that to him?**
> **PRUE: By telling him it is not true. That there is a lot of things he can't do any more but that doesn't mean he is stupid. That is probably his own description of himself at the moment because he is quite well aware at times that he cannot do the things that he used to do?**

She fast became frustrated in her attempts to help him understand what was happening to him, believing he needed someone with more knowledge of counselling people with cognitive problems. She felt angry that there was no expert counsellor available to do this for him.

> **PRUE: When specific things happened, or he said things that didn't make sense, we would talk about why he had said that and what he meant. But then he would have difficulty finding the right words to have the discussion that went after it as well! So you know... you were often left wondering if he had understood, but I still believe that he basically understands most of what he is told.**

Throughout this time the conviction was growing that somewhere out there there was the 'right' support, or the expertise which Max needed but that all her attempts to obtain it for him were

being thwarted by other people's ignorance, incompetence or by petty regulations written by people who had no idea of the overwhelming nature of head injury. How long the situation could have continued like this it is difficult to know. But after he had been home for about six months he had a seizure and was admitted to hospital for two days, prescribed dilantin and sent home again. A month later he caught a viral flu infection and became so ill he was again admitted to hospital. This time, Prue could admit to herself that she couldn't face having him come straight home again, that she couldn't carry on. Telling the hospital staff how she was feeling must have taken considerable courage and suggests that she knew inside she had reached a limit. That she managed to induce them to help her further so long after his initial discharge suggests either that her desperation was very obvious, or that she was very assertive and determined in her approach to them:

> **PRUE: I had had enough, I needed a break. So that is when they kept him on for another week. So that is when they started respite care for us at Waipata Hospital -**

Unfortunately, however, her troubles were a long way from over. The hospital doctor began to doubt that the admission was caused by something as minor as a tummy bug. Prue recalled her amazement when she later discovered that a diagnosis of a seizure had been made and an extra drug, tegretol, prescribed to be taken along with the dilantin already prescribed.

> **"...But they didn't tell me! They didn't tell any of this to me, they just sent him home. With two lots of pills, he had to take one of these in the mornings and you know, all the instructions... but nobody ever told me what they were for!. And then, when things started to get really bad and he was really violent, he would just go off his head. Screaming and swearing and yelling and he would wreck the bed he would kick everything to bits. It was always at night. He would rip his clothes up - he could lie in bed and he could shred his pyjamas until there was just nothing left of them and if I tried to stop him he would grab my arms and he would try and bite me wherever he could get hold of me.**

The combination of the two drugs caused a dramatic change in his personality. Instead of being given "respite" as a result of the hospital's intervention, therefore, things seemed to go from bad to worse for Prue. In desperation she took him to a neurologist who eventually righted the drug imbalance, but even then, for a long while Max and she struggled with the after effects of the hospital's mistake.

Not surprisingly, a different attitude toward medical professionals was emerging in Prue from dealings such as this. She was no longer so easily persuaded to relinquish control. Like other family members in her position she was learning that the only sure way of resolving the problems that arose was to work in partnership with those health professionals who had earned her trust. Willer, Allen, Liss, and Zicht (1991:463) observe that such assertiveness often plays an important role in the wife's coping:

> **The two most effective coping strategies the women described were identifying problems with a realistic but optimistic manner and becoming assertive in dealing with the daily obstacles they encountered.**

She began to seek out what information she could herself, to take control and then, armed with the necessary knowledge, manipulate the system to provide what she believed would solve the problems she was confronting.

> **PRUE: I actually got some information from the epilepsy society and in it there was a really good booklet that they gave me that explains all the drugs that they use to control seizures and the side effects of them are absolutely disgusting. Dilantin is just gross! And, do you know, he kept taking his teeth out all the time because his mouth was so sore and one of the side effects of dilantin is that your gums all swell up and eventually have to be clipped off and all sorts of gross things.**

The medical approach to Max's situation had lost its power for Prue. The cynicism of two and a half years of dealing with medical and bureaucratic institutions coloured her story. She had learnt that the only way to ensure that Max received what he needed was if she was prepared to understand, define and articulate those needs and to do this repeatedly to ACC, to specialists, to a range of different people who had a say over his future. This also meant she could not feel confident about Max's original treatment that, in a state of shock and distress, she had accepted so unreservedly. The way that she angrily recalled those two and a half years now was tinged with a feeling of being cheated, of having to deal with others' incompetence and ignorance at a time when she and Max needed more support than ever before. She felt that at a time she had most needed concrete information and support from the health system, she had been deprived of it.

As he recovered from the drug imbalance, the focus returned to 'rehabilitation', to his recovery from the original injury. Each day over this time, it was becoming more obvious to Prue that 'her Max' was not going to magically reappear, that the injury had left him so vastly altered in personality that she could not really regard him as the same person any more. As a wife, this realisation that her partner was irretrievably altered must have been extremely difficult to bear. As Willer et al. (1991:467) point out:

> **Able-bodied wives identified their husbands' personality changes as their greatest problem, followed by the cognitive difficulties encountered by their husbands. Third was the husbands' lack of insight and acceptance of their disabilities. Ranked fifth was the loss of emotional support and companionship they had previously received from their husbands... These women said they felt as if they had lost their best friends.**

Prue felt it took her a good year to reach this level of realisation, mainly because she was always too busy and too tired to think logically about him. Most distressing of the changes she began to confront at this time was Max's total lack of interest and motivation. People with certain forms of neurological damage may like Max, be quite unable to initiate activity for themselves and yet still appear to enjoy the stimulation of productive activity. Chapman and Wolff's (1959:65-7) description of patients with severe right brain and front lobe damage is very reminiscent of Max at this time.

> **They showed lessened ambition, initiative or imagination. .. Disinterested detached behaviour and the capacity to participate fell off concurrently. Several remained at home a good part of**

the day, staring into space, rarely seeking the company of others or the advantages of the community's entertainment facilities. Social responsibility was avoided and athletic endeavours were diminished or absent. .

Max had always been such an independent person and Prue felt uneasy about making decisions for him and yet she could see that any further recovery would require his participation and effort. All the health agencies and disability support services available assumed a purposeful person, capable identifying their needs and acting in their own best interests to overcome them. This lack of self-directed energy was a problem which no agency in Limmerton was designed to counteract. Prue never fell into the trap of defining Max as lazy. She had the benefit of knowing that self-directed and energetic man he was before. But it was becoming clear that all attempts to provide him with some sort of programme were getting nowhere. She was increasingly frustrated by the local agencies' lack of interest in Max.

PRUE: I tried the head injury society, I have been to my local MP.... I did that because ACC pissed me off so much for so long. They would not return my phone calls, they would not give me the answers I needed. They used to tell me they had lost his file sometimes - I got Graham Taylor (MP) on to them in the end in desperation - I had been trying to get - I can't remember what particular issue it was - there has been such a lot. They just wouldn't return my phone call.... and in two hours, they had finally rung me with some bullshit story of "Oh, we have just found your file and thought we would catch up with you. Such lies!"

Part of the reason for these increasingly aggressive approaches was that she began to realise that it was not only she who was 'going under' with this arrangement. Both Max and his carer were having a miserable time.

PRUE: Yes. Well you see, he got to the stage where he was sleeping up to 16 hours a day. He didn't want to do anything - absolutely chronic depression - he was sleeping all day basically. He would get up for breakfast and he would want to go back to bed. His carer would have a hell of a job. He would just go to bed.

Whichever way she went it seemed, it was fraught with pitfalls. She began to feel as if the agencies who should have been there to support her were making rules just to thwart her as they went along.

PRUE: I applied for more, they offered me another 8 hours a week just before he went away - in fact it was in the week before he went away. But to get that extra eight hours, I had to resign him from the old system that he was under and put him under the new system. And once I had done that they said I couldn't go back to the old system and there was no way I was going to do that because it obviously only benefited them, not us.

This 'Catch 22' situation is very intimidating when you are making decisions upon someone else's behalf. She did not like to take irrevocable steps when she could not know what the future held. There seemed no safe way left to go however. It was not in her nature to publicise their plight, yet she reached such a point of anger and indignation that she may have done this also if given the opportunity. Eventually the day came when she knew that she could not carry on

PRUE: He was so depressed and he was violent. I was worn out. Two hours sleep a night was about all I would get in the end. They said it was chronic depression and they wanted to put him on an antidepressant. And I just told them that if they wanted to put him on to drugs of

any sort, then they could take him away and do it because I had already had one really bad incident with drugs.

With this decision, she accepted defeat against the huge wall of bureaucratic indifference she had battled so long. And so, in June 1994, Max returned to Waimarie. In some ways there was a terrible irony that in accepting defeat and her ultimate powerlessness against faceless institutions, she was forced to take a course which placed Max (and her by proxy) even more firmly in the power of one of them.

BACK AT WAIMARIE

No one could pretend that the last six months of Max's story, which he spent at Waimarie, was in any way ideal. To start with, the abrupt and dramatic change in lifestyle must have been very confusing for him. Although he was not really oriented to place, time or person, there is no doubt that what little certainty he had begun to feel about his life disappeared. After eighteen months, he had come to believe that he belonged with this woman he had been taught to think of as his wife. He had also become very emotionally dependent upon her, probably more so than he had ever been before his accident when he was by all accounts a self-contained and independent person emotionally. He had left behind a secure and comfortable existence in a pleasant house, where the pattern of his days had become reliable and reassuring if not very stimulating, for an environment which (despite the remarks I have made earlier) even the most generous of descriptions could not deny was 'institutional' in character.

It is not surprising therefore, that he sometimes showed his displeasure at being thrust into such a setting. The little and basic bedroom, the rather barren lounge, the long linoleum corridors and the large communal dining room, must have felt cold, lonely and hostile in comparison. He often looked forlorn and lost and would constantly ask people when he was going 'back', although he still believed it was Ashton he wanted to go back to, there was no doubt that it was Prue he imagined he would find there.

This place did, however, offer what was most needed at this time. For Max it offered people and stimulation, while for Prue it allowed some valuable time out for reflection and re-energising. She knew very quickly that she had made the right decision for him as she saw him within a few weeks become more lively and alert.

PRUE: Since he has been gone I have been able to think about it clearly and realise that that was part of his problem, his depression problem. The total lack of stimulation here [in her own home]. He needs the type of stimulation he gets from lots of people and lots of organised activity and I just couldn't get that for him here in any way at all.

At Waimarie there were, of course, still many times when Max's life consisted of sitting passively and doing very little. He could often be found sitting in front of the TV set, staring blankly at it, or sitting in the dining room fifteen or more minutes before the meal was due, waiting for it to appear. Yet in an environment like Waimarie it was impossible for him to ignore the people and activity. His day was structured to ensure it included abundant activity and social contact. Filling a person's day with organised activities may seem demeaning, but for Max the result was a level of mental activity and stimulation he could never have attained without help and which he clearly appreciated.

> **DS: You enjoyed the computer?**
> **MAX: Yes it was nice.**
> **DS: Can you tell me what it was that you liked about being on the computer?**
> **MAX: Because I am moving around** *[uses hand to mimic holding a mouse and moves it around in a circle]* **that is what I like doing - feels nice.**

Despite the pleasure he obviously took from the workshop, the computers and recreational activities, it was still necessary for staff to prompt him, ensuring that he 'followed his programme' and was moving around the different areas. Gradually over the months of his stay, he began vaguely to seek out activities and mental stimulation, showing the first attempts to initiate and organise for himself something he remembered as pleasurable.

Although she knew she could not really compete with this more structured environment, there were times when the frustrations of handing over responsibility for his care to people who did not really care - who did not know the real person, who did not always understand all his needs, irritated Prue. Little things happened which built up into a picture of neglect and indifference. Each instance alone might not seem very significant, but there is an atmosphere which accumulates in such an environment where the residents do not have the ability to assert themselves, to make choices, to control their own lives. Max, for example, could not be expected to select the right glasses for a particular activity. He had a vague idea that he should be wearing glasses and happily put on either the sunglasses or the reading glasses interchangeably.

> **PRUE: His clear glasses are the reading glasses. He just seems to have them on all the time and nobody checks him. He won't see much. I know he wants them, but he shouldn't have them on, only for reading. His sunglasses are because he has a fixed and dilated left eye and it is really painful for him.**

The staff were fond of Max, they meant him well and believed that they cared for him adequately and met his needs. Their fond sentiments were probably in part because of his placid and polite manner, his usually calm, easy and 'stationary' existence. He was very easy for the staff to manage and control and very easy to ignore when they were busy. He was also more appealing as a client on an interpersonal level. In contrast to many at Waimarie, he had retained an ability to take part in a light 'social patter'. It allowed him to chat with the staff and visitors in a normal sounding

way, provided the exchanges went no deeper than the social conventions of greetings. He had a few stock phrases such as "Yes that's right too" and "How are you going? All right?" which served him well. He had a sense of humour, limited by his information processing problems to the more simple sort of jokes maybe, but he was always eager to find a reason to laugh and the staff were always glad to help him find one..

> **OLWYN (nurse): Oh. Teasing gets him going every time, especially if you are teasing someone else. He will laugh at that. And he is quite coarse. If he hears a sort of dirty joke or something like that - anything to do with farting - yes!**

He also had a charming smile which lit up his face when he caught someone's eye, inviting them to approach him and get to know him better. In this way he provided himself with the regular stimulation of social interaction, despite largely ignoring the other residents.

He regularly became irritable and agitated, however and often these episodes of irritation escalated very quickly into an uncontrollable fury where he would thump a table, wave his fists and make threatening gestures. The reasons for these outbursts were not always clear to the staff and they would shake their heads indulgently over his temper, regarding it as irrational and caused by his confusion and misunderstandings about what is happening around him. In this way, they gave themselves a convenient reason for ignoring his more confused attempts at communicating. Prue, in contrast, felt deeply for Max and could not ignore these episodes. Her response was to search for a reason underlying his behaviour and so, very often, she found one the staff had not thought of.

For example, Max frequently became enraged and aggressive because he said that people are coming into his room and taking things. The staff, who were sure that no one would have the opportunity or motivation to do this, believed when he was behaving in this way that he was confused and delusional.

> **DS: And people never do go into his room and take his things?**
> **OLWYN: No, it is purely fantasy.**

Prue, who visited him regularly in the weekends offered a challenge to this convenient if credible explanation, demonstrating the danger of making assumptions about confusion.

> **PRUE: This laundry thing too. That has come about simply because his clothes are not there any more! - it is true. His clothes are not there. I went through his drawers two weekends ago when I was there and I pulled out four pieces of clothing with other people's names on. So, his concerns about his clothing going missing are real. It is not "just a figment", which is what they gave me to believe - and he is angry about it. His clothes are all he has got left now.**

No doubt, returning to Waimarie confronted Max more constantly with his loss. There were many more situations occurring which must have forced him to recognise his new disabilities and his dependence upon others. I asked him how he felt once as he was waiting in the dining room for his meal to be served.

DS: [*watching videotape together in which Max is waiting for mealtime in the empty dining room*]
Well here you are, you are still waiting. How do you feel now do you think?
MAX: Empty as hell. I feel useless too.

This awareness was also thrust upon him because he was forced to live alongside people with similar problems. He fought against this recognition, however, as he was horrified by these people and failed totally to identify with any of them. I asked him about his avoidance of other residents which I had noticed in filming him:

DS: Are you interested in the other people in Terehi with you?
MAX: No. No not at all.
DS: You don't seem to be very interested in them.
MAX: No. I am not interested in them at all.
Ds: You don't really want to talk to them?
MAX: No.
DS: Why is that Max?
MAX: Because it is one sided. Some of them are stupid.

Institutional care, then, could not provide Max or Prue with a permanent solution, but it could be the best way to prepare for, or lead into, the ideal arrangement for both. The file at Waimarie stated that :

Prue's goals for Max are to: Increase activity and decrease tiredness, decrease weight, decrease inappropriate verbal and aggressive behaviour, increase independence, develop leisure pursuits.

Prue and the clinical team at Waimarie understood that once these goals had been reached, a placement would be sought in Limmerton so that Prue could be involved in Max's care without taking primary responsibility.

THE "AFTER" MAX

It is probably useful at this point, to draw a more detailed picture of Max as he was at the time of his admission to Waimarie and substantially, as he remained during the period of the research. This person had emerged from and been shaped by two and a half years of living with and recovering from a brain injury and it was occurring to him and to those around him that it might be as this person he was to live the rest of his life.

NEGLECT

Firstly, he was vastly altered in appearance. His body, once fit, firm and active, had become slack and overweight. This change had come about in part because he lived his life in a wheelchair. Although he could walk with the aid of a walker or a four pronged stick, it was a precarious process at best. The progress along the floor was painfully slow and he needed someone beside him to coax him through each step, reminding him to bend and lift his left knee. As the physiotherapist explained:

JOAN: Well you see he has his left side affected and those with a left side problem, quite often don't realise that they have got a problem at all, and they tend to keep walking with their right leg and they don't bother taking their left leg along.

Although this description of the problem may sound extraordinary, it really is the best way to understand what happened to Max when he tried to walk. The effect of right brain damage upon behaviour was often quite bizarre to others because of a phenomenon called "neglect" or "agnosia[92]". This altered his relationship to his own body dramatically, making those parts affected become more like pieces of equipment which must be consciously managed and controlled. Walking, for example, so dominated Max's more limited cognitive system that he was incapable of thinking of, or managing anything else, even conversation. His physiotherapist at Waimarie adapted the manner in which she instructed him to account for this.

JOAN: It's very rare that I ever introduce another subject [while he is walking]- - we keep on the task, because he is focused on the task. He knows he has to concentrate on it and I am trying to see that he does - to keep him - not in idle chatter, so that he can concentrate on it.

Max had become aware himself that to relax too much into his former habit, his old way of managing his body, was to invite disaster. His body was not the same now.

MAX: Sometimes, I go the old style and that's bad.
DS: You go the old style?
MAX: Yes. I use my old feet and that is bad. The old style.
DS: So you can't use your old style with your feet?
MAX: No you can't - otherwise I could be there all morning!

This 'neglect' of the left side of his body extended to his hand use also. Although he was perfectly capable of using his left hand, it would not occur to him that it was available unless he was prompted. This was not a casual matter of hand preference, but a failure to know of his hand's availability. Despite his remark above, Max managed to tap into the 'old style' of using his hand and leg quite effectively at times, particularly with those procedural skills that were so much a part of his previous existence that he was capable of carrying them out unthinkingly, as a habit.

SELF-AWARENESS OF DEFICITS

Max's cognitive disabilities often prevented him defining or even noticing his own disabilities. He did he seem able to mentally 'stand back' and critically assess his own behaviour. It was not unusual to find him solemnly persevering with some activity without realising that altered circumstances had made his actions absurd as the demands of his task changed. When his attention was called to his error, he would smile and placidly accept a redirection. The occasions when he independently adapted his own behaviour appropriately were rare and generally confined to physical needs. This dogged unthinking manner of relating to his world therefore reinforced an image of a passive, controlled and 'mindless' existence.

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[92] See Chapter 1, p.26.

However, with the right cues and with the support of someone talking it over, Max demonstrated he could understand at an "intellectual level" (Crosson et al., 1989:46) of awareness[93] something of the change in his cognitive and physical ability.

> **MAX: My foot won't go on the ground? - Sometimes I will put it on the ground and I need to tell it to pick it up - to put it higher - If I turn it off I get myself in the poop.**
> **DS: And what happens then?**
> **MAX: I fall over!**
> **DS: And does that help if you remember to bend at the hip and knee?**
> **MAX: Yes. I tell it all the time - this is how I am thinking - as I am going forward -**

At the time of the research, this self-awareness was too transient to allow him to apply compensatory strategies without prompting. Without an "emergent" or "anticipatory" awareness of his problems, any rehabilitation of his daily living skills was confined to moments when it was possible to provide him with prompts.

MEMORY

Asked what Max's biggest problem was, most people who worked with him at that time would probably have suggested it was his memory rather than his level of awareness. The way that his mind functioned, the way that he processed information, was very altered by his brain injury and this meant that verbal recall of events and his recognition of people, places and relationships he should have known about, was often erratic. As a consequence, Max was often regarded as having no memory. Most of the people in his world described him in this way and he himself saw his memory as a major source of frustration. During the filming period he discussed this difficulty several times:

> **MAX: No. I don't remember that - it goes in here** [*points to forehead*] **and it doesn't stay at all. There is nothing at all. I am just silly. If I am going to take it down - it's all gone - all of it comes out. It comes here and back it goes** *[with hand indicating that the memories come straight out of his head]* ... **Sometimes I used to go and do a job in the morning? And then I find I can't rely on it at all. I don't know where I have been or what I have done. It is bad. I can't feel it.**

The problem with using the word 'memory' to describe Max's problems however, is the wide range of quite different perceptual and cognitive difficulties which appear to have been implicated in his memory failures. The only certainty was that he had become forced to live with a dramatically altered awareness which gave him a unique relationship with his world.

Memory and Face Recognition

One difficulty which might be loosely classed under the term memory, for example, is Max's inability to recognise people's faces, a disability known as 'prosopagnosia'[94]. This problem

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[93] See Chapter 2, p.28.

[94] "Right temporo-parietal area notoriously produce visuo-spatial and visual constructive difficulties. These seem to lead to problems in facial recognition and recognition of emotional expression on faces" (Prigatano 1987:16).

occurred regardless of whether the person concerned was a recent acquaintance or belonged to the distant past, about which he was usually more accurate.

> **PRUE: He will call all men Paul and all women are Prue. That is how it worked for a long time. But Paul is his best mate and that is where that name came from -**

This was not only ineffective method of dealing with a bad memory for faces, but it was also very distressing for Prue, who interpreted it as evidence that he didn't remember her. It may have been more accurate to suggest that he didn't recognise her, but the differentiation was difficult to make, especially since he did not even recognise himself. I showed him a videotape where he was sitting beside another resident:

> **DS: So which one is you then?**
> **MAX: Which one is me? Nothing at all.**
> **DS: Which one of these two people is you?**
> **MAX: Oh. This one here [*pointing to himself on the screen*] No it's not. That one there is not.**
> **DS: That's not you?**
> **MAX: No. It's not me. It is too big and I feel stupid. And I might be too.**
> **DS; Might that be you?**
> **MAX: It's this short joker. Down here [*pointing to himself*]. No. Too short.**
> **Ds: That is you actually, Max.**
> **MAX: Is it really?**
> **DS: Yes, you see, you are wearing the same jersey today that you are wearing there.**
> **MAX: Oh. I'm sorry. No. I thought it was somebody else - now I do. It's me.**

This problem also meant it was almost impossible for him to recall what relationship anyone had to him, which in turn seemed to make it very difficult (if not impossible) for him to develop new relationships.

> **MAX: I don't know those two at all** [*pointing to Mark and Gwen, the two residents at the next door table who have both lived in the same unit as him for several weeks].*
> **DS: They are other residents at Terehi with you.**
> **MAX: Are they?**
> **DS: Yes they are, you don't really know them?**
> **MAX: No. But they might be nice too. That's good because now I can find out.**

The extraordinary thing about this was that although Max knew somewhere inside his head, who the significant people in his life were and how they fitted into his story, he was often totally unable to talk about them to others simply because he was unable to identify who he was talking about. This could make it extremely difficult for him to sound coherent even when, inside his mind, he was well aware of who he was talking about[95].

Memory and Words

In his case notes, Max was described as having 'expressive and receptive deficits' and 'anomia'. As will already be apparent from the excerpts of interviews with him, Max had an unusual way of

[95] See "Early Memories" for a further discussion of this phenomenon.

using words. There appeared to be a loss of memory of the meaning of words paired with a loss of the ability to string them together appropriately.

Memory is clearly a confusing word to use in this context. A closer examination demonstrates that Max's problem was instead one of processing information and integrating knowledge and experience. He chose to use a strange word because he was determined to express a memory for which he had no words. On one occasion, for example, when trying to explain to me what it was that made he and his fellow residents different, he demonstrated knowledge of a complex and sophisticated inner concept which had become disengaged from its label: wheelchair.

> **MAX: They are on job tools like this one [*patting his wheelchair*].**
> **DS: Job tools? Is that what you call wheelchairs?**
> **MAX: Yes. Traffic. It is almost that they are a piece of equipment.**
> **Ds: Piece of equipment?**
> **MAX: Yes that is right too - so I say them too.**
> **DS: That's what you think of your wheelchair.**
> **MAX: Yes that's right too, I'm sorry.**

In this excerpt, as in many of the conversations I had with Max, it was clear what he meant. There was a strange logic to the incorrect words he used too, which offered the listener some insight into what was meaningful about something for him. For example, when Prue and a woman friend stayed in a local motel one weekend and took him out to dinner at a local hotel:

> **PRUE: He wanted to know where we were sleeping and we said "Well we are not sleeping here Max, we have got a motel unit down town." Well, the next day when we went up to see him he asked us how our dining room was. But I knew what he meant - he meant how was our motel room. Unless you know him enough to know that you have got to interpret and you take it all literally then it makes no sense.**

Despite this quality of meaningfulness in his errors, he did not use the same wrong word consistently and Prue found that she needed to look beyond the words to understand.

> **PRUE: He has a number of words. Like asking to go to the toilet. He used to say some really silly silly things. And because he was actually usually obviously wanting to do something, I knew what it was he wanted to do. That he wanted to go to the toilet, because the words were just so strange.**

Sometimes it was not so much the words he used as the manner in which he used them which was unusual. It appeared that the syntactical relationships between words were not always easy for him to understand. This gave his speech an endearing character all of its own as when he remarked to me, "I lived on the farm because I had no marriage at all - ". He shared this characteristic which Prigatano (1986b) has described as 'peculiar phraseology' with many others who have brain damage.

"In a triadic theory of meaning, a speaker references an object with a symbol, the recipient of the utterance acts toward the object, as referenced in the symbolic gesture. Meaning is grounded in the conjunction of sound-image, object and concept" (Denzin, 1987:5). Each of these three

aspects of identifying appeared to be intact in Max's speech, yet the connections or relationships between them had been disturbed. As a result, it was necessary for the listener to relax their own symbol/object referencing system sufficiently to explore possible meanings and keep aware of the possible associations and tangential leaps he might have made. Then, in a partnership, it was possible to construct a joint meaning from his utterances and help him to link them together again.

Memories and Time Frames

As I have already discussed in recounting his early history, Max had very little memory of all the time he spent in Limmerton, both before and after his accident, yet appeared to have retained a good memory for his earlier life up until his early 30s. He was confident and lucid when he spoke of this early life. To him it was more familiar, more solid, than the present life he was living. After a question or two to get him thinking back, he virtually took over the tale and with only a bit of prompting, he provided me with a wealth of descriptive detail about his childhood.

> **DS: Where did you grow up?**
> **MAX: Manganauru, out on a farm - Out towards Haumatiki - near to the dairy factory - Out along here - [*Pointing to the map he is drawing*] - see, our farm is along here and there beside a river the town is there and the river is there - and there is the town there, the houses there - That's the farm house, that's the railway bridge - turn left here - that's where you go and there is the railway line -**

Despite the air of certainty with which he described details, as in the excerpt above, there were some factual errors in his stories which emerged later. These problems appeared often to occur because he had tangled together his time frames, mixing the memories for the time in Limmerton, which occurred more as vague and 'fleeting' flashes, in with the earlier Ashton memories which he felt more confident of fixing in time and space. This tendency also seemed to contribute to the problem he had identifying people and their roles. For example, he told me there was three boys and a girl in his family when he in fact had only one brother. His own 'reconstituted family', however, fitted this description. Later he accurately described marrying Prue who already had a boy and a girl, but in the same breath, confused her with his sister-in-law, Helen, who lived just down the road in his childhood. Later still, he confused her again with his first wife.

Unfortunately, those he shared such memories with often become too bewildered to rely upon them or learn anything useful from them. He required a perceptive interactant with a careful technique to help him tap into all this retained knowledge and separate it out into sequential and spatial order. Then he got great pleasure from these memories.

Memory and Tangents

There are some other obvious reasons for the confusions that occurred with these essentially intact earlier memories. Sequential thinking restricted Max's information processing (and so

information saving) methods to linear ones. If the questioner made leaps in time, the places and people were likely to be confused with each other in his mind. When he recounted memories himself, his thoughts was often equally disjointed because of a tendency to go off on unusual tangents. One he had pursued one mental direction in this way, he seemed unable to bring his mind back to where he had started. This could be just as bewildering for Max as it was for his fellow interactants and he often apologised for losing the thread of conversations in this way.

> **MAX: .. I just can't work it out either - it is bad for me. It's like that all the time - it's just always - subject so I just went wrong and didn't know a thing and then it did something else and I didn't know at all.**
> **DS: The subject you mean? That it changes?**
> **MAX: Dead right too. In fact it changes all the time. It makes it didn't understand at all - it does just change like that all the time.**

In telling me the story of his first marriage, he provided a poignant example of how these various difficulties (tangential thinking, anomia and prosopagnosia), combined to confuse him as much as those he is speaking to, even about the most memorable life events:

> **MAX: That's right too. I was married - I know that at all. There's Prue. Actually I don't think we should be married at all. Not at all. She is a nice girl Prue. She was too. A very nice girl. - 74 it was, we split apart. And I asked her because she is nice - Probably too my other lady she was nice too - she got money too. Maybe the matter is to me. - I don't know. I do all these stories strange again - I put in $300 each. I needed three or four wins and I didn't see any for a while - I don't know what they tell me - I go, "that will be nice" - go back again, come back again - nice to you - and this time I don't know at all. I don't know what to do because I don't know at all. Whether it is now because I wont walk so far - I stop I get so far , get myself around and then I can't go on. But probably I can't walk properly . To be able to walk properly would be nice.**
> **DS: What are you talking about Max?**
> **MAX: Me. Not being able to walk properly - when I go to bed? I pull the bed down then I stumble on to the bed.**
> **DS: Right.**
> **MAX: Don't really walk at all - And it's bad. Maybe it is because I can't walk at all. I used to be able to walk too when I was a little feller, when I still had all the parts.**

Together these difficulties called memory but more accurately understood as information processing, actively prevented him reintegrating his past and present. Even when he was able to recall incidents, because he could not organise and identify his experience, he was unable to place the present in the context of his past.

A DEFINITION OF THE SITUATION

It was not only his past that had become unavailable to Max, but also the present and the future. After a head injury, confusion and disorientation are common. With those less seriously affected by their brain injury this can spontaneously clear. But it did not work out like this for Max and many like him at Waimarie. He was clearly still unable to make sense of his experiences as he lived them and, as a result, he could not integrate them with related knowledge and experience. Anything he did retain was a 'hazy', or confused impression. He would remember isolated

fragments from conversations, or mental images of activities but without knowing when he had experienced it. The following conversation (initiated by the social worker who commented to Max on his pleasure in art sessions) demonstrates this confusion well. The "he" in this passage initially appears to refer to the present, but later he is clearly drawing upon something similar in his past.

> **MAX: I don't know - after I do art work - he will say you know you did a beautiful job and you do this job and he says all the time that you are doing good. And it just sounds good too. I don't know - I put up with it because he keeps telling me it's nice. Something he was trying to tell me to do was those - books. I took my time. And did it well. That is probably why I did it so well. The first time I thought it was good. That is probably why I feel it was good. That was right too. It was nice too. He said to me, he said he had a summer's job. Very nice. And this is going back maybe one or two years. I'd say it was too fast. I'd say you are doing a good job.**

This disorientation not only made it difficult for Max to understand his present, but also prevented him participating in any planning for his future. For example, there was a clearly understood goal to find a placement for Max in Limmerton so that he could be nearer Prue. Although I observed several occasions when this was explained to Max, several of his conversations showed his total failure to integrate this information. He was aware that some plans were afoot but confused about what they were.

> **MAX: I'm sorry, I was wondering how long I have to stay - I was told that I wouldn't be going back at all.**
> **DS: Going back where?**
> **MAX: To Ashton - won't be going back at all.**
> **DS Prue doesn't live in Ashton any more.**
> **MAX: No. Where does she live?**
> **DS: Limmerton.**
> **MAX: Does she? I don't know if I am going there or not - I think I am not going to her at all.**
> **DS: Do you think someone has told you are not going there?**
> **MAX: Yes they have.**
> **DS: There is a plan to try and find a place for you in Limmerton Max.**
> **MAX: Is that so? That would be nice that would - because, Joan[96], she is a nice girl. -**

It might be said that because he had no way of defining or understanding the incidents which made up his day, he could not organise them into a workable interpretive scheme. Without any way to organise the experience he was living, he was then unable to understand what was happening in his world or to participate in organising his future.

Autobiography and Self Definition

When Max spoke about himself, there was no sense of ownership in his remarks. Nor did he seem to recognise any coherent inner patterns to provide identity and continuity. This created an unusual style of self-commentary. He would calmly come out with remarks which were very personal in nature in an almost disinterested way. This appearance of indifference was coupled with a total lack of self consciousness in the way he approached his world and thought and spoke

about it. His accounts of himself were overly objective and based upon concrete or visual information available to other people as much as to him.

DS: How would you describe the person you were before your head injury?
MAX: No. Not at all
DS: You can't describe yourself?
MAX: No, I can't.
DS: But you were different from the way you are now?
MAX: Oh that is this here *[pointing to mouth].* **I am talking so funny .**

Without an awareness of an inner self as a guiding scheme to relate the lived present to a different past it was hard for him to have an opinion about what or how he wanted to be. Perhaps this is why he was at his most intent and involved when he tapped into a past experience or idea which reminded him of his past identity. For example, the excerpt above shows that in his mind there was a vague idea that he must recapture this sense of 'doing a good job' if he was to make sense of this new and very altered life. How much he wanted to recover this feeling of competence came through clearly (despite the rather meandering and disjointed conversational style). Similarly, he retained his fear of alcohol and although before his accident he would enjoy the odd beer, he now refused any alcohol firmly. Prue felt this was one of the few things which he felt certain about having a position upon and that was why he was suddenly so adamant.

Having no ability to recognise patterns in his past and present experience, Max had no ability to develop a new sense of self alone. Clues from the past which related to his identity became very important to him as he tried to formulate a new ontological core.

The Perspective of the other

A poor awareness or perception of others' interactive projections and an inability to take the perspective of others is commonly a consequence of brain injury (Ylsivaker et al., 1987:174). Max often assumed that his listener would know the places and people he spoke of. It seemed that it was hard for him to 'place' a fellow conversationalist, to locate them within his life and understand the role they had or the part of his story that that they could be expected to be familiar with. His solution (and perhaps in the circumstances the most practical for him) was to assume that anyone he was talking to had a very intimate acquaintance, not only with him, but with all the significant places and people in his life, sufficient to understand allusions to people and places. As a consequence, his fellow interactants were often very confused.

This characteristic may have been responsible for the appearance of confusion where in fact there was very little. When he launched into an account of his childhood he assumed I would know

[96] Joan, the physiotherapist at Waimarie, appeared to become confused in his mind at this stage, with his wife, Prue.

every small road and bridge and tiny village settlement in the area where he grew up. There was no doubt that he knew them all still and a question asking for clarification would usually prompt a wealth of this background information. What seemed disorientation was often (to him) a logical connection.

Without an awareness of self, without the ability to form a real personal opinion, it is unlikely that Max could have had much understanding of the perspective of the other people he interacted with. Yet symbolic interactionism theory would suggest that it is only possible to interact effectively if there is a capacity to internalise the 'other' in some way and so develop a projected perspective to self (Duncan,1968:103). Much of Max's inexplicable confusions might be explained by reference to Mead (1934), Blumer (1969) and Duncan's (1968) theory. It is possible that he was responding to just such an internal voice at times without recognising its source. There were many occasions in my interviews for example and his discussions with other people, when he spoke of a man who was angry with him and who impressed upon him that he had failed in some way.

> **PRUE: He talks a lot about people putting him down and about having these arguments with people and sometimes we have these great long protracted conversations with him about some argument that he has had with somebody and I really don't know if it is fictitious or if it is something that happened to him many many many years ago -**

Whether or not these incidents and characters were real eventually seemed immaterial. What assumed the most importance for Max, was the impact that such memories have upon his self-understanding. These critical voices were operating as a harsh internalised audience rejecting him. They expressed the same disgust and rejection that Max quite obviously felt himself in his more self conscious moments. In this way, the inner knowing 'I' was encouraging him to develop a helpless and passive persona.

Defining the Situation and Personal Power

The inability to organise information logically also prevented Max from solving his own problems effectively. If you want to find a solution to a problem, you must first define the problem. Max's attempts to find logical solutions were frustrated by his confused and disorganised understanding. During one interview, for example, he complained about his sneaker, which had lost its velcro strip and would not fasten. He had several rather mysterious reasons for failing to solve this problem.

> **DS: You can buy new shoes or get more velcro sewn on those ones.**
> **MAX: Yes I want to, but I can't.**
> **DS: Why not?**
> **MAX: They have gone away.**
> **DS: Gone away?**
> **MAX: Mr Mitchell. What is his name? Peter. Peter Mitchell?**

DS: Is he the one who does it and he has gone away?
MAX: Yes that's right too - it's terrible - it sounds good. But when it's going it's bad.

There was no person called Peter Mitchell at Waimarie but this sort of reason for putting up with an uncomfortable situation was typical. Everyday life presents each of us regularly with situations similar to Max's shoe fastening problem. They are often so minor as to escape conscious attention. If left unsolved, however, they accumulate until eventually everyday competence deteriorates. How well and efficiently we mobilise resources and people to deal with such problems may well best demonstrate the comparative adaptability, purposefulness and autonomy Wood (1990a:3) spoke of.

The common factor in these confused interpretations was the theme of a lack of control, a belief that someone else, someone he didn't really know and could not recognise again, was responsible for resolving this problem. It seemed that the consequence of not defining situations therefore, was a resignation toward powerlessness and passivity.

Fantasy and Reality

Another difficulty clearly related to this state, was a certain inability to distinguish between fantasy and reality. Max did not appear to separate out what he was feeling from what he did about it. On one occasion, for example, watching himself on film sitting in the diningroom, he noticed another resident was staring at him. He remarked to me:

MAX: I told them to watch themselves.
DS: You told them to watch themselves?
MAX: Yes that's right too.
DS: That's what you would like to tell them?
MAX: Yes. That's right too. I did tell them that.

Max did not in fact make any remark at that time, but, later erupted into an incomprehensible fury towards the staff member who brought him his meal, suggesting that the memory of what he felt like doing at this point, had become confused with the memory of what he did do.

EMOTIONALITY

Like many people with brain damage, particularly right brain damage, Max's temperament had become unpredictable. As Chapman and Wolff (1959:65-7) observe, affect is often "inappropriate" and frustration and tolerance levels are lowered after a brain injury. This man who was once self contained, good natured and easy going, now swung between his most usual placid "deadness" of emotion, a depressed despair and (occasionally, but very dramatically) a wild violent fury. During these periods of fury he could be verbally and physically abusive and seemed totally unable to control his rage and yet he would just as suddenly return to inert emotional stillness. These outbursts were as much a mystery to Max as they were to others and it was clear

that he was very uncomfortable with this new aspect of his personality. Max's emotional relationship to the past was just as altered as that to the present. He felt considerable confusion about his past interpersonal relationships. The accounts he gave of his early life, even when factually correct, may have been very removed from the original experience, because of a distortion in the way he remembered his own feelings and emotional responses at the time[97].

It is important to bear in mind that characteristic emotional responses will continue to influence a person's behaviour after brain injury (Pepping and Roueche, 1991; Prigatano 1987). The pre-accident Max had the matter-of-fact style of a down-to-earth man and this might suggest that the lack of affect was a personality trait rather than a neurological disorder. There is no doubt, however, that his feelings were less under his conscious control and so less open to emotion management (Hochschild, 1979). With less ability to define a situation, Max was unable to establish appropriate feeling rules. Instead, he attempted to mirror the attitude of the others around him and was thrust as a result into emotional conflicts he could not define or understand.

This failure to establish a coherent emotional position about anything, whether from the past or the present, caused an equal failure in Max to have an emotional position about himself. He appeared to have considerable trouble defining not only who he was, but also what he felt about who he was. Without an ontological framework to explain the positions in which he now found himself, there was no way he could effectively resolve negative emotions. This appeared to be the single most important change in Max's emotional experience. His sudden bouts of anger in fact appeared to occur when a link, even if very transitory, occurred between his feelings and his self-awareness. At such times his new powerlessness over his own life appeared to overwhelm him and he could only conclude that those around him were consciously and intentionally stripping him of power. When I talked over one angry episode with Max, his comments tended to support such an interpretation:

> **DS: It was for yourself, the anger?**
> **MAX: Yes. That's right too. It was for all the other people. This chap. He doesn't speak, he did not say a word, but, to me, he dismissed. It sounded like rubbish. And that's right too you bugger!**
> **DS: He felt that you were rubbish?**
> **MAX: No because I just, that is what I felt.**
> **DS: He made you feel like rubbish?**
> **MAX: That's right too.**

Prue and the staff at Waimarie who took the time to talk through such an episode with Max generally reached a similar conclusion and usually also observed that feelings of depression emerged at these times of heightened awareness.. It seemed that the most common factor in his moments of emotional distress was a higher level of insight or awareness into the loss he had

[97] See Chapter 1, p.34.

suffered and the changed nature of his life. One staff member I spoke to, was quite shocked when she saw more deeply into Max's mind on such an occasion:

> **OLWYN: When he is really throwing one and carrying on, you have got to work out what it is - and normally, when you can sit there, you can work it out. A few days ago I did this and I was quite surprised with what came out - he was suicidal actually - that was the first time I had come across that and I found it quite scary because all he could talk about was killing himself. Like "I am useless and there is no use in my life". I found that - yes it was a totally different side of Max that I had never come across before - I gather from conversation that he may have done it to another staff member once before. . I didn't think he was like that - I thought he was quite happy - These things are blocked out. Obviously that day he woke up and thought "What the heck is going on in my life - " This is how I read it and, I can understand that -**

This suicide theme had been recurring since his first discharge from hospital. The first time the prospect of living with his disabilities struck him, he tried to throw himself down the stairs of his home in Limmerton, frightening and distressing Prue. She still feels she has no way to answer him at these moments and her heart goes out to him:

> **PRUE: He knew then. It is not there all the time. I am sure it is not there all the time. But occasionally he has flashes when it is definitely there because he doesn't want to be this person.**

It seems that re-establishing the link between cognition and feeling may be a mixed blessing and something which should not be undertaken lightly by others.

The methodological position taken by symbolic interactionism assumes the centrality of meaning. Without reestablishing meaning Max's life in symbolic interactionist terms would seem only a half-existence. If Max was to create effective self-meanings again, he would need to reintegrate his feelings and his thoughts. If he could not recover this emotional engagement in his world then he could never experience a real and authentic consciousness again. Without re-integrating his emotional self feelings, as Sacks (1985:109-110) pointed out, Max in effect would lose "the very citadel, the self, the soul" of his being.

PREPARING FOR A NEW FUTURE

The second stay at Waimarie was a time of establishing a settled future for Max; a separate future from Prue. It was accepted that he would never again be independent in his daily living and yet everyone hoped he could learn to have more control over his life with appropriate support. Prue was adamant that home was not the right place to achieve this. She wanted to find a place for him living near her, but cared for by someone else who was paid to do it. She knew, once she had had the time out to reflect, that she could not go back to the exhausting lifestyle of the eighteen months he had shared her home. She spent the months during which Max was in Waimarie thinking about an alternative arrangement which would allow him order, dignity and sense of permanence.. The most likely possibility was a resthome, really designed for elderly people, but several in the Limmerton area were beginning to offer places to younger people with severe

physical disabilities. Once it became clear he was likely to be moving on to such a place, the task of Waimarie became clear: to prepare him as best they could, to be as active and independent as possible in such an environment. The themes which dominated the last six months of this story therefore, emerged from this plan. They are the themes of autonomy, habit and emotion control.

CONTROL AND CHOICE AND HABITS

Like Prue, several of the clinical team hoped by their intervention to encourage an independence and initiative in Max before he left Waimarie. They could see how, in a resthome setting, his compliant and passive manner might consign him again to the state of inertia a structured programme had rescued him from. However, such a goal required of Max's cognitive ability that he was able at the very least, to make a choice between options. There was some doubt among the various staff that this would ever be possible. Ginny, a nurse aide, felt that there were only some limited ways that he did make a choice.

> **GINNY: If he gets hurt. For example, he has been hurt by Tom[98] and he doesn't like Tom any more. Even when Tom is just walking past his door he starts off an outburst. So, yes, I suppose he does choose.**

She felt he was particularly inclined to act independently or initiate an activity when there was some sensory reward.

> **GINNY: And with food. Once he has seen it, he won't take his eye off it. And you know he is looking at it and you go "No Max. You can't have that." I think he has some understanding that he has got some choices... He knows he can go to breakfast, he can just waltz on down there - he doesn't need anyone to make it for him -**

She also felt that he was most likely to remember daily routines, and less likely to seek out intellectual pursuits.

> **GINNY: But then there are other times when he has to wait in the lounge for someone to take him to his programme. He can't remember it. I think he can only remember certain things. That is how he does it.**

These examples Ginny gave all suggest that Max's behaviour was based more upon a conditioned response than upon an intellectual awareness of his options, whether social, sensate or recreational. He always arrived early in the dining room, he avoided noisy areas or people and seemed cued by cold or heat, discomfort or comfort. It seemed that he was able to choose in as much as he was able to 'react', or differentiate between a personal 'good' or 'bad' appraisal, in situations he had encountered before. He was even showing some ability to seek out or initiate activities he remembered as pleasurable, while actively avoiding people and places he disliked.

Without an anticipatory or metacognitive level of awareness, it seemed that establishing procedural learning might be the most appropriate goal. People with brain damage often cope best

if their day is structured into stereotyped routines and they can "deal with daily problems by constricting the fields of interest and habitually performing old routinised patterns, at work, at home and in the community" (Chapman and Wolff, 1959:65-7). Max appeared to be able to establish habits if an environment was stable and predictable, but his dogged 'mindlessness' prevented the habits working in his best interests:

> **HILDA: We cannot leave food in front of Max because he just eats it. I mean he ate half a roast for lunch yesterday because it was left on the bit that turns around and he just turned it around and ate it.**

To be useful, habits and routines must still be sufficiently self-monitored so that the person can adapt to account for any changing conditions. Max could learn to perform a task all right, but then he would perform it too automatically. He made no attempt to critically assess his situation as he proceeded with a task and so could have put himself in danger if left unsupervised. Because of this lack, Max often made absurd mistakes while performing a task he has been taught and that he has practised regularly, such as putting peanut butter and pickle together on a toasted sandwich, or honey in the teapot, simply because those containers was the first to attract his attention. He knew this happened to him, but felt powerless to overcome it and because of this, he was unlikely to initiate any food preparation no matter how much rehearsal he was given.

> **DS: Would you like that? To be able to make your own snacks?**
> **MAX: No. Not at all. Because I would go wrong -- If the girl wasn't there to tell me how to do it - If I wasn't told to do it that way I would try hard but I wouldn't do it - I am stupid - wrong - That's how I feel all the time sitting here - I am not going to do it - it is wrong. It feels wrong.**

Gross (1987:111), like many rehabilitation practitioners who have considered the cognitive problems of brain damage, believes that establishing habits is a useful intervention strategy. He suggests that habits overcome some of the problems of a competitive cognitive system by "freeing up" processing space. His observations about figure/ground confusions, however, apply equally powerfully to Max and until he can define his situation more clearly, the teapot is likely to continue to need some protection from his ministrations.

There is a further risk which should be considered when encouraging the learning of habits. While coaching and training may be effective ways to increase independence in the mechanical tasks of daily living, it may not be so effective in meeting the social and emotional needs each day brings. Without a firm sense of self-awareness, Max already clung to many social habits without understanding and so was restricted unnecessarily by rigid patterns of social convention. As Denzin (1984:159) points out, a reliance upon such pre-established habits can increase the likelihood of spurious emotional intersubjectivity and emotional understandings:

> **The deep underlying meanings of the person will be glossed over through the use of surface, interpersonal rituals. Interaction remains at the "they-like" levels of the self.**

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[98] A fellow resident who sometimes lashed out at others.

Generally, therefore, attempts to establish habits in Max have been limited to the simple daily care routine and have not generalised to cover initiating interaction or recreation, time management, or other more personally satisfying mental and social pursuits. Some compromises have to be made, it seems, about what is meant by "adaptive, purposeful and independent" (Wood, 1990a:3) in a case such as Max's. The close link between autonomy and independence and self-awareness can not be ignored. To help Max learn independence, it would be necessary to help him understand his confused feelings about himself and the confused emotional reactions he had to his world.

EMOTIONALITY

If insight and self understanding were a goal of Waimarie, then the moments where he was more aware of the change caused by his accident should have been moments of celebration rather than concern. Yet, as described earlier, these were also the times he felt depression, anger and despair. Most of the people who worked with him would have liked to believe they were encouraging a development of insight, yet at the same time, not one of them would want to encourage suicidal feelings. It seemed in his case however, that the two might be inseparable: As Fordyce, Pepping and Roueche (1986:225) point out:

> **Personality disorders caused by the person's emotional reaction to the brain injury and to the failures in coping may increase as insight and awareness increases -**

The practices of the Waimarie staff over this time suggested that in fact, rather than assisting him in the expression of his own inner emotional response, much energy was directed toward helping him positively appraise the inevitable losses he was discovering in his life's quality. As Foucault (1988:18) comments, through our social relations, an individual is encouraged to:

> **..effect by their own means or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection or immortality.**

The people around him at this stage of his 'after' life began to focus upon this goal of inducing a "certain state of happiness" as opposed to any real change in his level of independence. If he was to be happy in a home and if the home was to be happy with him, a better level of control over his emotions and his emotional expression seemed a worthy goal. The aggressive outbursts could be frightening to other staff and residents and their fear could have prevented him forming the sort of relationships he needed. By convincing him to accept a new way of living they hoped to save him from a future full of despair.

Helping someone like Max to deal more effectively with his feelings is not easy. The staff at Waimarie ranged between those who would have liked to pretend his bad feelings were not happening and teach him to pretend this also and those who encouraged him to think through his feelings, accepting the person he had become and learning more appropriate ways of dealing with

the distress his losses caused him. These two separate strategies existed alongside each other, the first style generating habit and skill rehearsal, while those who helped him explore his thoughts and feelings concentrated upon attaining an "emotionally intersubjective" (Denzin 1984: 130-9) relationship. Only a few staff related to Max upon this more authentic level but those who did became convinced of his need for this sort of relationship in his life:

> **TRUDY: It is really important [*for Max to clarify who he is*], because once you start looking into that, this wonderful gentleman starts to come through. And he has really got it together - he knows what is happening and he is in control. That is why I try to get him talking about it -**

Having helped Max come to terms with his changed reality rather than trying to discourage his exploring it, Trudy and the others at Waimarie who worked toward encouraging insight, believed that their role was to help him learn more appropriate and controlled responses to his emotion. Such an approach immediately determines a focus not so much upon the damage or disability, as upon the person's response to his or her new situation. People are not passive recipients of the change wrought by a disability, but rather they are meaning-making interpreters who act upon the basis that situations have for them. As Sacks (1985:x) explains it:

> **The patient's essential being is very relevant in the higher reaches of neurology and in psychology; for here the patients' personhood is essentially involved and the study of disease and of identity cannot be disjoined.**

THE FUTURE ARRIVES

It is likely that Max would have been obliged to stay at Waimarie for the rest of his life if it were not for a change in the ACC policy which allowed people like Max, with multiple disabilities, to receive a higher living allowance than the previous maximum ACC could allocate. This new "Complex Personal Injury" allowance was sufficient to encourage private institutions to design and develop facilities to cater for their needs. Edenton Home in Limmerton was in the process of planning occupational therapy, recreational and physiotherapy facilities which their elderly residents would not require, but without which Max's future would be dismal and empty.

While Prue was glad for the existence of this allowance, she was frustrated that it placed her and Max once again in the power of ACC. During the last weeks of the research, an assessor had investigated his case and written her report, Prue waited for the verdict of this institution she felt so cynical about.

> **PRUE: Nobody has said that yet. They have done the assessments - I will believe it when it goes through and it is all approved. I just want to see it happen. I will believe it when I see it.**

At last however, she seemed to have jumped every hurdle and made it to some sort of final destination in her fight for Max's future. She knew now what she wanted for him and knew that it should be obtainable:

PRUE: I would like to see him doing the things he enjoys doing and obviously he enjoys computers, he loves using that. Exercise every day, physio, walking, whatever, woodwork would be wonderful... he loves to paint -

She believed that the environment would work for him, that his nature and his background made it fit him more comfortably than one might expect:

PRUE: I think that Edenton is going to be a really good move for him. Elderly people have got far more time... And he is used to mixing with older people - this goes back to his childhood when he used to spend so much time with his mother and he used to go to all the socials in the hall where he lived. He is very comfortable in that sort of situation.

On 18 December 1994, Max left Waimarie and moved into Edenton. Because his story was one of a health system which failed to be there when it was needed, there was another story running alongside his, of a wife who had two and a half years of struggling, and now had to let go to survive. If the support had been there for these two, this story might have ended differently. So many people were hoping that Prue was right when she predicted shortly before he left:

PRUE: He will finally be settled somewhere permanently I hope. To a place where he is happier. And where it is ethical for him to be and for his family to visit him.

Max managed to live through his brain injury. Now he needed to live, despite his brain injury.

CHAPTER 7

BRYCE LAWSON'S STORY

THE ACCIDENT

It was two o'clock on a Sunday morning in July 1994. Bryce Lawson had just left the nightclub in Matamoa with his friends Mike, Linda and Jenny. They were driving home to Wimberley, five hours south. It was going to be a long night and it was mad to be driving so far at that hour, but Bryce often did things like that and anyway, Linda needed to get home. She had only arranged childcare for the one day.

Bryce was driving. His alcohol level was under the legal adult limit, but he was only 19 and at 19, the blood alcohol reading had to be very low. Although he would have failed a breath test, this is unlikely to have caused him serious concern. He already had two drink driving convictions and he assumed the others were no more sober and able to take the wheel than he was.

They hadn't gone far when they reached a major crossroad. The road must have been very empty at that hour of the night and so Bryce probably wasn't very vigilant about other traffic, but it is difficult to understand how he could have missed the large semi-truck and trailer approaching and turned into its path. They were lucky. The car glanced off the side of the truck, scraping and denting both only, or so it seemed. But Bryce remembered the alcohol in his system and decided not to stop.

> **BOB LAWSON (Bryce's father): - and so instead of staying there, he panicked and thought you know, "the police are going to come and I am going to get in big trouble!" And so he started off down the road toward Limmerton**

He quickly discovered he had lost his headlights, but, committed to flight, he switched on the hazard lights and pressed on. There was a long straight stretch of about four kilometres after this crossroads and then an S-bend. Not a very tight bend, but nevertheless, it proved too tight for Bryce to steer through successfully. It is possible that the steering or the chassis had been damaged in the encounter with the truck, but perhaps Bryce just had insufficient warning from the hazard lights and failed to notice the corner coming up. No one will ever know for sure.

> **BOB LAWSON: What happened is they came along here and although they weren't speeding at all they went over the bank ... and hit the fence that was just down the bank ... and the top rail of the fence broke loose and came through the windscreen and hit Bryce in the face -**

The post quite literally 'pushed his face in', carving a great slice as it did so from the top of his forehead to his nose. Bryce was suddenly in trouble a lot more serious than the police or the truck driver could have put him in.

CHILDHOOD

Bryce was a second child, twenty-two months younger than his sister, Valerie. He had an unsettled childhood largely because of his parents' turbulent marriage relationship[99]. Both parents agreed that this had a considerable impact upon his developing personality, moulding him into a boy who was 'placid', quiet and good, something of a loner, someone who had learnt to be rather self reliant and who did not really confide in or trust either parent.

When he was five, his mother left the family home with the children. His father fought for and regained custody of Valerie but the issue of his own custody remained unresolved and contentious throughout his childhood years. He and his mother lived alone from Monday to Friday and in the weekends he would join his father, his new stepmother Pat, his sister and later, his new baby half-sister, born when he was ten.

To have such an uncertain family arrangement might suggest that the young Bryce was at risk of developing emotional problems. If so it was not immediately evident. He appeared to deal well with the conflicts and upheavals of his primary school years. He had two or three friends that he would spend time with and he was, from all accounts, a content and conscientious child in school. His mother remembered a calm and settled routine of church activities, homework and board games together in the evening. Bryce, looking back later as a 20 year old, could not remember any distress either, commenting to me that he had been indifferent and detached about the family situation.

Both parents later regarded this detachment in a more sinister light. As he grew toward teenagehood, they remembered him becoming 'unfeeling' and manipulative. Because of their animosity towards each other, his parents were unable to work together to overcome this.

> **BOB: He got very materialistic, like, they were having a psychiatrist to do a report for the court on who the kid should stay with. So Alice's family turn up with a nice big camera - "Here you are, you stay with your mother, you have got a nice good camera and you can join the camera club -"**

To a researcher many years later it seemed that the child, Bryce, had developed confused definitions of family where money and material gain were synonymous with love and caring. The strategies he had developed to manipulate his parents probably seemed very successful to him at the time but as he got older his demands became too ambitious.

> **ALICE: When he got to be about 12 or 13 he expected money a lot. But I had to put my foot down because I was only on a benefit and I couldn't afford to give him any money. He didn't like that and he used to get upset about it.**

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[99] Details about the relationship between Bryce's parents have been omitted at the request of Mrs Lawson. However both parents and Bryce himself are satisfied that this definition of the marriage is accurate.

Not surprisingly, he never really accepted that either parent had any right to control him, or make decisions for him and as he approached puberty, he became increasingly remote, barely interacted with his mother at all.

> **ALICE: I would go out sometimes and I would come back and sit down and I would want to talk to Bryce about what I had done. And he would be lying on the couch watching TV and I would be starting to tell him and he would look at me as if to say, "Mum shut up, I don't want to listen to you."**

There were sometimes signs that this self-contained attitude was something of an act. The confused child who wanted to belong in a normal family was, perhaps, just under the surface.

> **ALICE: Well he got upset one day when I had friends over for tea and they were doing the dishes. And one of them was getting smart and Bryce actually pulled a knife on him and I had to tell Bryce to put the knife down. I went up to his room and said "What is the matter with you? You don't pull a knife like that." "What is wrong?" And he was crying and he said "I just want things to be the way they were when I was born."**

The negativity also began to flow over into his approach to school and teachers. While he appeared to have behaved reasonably well at primary school he developed a reputation as a disruptive presence in his college classrooms. Bryce stopped attending school regularly at this stage and when he did attend, some of the subjects seemed irrelevant to him. He was still prepared to apply himself, but only when he had nothing better to do.

> **BOB: He would disturb the whole class... Just refusing to settle down. There were a couple of teachers he got on really well with and he would be good in their classes, but a lot of the rest he would just have on.**

When he was 14, Bryce's story took a bizarre twist. He became involved in a sexual relationship with Megan, a woman of 31, married with children near his own age. A friend of his mother's, the relationship began during a visit when she slept in the spare bed in his room. He began visiting her home during the day, forging his mother's signature on notes for the school. Eventually he moved in with her.

Both parents were quite naturally horrified by this development but found themselves powerless to prevent it. The police and social welfare were unable to support them because Bryce had reached an age where the court was only effective when the child concerned wished to comply with its ruling. From 14 until 16 years, therefore, any parental influence in his life disappeared, except when he condescended to consult one or the other of them over some practical issue such as a car mechanical problem. His mother limited her opportunity to change this when she refused to have anything to do with Megan, losing a gamble for his loyalty.

> **ALICE: So Bryce wouldn't come and see me. So I lost him for two or three years. She took him away from me.**

Bryce continued to insist that he loved Megan throughout this time and he was determined to stay with her. He attended school sporadically during the day and playing the part of a partner in the

evenings. He left school as soon as he could, just before turning 15 and without sitting school certificate and enrolled in a year long polytechnic carpentry course.

Alice and Bob had initially regarded their son's affair as a temporary situation. However, it cut into his time as a child growing up and learning, removing him from the company of those his age and leaving him with no experience of teenagerhood. When Megan gave birth to a child when Bryce was 15, the impact upon his mother was painful. She initially refused to accept that the child was her grandson, but gave in after nine months. His father also continued to ignore Bryce's partner, but dropped a parenting role for one as a friendly adviser. When Bryce thought about entering a dairy farm cadetship, he approached Bob, who encouraged him eagerly, offering to help him to move and to find accommodation. Bryce's story of this, the next major chapter in his life, demonstrates the remarkably casual way in which he was inclined to make quite major life decisions.

> **BRYCE: Well, after I did the building course I started work for a guy in Taiaha and then I sort of split from there, and I was talking to my mate on the phone and he said "What are you doing?" and I said "Nothing" he goes "Are you still working?" and I say "No" and he said "So you are not doing nothing?" And he says "How would you like to be a farmer?" And I say "Oh yeah okay, how do I go about it?" And he says, "Come up to Limmerton - go to the DFT and ask for the head supervisor there." So I went there and I was talking there and I came to Wimberley and about three days later he rang me up and said "Is that you Bryce?" and I said "Yeah" and he goes will you come up for an interview" and I said "Yeah" and he goes "Well we would like to offer you the position" .and I say "Oh! Okay."**

Clearly, dairy farming had never occurred to him as a possible career before; the real appeal was in having something new to do and perhaps, as his mother suspected, he was also escaping the situation he found himself in as he grew apart from Megan and began to find girls his own age more interesting. Perhaps because girls his own age became more available, Bryce's unusual relationship was losing its appeal and influence.

> **ALICE: He needed to do something because he was starting to get nasty where she was concerned. She actually found a letter he had written to another girl. -**

Whatever the real reason for his decision to leave Wimberley and switch careers so abruptly, it seems to have been a very successful move.

> **BOB: He was the only kid on the course that actually wasn't bought up on a farm and so I thought, "He has got an uphill battle here..", but, the way the Department of Ag[100] do things, they had their theory and then, they would show the kids fencing and to do that they would get a fencing contractor in and go where he was working on a fence and he would show them how you build the fence and, well, he actually topped the dairy class and he was first equal in practical - Oh yes. He got onto a farm and they do a year on different farms and he did his first year and did really well there and got really top references from that farmer and got himself another farm for the second year and did that -**

[100] The Department of Agriculture, often shortened to Department of Ag., is the government organisation funded to support agricultural industries in New Zealand.

His mother's theory about the importance of getting away appeared to have been borne out by the facts. It certainly seemed that this course, which separated him geographically from his own family and from what seems to have been an inappropriate sexual relationship, gave him the opportunity to make a fresh start. Over the two years of the course he showed himself to be capable of a more self-directed, motivated and purposeful lifestyle than he had ever managed in Wimberley. Megan followed him up to Limmerton a few months after the start of the course, but he never returned to live with her, although he maintained a friendship with her and visited his son. Instead, he flatted with other young men his age, worked hard and socialised even harder, in the pub or at parties. He drove old cars and a motorbike, often crashing them, usually under the influence of alcohol and indulged in a series of short and exciting relationships with a wide variety of girlfriends. He still found it hard to find a balance in his emotional life and was inclined to extremes.

> **ALICE: He had one girl and he only met her one weekend and then he rang me and told me that Laura and him were coming to see me and they had something to tell me. And he had known her one second and he had asked her to marry him! After a week of going out! And I said to him, "Look, you don't even know her!" I think it lasted about six months -**

Bryce himself took obvious pleasure from remembering these times. He was quite proud of how many car crashes he had had, of his drink-driving convictions and of his remarkable number of girlfriends. Quite obviously he gained a lot of self-esteem and pleasure from his dairy farming job which suited his temperament well, allowing him to work outdoors and independently. In fact he enjoyed work so much he sometimes worked two jobs at the same time.

> **BOB: He would have a job with a hay contractor at night ... he would be throwing bales of hay around till about two o'clock in the morning and then up again at five milking.**

Although alcohol would appear to have played a part in some less admirable episodes of his history, he believed, looking back, that much of his drinking behaviour at that time was social, driven by his desire to impress girls. Having a 'girlfriend' was of primary importance to him and getting or maintaining such relationships absorbed most of his energy and time.

> **BRYCE: Yes. Well, since I was 12 I started noticing girls. I have never been the same since! You know, I am the best, I am the fastest, take it or leave it - Yes. Like, from my first girlfriend at 13, I haven't been single since then. I would go out with a girl and then I would ask her out and she would say yeah, so then I would dump the other one and go out with her and -**

Quite obviously he took a very genuine pleasure in the relationships he made with all these girls, even if they were shortlived. However, it may have been because of his need to impress girls that he sometimes made what seem impulsive decisions. After two years up north, Bryce was prepared to completely rearrange his life and risk leaving his course prematurely because of a girl called Laura he had met while back down in Wimberley. Then, having made these major upheavals on such a seeming whim, he left Laura again just a few months later when he met

another girl called Stella. He became engaged to Stella within a few months. But before he had bought the ring the relationship was over. It was at the end of June, just a month before his accident, that he turned up to stay for his weekend off, only to be told that she had a new man living with her. Unfazed, he found somewhere else to stay that weekend and was soon looking around for a willing replacement. There seemed to be plenty to choose from.

Despite all these confusing upheavals in his romantic life, however, there is considerable evidence to suggest that Bryce always kept his own career in mind, thinking through some of the implications of his decisions anyway. For example, when he spoke to his father about the decision to move back to Wimberley.

> **BOB: He decided he was going to move down here, he came down to see me and he says, "Oh, I think I want to come back to Wimberley," and I said "why?" Because he still had another year to go. And he says "I can do my manager's - all my theory here. I could do it by correspondence." So I said, "well, if that is really what you want." So he got a job out by Whatapu on a farm out there-**

He settled down quickly in this new job and seemed to be enjoying himself, finding a social life similar to the one he had left up north. He managed to keep in touch with both groups of friends and frequently travelled back to catch up with people in Matamoa and Limmerton. These expeditions north sometimes occurred without much planning and the occasion of his accident was no exception. It appears that he had a sudden impulse to make the trip north and three of his friends, Mike, Jenny and Linda[101], at a loose end that day, decided to go along for the ride.

> **BOB: It was his last weekend off before calving started - and he was going up to Limmerton to see his friends up there for the last time because he would be stuck up on the farm for a couple of months while they were doing the job -**

He never did make calving and Linda would have been very late home to her baby. At two o'clock that Sunday morning, a fence post crashing through his windscreen changed his life.

FIRST DAYS AFTER THE ACCIDENT

One amazing thing about this accident, was that it was attended by the police almost immediately after it happened. This would be unusual for any accident, let alone one at such a time of night in a country location. Bryce owed his life to that truck driver he had 'bounced off' at the crossroads, because (probably in indignation over his dented and scraped truck) he had radioed the police and started their journey towards the scene before the accident had even occurred. By the time the car had settled into the fence at the bottom of the bank, the police were right there, only seconds behind them. They were able to inform the emergency services immediately that a

[101] Mike and Jenny were partners and the other girl in the car, Linda, was at that time was just a friend, not a 'girl friend'..

very severe head injury was involved and so the hospital not only sent an ambulance, but also a trained registrar with the ambulance crew.

This speedy discovery of the accident meant that it was only an hour after it occurred and still in the middle of the night, when the police were informing his father.

> **BOB: It was about three o'clock in the morning... and there was a big bang on the door and they yelled out 'Police!" ...they had rung all the Lawsons in the phone book and got my mother and asked her and she said "No I am his grandmother - "**

Bob immediately began to plan the trip north. Bryce's grandmother said she wanted to come along. Bryce's sister, who was a nursing student in another city at that time, asked Bob to wait until later on Sunday morning so that she could get a lift as far as Wimberley.

Bob rang and informed Alice of the accident early the next morning. The estrangement between this couple made it awkward for him to be telling her of a major crisis and even more difficult for Alice to accept him in this role. Rather than discuss it any further with him, she rang the Limmerton Hospital herself, only to have them confirm exactly what Bob had just said. She was alone, with no car and five hours away from a desperately ill only son. Eventually she brought herself to ring Bob back to ask for a ride and so it was that, later that Sunday, Bob, his mother, Valerie and Alice set out for Limmerton together.

When they arrived at the hospital in the early evening both parents were very shocked by Bryce's appearance. Alice found his appearance so disturbing that her mind refused to accept that this person in the bed could be her son. They both particularly mentioned the sight of his face, as well as the number of intimidating looking pieces of equipment attached to him.

> **BOB: Yes he was pretty bad. His head was right out here like a soccer ball and he was all bruised and swollen ... and he had seven drip feeds going into him and they had a bolt in the top of his head where they could release the pressure on the brain -**

The staff seemed to realise and take into account these feelings of disorientation and confusion, managing to find ways of explaining which penetrated the shock and horror and which made sense to a layman's mind.

> **BOB: Yes they had a monitor and they had it going and they didn't want it to get over 25 on this computer and sometimes it was getting up to about 50 - it was really worrying the Doctors there because the way they explained it to us if you sprain your ankle, your ankle will swell up, it can swell up but if you damage your brain and it swells up there is no room for it to expand and this is what causes a lot of the deaths. -**

Meanwhile, word about the accident was spreading fast among Bryce's friends. The three others in the car with him, only mildly injured themselves, had begun to telephone people in Wimberley. During that Sunday, even before Bob and Alice arrived, many of the friends from Bryce's Limmerton days arrived in the Intensive Care Unit waiting room. Because only two people at a

time were allowed at his bedside, this meant it was necessary to share out the time they were allotted by the medical staff to sit with him.

In contrast to the Johnsons, Whites and Kavanaghs, this family could not return home between their bedside visits. They haunted the waiting room and the grounds of the hospital. Although this dislocation could be expected to have caused some stress, it seemed that it also allowed them to feel a useful sense of belonging and a familiarity and ease with the others working in, or visiting the unit.

> **BOB: You stay there for about an hour and then you go out and let someone else in. They had some chairs straight outside the door of the waiting room - in the corridor where you could wait until you were allowed to go in - and then further down the hall they had another room with armchairs and TV and all that there -**

Bob, his mother and Valerie were in a difficult situation at the end of this first day with Bryce however. The weekend was now over and they had work commitments back home. They had travelled all this way to 'be there' for Bryce, but now that they had a clearer picture of the situation they realised that this was not something which would be resolved quickly. Although it was still possible that he would die, it was just as likely that he would go on for months in this limbo of unconsciousness. They could sit there taking turns to see him for months with little change. Because he was in a drug induced coma they knew that there was no possibility of him waking up and needing them. Although they understood and accepted the reasons for inducing a coma, it still stripped the family of any small control, any slight opportunity that there might be to contribute something meaningful. The value of a relationship is in its 'two-wayness' and this is negligible when one party to it is unconscious. Eventually, after talking it over with the medical team and with each other they decided to return home.

> **BOB: Well it was really work related - but in the early days he was kept in the coma - they call it a drug induced coma, because of the pressure on the brain - they said that they just couldn't have him awake and wriggling around - and we were told that after that sort of trauma if he woke up, he still wouldn't know anybody. You couldn't talk to him and you had to wait for this amnesia to wear off - Not that they were saying "Go away" but they were making it clear that this is not something the family can do anything about at the moment - they said "You are welcome to stay if you like, but, if you have got other commitments - "**

Bob found other practical ways to help Bryce while he waited for the dawning of consciousness. He became aware during that first visit, that some of Bryce's less honest acquaintances were using the uncertain situation for their own gain, claiming he owed them money, or that he had borrowed some possession they wished to reclaim. Bob was outraged that anyone should attempt to take advantage of someone so vulnerable and assumed a role as a financial guardian, arranging a temporary power of attorney with the bank. As Bob talked of these arrangements it was clear that he still felt a sense of satisfaction with his actions. He believed that by acting

promptly he safeguarded his son's interests and assured him of financial security when he recovered enough to need it.

Alice had no other commitments back in Wimberley at the time which could not be reorganised. She had no practical arrangements that she could make for Bryce, all she could offer was her presence beside him. She decided to stay on when the others left. She would not have felt any more 'alone', upon their departure, as she and Bob had remained distant with each other despite the crisis. She had made contact with the local Mormon church and members of the congregation arrived to pray for Bryce with her. She settled down, ready to remain beside her son for as long as he needed. She began that week alone confident that she could manage to do this indefinitely, yet by the end of the week, the stress of her situation overwhelmed her. In a fragile emotional state, she too returned to Wimberley.

> **ALICE: It was getting too much for me - I was there a whole week and there was no change. I would go up there and I would talk to him. And the pressure on his brain was going up and down up and down and one night it got really high. It was nearly in the danger part where he might not live and I just sat by his bed and I said to Bryce, "Don't do this to me, don't you dare do this to me" and I sat by the bed, telling him I was sorry for all the things I had done to him, you know.**

Although her son's precarious medical condition must have been the most stressful factor, there was another problem which also made Alice's continued presence in Limmerton extremely difficult. Bryce's most recent girlfriend Stella, the one he had broken up with only a month previously, had been rung and informed of the accident by a friend early on Sunday morning. She travelled up to Limmerton immediately and arrived at the hospital before the family and announced to the hospital staff that she was his fiancee. The staff had no reason to doubt her and so treated her as having the same if not greater rights than the parents or his other friends. This did not seem of great importance during the first day or so. The large group of family and friends introduced themselves to each other and got along reasonably well. But when Alice stayed on in the nurses' hostel after the departure of the rest of the family, the situation became more distressing for her. Alice found herself in the awkward position of having to fight over her son as if he were a possession.

> **ALICE: I would be at his bedside every day. His girlfriend would be there too so I never really got a chance to be with him by myself. I had to speak to her because it was like she took charge, she said who could go in there and who couldn't go in there. And I spoke to her about it and she said did I mind her going to visit him and I said "Yes I do" and it is because I feel I need this time with my son. - I have more right to be here than you do - She got to the stage where she was going around saying that she was pregnant and Bryce was the father.**

The nursing staff deserve considerable credit for managing such an unusual situation so well. Although Alice obviously found it very distressing, she continued to feel that the staff were treating her well.

ALICE: Well they believed that she was his fiancee. In the end I spoke to the Doctor and I said "Well she has been going around saying that she is his fiancee but," I said, "we have not heard it from Bryce himself."

The role 'fiancee' is a difficult one for the medical team. There are no clear legal rights or responsibilities to match it. The staff could not regard this woman as a next of kin when Bryce's parents did not acknowledge her. However, it is a word with a clear expectation or promise within it that she is 'about to become' the next of kin and, with this definition, she was obviously owed some level of support and information, similar to his family. The staff could not be expected to understand Bryce's unusually casual attitude toward becoming engaged, of course; even his parents found it hard to classify his relationships with the women in his life at this time. Indeed, Alice's feelings of resentment and anger toward Stella were tempered with an uncertainty about how Bryce would have ranked their relative importance in his life.

ALICE: And apparently he went over to Porterton before the accident to buy her an engagement ring. And he came back without it. And if he had gone over there to buy an engagement ring and he had just got engaged, he wouldn't have taken off to Limmerton with a whole lot of strange girls!

As well as dealing with this need to assert her rights for her son Alice found it very difficult to deal with the very unstable medical situation. Looking back, she believed at this point that she was really just waiting for him to die, yet day succeeded day without any change. She began to feel that there was no point in waiting; that this could continue without any sort of resolution or ending point for a very long time. By the end of the week she had returned to Wimberley with the understanding, like Bob, that the hospital would keep in touch and that she would return regularly for weekends.

After she left, Bryce continued to slowly improve and become more stable. When his father visited him a week later, there was still no certainty of survival, but the staff were beginning to talk to them about possible future scenarios. They still made it clear that there was a strong possibility that he would never become properly conscious again and, if he did, that it was likely there would be marked personality changes. The family had the opportunity to absorb these ideas slowly over the weeks, talking them over with other friends and family back in Wimberley. Despite the lack of real medical change, there was therefore an easing of tension in both the parents' households and some return to normal rhythms and work. Each time his parents visited it was a little easier, each time there was some visible sign of improvement. At the end of July, when he was moved from the Intensive Care Unit, it became clear that the hospital no longer regarded him as critically ill. His physical appearance also started to improve as the bruising diminished and the large gash across his face, still stitched together, had time to heal and fade. This, the improving physical condition, caused an interpretive 'shifting' or redefinition of his state.

No longer were they dealing with the life and death drama situation, now the issues turned to recovery and rehabilitation, the realistic appraisal of his probable future.

This loss of a sense of urgency and crisis made it easier in one sense for his family and friends. They no longer lived with the constant fear of death. Yet perhaps for the same reason it also made it harder. It was less romantic. The reality of having a son with a brain injury was not glamorous, it was a cheapening and lowering of the person's identity rather than a heightening of the drama of his life. As they turned their attention more toward his level of consciousness, the talk of the medical team and the thoughts of the family turned toward his probable future, towards the limits of his possible recovery:

> **ALICE: I was thinking of him being a vegetable. Because nobody knew how he was going to be. Whether he was going to get any better than what he was. The hospital couldn't give us any sort of idea of whether he was going to be just like that till the end of his life.**
>
> **BOB: They said to us in Limmerton if he does survive intensive care, he would not come back with the personality that he had and he would either come back with a better personality or a worse one - you just won't know and time will tell. They said he could come back as a vegetable and having to be institutionalised for the rest of his life. And I said "Well, what is the chance of him coming back and being able to work full time again?" And they said, "it is very very slim."**

In a physical sense anyway, it was soon clear he was not to remain in a vegetative state. As his level of consciousness gradually rose, he also began to move about, but not yet in any intentional or purposeful way as would suggest any real awareness or control of his body.

> **ALICE: I went up there three weeks after his accident and he was out of the coma, out of intensive care and in a ward. He wasn't talking but his legs were waving - they were going all over the place. And he had a padded sides on his bed so that he couldn't hurt himself. And he was on a drip, drip feeding and he had antibiotics going into him. It was hard. You would talk to him but you didn't know if he was really hearing you. I just kept talking to him, kept telling him how much I loved him. But he wasn't saying anything and he didn't seem to be fixing his eyes on anything.**

Like Juliet White's experience with her son Mark[102], Alice particularly remembered the moment when Bryce first smiled. It seemed to signal to her that he was again capable of engaging in a relationship - however minimal and lopsided - with her. It roused her maternal instincts and she tried to extend and build upon this moment.

> **ALICE: One Sunday night when I came back alone, he actually smiled. And then he was still smiling there and I took photos up of him when he was younger. Of his baby and of him and his grandfather and I and put them above his bed.**

Having established through this experience that he was in some sense now 'conscious', his mother began to see his actions as purposeful, as being attempts to signal his feelings. She began to impute motives, infer meanings from his reaction to different people and, in doing so, she reached

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[102] See Chapter 6, p.172.

the conclusion that a stillness or peacefulness signalled a liking or pleasure response, whereas agitation signalled dislike.

> **ALICE: But, whenever Laura his other girlfriend, or Stella went into the room he would go haywire - His legs would go to town. Like he knew they were there and he didn't want them there. That was his reaction to them.**
> **DS: And he was calm with you?**
> **ALICE: He wasn't reacting to me anywhere near as bad as that. I had been holding his hand and he would be okay. I would talk to him and his hand would come up over my shoulder and he would be pulling my ears and stuff like this.**

It was by now the middle of August. A month had passed since the accident and it was clear that Bryce would live on despite his brain injury. With the end of this crisis period, the hospital staff began to consider the best place for Bryce to be during the more protracted period of his recovery and rehabilitation. It was clear that his home was Wimberley and that that was where most of his family support was based. After talking it over with the family, it was decided that he should be transferred there. Bryce was flown to Wimberley Hospital on the 15th of August 1994.

WIMBERLEY HOSPITAL

Bryce had no memory of any of the time he spent at Limmerton Hospital. Over a period of the three months, He drifted gradually from a deep unconsciousness to a state of post traumatic amnesia (PTA)[103]. He was still emerging from this gradual 'waking up' process at the time he was flown to Wimberley hospital and although he might have seemed more 'awake' than during the coma stage, he was no more able to process the myriad of new and unfamiliar impressions that the new hospital setting must have been presenting him with.

This confusion started to clear during September, firstly, with the older memories from before his accident.

> **BOB: Yes because he started to recognise people and then his long term memory started coming back ... what was really interesting was how the brain had to reprogramme itself and the occupational therapist went through it with us... yes he went right through his memories up to the present day -**

Once he had been through this process of recalling something of his past, he was able to build some firmer ideas about who he was. Thus armed, he began to assert himself expressing opinions and beliefs. Although many of these were irrational and showed a failure to think coherently, they suggested he was beginning to act upon an the basis of interpretations again and the seemingly random reactions of post traumatic amnesia began to disappear.

This growth of self-awareness and coherence appeared to develop around an inner ontological "core" (Denzin, 1986:14) just as Heidegger (1967), Denzin (1986) and the other theorists who

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[103] See Chapter 1, p. 20.

inform the theoretical framework of this thesis[104] would have predicted. As can be seen in the following excerpt, however, it provided only a very fragile sense of order. The level of interpretation and understanding which satisfied him suggests he was still in a very vague and disoriented limbo.

> **DS: Well how did you explain to yourself what you were doing lying in that hospital?**
> **BRYCE: I didn't - I just thought I was there because Dad put me there or one of the nurses put me there.**
> **DS: You knew you were a patient?**
> **BRYCE: Yes. But I didn't know why I was there. I have only been in hospital three times.**

However emergent it was, this ability to explain, or make sense of events, appeared to allow him to remember more of his daily experiences. It was still erratic but he began to make sense of what was going on around him. At this point of his story therefore, Bryce began to be able to contribute some memories, their vague nature illustrating more clearly than any description, the unorganised and unreflective way he was absorbing his environment.

> **BRYCE: There was nothing to be worried about - they were feeding me and looking after me.**
> **DS: Not interested?**
> **BRYCE: No.**

As time passed, the awareness of who and where he was, shifted to a sense of who and where he would like to be. In this way he recovered the beginnings of a sense of purposefulness, still perhaps vague and almost instinctive rather than reasoned, but nevertheless sufficient to motivate him to assist in his own recovery process.

> **BRYCE: ... I used to be in a wheel chair and then they put me in a walker and I was right over the other side of the room and I just had to go, so I crawled to the toilet - stupid yes I know but I did it. And then I made up my mind I was going to walk back to my bed. - and I just walked back to my bed. I was real proud.**

As he regained his awareness, Bryce started to recognise and enjoy the familiar. His family and friends' visits became a source of pleasure and he began to enjoy outings with them. He began to seek out activities he wanted and to reject those he disliked.

> **ALICE: When he first started talking out loud all he wanted was, "how can I get out of this place?". A friend and I went up one day and took him for a walk in his wheel chair and he was rambling on a lot - swearing a lot. We took him over to the shop and got him some chippies and stuff like that - he enjoyed that -**

Slowly his awareness level improved. Although he was still often "rambling and swearing" and very irrational and impulsive, there were more and more moments where he seemed to approach a level of interactive competence where he could feel empathy. His mother remembered one such moment with nostalgia.

> **ALICE : He sort of got to the stage where he could understand what you were saying because I was speaking to him about his sister - and I said, "do you understand?" and he raised his eyebrows. And I didn't know whether I was actually seeing it or not. I couldn't believe that he did it -**

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[104] See Chapter 2, where the theoretical framework is described in detail.

The great advantage of Wimberley hospital for Bryce at this stage was its closeness and accessibility for his friends and family. His father was able to call in to see him each night and so became much more closely involved in the day-to-day care as his recovery progressed. He noticed the gradual change in the style of the intervention from nursing care to more interactive therapeutic endeavours.

> **BOB: and as he got better, the nursing role went down and the occupational therapist and the physiotherapist role increased and when they started with Bryce he was still in his bed and they had to roll him over and put the pillows behind him every two hours and then roll him back. Within a week, they had him up, sitting up then they would get him off the bed - they would tip the bed up so that he had to stand up - get his balance. And the OT was helping with the physical side -**

Closeness to home did not prove to be quite such an advantage in his relationship with his mother, however. For Alice the access was, at first, not really much improved and later, for a number of reasons, it was definitely worse. She had no car and the hospital was at the other side of the city from her house. In Limmerton, she had been able to live near the hospital. To visit Bryce in Wimberley, she needed to walk a distance of two miles, or take a bus that she could not really afford, without any certainty that he would be in a receptive state for a visit. This situation meant that she visited less frequently than she would like.

The second problem Alice had to face at this time was Bryce's attitude toward her. While he had been in a coma she had sat beside him waiting and praying for a return to consciousness. As it returned, however, Bryce was often either oblivious of her or uninterested in her and even sometimes extremely negative towards her. It seemed that his friends were more important to him than she was and, after the weeks of tension and fear, it was difficult for her to accept that the love she had given him was not to be acknowledged or reciprocated. She began to set out on those long walks to see him in trepidation, feeling like an unwanted intruder at that stage in his recovery.

> **ALICE:...and if his friends were there or a visitor by him, he would just push me away ... he got to the stage where he would just push me away.**

The time she spent alone with him began to assume a degree of importance in her life which left her very vulnerable to being hurt. This created a regrettable tension in the atmosphere around Bryce. It seems that one unfortunate incident, recounted by Bob, occurred as a direct result of this tension.

> **BOB: His friends had taken him into town and it was lunch time and so they said "Oh we'll shout you some lunch in a coffee bar" and they got back to the hospital about one o'clock and his mother had gone to the hospital to see him and he had gone. Nobody knew she was coming, she just turned up and she just tore strips off everybody right in front of Bryce there. The end result was that he didn't say anything, he just clammed right up and nobody could get him out of his bed for a week - he just used the bed like a security blanket.**

In her distress, Alice was unable to deal logically with the reality of a lessened consciousness. Bryce was not yet conscious enough to develop an 'awareness of the other' and made no coherent or consistent attempts to reciprocate the feelings of love and caring she felt for him. Yet, in the early days after the accident, she had been thrust abruptly back into a mothering role which she understood and felt comfortable with and now, just as abruptly, Bryce seemed to want to discard her again. She responded in ways which compounded this problem, making Bryce and the hospital a little wary of her. This situation was obviously not good for Bryce at this stage of his recovery, yet it was just as bad for Alice, who felt she was being shut out by him. She gradually lost confidence in herself and stopped believing that she had anything to offer Bryce.

> **ALICE: Yes. I had done something wrong one day when I went out there and I don't know what it was - he wouldn't tell me what it was. I still don't know what it was. I got all confused about myself in the end.**

This problem of Alice's is not unique. After a head injury, the rebuilding of an effective relationship with a family member seems to be extraordinarily difficult[105]. The difficulties lay not only with Bryce's lessened interpersonal and affective abilities, but also in the response of the family members to emotional crisis. As Roueche and Fordyce (1983:4) point out:

> **Family members and friends may distort perceptions of the brain injured person's situation as a result of their own catastrophic response and accompanying denial as they hope for a recovery.**

The inevitable result of course, was that Bob, Alice, Bryce, his significant friends and the medical team were all developing different versions of the situation Bryce was in. There is no doubt that this would have had an impact upon Bryce's rehabilitation process but this is hard to quantify from a distance. As Gans (1983) points out, the family members at this stage of the recovery will often feel insecure and powerless and have unresolved feelings of anger towards the person because of their role in causing the accident. In the initial crisis, it was not appropriate to direct messages of anger and blame towards the person, yet as Bryce recovered and showed signs of being cold and unfeeling and ungrateful about the hours spent by their bedside, Alice, like the family members Gans (1983) observed, felt some confusion about her own feelings and commitment. She was fortunate that a social worker became involved with her at this point and helped her work through some of these issues. Even so, it is clear that she was becoming increasingly left out of the information and decision-making network surrounding him.

> **ALICE: No. As he got to the stage where he could talk - I wasn't there when he spoke and I was the last person to know. Nobody let me know. I had to find out for myself. I wouldn't know anything unless I went up there and asked. And that really hurt.**

In this family, it was Bob who managed to find the best fit between his interpretation of what was happening and the prevailing interpretive scheme presented by the hospital. As time passed, Bob

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[105] See Chapter 1, p. 33.

began to be seen by the hospital staff as the parent who should be consulted. He also began to be seen as the parent with the key role in making decisions and plans about the future.

> **BOB: We used to have a meeting there each week where the Doctor, social worker, nursing, occupational therapist, physiotherapists, have a meeting and see how he is getting on and -**

Bob took on this role happily, assuming an authority over Bryce and a right to make decisions upon his behalf which he never had during his childhood. He seemed to see this as a 'second chance' at parenthood, but a chance this time to manage it without the interference of the custody issue. Probably this role as the next of kin happened without any conscious intention on anyone's part. It had begun back in Limmerton soon after the accident. It would have been perpetuated by his more constant presence and availability at Wimberley. However, while Alice was prepared to leave the early dealings with property to Bob, when she later felt neglected, she began to resent Bob's assumption of control.

By the time the discussion about discharge and placement began it was clear to everyone that Bryce's remaining problems were not medical, but cognitive and behavioural. Everyone could see that a hospital ward was not the ideal environment for a physically active but disoriented and confused 19 year old. He was walking and talking and medically fit, yet he still had very little understanding of what had happened to him and virtually no ability to act logically and keep himself safe. The medical team and his father agreed that Bryce would need an intermediate step between hospital discharge and a return to normal life. Waimarie was suggested as an option and Bob agreed to visit and consider it. Several of the medical team accompanied him on this visit and they had the opportunity to look around and talk to staff, going away again to make the final decision to apply for a place.

THREE WEEKS AT HOME

Despite there being a clear agreement that Bryce needed an intermediate step between hospital and home, the hospital discharged him almost immediately after this visit to Waimarie - three weeks before a bed could be made available to him there. Although the arrangement was temporary and the family were always aware of this, Bob remembered the three weeks Bryce spent at his house as an exhausting and stressful time, saying that he was "totally burnt out" by the time Bryce was admitted to Waimarie. Although the hospital regarded him as recovered in a physical sense, it was clear he had a long way to go in recovering from the other effects of his head injury:

> **BOB: Yes. He was like a baby with tantrums all the time at this stage.**
> **DS: How about his judgement, his information processing, was that coming right?**
> **BOB: No not good. Virtually nonexistent..**
> **DS: Memory?**

BOB: Long-term memory was good. Well it was coming right I should say. Short-term memory was hopeless. He really didn't remember what he was doing from moment to moment.

ACC did provide attendant care support for four hours each day, a nurse named Donna. But she did not arrive until nine o'clock.

BOB: I Got him up - sometimes I would have a bit of luck with giving him a bath - give him his breakfast and put him in the bath and if he was cooperative -
DS: So this is when he could be quite hostile?
BOB: Yes sometimes you would run his bath around eight in the morning and it would be 11 o'clock before you could get him into it! A real up hill battle.

One young woman alone in a house with Bryce was a situation which could have put both of them equally at risk. He was still not cognitively capable of being reasonable; his behaviour would have been as unpredictable and ill-considered as a very small toddler's. This home placement turned out to be a relatively positive and successful time, however, thanks more to nature than to planning. Unlike a toddler, Bryce was by now physically again a 19 year old young man. Being a 19 year old man, he had a very natural interest in this attractive young woman who had been employed to be his carer. The situation delighted him. In response he was not only willing but eager to work with her and cooperate with her plans and demands.

Donna often took him out alone in the car so giving Bob a chance for some time out, at the same time as she attempted some initial cognitive rehabilitation:

BOB: And she would come in and help and she would actually take him out in the car - take him to the park and that and go for a walk through it and she would pick out things like flowers and leaves and you know "what is this from?" and "what is this?" and that sort of thing ... and that was a big, major help. Without her I don't know what I would have done.

It is clear that Bob and Bryce were lucky with the quality of the attendant carer employed. She appears to have had some knowledge of head injury and a preparedness to go further than her job description would have demanded. Rather than being his 'caretaker' or 'keeper' in just the practical ways expected of her she was creatively addressing the needs she could see he had. With her help, Bryce learnt to identify common household items and understand his environment again. The home placement was, therefore, a successful and constructive time but this relied upon such serendipitous factors as Bob's flexible working hours and Donna's personal qualities. As a review of the literature showed[106], cognitive disorders which affect interpersonal skills place families under extreme stress and alienate employed carers. Without intending any disparagement of the carer or the family therefore, it seemed clear that without the admission to Waimarie this arrangement would eventually have collapsed.

On the 8th of November, 1994, Bryce was admitted to Waimarie. He told me the story of his arrival there with indignation.

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[106] See Chapter 1, p. 32.

BRYCE: I didn't know I was going until I was told to get in the car. And then when we got there, I said "What is this place?" And Dad says "This is your home," and I said, "No it's not - I haven't got a home." And he said "Well now it's going to be your home" and I said "Oh no it's not!"

Although he was not included in the discussions about his future at that stage, this exclusion was not motivated by a need to deceive him. It is simply that at this stage of his recovery he was incapable of looking ahead or planning. He lived moment by moment in a perpetual present, reacting to events and situations only when they were presented to him. For example, it was characteristic of him not to have been at all concerned about why he was making this journey. He was not yet able to suspect or draw logical inferences from his experience in order to predict. To have invited him to consider his future in an abstract way, or to make choices from alternatives, would have been only to give an illusion of empowerment or control. Although he reacted with horror when he discovered that he was expected to stay, until his arrival at Waimarie, he was not capable of considering the proposition. Unfortunately, however, this introduction to Waimarie coloured his initial attitude towards both the staff and the rehabilitation programme. Still at the time of the research, he regarded Waimarie as a place he had been 'put' rather than a place that he chose to live.

THE 'AFTER' BRYCE

At this stage of Bryce's story, a more general description of the person who was emerging from the "pivotal event" (Denzin 1989:197) of a traumatic brain injury is offered. In the early days after the accident any such description was impossible. There was no fixed quality to his existence because he was recovering consciousness too rapidly and no one could have predicted how he would behave or respond in any particular situation. Under such circumstances he could not really have been said to have had a 'personality' or 'identity' at all. However, by the time he reached Waimarie he was beginning to develop characteristic ways of behaving; ways which were different in many respects, from those of the pre-accident person. In effect, a 'before' and 'after' Bryce emerged in others' conversations and thoughts about him which began to influence their understandings about who he 'was' or at least, 'was becoming'.

Much of the energy of the staff and family over the time of the study was spent in trying to define this 'after' Bryce. Although his constantly changing awareness meant continual revision was necessary, unless everyone concerned had some agreement about who he was becoming, it was not possible for them to support him effectively.

PERCEPTION

When the fence post struck Bryce in the face, it thrust his brain forcefully against the back of the skull. In consequence, there was severe injury to the back of his brain housing the occipital and the parietal lobes. Luria (1987:27) suggests that these areas act together as a 'block' of sensory perception and interpretation.

When Bryce's brain lost accurate visual perception, the initial effect upon his consciousness must have been profound. It is impossible to interact with a world that there is no way to identify or make sense of. Zasetsky, Luria's subject in "Man with a Shattered World" (Luria, 1987:10) experienced a similar problem and wrote about the experience vividly:

> **Right after I was wounded, I seemed to be some newborn creature that just looked, listened, observed, repeated, but still had no mind of its own. That is what I was like in the beginning. Afterwards, when I'd had a chance to hear words that people use again and again in conversation or thinking, various clusters of "memory fragments" developed and from these I began to make some sense out of the life around me and remember what words meant.**

Bryce remembered being confused by even the most familiar objects, earlier in his recovery:

> **BRYCE: Simple things like tables and chairs came back to me first but other things sometimes I didn't know what to call them. I knew a heater was to heat up a house, but I didn't know what to call it. .."**

During the time he spent in Wimberley Hospital and after his discharge home, he felt a constant, frustrating blankness when confronted by something he knew that he should have been able to recognise. Like Zasetsky, however, provided he was given the time to 'think through' his blankness and sometimes after clues or prompting, he found that these "clusters of memory fragments" brought together his memories and his present experience and reconnected them.

Over the time since his accident this experience was repeated continuously until much of his every day world has become re-identified and reconnected with his memories and ideas. This experience of not recognising some common object was still occurring at the time of the study, but far less frequently. When he encountered something initially strange he was learning to pause and consider. He seemed to have come to terms with it and accepted a certain 'slowness' to his manner of experiencing his world as a result, saying "...sometimes now it will still take me about ten to fifteen minutes to work out what things are." Although he still failed to recognise the function of some less familiar objects, the difficulty was often just in finding its name. When someone reminded him he was likely to be mildly amused, perhaps berating himself for his own stupidity and then carrying on blandly as if nothing unusual has occurred.

Visual Interpretation

As well as not recognising objects, Bryce also had difficulty with 'seeing' spatial relationships. It was difficult for him to make judgements and estimates about size, distance and interrelationships between objects and this made his movements rather wary and cautious. Nothing about his environment could be taken for granted or assumed. This had an understandable impact upon his interactions with others. With less perceptual skill Bryce was less able to understand interpersonal situations. As Luria (1987:30) comments:

> **After all we do not simply perceive isolated objects but entire situations; we also note the complex relationships and correspondences between objects, their location in space. ... The ability to grasp situations, or gauge spatial relationships, involves something far more complex than the perception of figures or objects.**

Symbolic interactionism theory is based upon the premise that communication is the interaction of symbols in the negotiation of shared definitions. This can only occur when there is a reasonable agreement as to the nature of the immediate physical surroundings and this understanding must be sufficiently tempered or mediated by a learnt cultural understandings of how to interpret surroundings. Over the time of the study there were several occasions at Waimarie where Bryce had difficulty interpreting the meaning and nature of his personal relationships and it is very possible that this visual disorder was implicated.

Visual Perception and Memories

Bryce's visual perception improved rapidly over the time of the study. As he became more able to 'see' accurately, (or perhaps, as he became more accustomed to his altered perception) his difficulties were caused more by this secondary concern, his interpretation of his visual perception. Slightly different interpretations, it seemed, prevented him making essential links between new perceptions and stored memories. He would see a face which should have been familiar without knowing who it was, he would see a once familiar possession, or a landmark, without remembering its particular significance to his past life.

During the time of the study, particular change occurred in this area and it became possible to observe and explore something of the process of 'relinking' as it occurred in Bryce's case. A visit home to Wimberley for the Christmas break caused a sudden confrontation with a range of people and places with strong past associations. For example, he saw Laura[107] again for the first time since leaving Wimberley Hospital. He knew that a person called Laura was an ex-girlfriend, that he had been engaged to her for six months and he remembered many details about this relationship but he did not at first recognise her. He needed to be convinced that this was indeed

[107] Laura was an ex-fiancee (see p. 247).

the Laura of his memories and to reintegrate the two diverse images in his mind. Once this had been accomplished, however, memories of the time they had been together suddenly returned to him apparently prompted by her presence. Several other people had a similar affect upon his memory and the more he re-viewed objects and people from his past the more associations he became able to make, so tapping a rich store of reasonably accurate, episodic memories. For Bryce, these recovered memories were immensely valued and mulled over and, in consequence, the person concerned assumed a great importance in his 'after Bryce' life. Staff at Waimarie soon became used to hearing again and again not only the recovered memories but also and seemingly equally important, the stories of how these memories returned.

The use of visual prompts was also useful to fill the gaps left by the period of coma. Bryce initially denied that he had had an accident at all, because he could not remember it and so could not 'fit it in' to his own story. His mother had taken photos of him during his days of coma and when she showed them to him later during the three weeks he was at home with an attendant carer, she began a process of acceptance which he was still struggling to come to terms with on his arrival at Waimarie.

> **ALICE: ...and I said, "I can show you a photo of it taken two weeks after his accident." And Bryce says, "Can I see?" and I said, "If you want to have a look you can have a look." And he said, "I want to see what I looked like" and he had a look and he said "Oh Shit, I was bad wasn't I?" And I said, "Yes Bryce you were - you nearly died."**

A photograph is a concrete piece of evidence. Bryce could look at himself and, perhaps for the first time could imagine what it was like for those who saw him and what was occurring in their minds. When he said "Oh shit! I was bad wasn't I?" it suggested that he was able to 'take the attitude of the other' (Mead 1934) sufficiently to feel the anxiety and drama of the moment and in feeling this, imagine how it felt for those who were there.

Another advantage that a photograph had over words was its unchanging quality. Bryce could look at the photo for as long as he liked and it would still give him the same message. His perceiving and interpreting skills may have been becoming more accurate, but he continued to require more time to process the information he was receiving. With a slower processing ability, the solidness of a photographic image offered him the opportunity to perceive and interpret and reflect at his own pace - something which most interpersonal situations often lack, being influenced by a variety of distractions and other messages.

The confrontation with this photo no doubt caused some degree of acceptance but, after this, Bryce still often denied that he had been in an accident. The process of linking together image and memory continued steadily day by day up until Christmas. Gradually he pieced together returning

episodic memories and fitted people, places and events together into a sequential and logical narrative. By Christmas, he knew who he was again.

> **BRYCE: Well, up until Christmas time, when I went home, I didn't realise that I had crashed my car. It wasn't until I saw it in Dad's orchard and it was all smashed up and I said "Whose is that bomb?" And he goes, "It's yours".**
> **DS: How did you feel?**
> **BRYCE: Angry - and upset.**
> **DS: About having had the accident?**
> **BRYCE: Yes and about my car. Writing off my car. It almost wrote me off.**

Goldstein (1952:258) suggests "the patient must be able to regard the present situation in such a way that facts from the past belong to it." When Bryce saw that car in the familiar environment it prompted the return of facts from the past and allowed him to incorporate the reality of his injury.

This same visual prompting strategy appeared to assist the process of making sense of his experience since the accident. He could not remember the time he spent in Wimberley hospital, for example, until he visited there again.

> **BRYCE: The only reason I remember [Wimberley Hospital] is because at Christmas, Dad and I were up there and I saw all the nurses and Doctors and everything. When I saw them I didn't recognise them .... then I walked in and one of the nurses walked in and said "Can we help you" and Dad said, "Yes. This guy wants to talk to you." And I said, "What do I want to say?" And he goes, "Oh, this is Bryce by the way" and she said "You are different from when you were here last time, you used to lie down all the time then!" And I said, "give me a bed I will lie down again if you like!" And yes, I could even show Dad the bed I was in and everything!**

As Bryce put it, "It knocked my memory back into shape when I went back at Christmas" and once retrieved in this way, he became able to re-store (and so restore) these memories. They returned to him upon command and were no longer situation dependent. Presumably as a result of this reintegration process, the staff noticed a marked change in his attitude to the rehabilitation programme and also in his orientation to time, place and person. Until then, he was seen as reluctant and negative about everyone and everything around him, resentful of being placed in Waimarie and grudgingly 'going along' with activities only when he could not avoid them. After these experiences in Wimberley he returned to Waimarie with a clear understanding of what had happened to him and so a clear self-defined understanding of his own needs. It was as if the return of the memories had allowed him to reorganise his understandings about self in such a way that the concept of rehabilitation suddenly made sense. No longer was his rehabilitation something devised and directed by some faceless other; he had come to see the importance of recovering cognitive and interpersonal skills for himself. He was now much more self-directed and his level of concentration and ability to overcome difficulties by persevering improved remarkably rapidly from this time.

A changed visual perception then, was responsible for much that was different about Bryce's consciousness. Strategies such as photos and reconfronting the past, which attempted to support his ability to 're-picture' his life, appeared to be very powerful and motivating for him. There are very few absolutes in any discussion of brain damage however. Nor are there discrete categories of deficit and one step solutions to recovery from them.

LEVELS OF CONSCIOUSNESS

The remarkable thing about Bryce's perception and interpretation problems was that they tended to occur when he was 'trying' or 'concentrating' and when he was conscious of being observed. Often when he was left to carry out some task independently the prospect of failure did not occur to him and he experienced no difficulty. It was his conscious and self-conscious awareness rather than his unconscious level of experience which was the most disturbed. Particularly when he was engaged in something familiar, he seemed able to tap procedural knowledge without any intentional level of conscious processing, or "reawaken past impressions" as Goldstein (1952:258) would say. At such times words or knowledge he needed came easily to his mind. This preference for less conscious "circumspect" (Heidegger, 1967:66) modes caused a range of intriguing differences in the way Bryce dealt with lived experience. As he tried to read and write, he provided a useful example of how a loss of integration of conscious and unconscious modes affected his ability.

Reading

Bryce had great difficulty reading since his accident yet he had no awareness of this difficulty. He still believed he saw words, yet the words he reported seeing were different to those anyone else saw. He read 'gate' for 'frog', for example, and 'pink' for 'park'. This disability did not transfer into his writing skills. If requested, he could write words very adequately and without hesitation.

This problem appeared to be a difficulty with visual perception which was compounded by loss of ability to seek coherence and order in his own performance. Without monitoring what he was reading to ensure it made sense, he was unable to register his errors. He would read out a sentence which to others sounded bizarre without seeming at all concerned. The only way he could overcome this loss of a critical attitude was to accept he could not trust his own judgement. At first when others challenged him he would insist he was correct. Gradually, he learnt to accept that no matter how sure he felt he was sometimes wrong. Whether dealing with written text, spatial relationships, or interpersonal situations, increasingly he accepted that he made errors of perception and interpretation. Over time this allowed him to learn to adapt his behaviour. He

came to acknowledge a need to increase his level of concentration when he could not make sense of a sentence and also to ask for assistance.

After several months at Waimarie his reading improved to a level where it was difficult rather than impossible. Provided the words were boldly printed and provided he was prompted, he managed to read and understand even complex sentences. The recovery process appeared to be occurring because guided rehearsal of reading skills allowed him to learn to look for patterns or coherence in what he read and so self-correct more efficiently again.

Consciousness and Sequential Thinking Styles

Bryce's inability to perceive patterns was not confined just to skills such as reading. It pervaded his thinking style. He sometimes seemed determined to lose his fellow conversationalists in a bewildering sequence of apparent nonsequiturs. For example, he was talking to me at one moment about seeing his wrecked car then became distracted by confused thoughts about the missing contents of the car.

> **BRYCE: When I saw the car, I felt real angry. There was only two things I can actually, besides the parts of the car, there was only two things in the car that I can actually remember. That was a pair of my friend's daughter's shoes and a pair of gumboots. When I was in the hospital I used to wear gumboots all the time cos I had ugly shoes. I have still got them - I told Dad he could come and pick them up because I was going to wear gumboots now -**

In this excerpt, as on many other occasions, he spoke without any ordering of his thoughts and without relating his talk to a central theme. As a result, the beginning point, (his feelings about his car accident), was lost when he became distracted by thoughts of gumboots. This lead the conversation into the relative merits of gumboots and shoes. It can be hard to maintain a sense of order and direction to such conversations and, as a result, his fellow interactants sometimes became cast in the role of helpless reactors rather than equal participators.

Luria's (1987:113) comments concerning the lost "law of strength" and Gross's (1987:99-113) remarks about a competitive as opposed to an integrative style of thought[108], both offer some explanation of why Bryce could only relate to people and situations in this fragmented fashion. Without a mental 'focus of interest' he could only recount what he thought in a sequential fashion and subsequently sometimes seemed less coherent then he was. When the focus of attention shifted to gumboots, the preceding topic, the wrecked car, became unavailable to his mind. As Gross (1987:101) would say, Bryce was unable to "distinguish the figure from the ground". Much of Bryce's experience was only available in this reactive and disconnected way. Because he could not organise his experience into categories he could not reflect upon it in terms of abstract

[108] See Chapter 1, p. 41.

themes and so, as both Gross (1987) and Goldstein (1952) observed, he became confined to concrete definitions of even the more abstract qualities of his experience.

Obviously, this change in thinking style, had a considerable influence upon the way Bryce considered his own life. In the following excerpt he responded to a question asking him what his future goals were without appearing to consider that his needs might have been changed at all by the brain injury and in describing his goals, he was restricted to very concrete specific 'visions' rather than talking of more general directions:

> **BRYCE: Well, that is still the same as it has been since I was about 10. I want to get a job, get another car because I crashed my other one and get a girlfriend and get custody of my son. I have never had custody of him, but, I don't know, it can't be bad I suppose.**

It soon became clear to those working with him that it was necessary to adapt any discussion of his recovery and of the future sufficiently so that he could grasp very concrete and immediate symbols to guide his ideas.

Consciousness and Temporality

Perhaps as a consequence of this sequential processing style Bryce lacked the ability to mark the passing of time. It seemed that because they could not be processed in any but sequential order his memories could not be reorganised to assist him in defining time's passage. Consequently, there was little sense of continuity in his life at the time of this study. He had only the vaguest awareness that time had passed.

> **DS: Do you remember when you first came here?**
> **BRYCE: No. I don't even know how long I have been here.**

Bryce spent the first few weeks at Waimarie arguing that he had just arrived and encountered every item on his programme, no matter how regularly he had experienced it, as something completely new and unfamiliar. After he became involved in the tasks however, he would realise that he had done them before. The knowledge of his mistake did not appear to concern him. On the contrary, he seemed pleased to discover his previous knowledge and glad of the opportunity to demonstrate it. His learning and progress upon these tasks did not appear to be overly hindered by this manner of forgetting them between sessions, but understandably, it was not until he developed sufficient memory to recall what he was doing during the day, that he was able to feel a sense of purpose and direction in his programme. As his reflective, declarative memory skill increased so also did his ability to become self-directed and goal oriented. In the meantime, the establishing of procedural forms of knowledge provided him with an intermittent sense of achievement and a source of positive feedback (both internal and external) about himself[109].

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[109] See Chapter 1, p. 23 for a review of the literature regarding procedural and declarative forms of knowledge.

While Bryce was managing to develop skills and habits without awareness, it is clear that ultimately no sense of purpose can be attainable when living in a constant present. Until he could recognise a continuity to his life, his days would remain fragmented and isolated from each other. He might be competent once someone arranged an activity for him, but he was not likely to plan, to organise and to initiate anything himself.

MEMORY

In describing Bryce's cognitive and perceptual difficulties, it has been necessary to allude constantly to difficulties in storing and retrieving the experiences and information the world was presenting him with. This storage and retrieval process is commonly referred to as 'memory'. As the discussion so far has demonstrated, something far more complex and multi-dimensional than 'memory' was involved in his inability to retain what he was experiencing. Nevertheless, it is undeniable that the nature of his 'remembering' impacted upon the developing new self.

Remembering and Identity recreation

Bryce himself defined his main problem as his memory. He told me that he would be "exactly the same" were it not for his "eyesight and memory". He was clearly recovering memories, however and the difference between his memories and those of others was not in their number so much as their quality. His past seemed only to be available to him as sequentially organised and sometimes rather rambling and repetitive narrative. Even when asked a very specific question, he tended to respond by presenting a large portion of his life as a visualised scene. The following excerpt is typical:

> **DS: Have you ever been in trouble with the police?**
> **BRYCE: Yes. I have been caught three times for drunken driving. I was supposed to go to court but I was here. They rang up Dad and said "Where is Bryce?" and Dad said, "he is not here." And the police said, "where is he?" And Dad says, "Waipata." And they said "What is he in Waipata for?" And Dad said "He crashed his car." And they said, "He was drunk wasn't he?" and Dad goes, "he had been drinking but he wasn't drunk." And the police said, "Oh, well that's okay, but we have to lay some charges on him. " And Dad says "Well, if you can get him to talk any sense, tell me what he says because I can't get him to talk any sense." That was ages ago. That was before Christmas...."**

This style of narration was peculiarly disarming. It was also quite effective when you became accustomed to it. It allowed him to give his listener a very rich and detailed picture of the person he was. It was as if, in somehow recognising his own inability to effectively separate out "the figure from the ground" (Gross, 1987:101), he presented the story in as much detail as possible, so that his listener might draw the conclusions, build the appropriate interpretive scheme, or pull out the possible meanings.

It would be a mistake, however, to assume that his story lacked any selectivity at all. It is not possible to present any story without influencing it to some degree by one's own perspective. The difference in Bryce's stories appeared to relate to a lack of a coherent central theme. Selection of what he recalled next relied upon the associations which occurred spontaneously as the story progressed. Without such a central pole to his stories he was not motivated by a need to edit out extraneous facts, or to ensure the facts fitted the developing story line. Consequently, his stories were full of the sort of contradictions which are an inherent part of living a life and so perhaps, revealed the person more to others, than those told by a more theme-oriented story teller who is more competent at a 'presentation of self'. However, it is possible that this change in his thinking limited his understanding of his previous self to a more concrete level rather than any pattern of underlying meanings.

Memory and Lack of Affect

This inability to organise his past under themes may also have accounted for a certain sense of distance and objectivity Bryce brought to the telling of his stories. Perhaps best described as a 'lack of affect', this is evident in the telling of the following tale.

> **BRYCE: I can remember going to Australia when I was four. We lived in Arden and that is what I remember about Australia. Then we lived in Wimberley in a house in Tawhero St, that is with Mum and Dad, then Mum and Dad got divorced and then, after a couple of years, I went to live with Dad in Atangoho and then I went to Limmerton. And I stayed there and me and a girlfriend from Wimberley got close and so I moved back to Wimberley to be beside her but I drove up there and wrote off my car...**

Sometimes it seemed his memory was of episodic and geographical detail, rather than anything emotional or personal. Even when recalling an intensely personal tale (one which most would hesitate to share) he 'reeled it off' as if he had learnt it by heart so as to recite on demand. Even when speaking of situations which must have been intensely emotional at the time, he seemed to be talking of another person's anguish or joy.

> **BRYCE: Nothing ever really upset me unless I split up with a girlfriend. And then I would cry. I know that is sissy but I would - I would find a wall somewhere and just punch it. And then I used to real cry because it hurt my hand!**

This suggests that Bryce may not have been as fortunate as it would at first appear in recovering memory of his past. Memory without the emotion associated with it is dubious in quality and value. It is possible that it created as much misrepresentation than re-presentation of self, teaching Bryce to regard himself as more unfeeling and self-interested than he had been. By sharing such memories with others, he may then have perpetuated this inaccurate image of himself.

However, another more positive interpretation of what was happening to Bryce is possible. Bryce loved to tell stories of the less praiseworthy moments of his previous life and appeared to take a

perverse delight in exposing his own past mistakes and failures. Denzin (1987b:163) saw humour and the ability to speak openly of incidents which gave rise to shame and doubt as an important part of the process of distancing oneself from a destructive past and of developing a new and altered relationship to the world. By talking about more negative moments from a distance and without their original emotional charge, Bryce perhaps learned to discard more destructive past self-images, and so became more predictable and more inclined to take a positive and caring approach to others.

Metamemory

Another interesting difference in his manner of remembering was his difficulty with remembering *that* he remembered something. Quite regularly during our conversations he would deny any memory of a time or incident in his life until I offered him some more clues, or began to describe the occasion in some way. Soon after beginning I would be interrupted as, with pleasure, he discovered his own memory store and began to draw upon it.

> **DS: Can you tell me about the three weeks that you spent at your father's place after you were discharged from Wimberley Hospital?**
> **BRYCE: Did I? Strange? I don't remember that at all.**
> **DS: Well, do you remember that you had an attendant carer to help your father, her name was Donna.**
> **BRYCE: No. Oh! Yes I do know now. She used to come up and home help. And we ended up going out together. ACC put her on to my case.**
> **DS: Do you remember how old she was?**
> **BRYCE: Probably 20 .. or 23 about that ... I know she used to draw things for me to label. And we used to go to the park and play on the swings. She thought it was fun -**

Shimamura and Squire (1986) would describe Bryce as having an impaired 'metamemory' as the result of his brain damage. This ability to know *that* we have a memory appears to have a peculiar significance in the recovery of self after head injury, particularly when (as with Bryce) there is damage to the frontal lobes and so the executive system. Patients with frontal lobe damage have been shown to be poor at judging the accuracy of what they know (Sohlberg and Mateer 1989:150) and, without metamemory, Bryce could never feel totally sure that any newly recovered memories were accurate. When he was challenged, he would often discard tentative ideas about himself. He was slowly learning to distrust what he knew or thought and to look increasingly to others to guide him in reforming an identity.

These two problems with tapping into his past made it very difficult for Bryce to call upon his memory appropriately. In the quote above, for example, he only knew that he remembered after prompting. Such memories are far less useful as learning experiences as it is only possible to reflect upon and learn from previous occasions when others are able to initiate and guide the discussion.

Memory Gaps, 'Confabulation' and Imagining

Bryce couldn't remember his accident but his friends had obviously described their experience to him. When I asked him about it he spoke as if he recalled it, describing details and imputing thoughts to himself:

> **BRYCE: No I was just peeved off because thank goodness I was the only one that was hurt. And, my mate sitting beside me, I worried about him, because I fell on top of him and the two girls in the back got sore voice boxes because they kept yelling at me - I couldn't even hear them, I was out of it...**

As he told these stories of the time when he was unaware, he often bewildered others with this narrating style. He placed himself in the centre of his stories playing an active role. On these occasions, the impossibility of his version of the story did not appear to occur to him. This was so even for occasions in the story of his accident in which he could not physically have played an active part. His father even told me of a couple of stories Bryce told him which suggest he was awake and participating in conversations during the first two days in Intensive Care:

> **BOB: He said some really strange things like .. at one time on that first Sunday his friend was on the phone in the passage outside ICU talking about him and saying how they thought he was going to die and Bryce says he was there standing beside him telling him "Don't be silly I'm not going to die." For him to be standing there he would have had to get off that bed in ICU and go out the door and down the passage, when he was deeply unconscious - it was impossible for him to have been there but he is sure he can remember doing that.**

Of course it is possible that this is an instance of an "out of body" or "astral" experience (Bourne and Ekstrand, 1976:289-90); that some part of Bryce was really able to separate itself out and observe his own body during those early days. Because of the large number of such stories across a number of cultures it has become acceptable to interpret astral travel in this way as an authentic altered state of consciousness (Bourne and Ekstrand, 1976:289). Whether or not some such phenomenon occurred is beyond the scope of this project to judge. For a symbolic interactionist study, however, what is important in understanding Bryce's experience has less to do with whether or not it was 'true', than with how it altered his interactions with the world. In this regard, it is clear that his beliefs were significant in his reconstruction of events and so in his understandings of both self and other. This ability to mentally relive those parts of his story for which he was unconscious, seemed to allow him to situate the accident within his life more firmly and, in so doing, to explain his own feelings and behaviours more clearly. The following excerpt demonstrates something of this logic working within him:

> **BRYCE: I think that the fact that I accepted that I was in [Wimberley] hospital was the fact that I had been in the Limmerton one before.**
> **DS: You didn't really remember Limmerton did you? You can't really remember anything until Wimberley can you?**
> **BRYCE:** *(In a surprised tone)* **No. I was in a coma.**

It is as if he saw these periods of unconsciousness as still something experienced simply because he accepted that his body was experiencing all these moments. From this point it was possible for

him to conceptualise his recovery in terms of a dawning consciousness, in terms of levels of awareness, some of which he was more actively engaged during, than others. Initially as he emerged from unconsciousness, this 'visualising' technique probably allowed him to establish or reestablish relationships with those around him. Without being able to visualise something his friends' and family's experience over this time, it would have been difficult for him to know how to relate to them. It would have been hard for him to understand why, in their minds, his role and so their expectations of him had changed dramatically.

This tendency to visualise in order to fill blanks in his mind is termed 'confabulation', in the literature and, as Sohlberg and Mateer (1989:96) explain, although confabulations can be bizarre, suggesting unreal or impossible activities, "more often the wrong responses reflect plausible but incorrect information or are a recital of personal activities that did occur at one time but did not occur recently." When his anterograde memory loss was quite severe and when his orientation was still erratic, this imagining technique allowed Bryce to begin to make sense of his situation and to fit within it the probable parts played by those around him. Yet as the months passed and he recovered more, the same technique began to make it very difficult for these same people to relate to him. Remarks that would once have been regarded as understandable confusion could no longer be ignored. Once he was better oriented, when he told stories of incidents which did not happen they tended to be interpreted as 'lies', or fantasies. These were very embarrassing to his friends because it was difficult for them to know how to maintain their relationship with him while ignoring his often total misrepresentation of these same relationships and roles. A good example of this occurred when I asked Bryce to remember the three week period he spent at home before coming to Waimarie. Initially he could not remember this time, then when I reminded him that he had spent a lot of time then with an attendant carer named Donna, his face lit up with delight:

> **BRYCE: Yes I remember her very well but you wouldn't want to put in that sort of thing would you?**
> **DS: What sort of thing?**
> **BRYCE: Oh God! Well we became very close and we went out together and then we became intimate.**

Bryce sincerely believed that his relationship with Donna developed to a level of sexual intimacy. His father, however, emphatically denied it. Because Bob Lawson was self-employed, he was able to rearrange his work hours during this three week period and he and Donna very often worked together in a partnership. Pat also, although often away at her job, would have been likely to notice a change in their behaviour towards each other. Neither saw Donna ever behave in a fashion that was not consistent with her role as an employed carer.

After his accident, Bryce was particularly vulnerable to misunderstanding such situations involving young women. There were many times over the period of this project when he imputed

a sexual interest where there was none. During our conversations he often asserted that friends who visited him were in love with him or wanted to have an affair with him. This was not a matter of lying. The subtle signals which people of the opposite sex send to each other require considerable sophistication in the perceiving and interpreting of sensory input. These occasions require the most of one's ability to use imaginative 'gap filling' in a controlled and self-aware way (Goffman, 1969:61). Bryce, who was neither controlled nor self-aware, was not capable of making these finer distinctions. When he misinterpreted a relationship and made comments which exposed him, his friends responded with embarrassment and tended to ignore his inappropriate remarks, changing the subject or glossing over the moments. Bryce in consequence, had no clear feedback to monitor and adapt his incorrect imaginative endeavours. He had the normal drives or needs of a healthy 19 year old and an imagination to match, but lacked the normal social skills to assist him in meeting these needs. In his attempts to seek out female companions he imagined situations which might occur then confused them with the reality of what was happening. Once he had made these misjudgments the situation was compounded by the response of others around him. The problem, therefore, was not that Bryce constructed beliefs about his interpersonal relationships by drawing upon his own thoughts and feelings but rather that he failed to mediate between these beliefs and reality. The confabulatory elements of his story were allowed too great a role in the creation of self truths.

For a variety of reasons, therefore, memory as a concept can confuse rather than illuminate the field of rehabilitation after brain injury. In Bryce's case, the problem was that the term did not discriminate between his perceptual difficulties, his more cognitive 'interpretive' difficulties and his personal response to these difficulties. It would be rather more accurate and useful to suggest that he was exploring and organising his experience in unusual ways and so creating and recreating memories which sometimes bore less relationship to an objective or socially constructed 'truth' than they was needed to promote unproblematic interaction.

CONTROL

Wood (1990a:3) described the goal of rehabilitation after brain injury as "the recovery of a style of living which is adaptive, purposeful and independent." Similarly Ben Yishay (1985:255) regarded "control" and "mastery" as hierarchical steps necessary in reaching toward identity. For both Wood and Ben Yishay, as well as others quoted in the literature review[110], the priority for those working with Bryce should have been to establish a sense of inner direction or control.

[110] See Chapter 1, p. 43 .

In order to accomplish this from a symbolic interactionist perspective, Bryce needed to regain an ability to judge the situations within which he found himself more accurately. He also needed to develop confidence in these judgements. Situations are never static and constant, so this judgement ability needed to be sufficiently sophisticated to monitor and adapt for ongoing changes. In effect, he needed to learn not to 'define situations' so much as to negotiate shared definitions of situations.

As will be apparent from the preceding discussion of perception, memory and interpretation problems, the obstacles to accomplishing these goals for Bryce, as for Rob, Mark and Max, were vast. In this section some attempt will be made to list and describe in relation to each other, the various difficulties which were preventing Bryce achieving a sense of control or mastery of his world.

Control and the Definition of the Situation

Earlier, in discussing the concept of metamemory, I suggested that while Bryce did remember his past, the memories were not always accurate. I also pointed out how most of his pre-accident memories were either reliant upon the cueing and prompting of others for their recall, or in some other way they were situation dependent, and so not always available to his mental reflections. If they were challenged, he was likely to quickly discard them in favour of the alternative version offered by another witness.

> **DS: Okay. You remember being quiet and good all the time at school?**
> **BRYCE: Yes.**
> **DS: How would you react if I said that your parents told me you got into trouble at school?**
> **BRYCE: It wouldn't surprise me. Heaps of time I got in trouble at school.**

On many occasions, therefore, his memories were really just a reporting back of another's account. These reports are likely to have been adopted uncritically by a mind not yet capable of organising information into themes and patterns for further reflection. At the beginning of my first interview with him, I tried to explain the reason for my research and discovered that he had developed some initial opinions upon the meaning of his brain injury in his life. But that these opinions were in fact, very much the uncritical absorbing of the remarks of others, which did not stand up to examination.

> **BRYCE: It has improved my reactions with people.**
> **DS: Do you think?**
> **BRYCE: Yes - I used to not get on with anyone but now I get on with heaps of people.**
> **DS: You think you have got better? What brought you to that conclusion? Any particular things that happened?**
> **BRYCE: Just what all the friends I had from before my accident have said to me..**

Bryce's experience abounded with such situations in defining 'what was happening'. Because he accepted others' opinions uncritically he was at a loss when confronted by conflicting

interpretations of the same situation and was inclined to give up his attempt at understanding for himself at such times. He became a prey to the loudest speaker or the strongest personality in his definitions of his own world.

In the absence of strong defining powers, therefore, it can be seen that Bryce needed to trust those he interacted with more than most. In those early days of dawning awareness, while he was still in Wimberley hospital, Bryce had an experience of a sort of 'interpretive anomie' which left him unable to know which people to trust. On the occasion when his mother became angry with the friends who had taken him out, he, still disoriented, only just beginning to recognise the significant people in his life, must have become extremely confused. His friends and family were no longer a unified group of people offering him the same messages, but suddenly became individuals with separate interpretive schemes of what was happening. While most adults can accept this divergence in opinion among friends and family, Bryce did not as yet have the cognitive power to resolve such an emotional dilemma. After being forced to witness this conflict, he refused to leave his bed. It appeared that he had lost confidence for a time in his initial attempts to build new relationships.

> **BOB: Yes he just couldn't see what to believe or who was doing what so he just took to his bed and as far as he was concerned he was safe in his bed and nobody was going to get him out of it. And it took a week to ten days before anybody could get him mobile again.**

While he no longer experienced such catastrophic responses at the time of the study, there was still much in Bryce's interaction style to suggest that he was not ready to take back full interpretive control of his life.

Personal Power and Cognitive Control

When a person is more dependent upon the interpretive schemes of those around them, a dilemma is created when a family do not hold one unified interpretive scheme. There was a history of suspicion and misunderstanding between Bryce's parents. Before his accident, he appeared to have responded by removing himself from their orbit as soon as possible. While he recovered from a brain injury, however, his parents were the only people able to provide him with the cues and explanations to restore or clarify his past. He had begun to listen to and quote both parents and even accepted his father's right to authority over him. Over the months he was at Waimarie, however, the other, more independent Bryce of before the accident began to emerge again in his interpretations and, increasingly, he rejected parental overtures and made alternative plans for a future which excluded them.

Both parents seemed to understand this problem. They had become aware over the months since Bryce first started to regain consciousness, of how much more compliant he had become, a trait

which was sometimes an advantage in a rehabilitation program, but which ultimately made him very vulnerable.

> **ALICE: With his brain the way it is - anyone could fill his brain with a lot of rubbish and Bryce is bound to believe what he is saying.**

However, there were signs of a dawning confidence in his own interpretive powers and so a preparedness to take over the control again. This manifested itself sometimes in a suspicion about those he allowed so uncharacteristic a level of control:

> **BOB: I don't know what happened, but he got a bit uptight the other Friday actually, Philippa [*the social worker*] rang me up from there and asked me to tell him where his money was! Actually it was quite funny. It wasn't funny at the time, I thought that it was quite serious, she thought that I was taking off to Australia with the rest of his money or something like that -**

Understandably, his father felt wary, worried that others might be "filling his head up with ideas about him". He quite consciously took steps to ensure he was protected from any ideas about misplaced trust that Bryce might come out with.

> **BOB: Oh yes. I keep a record of it otherwise it might be a bit dangerous...I have been told that with head injuries that doctors have said that they can get very suspicious -**

Until Bryce could take back cognitive control over his life, his sense of personal power and self-direction would remain elusive and subject to doubt whenever contradicted.

EMOTIONALITY

Of course, judgement is not a purely cognitive matter. Any evaluation Bryce made of an interpersonal situation would have had an emotional component. As Denzin (1984:143) suggested, cognition occurs "through a veil of feelings, just as feelings are felt and thought through the screens of cognition".

Bryce believed, in fact, that it was in his ability to feel that he was most strikingly changed.

> **BRYCE: If something really hurts I will just break down and cry and that is not very likely from me either. I haven't cried since I was 14. And my baby sister reckons I was crying in my sleep at Christmas time -**
> **DS: So you are different emotionally, but it is hard for you to describe just how you are different.**
> **BRYCE: I am more stable than what I was before.**

However, as he showed in this excerpt, he (like most of those who knew him) was very confused about the nature of the change. His bewilderment was understandable. His behaviour often supported quite different conclusions. Sometimes, he would appear more at the mercy of his emotional reactions, making impulsive and extreme appraisals of situations.

> **BOB:...He wouldn't get out of bed, he was in one of his funny moods at that time - at that time, you would ask him to have a shower and he would say "No I am not going to do that" and five minutes later somebody would say "Go and have a shower" and he would go and do it!**

His definitions at such times appeared to be determined by the prevailing mood rather than any considered judgment. If he was 'primed' by a situation to feel positive, he would react in a positive and motivated way. If he was made to feel negative by surrounding events, he would interpret any choices presented as negatively as he could and be likely to reject any proposal, however useful or effective.

As well as being impulsive, Bryce also showed a generalised lack of concern. In social situations this translated into a more aggressive or arrogant manner.

> **ALICE: He is got more determined in what he wants to do. Rigid. He has changed in his language. He swears more. I would tell him off for swearing and he would say something like, "tough. You are going to have to put up with it just like Dad had to put up with it."**

He had become less inhibited by thoughts of what impact his words and actions would have and as a result could seem self-absorbed[111] and uncaring, only prepared to talk about himself and uninterested in the opinion or respect of those with whom he interacted. His mother felt this change was particularly evident when he was confronted by people with physical and cognitive disabilities at Waimarie.

> **ALICE: I have seen him there in the way he mixes with some of the people and I said, "Look, don't you speak to them like that." I said. "You ought to stop and think that you could have ended up like that yourself." And he says "He is nothing but a moron - "**

His father was concerned that this disregard of others' feelings might put him at risk.

> **BOB: There is a bloke over in Waimarie there call Charlie, and Bryce walks into the dining room and says "Hi big nose!" and I said "Bryce, that is no way to talk to the guy!" and he says "Oh he will get over it".**

Although this loss of sensitivity made him appear very egocentric, Bryce was also often described as having become more sensitive and caring as a result of his accident. Several people (often the same people who complained of his lack of regard for others) reported occasions when he would suddenly come out with remarks or behaviour which were remarkably thoughtful.

> **BOB: Yes he is actually coming back a different person all right, it is just like the specialist said. He is coming back more thinking about things now. Before the accident, he thought he was Arnold Scharzenegger or something. You know, indestructible. But now he will say, "Have a good trip home - drive safely - things like that that he would never have said before."**

While it was possible to establish definitely that there was a change in his emotionality, therefore, it seemed that the change was not in the range of feeling he was capable of so much as it was in his manner of interpreting and responding to situations. As Denzin (1984:143) would say the "screens of cognition" were not working effectively.

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[111] This self-centredness is frequently remarked upon as an outcome of brain injury and causes serious concern because of its destructive effect upon social and family relationships (Pepping and Roueche, 1991:233).See Chapter 1, p.33.

This lessened ability to interpret underlay both his new impulsivity as well as the lack of concern. In the first place, for interpretation to occur, a situation must "interrupt", "arouse" (Prigatano et al., 1986:4) and engage the reflective conscious mind allowing the information to be processed and definitions realigned. A lack of concern about a problem that would embarrass or worry most people, may sometimes have signalled a failure in Bryce of this interrupting process. Even when he did 'recognise' a 'sign' or 'disturbance', however, Bryce was equally likely to stumble at the next step in interpreting its ontological meaning. Because he could not define a situation as easily, he could not take an attitude toward it as easily. As Tucker (1981:29) explains, the problem became one of a failure to recognise and identify emotion rather than a failure to feel it. No longer able to process and explain what he was feeling, he was unable (as Bear (1982) would explain it) to discipline with the left hemispheric verbalising mind, what the right hemispheric 'feeling' mind experienced.

His unfeeling manner may also have been created by the catastrophic response Goldstein (1952:250)[112] hypothesises, which forces a person with a more limited and concrete processing system to avoid self-reflection because it creates an unbearable level of anxiety or tension. In the stories of both Max and Mark, catastrophic reactions had been very damaging, often disrupting the process of their rehabilitation or causing a loss of freedom and an alienation from others who might have been useful support people. Bryce, in contrast, was progressing without the need for such an extreme form of 'tension release', making the process of recovery more smooth, less erratic and problematic for family, friends and clinical staff. While there is no doubt that cognitive disorders were preventing him resolving ontological conflicts, any confrontation with the reality needed to stay within the emotional boundaries he could manage to prevent a return to this destructive and self-defeating coping style.

As well as being less able to manipulate and control the level of tension or arousal however, Bryce's emotionality was affected by changes in his interpersonal dynamics. His diminished social skill and his need to imagine or re-create what he could not remember made him unlikely to arrive at a common understanding of interpersonal situations. He had lost the ability to accurately project the emotional position of the 'other' and, as a result, he could not manage any degree of shared feeling or emotional intersubjectivity. Without this to guide his interactions he was unlikely to strike the appropriate emotional tone or avoid potentially hurtful remarks. Until he was capable of a more authentic reciprocity in his relationships he was at risk of alienating even those closest and most tolerant of him.

Another reason that Bryce's emotionality may have altered appeared to be a secondary effect of disorders to perceptual and interpreting skills - a changing sense of interpersonal power. Those moments when he seemed more thoughtful and more concerned about others were also the times he became aware of his new dependence upon others.

> **BOB: ... he would say sometimes, "I will shout you the petrol to come over and see us next week," and we used to say, "oh yeah" and leave it at that. But that is something that would never ever have entered his head before the accident. He is coming back a lot more caring.**

More dependent upon others to reach his goals, Bryce very probably 'changed his mind' about a feeling or evaluation in order to achieve approval. Of course, each time he did this he was learning to take the role of the other a little more. As Goffman (1968) has argued, taking the perspective of the other encourages the development of a self-critical attitude, and this in turn may cause a loss of self-esteem. A person with a disability may come to accept a role as a less valuable person, becoming grateful for the attention of others and feeling that, in order to earn their continued regard, it is necessary to play, a new more compliant role. As Goffman (1968:30) describes it, a ""self-consciousness" and "other-consciousness" occurs, expressed in the pathology of interaction uneasiness".

It is easy to see how Bryce could have become overcompliant and motivated more by a desire to please than to make inner-directed choices. Some of his behaviour suggested that there was a stage during his recovery when he risked becoming alienated from the rehabilitation process by this dynamic.

> **BOB: he knows that the only way he is going to get back to work is to be cooperative - at first he was fairly uncooperative over there, but now he realises that he will have to work to get out of there -**

Emotional dependence may be useful to family and rehabilitation staff in that it promotes compliance, but, as can be seen from the above excerpt, it has implications dangerous for his future ability to recover autonomy. Recovering from brain injury appears (at least in Bryce's case) to involve the recovery of the balance between feeling and thought. To achieve this Bryce needed not only to learn to identify his own feelings but also those of others.

An Emerging new Emotionality

Of course, in describing Bryce's emotions, it is important not to attribute to brain damage what may have been a pre-existing personality characteristic. It is also important not to assume that any changes in his emotions would be 'deficits'. Brooks (1988) comments that in some five per cent of cases, head injured persons become more placid and pleasant after the injury. Bryce appeared

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[112]"The quick response is an effect of their strong necessity to release tension; they are forced to release tension because they can not handle it any other way. They cannot bear anything that presupposes

to fall within this group and his history offered some reasons as to why this may sometimes occur.

As is clear from the description of his early history, Bryce behaved in ways considerably less rational and more impulsive than others well before his accident. In fact, it is when he talked about his past relationships and about his own feelings about these relationships his emotional reactions appear to be at their most bizarre and disjointed.

> **BRYCE:...and I so said "Goodbye, Laura." And I went out with Stella. And I went down with Mike to buy Stella an engagement ring, but I bought me a pair of gumboots instead.**
> **DS: Why?**
> **BRYCE: Because my other gumboots were buggered. They were full of holes.**
> **DS: You were really keen on this Stella but you hadn't known her very long?**
> **BRYCE: No.**

This strange manner of recounting events which for most people would have been intensely emotional may signal a failure to grasp the emotional reasons behind his past actions[113]. It may equally signal a failure back then, to use rational decision-making processes to make serious life choices. Either way, what becomes important in understanding Bryce's story, is not so much what aspects of his personality were continuous, but how his emotional response to the experience of brain injury influenced the process of recovery. There is in this regard, some evidence to suggest that Bryce's accident may have offered him an opportunity to resolve pre-existing emotional difficulties.

Bryce's early years were not ideal. It is very likely that he learnt to disguise and even to deny his emotions in order to manage his unusual childhood. As he grew, he showed evidence of a problematic emotionality severely affecting his relationships, both private and public.

> **BRYCE: I was extremely violent... I just used to pick on guys that were a lot bigger than me. I used to have fights all the time.**

The emerging concern and sensitivity for others that Bryce and others saw in his interactions since his accident therefore, although erratic, may have been something new and important. It suggested that there are occasions when a carefully managed rehabilitation process may realign self-definitions and discourage the use of destructive defence mechanisms built as a child.

Tracing the path of Bryce's emotional recovery suggested a continuing cycle of confrontation with his deficits and emotional and/or catastrophic reaction to these confrontations guided his mood and attitude. While some confrontation appeared to be an intrinsic part of engaging in living again, there were times when Bryce was overwhelmed, reacting with depression and despair sometimes and at other times, he would swing erratically between euphoria, a bland lack

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deliberation, considering the future and so on, all of which are related to abstraction."

[113] See Chapter 1, p. 34 "Emotionality".

of concern and a deep depression or anger. All of these extremes prevented him participating actively in his recovery and diminished the rehabilitation opportunities he was offered. Any strategies which helped him maintain some emotional stability and moderation, therefore, appeared to be important at this time.

Interestingly, Bryce's father believed that 'keeping him busy' was one of the most effective strategies for regulating his emotion and creating a self-directed and purposeful emotionality. Filling his day with planned activity, even if it was largely monotonous or repetitive tasks, seemed to allow him a sense of achievement and self-direction. Opportunities could also be presented before he was capable of seeking them out independently and this allowed him to rediscover pleasures and skills he had forgotten, as well as discover new skills. In this way he could work toward a sense of control and mastery (Ben Yishay et al., 1985:255) while still not fully self-aware.

It is also possible that the loss of affect mentioned above, allowed Bryce to accept correction without distress or anger and this meant that he did not divert energy into covering up his disability. Perhaps for the first time, Bryce learned to work with people who were in a position to help him rather than becoming suspicious of their motives. Without such monitoring and regulating of his emotionality, without the opportunity to reflect upon the meanings of his disabilities in a positive and hopeful climate and an "atmosphere of persuasion and inspiration" (Ben Yishay et al., 1985:256), it is doubtful that Bryce would have sought out the opportunities and experiences that a rehabilitation programme offered him. As he recovered, he began to recognise boredom in himself and seek out enjoyable and constructive activities independently. Previous habitual belligerence appeared to have broken down at least in the initial stages of reconstructing a self. The injury had given him an opportunity to learn new and more appropriate ways to deal with negative emotions.

CHANGING SOCIAL NETWORKS

Friends

The more his confusion and disorientation cleared, the more Bryce preferred the company of friends over family. He felt pleasure and pride that his friends still visited him and did not take their attention for granted as he did that of his parents. As described earlier, he had enjoyed a carefree and active social life and it seemed that many of the relationships in it were rather superficial. As a result, he felt genuinely grateful that the three people in the car with him were still writing to him and visiting him several months after the accident.

BRYCE:...They were my friends before the crash and they were after. They stood by me all the way...I thought they would have just left me.

However, during this rehabilitation period Bryce's notions of friendship were rather confused and contradictory. He was having difficulty with the abstract ideas that are involved in a close emotional bond. He relied upon concrete, visible evidence of friendship such as phone calls and letters to define the strength of a friendship bond and appeared to have lost any sense of the more subtle and intangible aspects involved. This limitation to the physical and observable appeared to lead him to limit friends as those people who visited him while he was critically ill or who still liked him despite the scar on his face. It also prevented him seeing a relationship as something mutual and interactive. As a result he could appear remarkably casual. He decided to marry one friend after ringing her and chatting on the phone, for example, quite forgetting about another relationship which might have been considered more intimate.

BRYCE: But anyway when I get released from here and go back to work, we are going to get a couples job, because she loves milking cows and so do I.
DS: Mary and you?
BRYCE: Yes.
DS: Well what has happened to Stella?
BRYCE: I didn't buy an engagement ring. I bought gumboots instead. My other ones had holes in them.

Without the ability to comprehend the meaning of abstract and intangible qualities and without the ability to put these into words, any deeper and emotionally intersubjective quality in his social relations appeared to have diminished.

Family

Obviously, an accident such as Bryce's places a tremendous stress upon a family, and would threaten the strongest of bonds. In Bryce's family at that time, there was very little trust and shared understanding. The accident did nothing to improve this situation in the long-term, but in the short-term the family did manage to act more effectively to support him than they had managed in the past.

Both parents appeared to see the situation as offering them a second chance at parenting. Because Bryce's father established an early role as a guardian, he resumed a role of protecting and guiding. Bryce's mother had more difficulty finding an effective role relationship. As Bryce recovered a sense of 'will' both needed to reinterpret and adapt their roles continually. Bryce's mother hoped to encourage a change of moral direction:

ALICE: I hope when he does realise just how bad it was, it will help him to realise that he does need to start again and help him stop and realise that drinking and driving is not good.

while his father was determined the accident would be only a minor pause in a life beginning to look promising after a shaky start. His efforts were firmly directed towards the goal of completion of the management certificate.

BOB: They have actually given him a year's leave. I am trying to get him back into it.

For Bob, therefore, the recovery had to be actively assisted and even hurried along. He was nervous about the time it was taking for his son to recover because he sensed opportunities slipping away. He saw this period of rehabilitation as time to be 'got through' as smoothly and quickly as possible by controlling Bryce and making decisions for him until he was capable of taking back the reins. He saw himself as assisting the rehabilitation team by exhorting and persuading his sometimes reluctant son. It seemed that for Bob, in his role as a father, this accident was a positive experience:

BOB: I have had the opportunity now to see a lot more of him and we can talk about things.

For Bryce, however, independence was too recently won for him to appreciate a return to dependence. It seemed likely that as soon as he had the opportunity to, he would again discard any parental control over his life. When he reflected upon the greater role his father was playing in his life at the time of his rehabilitation, he seemed more perplexed than anything else and showed very little appreciation for the months during which they had devoted themselves to his care.

SUMMARY

Bryce Lawson grew up with confusing and constantly changing notions of family and relationships. He appears to have reacted by rejecting all forms of control and (later), self-discipline as well. As a result he encountered the range of our society's sanctions against such self-interested excesses as he indulged in.

While his life at the time of the accident might at first appear to have been a fairly thoughtless pursuit of pleasure, there is some evidence of a search for stability and love. Beginning with his affair with Megan, his decisions appear to have been influenced by a need to find reciprocal loving relationships. A move away from his home town and a breaking off from his past appeared to provide him with emotional independence, while the dairy farming course gave him a sense of achievement and stability. At the time of his accident, therefore, he had achieved more sense of direction while still appearing to be having difficulty with personal relationships.

It is difficult to understand the nature of the accident's impact upon Bryce's life. Because it was so unsettled anyway, emerging themes of the 'Before and After Approach' have suggested as much the continuity of the past, as the discontinuity. The first such theme was that of 'relocation' as a strategy for making a new beginning. Bryce discovered in his teens the power of having

Megan's place to remove himself to. He used this same technique of geographical relocation to his distinct advantage again when he moved to Limmerton. A change of place was often an opportunity to shrug off disagreeable relationships, particularly relationships with those who were attempting to impose their will upon his life. After his accident, he was relocated several times by others. This allowed him to distance himself from previous experience as well as offering him the opportunity of different relationships.

Delaying was another theme in Bryce's life. He also learnt early that time eventually overcame everything. He saw how continual delays in the court process caused the issue of his custody to remain unresolved so long it no longer mattered to anyone. He appeared to have learnt from this that conflict could be avoided if time was allowed to pass. He allowed time to overcome conflict and resolve power issues with his girlfriends and his parents. He drifted back into relationships with both parents once they had been allowed the time to accept his relationship with Megan. After his accident, Bryce was still inclined to live in the present and drift. This meant that long term planning was not a serious option for him. A vague image of milking cows again and being a father was the nearest he was likely to come to planning. He was prepared to wait passively to be 'released' from Waimarie and then believed he would probably ring a friend and find himself a job.

Bryce's characteristic tendency to evade deeper and more meaningful relationships also affected the nature of his rehabilitation. The rather short term and shallow liaisons (although they might have been typical of a 19 year old person's relationships), were not ideal for a rehabilitation situation where there is a tendency for practitioners to assume a clearly defined social network capable of a long-term commitment. A situation where there was a fiancee not acknowledged by a family and a patient who rejected his parents made it difficult for the rehabilitation team to know who to involve in decision making . Because Bryce had a limited trust in his relationships, it must have been particularly stressful for him to rely upon others. He was in the process of learning that to recover any quality in his life he would have to learn interdependence rather than independence.

Another important theme was that of spurious emotionality (Denzin, 1984:133). It seemed that it had always been very difficult for Bryce to interpret the feelings and thoughts of others towards him. In inferring the underlying feelings, he reached sometimes bizarre and unusual conclusions. While it may have partly been the heritage of his unusual upbringing, this interpretive difficulty was compounded by the perceptual and cognitive disorders. The inability to separate out fantasy and reality, to perceive patterns and to discern and articulate his own feelings was particularly significant in this regard.

This discussion of the theme of interpreting skill, leads on to its companion skill: the ability to manage one's impressions (Goffman 1969), presenting an effective and coherent image to the world. In Bryce's case it seemed that the most difficult problem for family and friends to deal with was the change in this 'persona'. Changing personality, however, was not a new theme for Bryce. He appeared to have swung from one personality to another during the chapters of his history. While it was still unclear just how permanent the change was, it did seem that he had become more egocentric and his conversation suffered from cognitive rigidity, inadequate perception of or adaptation for 'feedback' and an inability to judge the feelings of others.

Bryce's story demonstrated the pitfalls of attributing to brain damage, personality traits and interactive practices which appeared to be causing problems as he recovered. Certainly there were changes, but a closer inspection suggested that the problem was in part at least, due to his leaning upon past coping strategies and habits. The brain damage perhaps merely revealed weaknesses in his coping strategies which may not have been evident with a more normal level of awareness. This is nowhere more obvious than in situations where he revealed that emotionally he was divided against himself.

Bryce's only long-term goal at the time of this study was to return to his past. He would have liked to return to that moment just before his consciousness was abruptly wrenched from him, imagining he would be able to continue on from there towards a settled and happy future as a dairy farmer, father and husband. He would have regarded the period of hospitalisation and rehabilitation as 'time out', best forgotten. An examination of his story suggests he might have needed to understand both his past and his future more fully than this if he was to overcome the interpretive and interpersonal difficulties described here. Unless he learnt to integrate his feelings and his thoughts, his perceptions and his beliefs, it is likely that his quality of life would have deteriorated steadily as his social network disintegrated.

If he was to manage his future with any sort of integrity or coherence, Bryce could not just aim to 'recover' his pre-accident self, but instead needed to integrate the two halves of a broken life. In order to live a more authentic present, Bryce needed to heal the scars of his past as well as those to his brain.

A DISCUSSION OF THE FOUR LIFE HISTORIES

CHAPTER 8

THE RESPONSE OF THE FOUR PEOPLE TO THEIR HEAD INJURIES

The life histories in the preceding chapters described the experience of four people with severe brain damage. They were stories about people experiencing a dramatic change in cognition and perception and although there was a considerable difference in the nature and degree of the damage experienced, from the perspective of symbolic interactionism, each story could be seen as a struggle to re-order and control the life by re-interpreting the personal relationship between self and world. When examined in this way several common themes emerged in the experience of the four men. Two chapters will be devoted to the discussion and analysis of these themes.

The present chapter examines the manner in which each of the people was altered by perceptual, motor and cognitive damage. Each of the four people suffered a range of neurological disorders and although there were vast differences in their degree and nature there were several common themes in the way that they responded to these changes. Theory and literature about inner brain processes is set alongside symbolic interactionist and phenomenological equivalents in order to explore these themes and reach some conclusions about the impact of brain damage upon the person as both experiencer and actor.

Later, in the second chapter, the role of the pre-accident person and his personal relationships is examined in more detail. Before their accidents Max, Mark, Rob and Bryce each had characteristic ways of interpreting and responding to their world. In spite of vast changes in mobility, thought and perception, these past coping strategies, values and beliefs strongly influenced their response to traumatic brain injury. Their four stories can only be understood when the continuity within the individual lives is understood and set against the discontinuity brought about by this brain damage. In this chapter some distinctions can be made between the effect of brain injury and the secondary effect which developed out of the response of the interpreting person by comparing the four stories using the "progressive-regressive method" (Denzin, 1989:197).

Related to continuity within personality is the continuity within relationships. The family members in each of the four stories, played a very influential role in the process of recovery. The actions and behaviour of those people most significant to the four men will be examined in this second

chapter and some conclusions reached about the impact of such a crisis upon the networks of interrelationships surrounding the person.

Because of the symbolic interactionist perspective of this study, the course of recovery and discovery charted in this and the next chapter, as in the preceding chapters, regards cognitive rehabilitation as the journey from unconsciousness to authentic self-consciousness. This is understood to involve the re-establishing of an ontological core which allows a more inner-centred control over one's own destiny and a more "adaptive, purposeful and independent" (Wood 1990a:3) style of living.

ORIENTATION TO TIME AND PLACE

Upon their initial emergence from coma, each of the four people spent a period of time in a state known as 'post traumatic amnesia' (PTA)[114]. Although they were conscious in the sense of having their eyes open, speaking and moving limbs, they were regarded by family and medical staff as really still 'unconscious', being unable to engage with the outer world effectively. This is the conventional and expected pattern of recovery and the families were all well educated about this and did not become alarmed when the person was unable to fix and maintain their attention upon anything and appeared to have no awareness or emotions.

However, from a theoretical perspective which stresses the role of an interpreting self in governing consciousness, this method of dealing with the early stages of dawning awareness can not be so easily accepted. What is highlighted instead is the way in which this definition of 'unconscious' allowed the staff to see the more important task over this time as one of caring for, monitoring and assessing the physical body rather than dealing with the disturbed perception and cognition. As a result any cognitive and perceptual problems which began to emerge in the early days of dawning consciousness could be ignored. This attitude perhaps seems acceptable when (as is the usual course of recovery) the person emerges quite dramatically after only a short period of PTA, just as he earlier emerged from coma into a different level of consciousness where he was again able to understand, learn and remember. For Rob the exit from PTA did appear to have just such a clear moment, when he "all of a sudden just got better"[115]. However, for the other three people involved in this study, as for many others who suffer serious brain damage, there was no magical 'waking up' process, but rather a gradual increase in the ability to 'interact' rather than react. Rather than being a state of unawareness, PTA may represent the earliest stage

[114] See Chapter 1, p. 20.
[115] See Chapter 4, p. 135.

in a gradual process through which a new relationship, a new way of re-engaging was built, like a bridge, between the person and his world.

If this period is seen as a different way of being rather than an absence of being, it is possible to regard it as a time when new connections (or new inner understandings) are being formed. The stories of emerging from coma which people recount later and the experiences and beliefs of the people who sit with them and interact with them at this time, then become considerably more significant. It is possible such anecdotes offer important clues as to what assists and what frustrates an effective re-engaging with the outside world. It may also offer a clearer understanding of what it is like for those people who never completely emerge from this different relationship to their world, suggesting new directions for working alongside and communicating with those defined as 'locked in', or in a 'vegetative state'.

The central aspect of this state appeared to be the inability to reflect or think through anything. The four people only seemed able to react to the immediate environmental cues and could not maintain their attention for long enough to process these cues so that they could acquire any more personal meaning. In the circumstances of course, it was impossible for them to engage meaningfully with any object or person and so it was impossible for them to re-establish relationships with the medical team or family. Any interaction that was occurring became distorted and unequal. For example, their relatives uniformly described them as "blank and expressionless" at this time and reported feeling that the person was alien and unfamiliar, as if they were not "really there".

One possible reason for this was the slower speed of processing. Knowledge and understanding was often not lost at all, merely inaccessible at the pace necessary to maintain interaction with the others around them. Bryce, for example, would see a chair without being able to remember what to call it and the other three reported moments of blankness and confusion created when they were unable to keep up with what was happening. This experience will create a sense of disorientation, as Max described:

> **MAX: ...It does that. I get stupid. You can go - you are talking about one thing - all right? and then you can go back to where, and I can't answer it - I think something else and I don't click on at all.**

Luria's patient Zasetsky, who was capable of describing his inner experience more explicitly than Max, also regarded a loss of processing speed as a significant problem, remarking, "there was a real time gap between my ability to remember a word and understand what it meant" (Luria 1987:92). A loss of interpreting skill within interpersonal situations would be an inevitable result in such a situation.

However, 'slowness' alone can not satisfactorily describe and explain the change in the quality of consciousness during this PTA period. The lessened processing speed appeared to be just a part of a much larger problem: a problem with time. As Heidegger (1967) and Denzin (1984; 1987a; 1987b) understand, to process experience effectively it is necessary to mentally manipulate time, moving backwards and forwards in a constant flexible re-ordering of events and ideas, 'situating oneself' within time. The four men appeared to have become fixed in the present during the early stages of coma arousal, and because of this they were unable to relate new experience to that already encountered. Their temporal relationship to their world had become so rigid and one-dimensional that they were unable to draw upon their own memories. As Zasetsky (Luria, 1987:92) describes in this excerpt, confusion and disorientation had become linked in a vicious cycle with memory and language difficulties.

> **After my injury my memory seemed to be shattered into bits and pieces....My mind no longer functioned clearly; it was just as confused as my memory of words and meanings.**

For the four men in this research, as well as for Zasetsky, the inability to tap the store of past experience effectively and appropriately caused much of the confusion and disorientation which plagued their attempts at interaction. Unable to connect past experience quickly enough to respond to others appropriately, the four men then appeared to become alienated from those around them. To a phenomenologist, therefore, PTA might be better described as the loss of the sense of the self within time. As Denzin (1984:263-4) puts it:

> **Meaning is located in the past, for actions taken in the present and the future are assessed against what has just been accomplished. Meaning is in the present as the present slides alongside the person as action that is now being taken.... The process is circular, temporally grounded and self-referential.**

Without self-references grounding it and without the ability to manipulate time sufficiently to look backwards over it, the knowledge available to each of the four people lost much of its inter-connectedness. As they recovered slowly it could be seen that these links were not suddenly restored but rather 'reforged'. The result was a form of information processing which was clumsy and slow. As they attempted to interact meaningfully, their past and present 'stumbled' alongside them, often failing to keep pace with the outside world. All four stories noted occasions when a failure to keep up with the mental pace of another may have been the sole cause of an apparent loss of memories or disorientation. A certain blankness characteristic of each of them appeared to signal a bewilderment or an incoherent inner searching for meaning. Without smooth effortless temporal manipulation, working out 'what was happening' did not become impossible but it did take considerably more time.

Clearly the response of others to this situation determined how well the four men mentally grasped the experiences which confronted them while in this 'fixed temporality' mode. It seemed

that the strategies that were most effective worked because they slowed down the speed of the surrounding world. Static, visual prompts such as photos and objects, for example, were most helpful in stimulating recall of significant situations and people. Repetition was also useful, allowing new ideas and meanings the time to be forged rather than just linked transiently. Similarly, when they were allowed to carry out tasks at their own pace, the men were more likely to rebuild the links which allowed them to comprehend their situation again. Along with the comprehension there came behaviour which was at least the beginnings of interaction rather than just a reaction. Hence memory and time are inextricably linked in the creating of meaning and action

REMEMBERING AND IMAGINING

As the consciousness level of each of the four men rose further, they began to recover memories and so became able to reorient themselves, even if somewhat tentatively, within the unreal world of the hospital setting. What has not been fully accounted for in some neuropsychological literature, however, is the interactive way that this recovery of memories was occurring. Several incidents observed and described in the lives of the four people suggest that the process is not one of recovery so much as of 're-creation' of a past life, fashioning it from images conjured out of statements and the visual media that surrounded them. Through the telling of stories, looking at photos, people and objects from the past and the imagining of oneself in situations recounted by others, Mark, Bryce, Rob and Max built up rich visual images of events, some of which were found to be factually incorrect, others were of times when they were deeply unconscious and could not have played the roles they clearly believed themselves to have had. Memory then, can not be regarded as just storing and recalling of events and ideas. It is also, or so it seems, the picturing and imagining of oneself in the past.

Paglia (1990:34) points out that western culture tends to overemphasise the importance of words in understanding and organising thought, underplaying and misunderstanding the "electrifying sign language of the image". She suggested that imagination can have a very strong influence over the interpretation we place upon experience. Throughout all four life histories there are continual instances when images had a powerful affect upon the person's beliefs about themselves. These images appeared to function as a whole, including "episodic" as well as "semantic" (Tulving, 1972) content. The people seemed driven to make sense of these mind pictures and to fit them into the totality of past history they were constructing. This need appeared to cause each of the people in varying degrees, to create memories of those parts of life that they could not remember, as if filling the gaps left by the brain injury.

In the medical literature such memory creation is termed "confabulation"[116] and often regarded in a negative light. However, in the story of these four lives, it was sometimes not a 'dysfunction' so much as a solution. The problems of disengagement and disorientation just described were often overcome by the creative use of such visualising and confabulating. These imaginings served an integrating function linking past to present where no more factual record was available. It is possible that it was necessary to create such images in order to achieve a sense of emotional as opposed to factual meaning in a reconstructed ontology. Poulos and Wilkinson (1984:71-8) suggest that the imaginal memory system may underlie the evocative property of all words and thought processes. Instead of using the word 'remember' in relation to anything personal, therefore, it would perhaps be more appropriate to use "evoke" (Poulos and Wilkinson, 1984:78) and instead of assuming it is word memory which is tapped, perhaps it would be more appropriate to see this 'evoking', as the engagement with what Sacks (1985:142) calls the "inner melodies and scenes". By implication, imagining is essential in reforging the emotional connections to a past ontology. Without mental images of the past which are recognised and owned, it seems unlikely that a person could again feel an emotional involvement in his or her present. The various ways in which this process of rediscovering one's history proceeds, therefore, probably offers more insight into ontological meaning-making as a process than it does into the recovery of some storehouse of factual contents. Memory-recovery is a process of 'reconstruction' rather than restoration, and a reconstruction which strives to make past and present fit with future, around the pivotal event of the head injury.

However, as important and positive as this creative rebuilding process might be in the early days, there is a clearly demonstrated potential for it to eventually thwart successful recovery, particularly when confabulatory ideas have contributed to the recreated ontology. The key appeared to lie in making a successful integration of *intra-active* and *interactive* meaning-making during the process of recovery. As Sohlberg and Mateer (1989:96) comment:

> **Confabulation.... is perhaps best correlated with the patient's ability to monitor his or her own responses and be self-corrective....**

This 'imagining to fill the gaps' appears to have interfered later with each of the men's ability to cope with the world. The more engaged with the outer world the person became through *inter*action, the more often their understandings would conflict with that of the others around them. They each reached a point when the level of consciousness was raised sufficiently to be confronted by this epistemological conflict.

Their individual responses to this experience of conflict reveal something of the inner workings of a possible 'image negotiating' process. Mark and Bryce showed increasingly sophisticated

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[116] See Chapter 1, p. 22.

attempts to align their self-understandings with those of others. There was evidence of a developing ability to accommodate and adapt for the conflicting ideas about them that others were expressing. They both also showed signs that they were learning to inhibit the use of their own imagination when its inaccuracies were fed back to them.

In contrast, Max was never able to develop any sense of certainty about himself. Whenever confronted with a conflicting version, he immediately accepted that his own story was incorrect. Although he listened politely to the other version, he did so with an expression of placid disinterest. He appeared to have no ability to adopt this new version and rearrange his own understandings around it. Because he was unable to picture himself in the scenes presented to him, they had no relevance for him and were like stories about someone else. Because he could not engage his ontological self within these stories, he failed to distinguish between fantasy and reality.

Rob's experience was is some ways similar to Max's, although he did have a much more coherent ontological scheme. His difficulty appeared to stem from a loss of certainty in his own evocations. Like Max, he was prepared to discard his own remembered versions as soon as they could be seen to contradict another's, yet these other stories never seemed real to him and he failed to fashion new memories which incorporated them. As a result, he was left in an ontological anomie, forced either to wait for others to define him, or to return to his now discredited original notions.

Together, these four experiences suggest that even when it is possible to recognise epistemological conflict between the imagined and the real, rebuilding a past and reconstructing a coherent self-image requires a reorganising of memories and experiences which blends past and present, creating a new reality which accounts for and makes sense of one's situation. Unable to manage this, the four learnt too often to discard their own beliefs and accept (wholesale and without engaging or interacting with it) the realities of the others in their world.

This technique of memory conjuring, therefore, initially needed to be encouraged to ensure that the person recovered a sense of personal involvement in their past, but later needed to be discouraged. The four people were progressively expected by others to align their definitions, adapting to and accommodating for others' ideas. While in the early days of confusion, some bizarre ideas were better than no self-concept or no self-engagement at all, there was an increasing need for the person to learn to blend their impressions with those of others, creatively resolving differences in order to reconstruct a workable identity.

A major task of helping people recover from brain damage may be to fuel and then rehearse accurate imaginal memory techniques, by using versions of 'visualisation' therapies. Offering back the past with visual media appeared to be a successful strategy, particularly with Mark, Rob and Bryce. Seeing photos, objects and people from the past helped to reengage the person in their own lives. Visual aids also encouraged a greater awareness of the impact of the accident. Photos taken in the hospital at the time of the coma were clearly powerful in helping these people to make the links between his present and past and to accept the reality of their accident. They could mentally place themselves in the centre of the dramatic situation that had been described to them but which they could not remember. This provided the basis for imagining the likely actions and thoughts of those around them which became translated into vivid episodes.

The ability to construct a new self-image can not be assumed however. Max's experience demonstrates just how alienated it is possible to become. He was often unable to recognise himself in the photos and although he enjoyed looking at them, it was as if he dispassionately inspected a stranger. For Max, this visual confrontation process did not seem to promote any acceptance of the accident, or any development of self-awareness. The two halves of his life remained unreconciled to each other and being unable to convert others' explanations and descriptions into inner images impoverished his sense of a self-concept and deprived him of a personal history upon which to draw.

THE DEFINITION OF THE SITUATION

It would be absurd to suggest that the recovery of a past is a simple matter of implementing an imagining process. As well as picturing, the minds of the four people needed to be able to explain what they were seeing. As they recovered, they progressively learnt to translate experiences into words and the words which then shaped their ideas helping them to make 'sense' of what was happening to them. It is therefore important to explore and understand the inner symbolic representations being formed with words or concepts as the four people struggled toward recovery.

Among the theories of the relationship between damaged cognition and behaviour reviewed earlier[117] was that defined by Goldstein (1952) as concretic personality syndrome. The characterological changes that Goldstein noted were clearly evident in the four men studied, influencing the way they were defining and interacting with their world. Examining these changes with the use of symbolic interactionist theory allowed a clearer understanding of how concrete thinking shaped the way Max, Rob, Bryce and Mark lived out their lives.

SEQUENTIAL AND RELATIONAL THINKING

All four people showed a tendency to think 'sequentially' or 'relationally'[118]. They were often unable to maintain a clear focus upon the object of their thought, being distracted by the next idea during the progress of a conversation. Conversations lacked a clear direction and the people all appeared "rigid, stereotyped and compulsive and abnormally bound to stimuli from without and within" (Goldstein, 1952:248).

Comments made by Gross (1987) about the competitive and the integrative styles of information processing suggest the main problem for the four men was one of limited mental space. A competitive brain clearly cannot manipulate a constellation of constructs or an "organisation corollary" (Kelly 1955:561) efficiently. If, as a consequence of the brain injury, a person's thought processes operate in a competitive manner, then each new concept will replace the last in a thinking 'chain' which cannot build upon experience. This conclusion is certainly supported by an examination of the four stories, particularly those of Rob and Max, neither of whom showed the ability to profit from experience or to mentally reorganise it. Action became arbitrary, just as limited in its coherence as the ability of the four people to make symbolic, conceptual sense of their world.

It should not surprise anyone who adopts a theoretical framework which assumes an 'interpreting self' that none of the four people completely stopped trying to explain and organise their experience. However, because this need to define what was happening persisted alongside severe difficulties in managing it, they were sometimes forced to act according to extremely incoherent understandings. The results were frequently bizarre and potentially dangerous. All four men demonstrated "triggering" faults (Norman, 1981:3)[119]. Their concretic thinking styles and "phased" consciousness (Luria, 1987:113), made them very susceptible to schema errors in the triangular link between symbol, image and object. Once produced, these faulty associations confused and disorganised their behaviour, making it seem irrational. Without effective metacognition, they were unlikely to notice such errors and correct them independently. This behaviour then tended to be interpreted by others as evidence of a lack of comprehension rather than as a triggering error and so no attempt was made to trace backwards, to understand and resolve the underlying schematic confusion. Since the problem was not resolved for the person, new and faulty schemata then emerged to progress and foster increasingly bizarre actions. Max, for example, rather than admit he had no idea what he was doing, calmly spooned honey into a

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[117] See Chapter 1.p. 23
[118] See Chapter 1, p.23.
[119] See discussion of the Executive System, p. 18.

teapot. Bryce would struggle to put something in the gaps on a form without knowing what the instructions meant.

Closer examination of many of these episodes of bizarre actions suggested a logic (sometimes unusual) underlay the actions of the four people even during the early days. One interesting possibility is that, lacking the ability to "associate" they were more inclined to "evoke" (Poulos and Wilkinson, 1984:78) the knowledge or ideas shaping their actions in more holistic and intuitive 'chunks'[120]. Max, two years after his accident, seemed totally dependent upon this mode of organising and directing his experience. Unable to reframe and reorganise, he relied solely upon the ability to 'recognise' a pattern in his attempts to make sense of the world and so decide how to act toward it. When alienated from verbal ways to interpret and understand situations and objects, tapping into a past habit offered a welcome release of tension and gave them a sense of direction, even when they were unable to frame the rationale for their action.

Clearly, the more access a person had to the familiar and habitual from their past the more likely it is he or she will discover connections and develop more appropriate discriminating powers. The four men were often able to access pre-existing knowledge and skills which nearly fitted present situations. There were occasions when use of these past habits triggered independent decision making, control and some adaptive use of existing skills. However, because the appearance of irrationality often led others to disregard the remarks and actions of the four people, they were frequently denied the encouragement they needed to explore and draw more effectively upon existing 'chunks' of habit.

Norman (1981:14) suggests that the causes and resolution of triggering difficulties are an important focus for future research. Similarly, Cicerone and Tupper (1991:272) believe that recovery should be understood as a re-linking of the "bottom up" and the "top down" styles of consciousness. The return to appropriate interaction might be characterised as the fostering of this fundamental drive to create meaning out of chaos. This clearly requires some 'putting into words' of experience, as well as the development of "deliberative rationality" (Dreyfus, H. and Dreyfus, S., 1986). It is only when they can be articulated that ideas can be shared and negotiated through interaction and so a more workable ontology can develop.

STORY-TELLING

Finding a more concrete, sequential way of recovering an inner ontology can be assumed to be driving each of these four people to some degree in their daily interactions. Three of the four

discovered that one effective method for accomplishing this, was the same forms of "story-telling" which Denzin (1987b:167-80) regards as being important to the recovery from alcoholism. Stories allow a person to weave together the past and the present so that they can learn to understand who they are and in this way a life becomes a whole. They also allow some objectifying of one's life, a standing back and assessing of it from the perspective of another. Denzin concluded that this has a powerful role to play in building a sense of identity and understanding and managing day-to-day existence.

There is no doubt that this story-telling technique was useful and effective and yet in each person's history there were occasions when the use of stories was counterproductive, confusing and disorienting the person rather than 'making sense' of anything. There were also occasions when the use of stories alienated others and caused them to be misunderstood and labelled as 'different'. There are several explanations for this and it seems appropriate to consider each of the men's use of story separately in order to understand the dynamics of meaning-making in this way more exactly.

Max's past was a confused blur to him and he had not, at the time of the research, recovered any sense of order and control over his self-stories. Nevertheless, when he was put in situations which drew upon past familiar and evocative scenes he became more keenly focused and able to situate himself within a story, linking the past and present. Although this may have given him a clearer understanding of his present position, the nostalgia for a time when he was competent and comfortable saddened him, making it painful to return to the present. The memory and the present reality were offering him dramatically different definitions of self. Definitions which he was unable to reconcile with the vague knowledge that he had "had an accident."

Mark, in contrast, who lost memory of his later teenagehood and remembered his childhood only vaguely, may have been left with very little of past mature interpretive schemes and negotiating skills to draw upon and his self-stories in consequence were more childlike. His inner scheme of self, as it was reconstructed within his story-telling, became dependent and approval oriented, impulsive and lacking in the level of mature judgement he was demonstrating at the time of his accident. It seemed his backward looking reflection confirmed this childlike ontological scheme. It is not surprising that Mark's parents regarded him as having regressed and saw the course of his recovery as similar to "growing up again".

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[120] See Chapter 2, p.69 where the Dreyfus, H. and Dreyfus, S. (1986) theory of consciousness and learning is explained in depth.

Both Rob and Bryce gradually recovered the ability to tell self-stories from their more recent past but for both of them, telling and retelling these stories became almost compulsive. Both had a tendency to dwell upon stories to a point where they were in danger of boring or exhausting their audiences. It seems very likely that the reason these stories were such compulsive subject matter was their essential role in reconstructing an ontological core in a mind limited to the concrete. It was as White and Epston (1990) propose, a "narrative means to reach a therapeutic end". As they told stories, the attention to detail suggested a form of 'rehearsal' was occurring, it was as if they were learning to play that role again and learning to place back within their present consciousness, the understanding they once had of how things were. Unfortunately, dwelling upon pleasant aspects of the past sometimes saddened and depressed them about a future which appeared less attractive.

Of course, there is one other obvious reason for the failure of each of the four to reconcile the past and the present through the medium of story. The recovery of both functions and memories was still occurring so rapidly. Although in their story-telling the four were able to incorporate and make sense of much that was altered about themselves, for any firm and fixed identity to re-emerge may require that they be confronted constantly with reasonably static deficits, allowing them to work these into their self-stories and build them into their ontological understandings. Only then would they have had the opportunity to reflect upon them and understand their significance.

Using narrative, therefore, may have assisted the four people in rebuilding an inner self, but it was not always easy to manage a simultaneous aligning of this emergent self with the present in which they found themselves. While Gross's (1987) and Goldstein's (1952) theories about limitations in cognitive styles certainly appear to fit the experience of the four, it proved very difficult to move on from diagnosing the attribute of cognitive rigidity to finding narrative ways to make sense of the world. Training a person to divide their focus between figure and ground was easier in theory than practice.

The central ontological core seems, therefore, to serve as both source and product of this process of story-telling, being constructed from self-stories which are re-creating it as they are told. The experience of these four men suggests that some semblance of a Heideggerian ontology is essential before a person can arrange experience in any but sequential or stimulus-response order. Until there is such a core around which to understand and arrange experience, no person can interpret his or her outer world in ways which integrate it into a coherent whole. The loss of a

secure and coherent sense of self may therefore explain many of the confusions with identity of these four people, as well as explaining their determination to tell and retell self-stories.

ENERGY AND PURPOSE

The discussion has so far focused upon the way in which four people were mentally restructuring their past and present through interaction and intra-action. However, living a purposeful life requires more than a present and past; it is also necessary to recover or reconstruct a future. Effective planning does not automatically follow recovery of past memories but requires an ability to programme, monitor and adapt behaviour to maintain a sense of direction. From a symbolic interactionist perspective, an adequate future orientation requires an ontological scheme which is sufficiently flexible to keep pace with interactive living and constantly renegotiate 'what is' to adapt for a changing world.

It is in this area of their life perhaps, more than any other that all four were failing at the time of the research. None of them was showing an ability to draw upon experience and self-knowledge and to rearrange it effectively to develop and carry out plans. Max and Rob were completely dependent on others, while Mark and Bryce demonstrated a cognitive rigidity in their attempts to plan and monitor which made their ideas unrealistic. All four men were still reliant to a greater or lesser degree, upon the significant other people in their lives for their sense of direction and this reliance was becoming increasingly pronounced as time went on. They were in a position where going along with what others suggested was rapidly becoming the only feasible option.

Effective future directedness clearly involves the monitoring, programming and verifying activities usually ascribed to the frontal lobes[121]. Often referred to globally as the 'executive system', the loss or less effective functioning of this level of consciousness can be seen as catastrophic for ontological self. A future oriented, self-directed and purposeful self requires the ability to objectify and analyse oneself in the "thrown" state of Dasein[122]. Crosson et al.'s (1989) model, which relates awareness level to compensation strategy, might be described, therefore, as a measure of temporal limitations upon one's ontological relationship to the world. Many of the cognitive problems of the four men can be seen as concerning the lessened degree of temporal agility available to them. While they often demonstrated an "intellectual awareness" and even sometimes an "emergent awareness" of their problems in interactions with others, "anticipatory awareness" (Crosson et al., 1989:47) was clearly still beyond the grasp of all four of the men. This restriction in their thinking seriously threatened their ability to take back control over their life. As

[121] See Chapter 1, p. 13, where the frontal lobes and frontal lobe syndrome are discussed in depth.
[122] See Chapter 2, p. 66 for a discussion of Heidegger's concept of Dasein in its "thrown" state.

Heidegger (1967:377) puts it, "Anticipation makes Dasein authentically futural... only so far as it is futural can Dasein *be* authentically." It may be that after brain injury, it is necessary to provide a person with a special sort of interpretive support or *scaffolding* to allow them to regain a future-oriented selfhood. By working alongside people and pointing out incidents which demonstrate how disabilities are affecting lived experience it may be possible to encourage the redevelopment of an anticipatory level of awareness along with its companion skills of self-monitoring and self-regulation. Thus a guided backward reflection may provoke new ways of framing the future. Using symbolic interactionism's concept of interaction as a negotiating of shared definitions, it can be seen that unless a setting allows (even prompts) a person to make associations between a current situation and a personal ontological core, only a passive and reactive level of participation will be possible. Creating the right milieu, one which is capable of controlling and pacing the development of insight alongside the rehearsal of everyday living skills appears to be a key function of effective rehabilitation.

COGNITIVE CONTROL AND PERSONAL POWER

In keeping with the symbolic interactionist tradition, the discussion has focused upon the defining and symbolising process and its role in recovery. The word interaction, however, presupposes an 'other' is involved in this reconstructing process. Symbols are negotiated in interaction and the meanings of other people therefore play just as important a role as one's own in a meaning-making equation.

Regaining consciousness, I concluded earlier, might be seen as the progressive process of making sense of one's relationship to the world. In all four life stories, however, it was possible to trace a parallel process taking place in the lives of the family members surrounding each of the four people, as they also attempted to come to terms with the crisis. The way they interpreted the situation then clearly had an important impact upon their personal relationship with this person in the hospital bed. Most of these family members talked to the four men about themselves. They talked about who they had been and how they would soon return to being that person again. Although Prue kept her talk to the most simple and concrete forms, the other three families were regularly offering a larger vision or picture of what was happening and giving indications of possible and probable futures. This talk was often directed at reassuring and sometimes at motivating them. The way in which these explanations were couched appeared to influence the attitudes the four men took toward their future and toward the recovery process.

For obvious reasons, these explanations and interpretations were strongly influenced by the medical definitions they were suddenly exposed to. The four people and their families all appeared

to accept and adapt to a way of seeing their situation as one of assessment and treatment. As a result, perhaps, they became accustomed to discussing the person as Foucault (1978) suggests, as a machine which was out of control, needing strong measures to discipline and realign it with the norm. Because of this, any activity which could be classified in a medical way began to assume an added importance and significance. Mark, for example, would participate in a simple family walk if it was called 'physiotherapy' and a game of cards if it was 'occupational therapy'; Rob happily subjected himself to art sessions when told it would develop his concentration and fine motor control.

Commentaries which justified and instilled purpose in daily activities, giving them a wider significance, were a common feature of the informal discussions, rehabilitation sessions and the review meetings. Bryce, Mark and Rob were soon able to enter into this defining process, reflecting upon their progress and upon the possible practical applications of new skills being learned. They could be seen to be slowly developing skills for managing this interpreting, allowing them to engage more equally in such conversations, learning to link together in their minds an activity or task in the present with a more abstract and general recovery goal; learning to see how certain difficulties they had might be representative of a more general change in the way they thought. They appeared to find these conversations satisfying and inspiring, showing in their responses that making these links was very important and self-motivating for them. Although some staff still tried to help Max reflect upon his recovery, he did not progress in this skill and by the time of the research a resigned acceptance of this had begun to colour the attitudes of staff and family.

Taking a longer term view, it is difficult to know whether these forms of interpretive assistance are a positive or negative factor in the recovery process. Sometimes under the influence of others' interpretations, the four people adopted self-definitions which removed their sense of control over their own behaviour. It was as if they began to view themselves as now living within an alien body and from here moved easily to adopting powerless roles which reinforced their feeling that they were incapable of controlling their own lives again. For example, Bryce learned and accepted that he could no longer cope with even small amounts of alcohol. He also knew that his visual perceptual difficulties had made it impossible for him to safely drive a car again. Both of these may seem important pieces of self-knowledge for him to own. Nevertheless, he happily, even proudly, informed anyone who would listen that he planned to hold a wild party as soon as he left Waimarie and as soon as possible he would also buy a car. When he took weekend leave he would regularly both drink and drive. It appears that, having lost control over such self-definitions, they lost any real power to influence him or change his behaviour.

This suggests that to become a whole person again required more than just accepting others' assessments and interpretations of the change wrought by the brain damage. It was necessary also to own these understandings at a deeper and ontological level. What it also suggests is that there is a period of time during which there is an intellectual level of disability awareness without an ontological blending. During this time, the person is at their most vulnerable to a loss of power over their own interpreting processes. The two levels of awareness did not occur together for any of these four men. Rob, Mark and Max, at the time of the study did not appear to have managed the transition back to self-constructed selfhood. Bryce, while having some difficulties in being consistent, was resisting any further loss of power over self-definition and determinedly interpreted his world according to his own inner scheme.

As Goffman (1969:2) points out, interpersonal power is expressed in the relative influence over the definition of the situation. Making the verbal links with the help of another's perspective did not necessarily translate into a change in inner self-beliefs nor a change in behaviour. Whether or not the reorganising of information promoted effective, independent and adaptive action seemed to depend largely upon the level of personal involvement within the creation of the interpretive schemes. Accordingly, it seems very important that this research make an attempt to differentiate between these two possible outcomes, looking for evidence of definitions that are negotiated and negotiated upon an ontological not an epistemological level of understanding.

Symbolic interactionism as a perspective and method focuses inquiry upon the varying influence of these inner and outer pressures upon the life being lived. An assumption is made that it is possible to "track down the ideological abuse" (Denzin, 1992:74) within interactions and identify how a person can trap themselves in oppressive relationships by adopting disempowering self-definitions. The experience of these four men suggests that when interacting with a person with traumatic brain injury, it may be necessary to adapt the normal flow of interaction, making conscious allowance for a slower, less integrative processing ability in order to avoid an unintentional imposing of alien interpretive schemes.

There was evidence of a some such shifting in the power relationships as the men moved from the Intensive Therapy Unit, to ward, home and rehabilitation programme at Waimarie, but it was not always suggestive of a move toward equality. There was a change for example, from 'treatment' to 'instruction' or 'guidance'. As the person recovered the ability to interact rather than react, the task of therapy changed from a concern with the purely physical and medical to educating and training. At the time of their arrival at Waimarie all four men expected to participate in their recovery but as instruction followers rather than active initiators and planners. Their compliance

was mutually rewarding, the staff feeling affirmed in their stance, the clients seeing evidence of improving skill with practice, of new learning and of growing confidence. Their non-compliance, however, was not interpreted as purposeful autonomous independence nor was it seen as a positive step forward. When they failed to perform activities designed for them the staff and family were more inclined to interpret them as lazy, or not trying. The downside of compliance emerges. The more the person accepted and shared the interpretive schemes which led to negative appraisals, the more he was inclined to give the power in interpersonal situations to others. Rob and Max had learned to let others define them, which was evident in their low self-confidence. They both constantly apologised for themselves in a vague attempt to become more acceptable. Mark, however, swapped erratically from using others' explanatory schemes to attempting his own and so sometimes displayed a proud confidence and at others times a despair and depression.

Bryce, whose rejection of others' definitions caused him sometimes to be labelled as difficult, appeared to avoid negative and disempowering self-appraisals. His ability to shrug off others' beliefs and live with the contradictions of a world without shared understandings left him with a sense of power and control. However, the control was illusory, as his beliefs put him in serious danger of harming himself or someone else. If he left Waimarie and proceeded to live the way he believed he could, he would very soon have found that society would remove from him the right to remain in control of his destiny. Clearly, encouraging self-definitions which were divergent from the others around him was not a responsible or ethically acceptable solution either.

Controlling the definitions of world then, must be regarded as a particularly significant skill which is severely threatened by brain damage. This finding closely reflects those of Goldstein (1952), Prigatano (1991), Crosson (1987) and Gross (1987) which call upon much larger sample groups. It is thus important to examine any possible strategies for overcoming this problem. As has been demonstrated in the discussion of interpersonal power, there is no way to understand the experience of the four people separately from their own personal involvement in their definitions. Defining is never a purely rational enterprise. It is always also an emotional appraisal. Unless a better understanding can be developed of the relationship between emotion or mood and information processing this field of rehabilitation will risk creating mindsets in people which are divorcing them from the inner self and real lived experience.

EMOTIONAL ENGAGEMENT

I have been concentrating until now upon the symbolic interactionist notion of interpreting and negotiating definitions of the world from which to act. The result is a view of human behaviour

which may appear overly rational and cognitive. However, during this discussion I have referred frequently to an inner ontology and suggested that unless there is a sense of personal involvement in the new understandings being built, there will be no purposeful, autonomous person at the end of the rehabilitation process. It is now time to examine further the role of emotional engagement in rebuilding a self after brain injury.

There was wide agreement from those who knew them before and after their accident, that the four men had less interest in the world around them, that matters that would once have engaged their attention now failed to do so. With Max, a bland, impersonal manner was only interrupted by occasional bouts of fury. Bryce, while seeming fascinated by his own past life was regarded as having a certain insensitivity to others and disinterest about some aspects of his new future life. With Mark the picture was not so clear but some similar change appeared to have occurred. He showed an intense interest in himself but less concern for others, less interest in the world outside his own immediate domain and less concern for anything related to his future. Rob was not regarded by anybody as different in this light and yet a tracing of the pattern of his days suggests a similar blandness and lack of intensity in his involvement with the world.

In Max and Rob, this lack of concern appeared to translate into a remarkable lack of engagement or a tolerance for doing nothing. Both had daily living patterns which included large sections of time sitting inactive, disengaged from the immediate environment. When an activity or an interaction stopped, they appeared to sink into a passive lifelessness. Although in contrast Mark and Bryce showed a need to seek out some form of stimulation, they sought activities which others would have seen as monotonous and repetitive. Mark would spend hours watching the road, counting cars and trucks, or shaking and throwing dice alone in the games room. Bryce would sit placidly through children's TV programmes, his eyes glued to the screen. Both these two would roam also restlessly and apparently aimlessly, around the buildings and gardens.

Thus, although two preferred activity and two inactivity none showed any desire to seek out stimulation or initiate anything creative or productive. Because they seemed unable to manipulate the level of their arousal, there was very little that was purposeful or autonomous. No doubt the same periods of inactivity could be observed in any one, at some moments over a typical day, but this pattern dominated the lives of the four men. The only stimulated and goal-directed activity appeared to be suggested and even arranged by others. As if to compensate for their loss of initiation ability, they all appeared drawn to look for it from another outer source.

Goldstein (1952:250), continuing his conceptualising theme, remarks upon his patients' apparent lack of emotion, suggesting that sometimes when there was no emotional reaction, it is because:

...he has not grasped the situation in such a way that emotion could arise... the patient may have grasped only one part of the situation - the part which can be grasped concretely and this part may not give any reason for an emotional reaction.

If Goldstein's understanding is correct, then a lack of affect does not indicate an irreversible personality defect caused by brain damage, so much as a problem in seeing connections and interrelationships which would once have incited an emotional reaction. The inability to define situations can be seen to have a serious impact upon the person's ability to engage with his world at all.

Constructivist learning theory assumes that when there is epistemological conflict within the human mind, it will stimulate a more reflective engagement. Similarly, from a phenomenological perspective, Sartre (1962:86) describes how at times of conflict between reality and beliefs, a magical transformation occurs, capable of altering the emotional charge with which the person appraises his situation. From both a constructivist and an existential phenomenological position, therefore, interpretive conflict is a prerequisite for a real inner engagement in the activities of living. A failure of cognitive processes to organise and of perceptual processes to perceive feedback together prevented the recognition of conflict. This in turn prevented the sustaining of a level of cognitive arousal necessary for any of the four people to be considered fully conscious or aware.

Manipulating interaction and environment to ensure the people are engaged and stimulated may, therefore, be a key part of successful rehabilitation after brain injury. In order to maintain an "optimal level of arousal" (Mirenda 1994) a careful fostering of the meaning-negotiating process may be necessary to ensure that positive and self-oriented meanings are created out of situations. People also need to be urged in a climate of "inspiration and persuasion" (Ben Yishay et al., 1985:255). Ideally such arousal manipulation should be a temporary measure as any outside source of stimulation, such as a structured programme, is potentially disempowering because it shifts the power back into the hands of the therapist. The four men's stories suggest a need for an increasing participation of the person in deciding upon the goals and procedures of recovery.

Of course, emotion is not as one dimensional as the discussion so far might suggest. Interaction situations generally require both emotional expression and emotional comprehension. These two functions involve skills which are qualitatively different from each other and it is possible to have an impairment which affects one more than the other[123]. The symbolic interactionist concept of a self can be seen to allow an awareness of this duality of experience and to focus attention upon

the processes which bind the two into an emotional intersubjectivity within which effective relationships are possible. Clearly those who work and live with people who have brain damage must acknowledge the human need to engage emotionally with the world and the converse need of social groups to inhibit and shape this emotion into acceptable forms which do not inflict its uncontrolled expression upon others. Just as is the case for those of us with a normal consciousness, the four people must find ways to express their emotion in their living without alienating either those around them, or the inner person. As Denzin (1984:273) says:

> **The subject then must learn his emotions if he is to learn who he is and who he can be. He must learn how to feel inside his emotions. He must learn how to place words in front of, alongside and behind his emotionality. He must learn too how to weave his emotions into himself and into his thoughts about himself.**

Central to both these symbolic interactionist theories, is the assumption that in fashioning our realities, it is necessary to "take the perspective of the other."

PERSPECTIVE OF THE OTHER

For a symbolic interactionist, social relationships are governed by people's projections of the attitude others might be taking toward them. Thus, effective human social interaction can only occur when people have sufficient abstract imagining ability to take (at least in some degree) the perspective of the other. As Goffman (1969:2) explains, we live "inferentially", and if our inferences are constantly incorrect, we become alienated from others and consequently alienated from our selves. This recognition that for effective living it is essential to manage this skill is one of the most distinctive themes of symbolic interactionism.

To manage this sort of self-reflection a high level of perceptual, cognitive and emotional integration skills are necessary; the very skills which research has constantly demonstrated, are most severely affected by head injury[124]. The four men in this study were all finding it nearly impossible to reflect objectively upon the impression they were creating. Many examples occurred of how this failure affected their relationships. Perhaps the most striking examples were those provided by Bryce in his attempts to establish effective intimate relationships with the opposite sex. Once he had misconstrued such relationships, his judgments about appropriate behaviour became hopelessly out of step.

For most of us, social interaction provides the arena within which shared definitions can be developed. By projecting our impressions and monitoring feedback, it becomes possible to align our own understanding more closely with others in a social situation, so ensuring that we

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[123] See Chapter 1, p. 34, "Emotionality" where the literature about the effects of brain damage upon emotions is reviewed and discussed.

understand our own role and the appropriate responses to make. Our behaviour is continually being regulated and controlled from within without the need for external sanctions or embarrassing disagreement. However, with a lessened ability to assess from the environment what is going on, people like Max, Mark, Rob and Bryce become more dependent upon their inner judgment. Although they all often became aware that their understanding of situations was not shared by others they could not proceed unproblematically to negotiate a more shared definition. In attempting to mediate between inner and outer demands, the inner "I" was too influenced by the "it" (Sacks, 1985:91) of the cortex, or the less controlled emotional and sensory needs, and not influenced enough by the more subtle cues from others, or by the "feelings of the moral self' (Denzin, 1984:124).

A careful reading of the four stories suggests that because this balance between self and other had been disturbed, the person often felt an "interaction-uneasiness" (Goffman, 1968:30) and they responded to this by attempting to rediscover these feelings of the self and moral person which Denzin described. It is possible that Max in particular, but also all three of the others, particularly at earlier stages of recovery, were externalising some of these once internal voices, taking a more concrete approach to conjuring an attitude from the other. Many of Max's more confused stories might be explained as moments when he became aware of a disapproving 'other' within him.

> **PRUE: Yes. He talks a lot about people putting him down and about having these arguments with people and sometimes we have these great long protracted conversations with him about some argument that he has had with somebody and I really don't know if it is fictitious or if it is something that happened to him many, many, many years ago.**

Without a clear inner voice of the other all four men would have become confined to the 'centre' of their inner stage. Other people could only be interpreted in terms of their relationship to them. Many of the more misguided conversational gambits could be explained in this way, suggesting that the cognitive damage had left them with an egocentric approach not because of a disregard for the perspective of the other, but because of an inability to take it. 'Egocentricity' is the word often used to describe this change after head injury but it has a judgmental and negative implication. Our culture clearly sanctions against a perspective grounded totally in one's own reality. A symbolic interactionist perspective in contrast, recognises the importance of finding the balance between the needs of the inner person and the perspective of the other in presenting oneself within relationships.

Appraisal of one's self from without and within can be seen to be essential to the rebuilding of an ontological basis for action. To accomplish this, the person must learn to create appropriate inner

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[124] See Chapter 1, p.34.

dialogues again. The use of 'feedback[125]' appeared to offer the four people the best opportunity to resume the monitoring of their behaviour. According to Keilhofner (1985:38), there are two forms of feedback, "external", or offered by the environment and other interactants and "internal", which includes enjoyment, competence and seeing progress toward a goal. Internal feedback will clearly cause a growing confidence in one's own ability to control one's destiny, while external feedback potentially threatens self-belief. Keilhofner (1985:16) suggests that how autonomous we feel will depend largely upon how much, in our ongoing monitoring of situations, we take into account the internal sources of feedback, as compared to those that others offer. For rehabilitation from brain injury to be successful, it will be necessary for the person to learn to align the inner voices of the social 'me' and the personal 'I' to an ontic and ontological self. The balancing of these two sources of feedback cannot be left to chance.

IMPRESSION MANAGEMENT AND ROLES

Without a sense of the perspective of the other, Bryce, Mark and Rob all had a problem understanding and interpreting the meaning of the different relationships they had with those around them. Because of this, they would often behave in ways that might have been appropriate for one sort of relationship but not for another. Mark kissed his grandmother in a rather sexual way, Bryce assumed all young women friends of the opposite sex were keen to have an intimate relationship with him. Max treated every woman as if she was his wife, even calling them all Prue and expecting them to know the details of his life. This inability to differentiate between roles was a source of embarrassment to family and friends:

Goffman (1969) recognises how often behaviour is really a performance of roles, or a "training ourselves from the outside inward" in the managing of effective relationships and a coherent identity. All four of the people were regarded as having lost some previous roles as a result of their disability. Because all these lost roles were so central to their sense of identity, however, the four men often still 'acted' them from habit. Goldstein's (1952:258-60) "past impressions", while allowing the retaining of some sense of identity, seemed also to hinder them sometimes, or expose them to the pity or embarrassment of others. To acquire new roles seemed to involve a clearer understanding of the impact of the accident upon their perceived identity.

It was not just their failure to adapt the roles they played, it was also the related problem with understanding 'team membership' and so shaping their actions to suit the particular person and situation. Goffman demonstrated how those who failed to "collude", or who betrayed the team

[125] The term 'feedback' is used, particularly in learning theory, to describe responses which provide the person with information about their actions.

projection, became treated as "non-persons" (Goffman, 1969:137). None of the four men were managing the reciprocal interdependence necessary to maintain a team front and as a result were largely excluded from group membership. Much of the behaviour of these four people can be interpreted as attempts to regain team membership. Bryce and Mark were finding this particularly difficult.[126] Rob however, who was nearing discharge, was playing quite successfully with team roles in group situations and with staff members whose company he most enjoyed. He appeared to be using these team relationships to "try out vaunted selves" and to "enter into collusive intimacies and backstage relaxation" (Goffman, 1969:181).

It is in examining these difficulties the people all had with achieving the sense of belonging and with understanding role relationships, that the pitfalls of lessened interactive competence was most pronounced. Within a residential setting, the nature of the audiences available limited the type of roles which could be rehearsed. The various settings of work, family and relationships with the opposite sex, were all now condensed into one space and role, that of a 'rehabilitatee'. The clear consequence of losing roles and losing team membership was a profound alienation from others and a loss of much of what was once central to their sense of identity and ontological self.

COPING STYLES AND PROTECTIVE MECHANISMS

One theme that occurred continually throughout the post-accident period was the confrontation with loss. In particular, I am thinking of times when the person was brought face to face with change to those aspects of himself upon which his identity was based. Day by day as awareness dawned, awareness dawned. Each was learning in his own way and at his own pace that life was going to be irredeemably altered.

All four people faced a vastly changed future from the one they would have seen for themselves just before their accident. Two had to deal with severe physical disability. All four had to deal with major changes to their cognitive and perceptual powers. Although Bryce, Mark and Rob all made some attempts to see a positive side to their injury, usually by vaguely suggesting that some changes might be "for the better", the truth was that in each case the changes threatened abilities and functions which were at the very core of his identity. Rob and Mark, for example, were both becoming recognised for their sporting prowess and now neither could play again; Max, now dependent upon others for his smallest practical need, was once a carpenter, capable of taking on any building or decorating problem and carrying it through from the design stage, to the physical

[126] See Chapter 13, p. 495, "Team Membership" for a discussion of the interactions filmed in the participant observation phase of this research.

details with hammers and saws. Mark was about to embark upon a university degree yet now had difficulty with a primary school level of written work. Bryce, the party goer, the heavy social drinker, the daring performer in cars and motor bikes, was to be deprived of all these roles. Each therefore seemed to have lost what was most central to them.

Because of the theoretical perspective, however, the concern in exploring these four changed lives has not been to assess the nature of the damage done by the injury, but rather to consider the response of the person to this damage. The research asks how the meaning-making person, faced with such facts of disability, used his information processing powers to mediate and shape this knowledge into definitions he could and did live with; definitions which allowed him to continue to take part in the world. Since it was these very same information processing powers which were an intrinsic part of the disability acquired, it can be seen that discerning and describing this process has been a complex exercise. It can also be seen that the issue often became not so much whether or not the understanding developed was 'accurate' or 'true' in any objective sense, but whether it was a useful understanding; whether it was a definition of the situation which allowed the person to reduce their level of handicap, to regain as much independence, adaptability and autonomy as possible.

CONCRETISING AND CATASTROPHIC REACTION

Sometimes it seemed that the secret to doing this well, was in unawareness, not awareness. I have already described how the four people lived in a world more confined to the concrete and explored how the loss of analytic forms of information processing had limited their re-developing interpretive powers. This appeared to affect the way they identified and described their disabilities, causing a preference for explanations which separated out one aspect of the body. Memory, eyesight and legs were spoken about as if they had become split off from the person and were now unwieldy malfunctioning items of equipment.

To a symbolic interactionist, a lessened ability to define and negotiate symbolic realities must be regarded as a severe threat for the emerging new self. Goldstein's (1952) analysis, however, leaves open to question how much these concrete limitations were caused by a need to protect an inner self and how much the limited capacity itself was creating the altered thinking pattern. It is possible that separated-out and self-limiting definitions like 'memory' allowed the preservation of an intact inner self. Concrete thinking styles may have functioned as powerful "protective mechanisms" (Goldstein, 1952:257), preventing the despair and frustration which might accompany a more authentic self-awareness, while still allowing the person to experience a full life. Because their awareness was more fixed in the present and more simple, the four men were

able to find intrinsic rewards in their day-to-day activities in a more transparent mode, without being thrust into a "thrown" state (Heidegger, 1967:174) where they would be forced to acknowledge their disabilities. Perhaps this is why their stories sometimes suggested a quality of peace elusive to many with far more sophisticated thought processing.

Goldstein, recognising how threatening a full awareness of disability might be to the person's sense of integrity, believes that catastrophic reactions occur to protect the ego from awareness. In three of the four people[127], catastrophic reaction could be seen to have performed just this function.

ANOSAGNOSIA AND DENIAL

Another concept which leaves open to question the positioning of cause and effect is "anosagnosia" (Babinski 1914). How to deal effectively with this lack of insight so common after a brain injury and how to distinguish between a clinical anosagnosia and a more psychological denial are recurring themes in the literature in this field[128]. Whatever position is taken upon the neurological processes involved, however, the result in practice is indisputable: there is an inability to profit from experience and an equal inability to record and organise it in a way that allows later self-reflection and self-correction. The perceptions the four men were developing of their disabilities differed considerably from all those around them and this interfered with their interactive competence. Just how such a phenomenon impacted upon the process of recovery and whether it was positive or negative in effect is difficult to establish clearly. It is possible to trace the impact of this lessened self-awareness in the lives of the four men, and to understand the dynamic interaction between insight and a developing new ontology. Each story reveals different ways in which these changes in thinking changed the experience of living.

Bryce, as he learned to read again, described the problems he had by the concrete and discrete definitions, memory and eyesight.[129] This interpretation allowed him to look objectively at a difficulty without losing his sense of self-worth. However, it also removed from him any personal control he could feel over his recovery. He could not, with heightened effort or with increased concentration, or with practice of skills, overcome such a problem. He became the powerless person waiting for the professional, the optometrist, to assess his loss and put in place a treatment. The more he talked of his disabilities in this way the more he was inclined to sit waiting, suffering Waimarie as a place in which to exist until his missing faculties would be

[127] In Rob's case there is no reported incidence of catastrophic reaction, perhaps because he never achieved this level of insight through information processing, or because he was never so threatened by the thought of cognitive loss.

[128] See Chapter 1, p.28.

magically restored to him. The reality was, however, that the damage was not concrete nor was it confined to his eye ball, but to his visual interpretation and perceptual centres. Every time he exercised his visual perception through interaction and then interpreted what he saw, he practised these skills whether voluntarily and consciously as during rehabilitation sessions, or involuntarily and unconsciously as during what he saw as the more recreational periods of his day. Over the months of his time at Waimarie, there was clear evidence of the gradual returning of more accurate visual perception. Although he was still far from normal in what he saw, he was less likely to offer a bizarre interpretation and his errors were more understandable and closer to what others saw. Gradually, therefore, with continued practice throughout this period, he also improved his reading skills.

The most interesting part of the story is what happened next. Bryce came to believe that the reading and writing practice and the occupational therapy sessions, were having an effect upon this returning function. Despite an initial reluctance to work at rehabilitation, an initial feeling that he was tricked into going to Waimarie, Bryce came to see himself as improving and to feel a sense of pride in his achievements. The combination of organised programme and supportive environment allowed him to blend together some compensatory strategies, the effects of spontaneous recovery and learning to apply himself and concentrate. These different factors combined to give him success and a heightened sense of hope, self-directed energy and most importantly, a sense of his own self-worth.

Mark, beginning with similar overly concrete notions of his problems, had, with the encouragement of his family, developed an interpretive scheme which defined effort as the key to recovery. He believed that he could influence his own recovery of memory, of physical strength, and of word use but that this involved 'trying', something that he was finding bewilderingly hard. Although his interpretive scheme allowed him to be in charge of his own fate, his deficits by the same definition, had to be owned as a personal failure. The result for Mark was the operation of the "double bind" which Bateson (1972) describes in relation to alcoholism. Believing that he was the master of his destiny, Mark needed to continually demonstrate his mastery to himself through 'testing himself out' in his interactions and activities. In the process he was so busy trying and competing and watching for signs of improvement and recovery, that he lost sight of the ability to live and life became a desperate and effortful cycle. As Bateson (1972) shows, the belief that one can control one's own body is all too easily corrupted into the belief that one 'ought' to be able to control one's own body.

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[129]See Chapter 7, Bryce Lawson's Story, p. 268.

An examination of Rob and Max's recovery processes reveals the operation of a similar general conflict between trying or waiting. Both men clearly lacked the planning, verifying and programming skills which Luria (1966) associates with the frontal lobes and so they had a very fractured and ineffective "Supervisory Attentional System"[130]. Under the circumstances they showed a tendency to act without noticing or reflecting upon their action at all. Instead of self-direction there was a placid acceptance of others' plans. They were content to take up any activity suggested to them and continue until required to do something else. This made them fit very well into the ethos of Waimarie where a structured programme kept them busy and actively engaged upon tasks which were regarded with approval. Interactions with the rehabilitation staff were full of good will as together everyone worked plotting, planning, charting and sharing the mutually rewarding pleasures of achievement and recovery. However, their rehabilitation programme was ultimately less effective than Bryce's because it did not inspire a more self-reflective attitude and encourage an independent building of a new identity. Without a redeveloping inner self-power, they risked remaining forever dependent upon others to offer their life a direction and a sense of quality.

Perhaps it was not so much the degree of self-awareness that the men brought to their activities at Waimarie which was important but rather how much they were influencing the shared definition of their problems and so, by implication, how much ownership they felt of the goals and processes of recovery. Equally important, perhaps, was whether or not these definitions allowed them an important role to play in assisting the recovery process, or consigned them to the role of powerless resignation. Together these two factors appeared to determine the degree of involvement and engagement the person felt. A person who feels an inner motivation is more likely to attend keenly and maintain concentration.

The important issue to remember when thinking of recovery is, therefore, not how aware people are of the nature and degree of their initial impairments, but whether or not they believe that they have a role to play in the rehabilitation process, or instead see themselves as waiting in a quasi-limbo state for the recovery process to conduct itself. Constant feedback which demonstrated progress, both internal and external, appeared to be particularly important in circumstances where there was anosagnosia, as well as a deliberate encouraging of the person to negotiate the definitions being made of their disabilities by others.

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[130] See Chapter 1, p. 18.

HUMOUR

Changed notions of humour were a feature of all four of the people's lives. Although each had his own distinctive post-accident style of joking, there were similarities between them which allow the development of theoretical ideas that relate the experience and expression of humour to the recovery of self after a brain injury.

Max once had a quiet wry humour but now he erupted into laughter at the slightest mention of anything to do with bodily functions. He also enjoyed any stories of others' humiliation and self-exposure. He never told such jokes himself but laughed when they were told to him, which they were as soon as the nursing staff knew it would 'get him going'. Mark and Bryce, in contrast, loved to make jokes themselves and, seeming to delight also in others' misfortune or failings, their main mode of humour was to tease others. Both were firmly convinced of their ability to make others laugh with their teasing remarks despite considerable evidence to the contrary. Mark would often be overcome with excitement when he managed to tease someone and would proudly draw others' attention to his joke. Bryce liked to turn his own exploits into stories which were on the surface humorous, but which seemed motivated by a need to promote an image of himself as reckless and feckless, denigrating others and particularly women. Bryce's flat mate, family and friends became irritated and embarrassed by constant allusions to his sexual prowess and to his supposed conquests, all couched in joking terms and by his attempts to use insulting remarks as humour.[131]

Denzin, Duncan and Goffman have all addressed the use and functions of humour as a social practice and their comments appear to be relevant to the interactions of these four people. Firstly, humour may play an important role in the developing of a new self-image. For Denzin (1987a; 1987b) in telling self-stories, a person creates a renewed sense of identity. An essential ingredient in this story-telling process for Denzin is humour. His phenomenological studies of alcoholics have convinced him that telling stories about degrading and humiliating episodes in humorous ways allows people to laugh at their own mistakes and deal with the sense of self-degradation which their alcoholism caused them. Like the alcoholic, the person with brain injury is very often divided against him or herself. As is frequently acknowledged in the literature about brain damage, a new self-concept must emerge during the recovery process; one which resolves the conflicting images of past self and new and altered self. In a sense, the self of the past must be laid to rest. In constructing this new image, it may be necessary to accept some negative ideas about oneself. There may be potentially humiliating aspects to one's new story. The residual physical disabilities

[131] See Chapter 10, p.396, 400 (BL Cycle 1, nos. 2 and 5) for examples of this humour.

may make one appear odd, the difficulties with memory can cause awkward and embarrassing moments. In coming to terms with these disabilities, it is helpful to be able to laugh at oneself, to stand back a little in order to recognise and enjoy some of the situations which can occur. Those who worked with Bryce, Max, Mark and Rob, have all recognised a place for laughter in affirming the emerging new self. It placed the problems at a distance from the people, so achieving a balance between accepting the fact of the brain injury and retaining a sense of inviolate self. This then encouraged autonomous action.

A self is not just an inner and private concept. It is equally that persona or front which we present to the world. Techniques which helped the four men to resolve "front management" (Goffman, 1969) problems with their now less controlled physical body are particularly important in this context of rehabilitation. Goffman (1969:202) suggests that in socialising with each other, we are "selectively inattentive" or we politely ignore the physical evidence of disability or any other difference which might threaten a person's presentation of a front. When situations thrust these problems forward, however and it becomes absurd and impossible to continue to pretend there is nothing different about the person, humour then allows the smooth integration and acknowledgment of such differences. Such humour may involve an open allusion to a handicapped condition to break the ice (Goffman, 1968). Max and Rob had mastered this social device more effectively than Bryce and Mark at the time of the research. Perhaps because their more obvious physical disability had denied them the level of control over appearances which Bryce and Mark believed they could sustain, both developed skills in integrating their disability through humour. With Max this was usually just a resigned or bemused smile (often paired with an "I'm sorry"), signalling his awareness of his own failure. Occasionally he would venture a self-derogatory remark. Rob, who managed humorous exchanges most successfully, also relied heavily upon these self-denigrating forms. His jokes usually concerned his own humiliation or front slippage (Goffman, 1969) and the resulting self-deprecating manner appeared to endear him to staff.

Because of the more frequent failures to sustain a front, the four people were also in danger of losing their power in interpersonal relationships. A doubt about one's self-presentation became a doubt about self-worth. Duncan (1968:60) suggests that comedy could serve to sanction doubt and it would seem that it had such a soothing and sanctioning effect. They all needed to relieve fears about their acceptability to others, particularly when they failed to control their now unruly body and mind. Mechanistic models, which assume it is possible to treat the physiological conditions without regard for the lived consciousness, ignore the destructive role that self-doubt can play in recovery. Benner, who urges the practice of phenomenological research in the field of

nursing practice, would suggest that this framework views "self as a possession" (Benner, 1985:1). To support and assist a self-oriented recovery requires instead non-dualist notions of subjectivity (Gatens, 1992) or a "self of possession" (Benner 1985:1), "inhabiting" the world and pervading our relation to other objects (Dreyfus, 1991:44). It can be seen, therefore, that in a setting where self-doubt is an intrinsic part of the recovery process, humour offered the four people a strategy which reintegrated their experience with their developing understandings in a self-affirming way.

The humour they used, however, seemed limited and distorted. If anything, this humour alienated the four men from others rather than allowing them the sense of positive acceptance they sought. While it might sanction doubt, it was likely also to encourage it; while it might play a positive role in self-acceptance, it was likely to prevent the development of equal relationships and team membership. To understand how humour failed them in interpersonal situations at the same time as it met their personal needs, requires an understanding of the levels of emotional intersubjectivity (Denzin, 1984:129-59) and their application to humour. Two categories in Denzin's typology seem particularly relevant, because they describe forms of intersubjectivity which occur when there is an inauthenticity in the emotional climate. The first, is "emotional infection" (Denzin, 1984:149), the second "spurious emotion" (Denzin, 1984:151).

In "*emotional infection*" there is no real feeling in common with the 'other' occurring, yet the sense of hilarity spontaneously gathers momentum and reproduces itself anyway. This is characteristic of the humour of Mark and Bryce, both of whom seemed to draw out jokes because of the sense of emotional arousal and pleasure which they were feeling rather than because of the response they got. Denzin suggests that this form of emotionality is often consciously sought out as a reaction to boredom, depression and loneliness, but that the person, rather than wanting a true intersubjective sharing with another's' feelings, wants to be caught up in his own pleasure. This description appears to fit the pattern of joking and teasing seen not only in Mark and Bryce but in several others at Waimarie, a pattern not exclusive to the people with brain injury but also used as a strategy by some staff, to keep themselves amused at what sometimes seemed the expense of the residents. The problem with this use of "emotional infection" is that it does not involve any real and authentic understanding of the other's feelings and so can be alienating and demeaning to all those who take part in such conversations.

The second relevant category of emotional intersubjectivity is that of "*spurious emotionality*". Denzin describes this as the equivalent of the psychological term, "egocentrism", characterised by an "inability or refusal to enter into the other's field of experience and view from that perspective"

(Denzin, 1984:154). The jarring lack of sensitivity described earlier in Mark, Max and Bryce demonstrated just such an loss of ability to empathise with an imagined 'other'. Once confined to a one dimensional style of thinking, humour lost its shared quality. It usually functioned as a rather crude (and unsuccessful) way to disguise intrusions of self into a conversation, a strategy that Goffman (1969:55) has described. Humour designed to attract attention or to shift the emphasis back to oneself is of doubtful use in developing more reciprocal relationships and yet in Mark and Bryce's case, it seemed to be the only humour they were managing.

Analysing the experience of humour in terms of a level of emotional engagement in interactive relationships underlines yet again a recurring theme of this research, that to develop an authentic ontology ultimately requires mutuality or reciprocity. It is not by interpretation so much as by negotiation with other people that new understandings about self are formed. Effective humour, because it involves the taking of each other's attitudes in the creation of shared meanings and understandings, is the playful manipulating of this negotiation process as part of the development and clarification of relationships. Humour is a potentially powerful tool in re-acquiring a balance within one's interaction and so a balance within the developing understandings of self.

THE DIVIDED SELF

The concept of a "divided self" (Denzin, 1984:202-205) reviewed earlier[132] may also have some significance in this discussion of coping strategies. I have previously described the characteristic egocentricity which can accompany brain damage, showing how it was an expression of an inability to take the attitude of 'the other'. I have also described how this egocentricity was often paired with its apparent opposite, a "losing of one's own self in listening to the they-self" (Heidegger, 1967:315). Rather than having a disregard for others, it seemed these people lived the contradiction of a *simultaneously self-centred and other-centred* way of being. Many of the conversations I had with the four people and their families suggested that it was just this pairing of an excessive self-consciousness with an equally excessive other-consciousness which was making it so difficult for everyone to grasp who the four people 'were' and, as a consequence, how best to support them in their 'becoming'.

For Bryce, being divided against himself was not a new experience. He appears to have spent most of his life swinging erratically and impulsively from one extreme to the other in his relationships. He appeared to make even major life decisions to gratify an immediate need, or to have a satisfactory impact upon others. As a result, his story at the time of the accident had little coherent direction. Denzin would say he had never managed to create within himself a

"meaningful grammar" (Denzin, 1984:108) of interpretation and emotional expression. This divided persona in Bryce's case may have established itself as an adaptive response to an uneasy childhood, but after his accident it appeared to have become more central. Perhaps attempting to mask his fear and deny the dawning awareness of cognitive and perceptual damage, he used his already established coping techniques (such as his 'macho' image) more extensively, interpreting situations as he believed this personality would. Because of this he was inclined to incorporate past memories and to interpret new experiences in a way which denied or distorted the role of emotion in his life.

Rob's pre-accident ontology in contrast, had been built around notions of self which were now impossible for him to manage; Rob the sporting hero, the stud, the 'body' was gone for ever. His accustomed way of relating to others, his ontic existence, all his roles within the family and community were very bound up in this identity, however and he was finding it difficult to re-create himself. As a result he showed many signs of interaction uneasiness[133] (Goffman, 1968:26) and uncertainty of status in his frequent apologies, in his submissive body language and in his quiet voice. He never seemed to feel sure what the 'attitude of the other' would be towards him, simply because his usual schemata of interpretation had become undermined by this loss of belief in his ontological core. Although he was managing to rebuild some sense of identity, this new identity was a very poor and powerless creature compared to its predecessor. Uneasy in his interactions, an other-consciousness began to dominate his relationships. This was not because he had failed to build a new self-concept nor because he was divided against himself, but because his new identity was considered too insignificant and worthless in comparison to that of staff, friends or family.

Mark, of course, also had a physical and outdoor pursuit oriented self-concept before his accident, but in his case it appears that it was not so central to his identity. He was more able to discard it, calmly talking of the need to give up rugby and of his inability to excel physically any more. For him, what appeared more central and important to an identity was to believe in his ability to build and sustain meaningful reciprocal relationships. Using the concept of a divided self, it becomes clear how this need to prove that he could love and be loved, in order to possess himself again, was causing him just as powerful and disturbing a sense of interaction uneasiness as that experienced by Rob. He needed to believe so strongly in the strength of his close relationships with others that he had to protect himself from any evidence which appeared to contradict this and in the process of providing this protection for himself, he would sometimes become angry and

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[132] See Chapter 2, p. 82.
[133] See Chapter 10, p. 364 (RJ Cycle 1, No. 4. "Relating to the Staff.")

abusive toward those whose affection and approval he most craved. Alternatively, he could seem blank and uninterested, lacking any concern about another's feelings towards him. There were several instances recounted during the interviews and acted out in the videotape collected[134] where his explosions of fury and temper could be seen as his fear of the appraisals being made by his 'other-conscious' self.

Denzin's emotional intersubjectivity typology includes the experience of "*emotional identification*". He describes this as the "submersion of the self in the other" (Denzin, 1984:151) and suggests, drawing upon Scheler (1970:13), that the person may in this way become 'lost' to himself. In Mark's case, his great need to be approved of was causing him to identify strongly with others and even to imitate them in an attempt to belong.[135] It can be seen now, that the greatest risk in this practice was that, in attempting to adopt for himself the roles of those he loved, he would eventually lose touch with his own inner ontological core.

Max it seems, had not developed anything remotely like this divided self at the time of the research. The reason probably had little to do with the interactive strategies of others, however and more to do with his lessened information processing ability. It appeared that he simply did not have the cognitive ability to manipulate and reorganise his experiences in terms of an imagined perspective of the other at all and had long ago given up any belief that he could. While he was certainly unpleasantly aware of his own inadequacies, both physical and cognitive, he did not believe that he could have any influence over the definition of himself that others held. This perceived inability to influence the definition of the situation should, according to the perspective of symbolic interactionism, be interpreted as the ultimate in powerlessness. Yet, in a strange way this also gave him a peculiar advantage over the other three. In this matter of ontological core anyway, he could be said to be at peace within himself. The sense of peace emerged, however, because of his total trust and faith in those around him, particularly his wife Prue. This unfortunately made him both vulnerable and dependent.

For Denzin, Sartre and Laing, this 'divided self' way of relating is clearly a learned behaviour; essentially a coping mechanism 'gone wrong'. Denzin believes that the stress of attempting to live with such a false self-system may be responsible for much of the violence and alcoholism within western society today. What becomes important to understand in the four stories, therefore, is how to foster those coping practices which protect the person from an awareness of deficit which threatens the sovereignty of their inner self, while at the same time preventing these same coping

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[134] See Chapter 10, p. 382. (Behaviour Exemplar MW Cycle 2, no 3. "Negotiation") and p. 378 No 1. Standardised Assessment.

[135] See Mark White's Story, p.178.

strategies from having a distorting effect upon the lived experience which eventually denies the person self-grounded power over their living.

EMERGING OR BECOMING

Perhaps then, there are some ways of coping mentally or emotionally with brain injury which are less effective than others. Some coping styles eventually appeared to work against a full holistic recovery because the person sacrificed inner emotional needs in order to satisfy outer demands or failed to find socially acceptable ways to meet these inner needs. Any useful framework for those who work or live with people with TBI appears to require some acknowledging that, although people will need to work through the recovery process at their own pace and in their own way, they will not necessarily have the cognitive skills to ensure an outcome which safeguards an inner self. This emerging process may well become destructive if there is insufficient support for an inner reconciling when crises occur.

In each of the stories, with the possible exception of Rob, there was a period during which a return into the community and family was attempted early in the recovery of consciousness[136], when the person was still clearly unable to deal cognitively or emotionally with the changes in relationship patterns and the increase in expectation of independence. In each case this experiment failed. The person, far from becoming more independent and 'normalised' with discharge, became more noticeably disabled when out of the setting of the hospital and any progress abruptly ceased. Without the support and security of a structured environment, the family members found the stress of caring for their relative overwhelming. There was considerable bitterness still evident as the stories of this time were told.

These experiences suggest strongly that there is a need to recognise a *liminal stage* (White and Epston, 1990:7; Turner, 1969) in the recovery of self after brain injury. It might be said that the four people at the time of the study were caught between the person who once was and the person who might become. During this time, it is possible that different rules need to govern the relating styles of the others around the person. Even when there is a completed physical and medical recovery, a person who has not fully 'emerged' from unconsciousness may become subject to an alienating epistemology without the opportunity to resolve the conflicts which arise. At this point, therefore, it seems important to reframe the recovery of the four in terms of a process of coping styles which represent 'steps' or 'phases' along a journey back to self-oriented

[136] Rob was in the Limmerton Hospital Assessment and Rehabilitation Department for considerably longer than the others. The breakdown of his support system at home before his admission to Waimarie appeared to have had less to do with returning consciousness and more to do with failures of practical arrangements and lack of family financial resources to counteract this.

awareness. If change and process is the most fundamental of the properties of recovery, then step or phase models deserve particular attention.

In recounting their stories of recovery, the experiences of the four people have so far been divided into a number of processes rather than a number of stages. However, there was some hierarchical ordering of these processes implicit within my descriptions of their experience. *Orientation to time and place,* for example, was shown as linked with the recovery of memories and particularly self-memories. And it was only when they were able to turn these memories over in their minds, rehearsing their meanings, that the four could move onwards and realign their self-understandings further. The gradual recovery of *awareness*, then brought about an even more gradual recovery of *insight.* In response to the developing insight, the four fashioned self-definitions and interaction styles which almost seemed to slow the return of a full consciousness, building themselves into a world which was in some ways self-limiting, while in other ways self-nurturing; preventing themselves from achieving more shared definitions and realities at the same time as it safeguarded their sense of self-worth.

In reviewing current rehabilitation models earlier in this thesis[137], I suggested that Ben Yishay et al.'s (1985) holistic model was a useful way of conceptualising the hierarchical ordering underlying recovery. It recognises both cognitive and psychosocial processes and sees the recovery process is one of progressive '*challenges*', not rigid 'phases'. Challenges involving a unique combination of needs and problems. Although each challenge is dependent upon the other, the six steps to "identity" are in essence the progressive blending of an outer social world with an inner mental world. The model is certainly useful in explaining the experience of Max, Mark, Bryce and Rob, perhaps because Ben Yishay's descriptions are more phenomenological than mechanistic, describing as they do a realigning of self and world. Although Max, Bryce, Mark and Rob responded to the crisis of brain injury in vastly different ways, with this holistic approach, themes and patterns, both individual and nomothetic, can be seen to underlie the diversity. By using this model, therefore, relationships can be drawn between sometimes bewildering behaviour and a slowly emerging ontology.

"Engagement" (Ben Yishay et al., 1985), the first challenge, is clearly essential before any real 'work' whether affective or cognitive, can be carried out. In discussing orientation to time and place[138], the distractability and shortened concentration spans of the early days of recovery were shown to be a serious problem for the four men because it prevented them making sense of their world and so developing a new relationship to it. However, this disorientation was erratic,

[137] See Chapter 1, p. 36.

improving when the person could link objects and situations to himself. A greater level of engagement was possible whenever strategies were discovered which allowed the person to reconnect his past knowledge with present experience. This reconnection allowed the person to interact or 'engage' again.

In the telling of all four stories there were several occasions when a lack of *"awareness"* (Ben Yishay et al., 1985:255), the second challenge, became the major problem for the four people and those working with them. This awareness was not an early challenge to be mastered once and then moved on from, but instead reflected the gradual, sometimes fluctuating process of adapting one's self-awareness to incorporate the knowledge of disability. Because none of the men were able to manage a consistent self-awareness of deficit, it was difficult for them to enter into a "therapeutic alliance" (Cicerone and Tupper, 1991:275) with family or rehabilitation team, with its associated qualities of "belief", "commitment" and "collaboration". When they were defined as insufficiently aware of their own problems, the men lost their right to contribute to the self-definitions used in setting the goals of rehabilitation. Max and Rob had reached a stage where they were content to let others define their problems, while Bryce and Mark still struggled for independence and denied cognitive and perceptual problems which seemed obvious to others. Until the awareness was authentic and came from an inner conviction, the only resolution of this conflict appeared to be to accept the imposed definitions and surrender some rights to sovereignty, at least temporarily. Without meeting and resolving the challenge of awareness well, therefore, the person will risk the fate Foucault (1988) sees of the many people who are oppressed by a self-negating "policing" process (Hutton, 1988:127), or an understanding which places socially prescribed goals of 'appropriateness' ahead of personal needs, confining him or her to ever more limiting definitions of self.

"*Mastery"(*Ben Yishay et al., 1985:255), the third challenge, is the level which a 'bottom up'[139] style of rehabilitation programme might call a 'successful outcome'. This is the moment when a person has adapted to the residual disabilities and again manages the skills of everyday living. The acquiring of skills, however, does not alone resolve the issues created by a brain injury. Damage to consciousness can leave a person capable of and yet uninterested in returning to his previous life, or alternatively unable to plan, regulate or initiate this 'living' performance. In fact, functional skill recovery in Bryce, Mark and Rob's case was almost a disadvantage for them. There was now nothing concrete upon which to focus in their need to rehabilitate themselves and yet they would still have failed in the real world because of their lack of adaptivity, purposefulness and

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[138] See p.287. of this chapter.

[139] See Chapter 1, p. 36, where models of Rehabilitation practice are reviewed.

autonomy. Once they felt capable of a task such as washing clothes or preparing lunch, once they had learnt it again, each of the four began to resist the daily practice of these tasks in their independent living situations. 'Just doing' such daily things began to seem meaningless in a rehabilitation setting where the person believed their only goal was to learn 'how'. Having achieved this and demonstrated it, it became important that the setting encouraged the move to the next level, *"control"* (Ben Yishay et al., 1985:255): that level of consciousness where the collection of tasks which make up the skills of living become effortless and automatic and it becomes possible to focus upon "the idea behind the act" (Ben Yishay et al., 1985:255). Without this level of consciousness reestablishing itself within, life for the four would remain either the effortful 'trying', interspersed with moments of 'giving up', or it would be the dependent, 'policed' living styles of Max and Rob. Control is perhaps a step toward making life meaningful in a more global sense again, because without ideas behind acts, there can be no real self-direction.

Heidegger (1967) and Dreyfus, H. and Dreyfus, S. (1986) recognise, as do Ben Yishay et al. (1985) that in most everyday activity, intentional consciousness is a poor substitute for unconscious performance. Until experience can return to an effortless "kind of sight" (Dreyfus, 1991:85) that blends thought and action into holistic chunks, living will remain clumsy, slower and effortful. Dasein needs to inhabit the world unself-consciously the majority of the time, only tapping into a reflective and objectifying consciousness when forced to[140]. The achievement of control is not, therefore, a learning task which can easily be fostered by effort or by the intervention of others. Clearly if it is to occur, it will require the informal settings of play and interpersonal socialising not the task and goal-oriented setting of a formal and structured programme. It is no wonder that it was this challenge that was proving so difficult for Bryce, Mark, Rob and Max to meet.

The model of holistic learning that Dreyfus, H. and Dreyfus, S. (1986) propose[141] offers a useful theoretical framework for working with people who are encountering the challenges of mastery and control. By the encouraging of *"grokking"*[142], a transition from problem solving to holistic pattern recognition and frame proliferation is facilitated. Therapist staff could further a sense of control by environmental adaptations which 'scaffold' engagement and awareness, holding these constant while the transition occurs from skill learning to the unconscious performance of the *"idea behind the act"* (Ben Yishay et al., 1985:255). In this way, a sense (even if transitory) of acceptance and identity may become available to people in the more 'transparent' states of

[140] See Chapter 2, p. 64 where Heidegger's concept of 'Dasein' is explained.
[141] See Chapter 2, p. 69, where Dreyfus, H. and Dreyfus, S.'s learning theory is explained in detail.

"proficiency" and "expertise"(Dreyfus, H. and Dreyfus, S., 1986:30), which might never be possible for them by abstract and metacognitive means. Even if people will require the external world to be pre-structured and pre-interpreted for them for the rest of their life, if this helps them to experience competence and transparency, then it is a goal worth pursuing.

The final two challenges in Ben Yishay's et al.'s (1985) hierarchical model are *"acceptance"* and "*identity*". The calm resignation of "acceptance" was evident in both Rob and Max, but the challenge of identity, which turns resignation into a redefinition of self, was a more difficult step. To understand the tasks involved, it is helpful to extend the analysis with theory from a phenomenological perspective. Heidegger and Denzin focus upon "authenticity".[143] The elusive ideal of authenticity is not seen, however, as something which anyone with a 'normal' brain automatically possessed, but instead as a certain 'intersubjectivity' toward which Dasein constantly strives. Perhaps the most effective description of this ideal of identity, therefore, is a sense of one's 'connectedness' or 'belonging' in the world rather than some isolated inner pinnacle of individuality.

When the four people's experiences are considered again in this augmented version of Ben Yishay et al.'s (1985) holistic framework, the six challenges can be seen as ongoing and never totally achievable 'fundamental properties' which those with brain injury share with us all. They are not steps to be climbed and left behind, but instead reflect the challenges demanded in any social living. Their theoretical separation from each other, however, appears to offer creative solutions for therapeutic situations which might not otherwise be evident.

In Max's case, for example, just because acceptance and identity are higher in the hierarchical order, they were not denied to him totally, but instead, appeared to fluctuate. When the environment allowed him to feel a sense of mastery and control he would relax into that transparent state of Dasein within which he appeared to feel 'at home' within his body. The carpentry activities he pursued in the sheltered workshop and the computer games he enjoyed and knew well enough to play 'without thinking', allowed him to achieve this state. He might never have recovered a constant orientation to time and place, yet because of his efficient procedural memory (Willingham et al., 1989:1047), even if it was stimulus bound and non-reflective, he could often manage a sense of self-assurance and integrity.

Mark's situation too, appears to confirm the value of this combined phenomenological/holistic approach for understanding experience. He had reached a point where he was beginning to feel

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[142] See Chapter 2, p. 70 for a description of this term.

[143] See Chapter 3, p. 64, where Heidegger's concept of authenticity is explained in detail.

competent again, but finding it extraordinarily difficult to switch effortlessly into the non-reflective absorbed competence of "*proficiency*" and "*expertise*"[144] and so he remained focused upon the mechanics of tasks. Although he had begun to tackle the challenges involved in *acceptance* and *identity,* he was often thwarted in this endeavour by the 'policing' tactics he had imposed upon himself earlier in his recovery in order to win approval from others. As a result, many of his attempts to negotiate these final challenges were unrealistic and doomed to fail. It seemed that until he left a residential setting, he would need to be thrust into progressively more real and unsupervised social situations where he could encounter interpersonal and emotional situations without anyone watching and ready to reward him for making the 'right' response. Hopefully, in such a setting, he could slowly learn to draw upon more internal forms of feedback and his actions would become as guided by inner needs as outer demands, causing him to develop skills of adaptive, purposeful independence.

Bryce, at the time of the research, was still early in his recovery as far as any time measurement was concerned. He took some time to become engaged and aware and had only recently become oriented to time and place. His awareness had abruptly increased during a home visit and, as a result, he was beginning to acknowledge his injury. He was, therefore, most engaged in "mastery" but having difficulty making the functional adjustments necessary to achieve "control", perhaps largely because the spontaneous recovery of sensory perception and cognition altered his lived experience too dramatically day by day. Until this emerging process slowed, it was unlikely that he would be able to accept his new limitations and refashion his sense of identity, simply because it is impossible to define something that is changing too rapidly. This highlights an important issue for those who work alongside people who are still spontaneously recovering, the need to help the person confront disability without the premature assessing of its nature and degree. In Bryce's case this uncertainty put him into a position of having to passively wait and accept his inability to predict and plan his future and this actively worked against his parallel need to take back the control of his own life.

It is especially interesting to measure Rob's recovery in terms of these six challenges. This is because he appears to have mastered the challenges of acceptance and identity, and yet his level of engagement and awareness was not very high and he had very little "control". As with Max, Rob's story demonstrates that although resolving higher crises does not depend upon mastery of the lower orders, without a competent self-awareness, the resolutions he negotiated for himself might be self-negating and disempowering. In his search for an acceptable ontology, he appeared

[144]The final stages of learning according to Dreyfus, H. and Dreyfus, S.'s (1986) model.

to have focused upon his losses giving a "passive, dependent and stigmatised" (Fugel-Meyer, A. and Fugel-Meyer, K. 1988:53) form to his new identity.

Despite this reservation, Rob's story deserves our further attention simply because he regarded himself and was regarded by others, as having achieved a quality of living which can only be called a sense of 'peace' and he appeared to have a firm sense of "connectedness" to his world. This was brought about by realigning his self-definitions so that they fitted with the ideas held by those around him. Although in accepting the changes wrought by head injury he came to regard himself as different and damaged, he was still convinced he had achieved an acceptable quality of living. He based his belief largely upon his knowledge that he was loved by his family and that he had developed caring reciprocal relationships with staff at Waimarie. For him this was proof that he still had the most valuable aspect of living in his grasp: meaningful interpersonal relationships. His life had become focused upon building such relationships with all those around him. Denzin (1984:201-238) would say that although he certainly showed some interaction uneasiness, some loss of self esteem and some other-consciousness, he had avoided the "divided self" approach to living and instead of being intent upon hiding his inner self from himself and others, he could calmly and freely admit his losses and his feelings of inadequacy, while still retaining a sense of self and of self-worth. Acceptance is "that calm resignation of the fact that some things cannot be further improved upon" (Ben Yishay et al., 1985:255) and following upon such acceptance, he was able to rebuild a self. To have managed this is quite an extraordinary achievement in the circumstances and suggests the power of the particular strategies Prigatano (1991) describes which draw upon Jungian notions of a soul in need of meaning and purpose. As was remarked upon in his life story, Rob instinctively turned to the "symbols of work, love and play" (Prigatano, 1989b:4) using the medium of song and poetry, so as to achieve with the concrete thinking processes and poor memory skills what even those with a high level of abstract and conceptual functioning could not manage. Rob's experience, it seems, offers something important to our understanding of the possible quality of living with a brain injury.

If independence, purposefulness or adaptivity (Wood, 1990a:3) are effective values for measuring quality of life after brain damage, therefore, it may be important to recognise they need not imply the level of intentional consciousness and abstract thought that would usually be associated with them. Sacks (1985:163-5) has written convincingly of the power of the concrete mind to grasp the most important and essential qualities of living:

> **Qualities of mind other than the conceptual - this is what we may explore with peculiar clarity - Much easier to comprehend and altogether more natural, is the idea of the preservation of the concrete in brain damage not regression to it, but preservation of it so that the essential personality and identity and humanity, the being of the hurt creature is preserved.**

Max and Rob's experience suggests that provided some form of meaning-making is occurring, it is possible to achieve an inner authenticity without the conceptualising and metacognitive levels of thought.

The experience of the four men suggests that while Ben Yishay et al.'s model is useful, it is important to beware of the risk of overly concentrating upon hierarchical stages. Each of the four men appeared to be dealing with more than one level simultaneously, but they were sometimes more focused upon resolving one aspect of self than the others. Despite this need for caution, there appeared to be role for such a model to inform people working to support a person's development of self-awareness.

Perhaps such models of phase and process are most important because they acknowledge a need for time delays which allow for the person to become progressively aware *through their interactions* of the problems they need to face. With Max, Mark, Bryce and Rob, the deficits and disorders were clearly evident to the medical team, but because of their cognitive problems, not to them. A successful therapeutic partnership, one which encourages participation and commitment, appears to require the pacing of rehabilitation in response to the level of awareness. Over this period, however, it is also clearly extremely important that the deficits in awareness be compensated for, that a supportive and caring atmosphere is provided within which the person can safely explore the way his perception and cognition is altered and learn how this is altering his relationship with his world.

It seems that the most appropriate interpretive framework for understanding recovery from brain injury may be not so much one of restoration of functions as it is one of monitoring and manipulating the rehabilitation environment, so fostering the most effective coping strategies for the available level of ontological skill. The role of the therapeutic staff suddenly becomes secondary to and dependent upon the inner self-defining processes of the person. Fugel-Meyer, A. and Fugel-Meyer, K. (1988) address the issues of rehabilitation in this way. For them, successful recovery is a reorientation which minimises the impact of the disability. Recognising the need for some concept of 'readiness', they suggest that in the early stages of recovery the person may develop permanently maladaptive defence mechanisms, ultimately preventing a more realistic self-awareness. They suggest that adequate empathy combined with the judicious feeding of information are essential if self-knowledge is to develop effectively. Fugel-Meyer, A. and Fugel-Meyer, K. (1988) would probably have classed Bryce and Mark as examples of 'pseudohealth" and Rob and Max as "passive and dependent" in their focus upon failure.

Perhaps equal interactive and interpretive power is not, after all, always the most effective mode of relationship during recovery. If a sense of peace can be achieved at other levels of awareness, it may be a more important role for the rehabilitation team to preserve the person's rights to control and dignity during a liminal stage when they have been involuntarily abdicated. It may sometimes be necessary to structure and arrange a setting so that the process of recovering awareness can be controlled and managed, not placing excessive stress upon the person, nor confronting him or her with ontologically threatening knowledge. Adapting of interpretive schemes so that they allowed a positive appraisal of the residual disabilities was essential to the acquiring of effective compensatory strategies. Provided this monitoring process is carefully managed there is no reason why even someone with severe deficits in awareness, with a permanent loss of arousal and engagement, can not recover a secure sense of ontological self upon which to base his future action, so becoming again within the limits of his brain damage, purposeful, adaptive and independent.

SUMMARY

This is a story about four people who had each grown up and developed characteristic ways of defining and interacting with their world and then, suddenly they acquired serious brain damage. Because of its potential to disrupt cognitive, perceptual and emotional processes, this injury was shown in each case to have put the four at risk of a profound form of alienation, from both self and world. From the time of their first stirrings from coma, each person had a different story to tell but in each story it could be seen there was the overriding theme of alienation and of a need to return some order to their understandings of the world before they could become reconnected meaningfully with it.

This study began with an assumption that there is within each of us an inner core of self. Much of the discussion explored the re-emergence of this inner self within both the interpretive schemes and the interactions of the four men. I have insisted throughout this discussion upon the power of a symbolic interactionist perspective to provide new insight into this process. The focus upon interactions and interpretations can be seen to have allowed a tracing of the dawning sense of self and a mapping of the re-engagement of this self in the world. Throughout this chapter, therefore, no matter which aspect of consciousness was examined, there emerged one central theme: the 'moulding' of definitions and understandings so that the four people moved gradually from a position of alienation to one of shared reality. They learned, it might be said, what it was acceptable to think, how much emotion was appropriate, what was realistic and what was fantasy. They learned what Blumer (1969:5) noted, that meaning is a social production and can only be derived from social interaction. The set of skills and the types of relationship which allow the

negotiating of shared understanding appear to be those most essential to recovery from brain damage. It was demonstrated continually in the four stories that a lessened ability to align actions to incorporate the view of others prevented the resumption of the role of a social human being.

The four stories then might be seen as the resolving by the person, the families and the various helping professionals, of a tension between difference and sameness. From the moment of their accident the four became 'different' and their efforts and the efforts of all those around them became directed toward overcoming this differentness. What these four stories suggest most strongly, is the two-fold nature of this task. It was important for them to develop an understanding of and respect for their unique inner 'I', yet it was equally important for them to redevelop an effective social 'me'. They needed to discover their difference, but also to rediscover their 'sameness'. Effective interaction and reciprocal relationships can only occur when it is possible for people to align their ontologies so that there is some intersubjectivity, both emotional and interpretive. The stories of Rob, Mark, Max and Bryce are stories of people learning to act symbolically in the world again by negotiating increasingly shared definitions.

What this finding suggests most strongly, therefore, is that an inner core of self is not separable from the world of people, objects and past history which created (and continues to create) it. Any examination of the process of recovery of a self must by definition become also an examination of the changing role of the 'other', whether an internal or external voice, in shaping ontological schemes. In the next chapter, the changing relationships the four people had with others and with their past self are examined and the way in which these relationships shaped the emerging new moral self are considered.

CHAPTER 9

RELATIONSHIPS AND RECOVERY

The previous chapter drew out the common themes in the experience of four men struggling to recover from the crisis of severe head injury. In each case it was found that although the nature of the neurological damage was significant in determining the nature of the impairments it was not possible to understand the disability merely by assessing the location and degree of the injury. The consequences of the brain injury could only be understood by studying it as it was transformed and responded to by the person.

This raises an important issue. The person encountering the changed situation already had characteristic ways of understanding the world and was already a part of a social network. Each of the four men had a history of roles, habits and relationships which they brought to the experience of recovering from a brain injury. There is no doubt that these had a major influence upon the stories. To answer the important questions in the field of brain injury appears to require of us that we explore "relationships" and not the "attributes" medical science has attempted to define (Goffman, 1968:13).

In this chapter, the influence played by the four people's relationships during the recovery process will be explored in more depth. Firstly, the impact of the pre-accident personality will be examined and secondly, the influence of significant other people will be considered.

CONTINUITY AND DISCONTINUITY

> **Any attempt at brain injury rehabilitation that does not carefully account for the factors predating the injury is probably doomed, if not to flamboyant failure, then to quiet ineffectiveness.**
>
> **Pepping and Roueche, 1991:217**

There is no doubt that the way in which Max, Mark, Bryce and Rob related to others, reacted to stress and assumed or avoided responsibility or power before their accidents, had a strong influence upon the manner in which understandings of self and world were being reconstructed after the event. Using a "Before and After Approach" (Sartre, 1963:85-166, Denzin 1989:197) in the writing of each life story has suggested that despite the catastrophic and life-transforming nature of the brain damage there was as much, if not more, continuity of the past as there was discontinuity. Past experiences shaped the person who encountered the experience of brain injury and to understand the experience of each man it was necessary to explore and understand the stories of events and people who belonged to this past.

PAST AND FUTURE IDENTITY

Because Bryce, Mark and Rob were all young at the time of their accidents, it was sometimes difficult to establish just what characteristics were fixed, habitual and consistent enough to be defined as personality. They all still seemed to be experimenting with roles and developing the reasoning and interacting skills which would eventually mould them into a more definite identity. Perhaps this framing of a young life as a biography can ascribe to it a sense of direction and intentionality which has not really yet emerged. Buhler (1968:184) suggests that although healthy persons experience their lives as a unit, this integration process is often not apparent to the person or others around him or her, until the individual is around 50 to 55 years old[145].

The work of Erikson (1959), a developmental theorist, is therefore used in this chapter to augment the main theoretical framework. This model allows the tracing of coherence and self-direction in a life still perhaps progressing, at the time of the accident, through developmental 'stages' toward adulthood. Erikson's work is used because of its clear alignment with the Ben Yishay et al. (1985) model in the rehabilitation literature and because of its dual or 'psychosocial' emphasis. The concept of a consistent identity can in this way be seen in relation to the more discontinuous notion of various and diverse challenges.

Bryce's story showed very little of a sense of coherent self-direction. His earlier life was sharply divided into chapter headings and in each chapter he was a different person playing a different role. His early childhood was characterised by uncertainty, to which he appears to have responded initially with compliance and later by withdrawal. The unusual relationship with an older woman thrust him into roles that very few other teenagers would have been familiar with or competent in. Later, when he moved to Limmerton, Bryce appeared to begin developing a more inner-directed sense of self. Although these later years were characterised by excesses, of sexual relationships, alcohol, cars, parties and drama, he was also working steadily toward self-defined goals. The geographical relocation appeared to allow him to develop a sense of purposefulness, evident in the successful completion of the dairy course.

In Bryce's case it seems that the event of the accident and its associated brain injury did not cause his identity to become fractured, it already was. He appeared to regard his life as a long battle to achieve independence from authority and control by others and as a result, resisted stability and close interpersonal relationships whenever they threatened to give another control over him. This habit of perceiving the world as hostile and potentially abusive, sometimes caused a negative and

alienating approach to the people involved in his recovery. He needed to demonstrate repeatedly that he was in control and so fell into the "double bind" that Bateson (1972:331) notes and actively thwarted his own recovery of control. He constantly made it clear that he intended to reject any advice which conflicted with his image of himself as reckless and pleasure seeking.

In terms of Erikson's theory, Bryce had negatively resolved several of the psychosocial crises already and as a result showed signs of "alienation" and "role diffusion" and "isolation" (Newman and Newman 1975:19). Before he could feel a firm sense of identity, therefore, he needed to achieve a sense of belonging and "group identity". This need may have been very significant in determining his sometimes negative attitudes to parent and staff figures, who were unwittingly standing between him and his peers because of the constraints placed upon his lifestyle by the brain injury.

In Bryce's case, the past history suggests that a geographical separation from any forces of control by others might elicit a more goal-directed approach. Waimarie and the staff within it, having a more impartial, defined and limited role in his recovery, could fulfil an important role in fostering a forward-looking and positive appraisal of the future. Rob and Mark, in contrast, showed considerable sense of purpose and direction in their pre-accident history. They were both successful goal setters and attainers. Although Rob had not established a settled employment history, this was a problem he shared at that time in New Zealand's history with many other young men with no qualifications. When he did find work he applied himself to it enthusiastically, not so much because of a wish to build a career, as in order to acquire the sort of possessions and lifestyle which a wage could provide. Mark's motivations for effort were perhaps more approval oriented than Rob's were. It appeared that he may have worked hard in part to achieve recognition from his parents and other authority figures. Because he had always managed to achieve this approval, however, the strategy had been an effective one for him.

Both these two young men could be said to have achieved positive resolutions of 'initiative', 'industry' and 'group identity'. At the time of their accident, their sense of identity was stabilising and, in line with Erikson's beliefs about the psychosocial tasks of early adulthood, they were developing a deeper sensitivity within their interpersonal relationships (Newman and Newman, 1975:270-274). In their case, therefore, the brain injury was interpreted by them as catastrophic because it interrupted their sense of developing integrity.

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[145]This remark does not, as it may seem to, contradict the central assumption of this thesis, that each of the four men needed to rebuild an ontological core. Heidegger and Denzin both understand this core to be non-conscious and comprised of relationships patterns rather than concrete and definite attributes.

Bringing their characteristic goal-directedness to this new situation, both Rob and Mark could initially be seen to address rehabilitation as a new challenge and earnestly apply themselves to overcoming the disabilities. Rob, however, after six years without having attained any of his initial goals had gradually lost the sense of direction and was settling for a more passive and dependent "pseudohealth" (Fugel-Meyer, A. and Fugel-Meyer, K., 1988:53). Mark quickly exchanged his scholastic and sporting goals for rehabilitation goals and applied the same rather erratic energy to this new challenge. There were signs of emerging disenchantment already however and like Rob, it seemed likely he would resign himself to 'pseudohealth'. Disorders of subtle judgment and interpersonal skills did not respond to effort and energy for these two men, as sport and school work did. The harder they tried to 'be normal' the more 'abnormal' they sometimes became as, in becoming a body-for-others (Denzin, 1984:126), they became alienated from their inner selves and policed by "rule of the moral" (Heidegger, 1967:312).

Max's story shows yet another pattern of continuity and discontinuity, one which had clearly been influenced as much by his manner of resolving these earlier psychosocial challenges as by recurring psychological characteristics. Max had always been self-reliant and conscientious in his approach to challenges. He enjoyed many forms of physical mastery over his environment and had the perseverance to achieve results and to improve his skill at any activity he enjoyed. This same characteristic was very evident in his approach to rehabilitation activities. He liked to be 'doing' something and provided he had a task to concentrate his attention upon, he would remain contentedly involved for hours. However, because of his confusion and disorientation, he was never able to move from a pleasure in the present to a wider understanding of his place in time, an ontology with which to regain interpretive control over the course of his recovery.

Despite the difference in their ages, there is much in Max's story which mirrors that of Rob. Max, before his accident, was also one to set and achieve goals, but in contrast to Rob and Mark, he took a great pride in doing a job well for its own sake and his life showed a pattern of unassuming effort and service to others without expectation of reward or recognition. Like Rob, however, he gradually lost this sense of direction because he lost control over those aspects of his life which had given it purpose and direction. Max could no longer work independently. Rob could no longer achieve sporting honour. Neither could manage a sense of equality or reciprocity in their interpersonal bonds. The loss of a sense of physical power translated in their minds into a more total loss of a sense of control. Neither could now see himself as a sexual being, for example, and both felt inadequate because of their perceived inability to impress a woman. Both had at the time of their accident been involved in a long term sexual partnership and in both cases (although this relationship had become even more important) it disintegrated and both felt personally responsible

for the breakdown. Max then, could be seen to be in danger of the "stagnation" and "despair" associated with middle and later adulthood, while Rob risked "isolation" (Newman and Newman, 1975:19).

There is no doubt that feeling a sense of continuity allowed the four men to make sense of their lives and rediscover inner direction and purpose. They were all inclined to grasp eagerly at any activity which allowed them to draw upon past knowledge and skills. However, it is important to point out that the stories also suggested that pursuing a sense of continuity too vigorously could have a negative effect upon recovery. When writing of continuity, it is important to remember that it is a fundamental property of human nature to manufacture it (Saillant, 1990; Buhler, 1968). It is possible, even probable, that each of the four shaped their self-stories to give them a greater coherence than may ever have been implicit within the lived experience. The need to create memories to fill the gaps in the past gave them a greater licence in such an integrating endeavour. This may have had both a positive and a negative effect upon the recovery process. As they dwelt upon the past they managed to own again some of their former status; and this was transferred then into their presentation of a self as much as their task performance. While this may have allowed them to avoid some of the fragmentation and alienation which a sense of discontinuity could bring it may also have encouraged them to draw upon past habits and roles which were no longer appropriate. This actively prevented them resolving the new problems which their disabilities were creating in their lived experience. The result may have been to present an image to the world of a greater continuity and endurance of personality traits than would have existed previously.

CONTINUITY OF A SENSE OF PERSONAL POWER

It is not only the pre-existing identity and coping strategies which influence the nature of recovery, but also the characteristic perception of the 'attitude of the other' and of the personal power held over the course of a life. To an interactionist theorist, realities are always inferential and how much notions of self are coloured by inferred notions of others' attitudes towards one's situation have important implications for recovery.

Bryce's previous life seems to have been ruled by a 'they-self' whose only morality was the pursuing of pleasure. The accident had not changed this situation, although there were indications that he might develop a more effective inner audience as a part of the rehabilitation. Max and Rob in contrast, would both once have been good examples of people with a strong sense of inner-directedness, but, as a result of their accident, they had come to feel more controlled by others and by outside events. Mark, unable to sustain a sense of personhood, was erratically

switching between external and internal sources of self-appraisal. In this way he would develop a moral point of view about his own action and situation and then find the expectations he had placed upon himself too demanding and reject the inner audience's voice in displays of anger and withdrawal.

This issue of inner control demonstrates the importance of maintaining or re-establishing an inner ontology which can account for and yet remain inviolate from the brain damage and associated disability. Max and Rob had come to regard what were in effect behavioural, physical and cognitive disabilities associated with their brain injury as indications that they were less valuable as people. Janoff-Bulman (1979), who distinguishes between behavioural and characterological self blame, suggests that to interpret failure or loss as characterological in nature will result in a sense of being powerless to correct it. Before their brain injury both Rob and Max had been more likely to frame their problems and challenges as behavioural. This had allowed them to feel capable of and in control of solutions. Because they had not been able to define the problems of brain injury in this way, they had made an unfortunate assumption that they had suffered a characterological change and so discarded their existing ontological understanding of the world. They immediately became powerless to act independently.

It is very likely that the reason Rob and Max were more susceptible than Mark and Bryce to such a devaluation of their own character was the more physical nature of their disability. The body-image they presented to the world was undermined by physical change too immense to be hidden from oneself or others. There was a constant reminder in interaction of the 'embodied' nature of one's experience. Their physical body had become external, like "equipment" (Heidegger, 1967:97), profoundly changing their relationship to the world. This necessity to think of one's own body as opposing and thwarting one's 'will', will clearly confuse the rebuilding of a new self-image.

Sedgwick (1985) suggests there is a tendency in the constructing of self-stories and in the writing of biography, to ascribe to the subject the role as the controller and central player and so to underestimate the role of social processes and other forces upon the story. It seems important in judging this issue of continuity of self-worth and self-power, therefore, to examine how social norms and expectations may have shaped the emerging new self-understandings. While Rob and Max, the more physically affected by their injuries downgraded their sense of worth and power, the other two, physically more 'intact', were more inclined to separate out and externalise the effects of the brain injury and so see them as something 'behavioural' which they still had the power to act upon. It is difficult not to conclude, therefore, that the variation in their self-

definitions were governed and determined largely by structural or societal assumptions about physical disability. There can be no incident more threatening to a person's sovereignty over self than a brain injury which combines cognitive with severe and visible physical disability. In such a situation, the inner person and the outer projected persona are simultaneously threatened.

EMOTIONAL CONTINUITY

It was in the area of emotion that perhaps there was the most confusion about continuity and discontinuity. Each of the men and their families made contradictory remarks, suggesting sometimes that they were less able to feel, sometimes that they were more able to; sometimes that they were expressive, while at other times repressing their emotion. One source of this confusion was that the four men could no longer understand or explain their own emotionality. This highlights a serious methodological difficulty in the study of inner feeling states after brain injury: the need to rely upon self report. The family of three young men and one self-contained middle-aged man, are not likely to have been privy to the inner emotional experiencing of their lives before the accident occurred. However as noted in the reviewing the literature[146], after any brain injury, but particularly one which has affected the right hemisphere of the brain, the ability to comprehend, judge or express the emotional content of stories and memories is considerably impaired. It is possible that the pre-accident stories given to me during the life history interviews, therefore, were already stripped of the emotion felt at the time, as the following account of a friend's suicide appears to have been in Bryce's case:

> **BRYCE... and we all went to bury him and we sat around the graveyard drinking beer. - I was just sort of peeved off with him, because he was just a year or two older than me and he goes and kills himself.**

It is clearly difficult, in this and many similar stories told to me, to separate out a neurologically related 'lack of affect' from a characterological trait.

As well as subjective reports about emotions, of course, the research was also able to draw upon the more objective data from the participant observation stage of the study. This material showed that, despite the remarks made earlier about the increased difficulty they appear to experience engaging their emotions appropriately, in their general emotional attitudes toward themselves and others, the four people all showed the strongest evidence of continuity with their past personality. Max was still placid and secure, Mark was still eager and ambitious, Rob was still laid back and easy going, while Bryce continued to be fiercely independent. Although the situations they encountered had changed, they appeared to bring to them their characteristic ways of appraising the world.

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[146] See Chapter 1, p. 29, "Language and Communication".

Hochschild, (1979:551) with her "emotion management perspective", offers an explanation for this observed continuity of emotional expression after brain injury. Although they had considerably more difficulty interpreting and making sense of their life, the four all still called upon habitual "feeling rules" and "emotion work" to govern their behaviour and appraisal of situations. Because these characteristic ways of feeling had become habits, the emotion in its expression may have appeared more continuous than it really was, being now less representative of the inner feeling state. The person, changed in his experiencing of the world, was not yet capable of constructing a coherent new ontology and so adhered to habitual ways of appraising situations.

Defining any situation involves some degree of emotional judgment and the emotional attitude determines the degree of energy and commitment brought to a project. Pepping and Roueche's review supports this remark, suggesting that past emotional habits strongly influence the attitude taken toward rehabilitation and in particular, the degree to which an individual will deny or minimise impairment (Pepping and Roueche, 1991:220). Since prior to their accidents, these four people could not have been more diverse in their habitual emotionality, they offer us an opportunity to explore the range of possible emotional resolutions and their relationship to the process of recovery.

It is possible that Bryce's characteristic resistance towards others' opinions had some advantages in this rehabilitation context. By rejecting any definitions of himself that involved a concept of disability, he maintained a strong sense of self-worth and believed in his ability to establish relationships and achieve vocational goals. When he did receive set backs, he shrugged them off with a grin, unconcerned about the opinion of others around him. Rob and Max, in contrast, both placid and accepting, approached people and situations with a trusting compliance which may have unwittingly deprived them of interpersonal power, even while assuring for them the goodwill of their family and the staff. A previous tendency to be eager and approval-oriented perhaps caused Mark to feel more depressed by his failures than the other three. As a consequence, it was he of the three who was most inclined to lapse into a furious anger and distress, a tendency which had not previously been characteristic of him.

The incidence of catastrophic reactions which I described in Mark and Max was a new component of their emotional make up[147]. Goldstein (1942,1952) relates it solely to brain damage. These two stories reveal another theme, one of a continuity of self-denying emotion management techniques. Max, for example, had always repressed anxiety and negative feelings. He was a quiet and self-contained man who had not ever really discussed with Prue some of the

emotional crises in his life. He expected to bear emotional pain alone and silently before his accident and appeared to feel obliged to continue this practice after it. Max, Rob and Mark, all once regarded as emotionally secure and well balanced by their families, might be described after their accident as trapped within a "false self-system" (Denzin, 1984:208). They had all lost the ability to feel authentically and their methods of resolving emotional conflict were now ineffective. The explosions of uncontrolled rage in both Mark and Max suggest the frustration of being disregarded and of losing their once secure personal control of their lives. The experience caused a "splitting apart of the circuit of selfness" which Denzin (1984:202) describes as implicated in the development of a divided self. Living with a divided self made each of them feel uneasy, anxious, guilty and sometimes lost, as in their attempts to rebuild an effective presentation of self they became overly submerged in the other, or conversely, absorbed by their inner emotional processes.

Although clearly the concept of a divided self is a very powerful one in the context of recovery from brain injury, there is also some evidence that becoming divided against oneself is not always a 'discontinuous' element in the life of a person with brain damage. In two of the four accidents reported upon here, alcohol was involved. In three there was an element of recklessness and irresponsibility. Many other situations where a serious brain injury occurs involve violence. Denzin (1984:238) equates such lifestyles with the distorted forms of emotionality and emotional intersubjectivity which are associated with the "divided self". In the small sample of this study, while there is no evidence of problematic emotionality in three cases, Bryce Lawson's belligerence and negativity clearly contributed to his accident. Earlier I suggested that well before his accident, he already had developed a 'divided self' approach to his own emotionality and in his attitude towards others. Because of this, his life had a certain instability and incoherence which might easily be interpreted as a consequence of brain injury, but which could equally have been the result of an existing spurious and inauthentic emotional process. Problematic emotionality then should be regarded as much a possible contributing factor as a result of brain injury.

Using Hochschild's framework also offers another possible source of emotional discontinuity, this time related to the loss of a metacognitive level of cognition. Once taken, Hochschild assumes there will be the ability to monitor and sustain an emotional attitude. It is possible that some of the instances of inappropriate emotionality in the four people suggest a failure in the metacognitive monitoring of emotional action rather than in the interpretation of the situation. With their lessened meta-awareness, the four people were less able to maintain a consistent emotional

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[147] Because at the time of the research he did not appear to experience any catastrophic reactions, I am assuming this was not an issue for Bryce Lawson.

approach. Each was regarded has having some degree of lessened inhibition and an impulsivity which can be seen as a failure of this process. It is possible that where there was continuity of feeling, there may not have been the same level of left hemisphere discipline (Tucker, 1981:20) over that feeling and so its expression suggested a different feeling quality rather than a different level of interpersonal and social skill. As Hochschild would say, the primary acts may have remained unchanged, but in the secondary interpretation become 'discontinuous'.

At this secondary level also, the emotional behaviour may be a pre-accident characteristic exacerbated by the lessened orientation, attention span and lessened awareness of the perspective of the other. Impulsivity was evident in Bryce's before-accident personality as much as in his later personality. Although not precisely impulsive before, Mark was described as not always having the commitment to succeed. What was previously a slight lack of ability to sustain attention, or a slight problem with emotion management became magnified into a problem affecting recovery. As Pepping and Roueche (1991:219) suggest: "It is fair to say that the brain injury tends to exacerbate or intensify preexisting personality difficulties."

THE INFLUENCE OF THE FAMILY UPON THE RECOVERY PROCESS

Characteristic patterns then, can be seen as an important factor in determining the approach a person will take to the crisis of brain injury. These characteristic patterns were not developed in isolation, of course, but evolved in interaction with a family group and others. The people who knew them most intimately before their accident and related to them as people rather than as 'patients', had now become thrust into a new relationship with them and with each other. They all experienced a crisis as real and life-changing to them, as it was to the person with the injury. The way in which they dealt with this crisis and the way in which they adapted their lifestyle and family relationships had a very significant impact upon the four men, upon the process of their rehabilitation and upon their return into the community. This second section describes the influence the family of each of the four men had in shaping the person during the recovery period. It describes how the significant people in their lives defined and understood the new situation; and how this influenced the men's actions and decisions.

Pepping and Roueche (1991:222) point out (and the four stories in this study confirm) that the family the person was living with at the time of the accident is likely to be drawn into any treatment regimes. An assumption is made that this family will always be healthy, present and able to involve themselves in the rehabilitation process. The experience of the four people revealed the reality of families did not always fit either of these assumptions. Rob, Mark and Bryce were all at that time in their lives when they were leaving home while Max's living arrangement was a

reconstitution of two grown and departed families. Each family in its own unique way was not so much either "healthy" or "present" but rather a complex of interdependent relationships and roles, some of which were more easily adapted to the new situation than others. Sometimes they could function as healthy and present, at other times this was too excessive a demand upon a busy life. Taken together, these four stories suggest a more careful analysis of the impact of brain damage upon relationships within family groups may reveal important ways in which close others influence the renegotiating of self. Armed with an understanding of such interactive dynamics and recognising the uniqueness of individual family patterns, it may be possible to involve families more effectively in the rehabilitation process.

Earlier, in examining each story, considerable attention was paid to the developing interpretive schemes and coping strategies of the various family members. Clearly there were (running parallel to the story of each subject) other stories of conflict and change to be told. In some ways, this second-hand experiencing of head injury could be said to have been equally as devastating, pivotal or epiphanic. There are a considerable number of studies which address these family issues directly and explore the question of brain injury from the perspective of the family members[148]. This research in contrast, specifically concerns the individual and his or her intra-active experience of brain injury. The focus of this discussion will, therefore, be limited to the manner in which the developing interpretive schemes of the family members and their actions as determined by these, affected the process of recovery of a self in each of the four people.

THE NEXT OF KIN AND THE POWER OVER DECISIONS

It is important at the outset, to identify just who is being referred to in this section as the family and what relationship, both official and emotional, existed between them. The family members with whom an interview was requested and granted were in each case regarded by the clinical team of Waimarie (and earlier by the acute medical team and all other agencies implicated in the story), as those with the next of kin status. Because of this, during the period when the people were unconscious and in a situation of serious medical crisis, any important decisions were referred to them. In three of the four cases the identified family involved the two parents, while in the fourth, Max Kavanagh's case, the most significant family member was his second wife, Prue.

The role definitions could not always be so simply established as could the next of kin status. Nor could an assumption be made that these definitions were always shared by everyone who was involved in the playing out of the four stories. Max, for example, had first to relearn who Prue was before he could regard her as his family. Having completely lost any memory of the time they

were together in Limmerton, he was initially bewildered by her presence and inclined to look around for a parent or for some other person from his past to take charge. He had managed by the time of the research, however, to place Prue back in the centre of his world and she was by then probably even more important to him than before his accident. He anxiously turned to her to interpret and control every detail of his life.

Although Max was eventually happy to accept Prue as family, he didn't really accept that her own family and friends had any relevance to him and perhaps because of this, he didn't really belong again in Prue's family as a part of the whole interdependent system. This put some pressure on Prue who seemed to feel, as a result, that she had a personal obligation to her own family and friends for the support they gave her so that she in turn could support Max. It is interesting to speculate as to what would have happened to him if he had not married Prue and had been single at the time of his accident. It may be that his own sons, his brother or his ex-wife would have been obliged to play a larger role.

In the Lawsons' story, the fact of a broken marriage again caused some confusions in establishing the acceptable and legitimate role relationships. Ann Lawson, like Prue Kavanagh, was in a position of having more choice about assuming a caring role and yet at the same time less obligation. Because of some misunderstandings (and perhaps on the part of the Wimberley Hospital staff, for the sake of convenience)[149], she also suffered from the assumption that she had proportionately less right. She eventually came to see her position as one of competing with her estranged husband for Bryce's attention and for the right to a parenting and caring role. Although she sometimes asserted herself and demanded to be involved, the sense of competition and suspicion persisted throughout the period when Bryce was unconscious.

It is interesting that in two of the cases, issues of broken marriages confused the role relationships and made it difficult to establish clear expectations about how to involve the family in the recovery. This has implications for New Zealand where reconstituted families are becoming common and yet institutional assumptions about the family's obligation to provide unpaid care remain unchanged. Belonging to a conventional nuclear family with a set of unconditional obligations towards each other gave Rob and Mark an important sense of belonging and security. Their primary relationships were unambiguous, understood and accepted by everyone involved and this gave them a distinct advantage over Max and Bryce. Nevertheless, in retrospect, both of these families felt that the institutions assumed too much of a nuclear family's ability to provide

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[148] See Chapter 1, p. 32 "Social Interaction".
[149] See Chapter 7, p.256.

care when the adult members were committed to full time jobs and other siblings had emotional and financial needs of their own. Both families felt that the resultant stress was destructive.

Because of Mark, Bryce and Rob's age and status as minors at the time of their accidents, there would never have been much doubt about the most appropriate person for the health system to identify as next of kin. But it is interesting to note that even at the time of the research, when these three were young men of 19, 20 and 24, their relationship with their parents was similar to that of a dependent younger teenager, expecting to be controlled and organised. Mark and Rob quite clearly saw themselves and were seen by their families, as being an important if rather dependent element in a close-knit, supportive nuclear family structure with a strong extended family network. Bryce, although he had left home long ago and resisted control by anyone, could be seen to regard his parents as having some rights over him and responsibility for him, particularly during the earlier days of his recovery. This reflects a finding of Oddy et al. (1978:614) that a very severely injured group[150] of single patients returned to dependent relationships with parents. Because of this high level of dependence assumed by the parents and accepted by the people in three of these four cases, it is possible that there will be a risk of over-estimation of the influence that family members in a more general sample of the brain injured population might have.

Bryce's relationships at the time of the research were perhaps the most complex and, because this had considerable impact upon the playing out of his story, it requires some further clarification. Although his father was regarded (by the two hospitals and by other agencies involved) as the next of kin, Bryce, over the time during which this research was conducted, changed his attitude from one of calm acceptance of his father's resumed power and control over him, to a resentment or irritation about the presence of either parent. As he gathered confidence in his own position, he increasingly came to assert that he felt he had nothing in common with his parents and preferred to identify a small group of friends and later one particular girl friend, Stella, as his most significant family. Interestingly, in the early days of crisis, Stella attempted to assert her right to a more central role but when Bryce was unable to confirm her statements the acute medical team were unable to give her a role in decision making[151]. Later, when conscious, although he could not remember her and although his other friends insisted that they had parted some time before

[150] This term was defined by Oddy et al. (1978) to mean a PTA of more than seven days. All four of the people in this study experienced PTAs considerably longer than seven days.

[151] See Chapter 7, pp.248. Although Bryce believed he wished to live with Stella during the time of gathering data for this research, their relationship only survived for a few months after his discharge and, at the time of writing this thesis, Bryce was denying his paternity of her son and had moved back to Limmerton to be near his other son.

the accident, Bryce eagerly accepted her offer to partner him and so forced the rehabilitation team at Waimarie to acknowledge her right to be involved in future planning.

While happy to have them interviewed for the purposes of the research, Bryce was inclined to disagree with any interpretation his parents placed upon anything and to reject any ideas about his future they might have offered him. Nevertheless, since the accident they had been involved by all the relevant agencies and had, almost by default, assumed power and control over his recovery and so over his future life. Because of this they had, regardless of his feelings, assumed the same influence as the other families had. They were also in a position of having information about the period of his unconsciousness and PTA which he needed to reclaim from them as a part of his recovery process.

Bryce's story, like Max Kavanagh's to a lesser extent, demonstrates how conventional assumptions about families influenced the rights and obligations placed upon the various players in these four dramas. These assumptions it seems, became like self-fulfilling prophecies, shaping the course of the person's future life and the roles available or expected of him. No obligation could legitimately be placed upon Stella while her status was so unofficial, nor could it upon Bryce's other friends. No matter what feelings they professed to have during the early days of drama and crisis, without the status of kinship, according to societal convention, nobody could hold them to any long term commitment to care. Bryce's parents were very aware of this and tried to persuade him that their own commitment was likely to be the more durable and reliable.

One clear disadvantage of a residential setting may thus be that issues surrounding the reworking of family role relationships can remain unresolved over the time when long-term future planning needs to occur. When the person and the family sit down together and visualise the future, it may be an unrealistic picture which emerges if they have not had time to live the conjectured roles and discover in practice how it will affect their interrelationship. It was difficult from within a residential setting for example, to be sure whether or not Bryce's relationship with Stella was or would become the reciprocal and supportive one he believed it would be[152]. Mark could not imagine living independently of his parents in the flatting situation nearby that they hoped to arrange for him and clearly (at the time of the planning), hoped that he could return to being 'cared for' at home. It was equally difficult for Rob and his parents to imagine him managing independently as an adult in a flat attached to their house, as he had always been cooked for and cleaned up after, when he had lived at home. Prue, because of the eighteen months of struggle,

[152] The findings of other studies suggest this may depend upon the extent of the permanent damage to his functioning. Oddy et al. (1978:614) found that for the very severely injured, there was a significant fall in the number of close friends at a six month follow up interview.

was in the strongest position regarding role relationships. She was well aware that the transition from wife to full-time carer was unhealthy for both her and Max and she actively worked to avoid it happening again.

BEING THE NARRATOR OF ANOTHER'S STORY

The first concern I had in interviewing each of these next-of-kin relations was to fill in those parts of the story which the four men were unable to tell for themselves; the details of the accident and the early days of acute hospital care. It was soon clear that filling in these gaps would not be difficult. It was striking how vivid and detailed a description each family member was able and willing to give of this time. It seemed that, in its telling and retelling, the story of those early days of crisis and drama had assumed a solidity not in the original experience. It was not so much 'told' as 'recited' to me in each case, as if it had been told many times before. Even when, as in three of the four cases, the family member was miles away at the time of the accident, the story was told with a sense of certainty and truth and when anything could not be verified, or when there were two possible interpretations, that too was included in the telling.

It occurred to me that the stories had acquired this quality because of the need to tell and retell them to different people, including ACC officers, the medical and rehabilitation staff, the family and friends. Last in this line of recipients was the person with the brain injury himself. By the time Max, Bryce, Mark and Rob heard the story of their accidents, therefore, it was coloured with an air of certainty, of ritual and of official importance and sanction which may have made it more believable and more significant than any more personal impression of that few minutes of human error and confusion could have been.

One of the main themes of this telling and retelling, at least during the early days, appeared to be to resolve the issue of blame. In these four cases, as in most others where a serious accident has occurred, there was an opportunity to lay the blame at someone else's door. In Rob's case it appeared that the accident was the direct result of someone else's neglect, while in each of the other three cases, but most obviously Bryce's, the accident may have occurred because of the person's own error of judgement. The eventual conclusion reached by each family, however, was not that there was no blame to apportion, but rather that there was no point in tracking down and punishing others for errors of judgment. It could be that the needs of the unconscious person to have a calm and reassuring presence conflicted with the needs of pursuing vendettas.

DS: You didn't take this any further though, why was that?
FRASER: I don't know.
PIRI: We were just so involved with Rob -
DS: Right, so it was easier to drop it than to -

FRASER: Yeah. Well I had that much hassle on my mind then I just thought well, its happened now so even if I went any further, that wasn't going to get Rob back on his feet again, you know ..

Although Fraser and Piri Johnson spoke only of the best use of their time and energy, it did seem as if both they and the White family were reluctant to attribute blame. There was a sympathy for those who might be expected to feel some guilt and perhaps a wish to protect them. This understanding was apparently passed on in the telling to the four people - none of whom felt any bitterness about the actions of others, or of themselves.

It was probably significant to the person's recovery that this positive resolution occurred. It would have discouraged any dwelling upon what was lost and focused conversation instead upon the future. This is perhaps particularly important in situations where the person might have been expected to feel a sense of personal responsibility. Gans (1973:178) suggests that it is possible for some family members, because of unresolved feelings of anger and blame toward the person, to disregard his or her feelings and thoughts during and after the recovery period.

A similar telling and retelling treatment was also given to the story of the days that lead from the accident until the emergence of each person from coma and it is interesting to observe that the families were not always so forgiving of others about the difficulties that occurred over this later time. Originally each family, feeling powerless and shocked, was more than prepared to rely upon the medical team for definitions of what was happening to the family member. As the people who had the right to hear any information first, they then became the 'passers on' of this information they had absorbed uncritically, to all the others who inquired. In the telling and retelling, it seemed that they built confidence in these interpretive schemes, elaborating upon them with examples and qualifications and adopting them as their own, eventually coming to regard themselves as having some authority and ability to draw inferences and to see changes in patterns.

Being in possession of the 'whole story' clearly made the family important over this time. New people who needed to be involved in the drama, such as ACC staff, therapists or social workers, generally required such information and in circumstances where the person was unable to tell their own story, family members were often the only others who had been present throughout all the stages of the drama. Most importantly too, once the four people themselves began to emerge from coma and interact again, they were able to pass on and repeat as often as necessary, the details which the people needed to hear in order to fill in the gaps and reclaim that part of their life.

Saillant (1990:97), in writing of the experience of living with a terminal illness, describes this interpretive process as the building of a "semantic network", or a synthesis of all the points of view available. She suggests that this explanatory scheme would be as much a product of personal history and belief systems as it was a synthesis of the information given by the medical professionals. This constructed story then clarified what role or part to act and so influenced the way in which the people approached this crisis in their lives. As they waited beside the bed in those early days, the closest family members would turn over what information they had available in their mind and build coherent explanations of the experiences their unconscious family member was going through. Gradually, as it developed, this semantic network transferred the interpretive power from the medical professional to the family members. These developing interpretive frameworks then began to guide any appraisal of the medical team's performance and to shape the images and goals of possible futures and so, by implication, the roles the four men took in the present.

Severe brain injury is not easily 'interpreted', however, no matter how much knowledge is acquired. Accurate prediction is impossible and the situation can change bewilderingly from day to day. For example, whether or not they should be glad of their relative's continued survival, was one question very few of the family members could have answered with any certainty even months after the accident. Whether they should hope or grieve, therefore, was a constantly renewed judgment call. This confusion about what to believe and what to hope for, coloured the stories which the families were constructing. Because it continued well into the later period of recovery when the four were becoming conscious and beginning to build their own understandings of their situation, it very probably affected their self-perception as well. Being the historian and the archivist became increasingly more difficult for family members when Max, Mark, Bryce and Rob began to play a role themselves in the interpretations produced.

Each family member could be seen to compensate for this uncertainty in their story construction and the way they resolved this issue appears to have been very significant in determining how they responded to events and situations which occurred later on in the recovery process. In creating meaning, they clearly also created roles for themselves. Juliet White, for example, tried to educate herself and became something of an expert on brain damage so that she could get the detail of the story right. Bob Lawson and Prue Kavanagh, finding more practical roles to play, accepted for the meantime the explanatory schemes offered by the experts and recited these as truth or fact. When in Max's case recovery slowed down and 'plateaued' sooner than everyone had hoped, Prue's stories were told with an increasing cynicism and bitterness in her tone and a tendency to divide up her narration into what 'they said' and what actually happened. Clearly, in her story, the

experts had become responsible because their failure to predict the future accurately had prevented her getting the story 'right'.

While the Whites and Prue Kavanagh based their semantic network upon a medical model of interpreting, the Johnsons and Alice Lawson appear to have found religious beliefs and an intensely emotional appraisal the most useful meaning framework within which to describe what happened. Because of this they managed to reframe the accident in ways which gave it more purpose and meaning within the larger scheme of their lives. This way of understanding had the advantage of giving them more powerful roles to play in the drama.

> **ALICE: ... I was praying and asking the Lord because I believed that he was going to be a vegetable and I asked Him to take him if he was because I wouldn't be able to handle it if he was a vegetable -**

It is interesting to note that while the families were devoting considerable energy to creating these epistemological frameworks, the four people who might be thought to have the most need to explain and understand this pivotal event in their lives were far less inclined to do so. None of them seemed to question why the accident had happened to them nor did they attribute any deeper meaning to it. It was an accident. It was as if, in taking on the role of the narrator at this time, the families had absolved the person of creating meaning out of chaos. Each was able to accept wholesale the pre-interpreted version which was handed to them later in his recovery.

THE FAMILIES' ATTITUDE TOWARD THE MEDICAL AND REHABILITATION TEAMS

All four families clearly had several important roles to play to maximise the recovery of a purposeful, self-oriented life. As the main source of a personal history they, more than anyone else, could define for the four men, who they 'were'. As the next-of-kin, they had the strongest legal rights to make decisions, effectively controlling the range of possible futures. For these reasons their interpretations about what was happening probably had more influence over the person's self-perception than any other person. At some stages however, the medical and rehabilitation staff, assuming that their expert knowledge was important to recovery, asserted a greater degree of control than the family. In such circumstances of shared interpretive control, it is clear that the nature of the relationship between the family and these teams was an extremely important one, potentially encouraging or discouraging a successful and happy outcome. Although an ideal scenario would clearly involve a consensus and partnership in a shared vision of recovery, the experience of these families suggests that some degree of tension and conflict is almost unavoidable in the particular set of circumstances which surround severe brain injury. Only one man, Bob Lawson, of all the people in all the four families, felt he was always working in concert with the people within the system.

A closer examination of the four stories suggests that the primary reason for this sense of conflict was the complex and changing nature of the recovery process at a time when it was important for everyone to agree upon a common and stable interpretation of it. It is extremely difficult to find a consensus about what it is appropriate to feel and think, or what it is realistic to predict for the future, when the person concerned is changing daily, even hourly. Because of this uncertainty however, it was difficult for the parties to arrive at shared plans and agree on common goals. In each case interpretive frameworks were continually being created, dissolving and being recreated. As the situation changed, the people concerned relied upon their own set of knowledge about the person, on the one side personal and on the other clinical in tone, in order to interpret what the change would mean. The conclusions drawn about what some new change would mean and what was the most appropriate response, were understandably often very different. This was frustrating and destructive of efforts to work together.

Since they did not define the situation in the same ways, the family, the rehabilitation and medical staff would not always promote the same attitude toward the present or the future when they were interacting with Max, Mark, Bryce and Rob. While Mrs White wanted Mark to develop fixed routines of flatting skills, the occupational therapist wanted to teach him to set priorities, plan and make decisions about his everyday living. Until all parties were agreed as to the nature and degree of permanent disability and until some hierarchy of needs was established channelling everyone's energy, it seems likely that this shifting quality to the interpretation and the interactive conflicts it created, was inevitable.

Another possible reason for these tensions between family and staff was the greater emotional investment of the family members in the person and his recovery. The confrontation with the reality of disability in a loved family member is clearly a painful experience. It is possible that some of this pain became transferred into anger against those who were making them confront the changes. Several of the family mentioned feelings of resentment about the apparently dismissive or demeaning attitudes of medical staff, particularly after the initial medical crisis. In each case, the sense of being dismissed appeared to be related to the different quality of the attitudes expressed about the person. Slowly, the drama and importance faded from the conception of everyone else except the immediate family. As they were increasingly out of danger but still 'disabled', it seems that except to those who loved them, they became less romantic and less important. These people who once had seemed to care as much as they did, were beginning to disengage from the situation and it dawned upon the family that their involvement had been a 'role performance' rather than an authentic emotional intersubjectivity. The reality of having a son or husband with a brain injury was suddenly not glamorous to others; it was instead a

devaluing of his identity and, by implication the identity of his family, rather than a heightening of the drama of his life.

This greater level of emotional investment which the family members had, led to a greater investment of time and thought. This unequal energy input was then yet another possible source of tension. At the same time as they were experiencing this sense of being less important some of the family members gained a confidence in their own significance and centrality to eventual recovery. As they informed and educated themselves further, both about brain injury and the structures and systems which had power over the resources they needed, Juliet White and Prue Kavanagh and to some extent the Johnsons, discovered that the experts or officials upon whom they had earlier depended for understanding and definitions were often uninformed or thoughtless. Although they may have known more about their own immediate area of expertise, very few had reached the same level of holistic awareness of the person's situation as they had. They began to see that their own views were just as valid (if not more valid) and that the 'experts' really only assessed and charted the course of the unconsciousness and physical stress, rather than altering its nature. The former deference became sometimes even a disgust and distrust towards those in whom they had put their trust earlier on; in those who had seen them at their most vulnerable and let them down. As a consequence of these discoveries, Prue Kavanagh and Juliet White stopped relying upon others from within the system to meet their needs and took control of regulating and organising the recovery process for themselves. From that time onwards they saw themselves as using or manipulating the system in a rather cynical but proactive way. They became more assertive, defining the relationship they had with professionals upon their own terms. Willer et al. (1991:463) have pointed out how empowering an experience it is for the family when they discover these resources and energy within themselves and begin to take over the control of the course of recovery.

These negative feelings were not necessarily passed on to the person with a brain injury however. In all four cases the family seemed to see their role as one of "shielding" this person from the system's hostility or impotence to help them, acting as reassurer, security provider, advocate and even possibly political activist on their behalf. The view of their recovery being offered to all four men during the research period was a very positive one. The message they were uniformly being given by both staff and family was one of hope. This attitude was often more significant and influential than it would have been in a nonbrain-injured person, being absorbed wholesale and yet ultimately it probably had less influence upon the person's own interpretive scheme, being either misunderstood or forgotten. Without a more authentic negotiation between the person with the

brain injury and his significant others, shared understanding was unlikely to guide the rehabilitation process. The scene was set for conflicts and misunderstandings.

Another possible cause for negativity of family toward staff was the differing ideas about the likely permanence of damage. As the emergence from PTA progressed and signs of more permanent damage began to be evident, there was a gradual shifting of attitudes occurring and it was at this point that there was some splitting off of the family's definitions and appraisals from those of the medical professionals. It appeared to be easier for family to adjust to and accept physical disability than it was to accept cognitive and emotional change. With Bryce and Mark, who had very little visible change in physical or motor ability, there was a tendency to be considerably more optimistic about eventual future recovery. Bryce's parents believed that the accident would make no difference to his life in the long term, but hoped that it would serve as a lesson to him. The Whites accepted that Mark might not manage a university degree, but hoped that he would manage some sort of tertiary level training and an independent career and living arrangement. These two families still felt hopeful of a full cognitive rehabilitation and seemed inclined to wait a little longer before reorganising inter-family roles, or taking a particular attitude to the accident and its meaning in their lives. The two families dealing with physical disability found it easier to imagine a future which would require major adaptation and rearranging of everyone in the immediate social network. Perhaps because of this, Rob's and Max's families never criticised them for a lack of effort as did the other two: failures and problems were more likely to be attributed to disability than to personality. While this may have made Rob and Max feel more acceptable to their family, at the same time the implicit implication was that they had less potential to become more valuable in the future.

Obviously also, the placement in a residential setting at the time of the research had considerable impact upon the reflections of the family members. Waimarie perhaps served as a welcome respite from the need to keep up with the constantly altering interpretive schemes. As a residential rehabilitation setting, it offered the families time to adapt and rearrange their thinking. It was also easier for them to put off making such realignments until they could feel more certain about what was appropriate or possible. Turner's (1969) liminal stage, therefore, may be equally relevant to understanding the experience of the immediate family as it is to understanding the person.

Thus it was not only the person with the brain injury who needed to negotiate a new reality but also each significant family member. The way family members interpreted and presented the four men's situation and future prospects to them was extremely significant in governing the direction of the recovery. The family were in a position to encourage a sense of vision and to create a new

sense of purpose and self-direction. Yet this interpreting and explaining role was a skill which required considerable mental agility and the four people were not equally served by their families.

RE-NEGOTIATING FAMILY ROLE RELATIONSHIPS

Severe brain injury, because it disturbs the organic and emotional bases of awareness, can permanently alter 'character' (Pepping and Roueche, 1991:215). A large part of character is the habits and roles which shape and organise it (Keilhofner, 1985). Without roles "people tend to experience a lack of identity, purpose and structure in their everyday life" (Keilhofner, 1985:27). From the perspective of symbolic interactionism, recovery from brain injury could be regarded as largely a matter of role recreation and reorientation. Understanding how this process involves the family as a system of role relationships is therefore extremely important to understanding recovery.

The concept of role which Goffman (1969) and Kelly (1955) propose is essentially interdependent. Because of this when a person is initiated into new and altered role relationships there will be a period of negotiation (Keilhofner, 1985:29). In the context of head injury recovery, it can be seen that the period of time during which the four people were studied was one of one of renegotiation of roles. Having recognised this, it may seem that the only place to reestablish relationships after a brain injury is within the family and community setting in which the new roles will eventually be played. What is essentially reciprocal and symmetrical can surely not be re-instilled either in isolation or in a residential setting where none of the fellow players or team members (to use Goffman's dramaturgical metaphors) will be present. The problem with this logic, however, is that it ignores the potential for disempowerment, for becoming a "non-person" (Goffman, 1969:137) or of managing only a "sick" or "invalid" role (Keilhofner, 1985:26) when thrust into everyday life situations while confused, disoriented and unable to process information effectively. In a stable family this loss of interpretive skill could and did create a dangerous vulnerability; in a family simultaneously reorganising itself after a crisis, the effect will be even more unpredictable. At the time the person became medically stable and could be returned to the home setting, the emotional stress and the drain in energy resources which caring for the person had placed upon the family was already causing strain. Once combined with the demands of caring for the person at home, the burden was almost intolerable, as Klonoff and Prigatano's (1987:382) research also confirmed:

> **...typically full-time supervision is required initially and the entire family's routine is shifted to accommodate these demands. This results in feelings of anguish, confusion and frustration. The end result is often marked disruption of family functioning. At the same time, family members are still likely to be in the grieving process, asking such questions as "How did this happen?" or "Why did this happen?. Throughout this early phase after discharge, however, hope generally continues that the patient will be restored close to his or her pre injury state.**

Being alone in the house with the person with TBI was very different from supporting them in a hospital setting and it became considerably more difficult to absolve the person from blame and regard the emotional and cognitive disorders as disabilities rather than personality defects. Eventually, the families attempts to manage at home, seemed to strip the four men of whatever previous identities and responsibilities they had within the family unit. What could be casually referred to as "agitation and confusion" in a hospital setting, became a frightening unpredictability in a private home. What could be defined as 'managing with assistance' in hospital, seemed like exhausting, back straining, physical dependence at home.

In the case of Max, Bryce and Mark[153], it quickly became clear also that it was not only the person with the disability who was made vulnerable by an early discharge home. In two cases the women in the families remained at home alone with a much stronger man and experienced real fear. These two men learnt the power of violence and unpredictability to control and manipulate others. When the primary consideration is to keep the peace, the roles which develop may satisfy the immediate situation but be unacceptable and inappropriate in the long-term. This was clearly not the ideal setting within which to renegotiate any role relationship.

Because of the pivotal role being played by the crisis of the head injury, there was also a danger that, at the same time as they were having difficulty reestablishing the previous social roles for themselves, the family's attention was focused upon the disabilities of its injured family member rather than abilities. The result was a tendency for each man to feel that he had become important to his family *because* he had had a head injury rather than in spite of having had one. In order to sustain the interest and attention of their family, it may sometimes have seemed to these four people that it was necessary to 'play upon' their disabled condition, reminding their family of their need and right to claim more than their share of the family's energy.

This negotiation process cannot be separated out simply, therefore, from the reality of physical and cognitive disability and because of this, it cannot be managed by just anybody whom fate has placed in this position. Although families and others in their immediate network would have longer term relationships with the person than the medical and rehabilitation staff would, perhaps during this liminal stage it was better if Rob, Max, Mark and Bryce rehearsed and negotiated new roles with people who had more knowledge and expertise in the area of brain injury and less emotional involvement than the immediate family. The family may also have benefited over this time from support which assisted them to reflect upon and reshape their own roles.

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[153] With Rob this was not as clear. The period he spent at home prior to his admission to Waimarie appeared to be more one of a gradual disengagement from the family life, until he was sitting around without any structure, purpose or identity left at all.

An important role that each family played during rehabilitation was to maintain and share their image of the pre-accident person. In each case the family insisted this person was "still there", but was hindered in his expression by the problems in cognition. This belief could be extremely painful and difficult for the families to live with. Prue, for example, was quite sure that that part of Max who was still her "old Max", was observing these events with horror and despair. She believed the periods when he had flashes of insight and awareness were overwhelming for him; that he could not accept the great changes in his ability, both mental and physical. By continually offering the staff this conception of the person as he was, the family had an important role in maintaining that identity for the person, ensuring that it was not stripped from him by those more inclined to think of him purely in terms of his brain injury and the characteristics which related to that.

Another problem with roles which all the families were forced to confront at this time was the socially acceptable limits placed upon the disruption to their own life. Work commitments could only temporarily be laid aside. It was not acceptable for support of a family member to continue too long. After a day or two the pressures of their own outside worlds began to impinge upon each of the family members. The situation created by the brain injury could not be neatly contained within a quantifiable time span around which energy and attention could be organised. The families could not easily explain to employers and friends what was happening, nor could they predict how long it would take for their lives to return to normal. The commitment required of them during this time of recovery was equally as erratic and unpredictable. There were periods lasting weeks when they could do nothing but wait. All of the more significant family members returned to their own jobs and lives well before the need for their presence and commitment had diminished. As a result, all found themselves juggling an impossible burden of obligations. Torn in several directions and distressed at the needs they could see but not meet, there was a sense of guilt colouring the stories along with a sense of resentment and frustration that they were feeling this guilt.

Although this burden and stress must have seemed a very negative factor to the family members, to Max, Rob, Mark and Bryce it served an important purpose. It was interpreted by each man as meaning that they were the object of considerably more love than they realised and this belief had a very powerful effect upon their self-esteem. Mark constantly told of his mother's two months off work, of his wider family's hours and days beside his bed. Max, whose memory loss meant that he had to relearn who Prue was, came to believe, because of the amount of time she devoted to him, that she was the centre of his world.

In conclusion it would seem that the re-creation and renegotiation of roles is an essential part of recovery and an aspect which can only be achieved satisfactorily when the family and rehabilitation team can work together. This process must be carefully paced, however and must recognise the outside stressors upon the family and its concurrent need to adjust and reorganise itself. There are also limits upon how long a family can divert its energy to one member and still remain emotionally healthy and it is important for the rehabilitation team to recognise and allow for this. While Oddy et al. (1978:615) note that even six months after the accident there was no real evidence of strain, there is considerable evidence that the social support network surrounding the person with brain injury eventually disintegrates (Oddy et al., 1985; Thomsen, 1990:62). To capitalise effectively upon the energy and commitment of family, rehabilitation efforts must ensure that the renegotiating of roles is occurring before the energy and commitment of the person's network diminishes. Because this may mean reestablishing relationships which the person is not yet capable of managing alone in a private family situation, in the early stages the process may need a "scaffolding" structure supporting rehearsal and reconstruction of roles in a safe therapeutic setting.

PERSONALITY DEFECTS AND COGNITIVE DEFICITS.

There was, in each family story, an interesting relationship between the definition of how conscious the injured person was and how much his behaviour was seen as something which he 'should' take responsibility for. As I mentioned, the moment that the person smiled was remarked upon as significant in three of the four cases because smiling signalled an ability to interact again. With the resumption of interaction came the assumption of intentionality. Actions could again be regarded as purposeful and they could therefore be interpreted in terms of motives and meaning. Of course, as soon as the families began to impute motives and infer meanings from the reactions of the four to other people, they began to apportion blame. What was once defined as cognitive deficits, now became reframed as personality defects. Rob and Mark became 'lazy' and 'irresponsible' rather than working at a different processing speed, or having memory problems; Bryce became "an idiot" or "up himself" rather than having difficulty with interpersonal skills, memory and social appropriateness.

Not only family and friends fell into the trap of sometimes assigning blame where behaviour was more accurately the product of confusion or unawareness; rehabilitation staff clearly made this error as well. Pepping and Roueche's (1991:224) review of the literature found a pattern among rehabilitation staff of failure to make appropriate distinctions between deficit and disorder:

> **It is our feeling that unless rehabilitation specialists have some degree of education and sophistication regarding the role and nature of organicity as it determines behaviour, it is easy**

to slip into an attitude of blame, unrealistic expectations and frustration vis-a-vis a particular patient's progress. Knowledge of brain function and dysfunction has a direct effect, or should, on the kind of rehabilitation strategies one chooses.

Again, the issue for recovery can be seen to shift in the reality of living, from the damage itself to the way in which the damage is interpreted and appraised. It is the nature of the interpretive schemes which will determine attitudes and it is attitudes which will determine how the person is treated and what expectations and rights are placed upon him. In the four stories of this study, the assigning of personal blame was clearly paired with the withdrawing of emotional support. Dislike or impatience was a response to which all four men had been subjected on occasions, if not from family and staff, then from fellow residents.

There is no way to assert with any authority that the one or the other interpretive option here is more appropriate or effective. While it may allow more empathy and a caring attitude, the greater disservice may be to excuse behaviour on the grounds that someone is incapable of controlling it. There is no more damning definition surely, than one that denies the person the capacity to "reign over the "it" of cortical forces" as Sacks (1985:91) would put it. Even if people are sometimes unfairly blamed for something still beyond them, higher expectations may challenge and 'disturb' them, causing a higher level of arousal and so a greater ability to focus and concentrate in the learning of compensatory strategies. Being regarded as having a personality problem may also prove less disempowering as a label than being regarded as impaired and different, since to a symbolic interactionist it is clear that the sense of being stigmatised is as likely to influence self-expectations negatively as it is to lower those of others.

The ideal then, is to avoid stigmatising a person, but without making unreasonable and unachievable demands and then despising their failed efforts. All four families could be seen to swing between these two extremes. How much stress they were experiencing themselves at the time probably influenced the pole of the continuum to which they veered day by day, but gradually over a longer period, some families learned to regulate their expectations more effectively to suit the person's ability. It is clear that the more knowledge of the common sequelae of brain damage that was made available to them, the more likely they would strike the most appropriate balance in making these judgements. The availability of trained and knowledgeable staff within a residential setting was a clear advantage here for all except Juliet White, who had probably educated herself beyond what such staff had to offer.

In practice, this issue of deficits versus defects became converted into one of personal power or dependence. An example of this is the notion of 'regression'. All four families showed a tendency to regard the people as having become more childlike and in this way they aligned their new

situation with a more familiar explanatory scheme. This appeared to be a useful and even effective way of understanding the problems of recovery because it allowed them to regard the person as needing more support in understanding, yet needing to be given a gradually increasing amount of responsibility and accountability. It allowed a redefinition of rehabilitation as 'learning' or more nearly as 'developing' and, because of the particular cognitive demands involved in recovery, this conceptualisation appeared very apt. As with children, this need to redevelop and relearn could be seen to include also the building of the structures of the learning process itself.

Mark, being the youngest of the four people was the most strikingly childlike with his low frustration threshold, impulsivity and frequent mood swings. By interpreting these traits as childish rather than 'brain damage' behaviours, Juliet and Daniel White were encouraged to persevere with the use of coaxing, coaching and reasonable discussion in their attempts to re-instil a mature attitude. Rob and Max however, because of their greater level of physical dependence and because of the placid trusting manner they had developed, were regarded as childlike more because the relationship had become one of caring for a biddable and submissive person. The resumption of a reciprocal caring parent and dependent child relationship allowed the Johnsons and Prue Kavanagh to give Rob and Max, respectively, a sense of belonging and of security without the same expectation of recovering independence. In this situation the equating of dependence with childishness may have disadvantaged both parties. The emotional drain upon the person expected to be a perpetual parent was as clearly unacceptable as the loss of power in the person expected to play the child role. Other family members, such as siblings or 'real' children, may be deprived of attention or freedom that would otherwise have been possible. Mark's brother Simon, for example, became obliged to manipulate his own social life and recreational activities to make them double as "therapy" for Mark. Moreover, because he was uncomfortable with his new position as a role model for his older brother Simon was at some risk of becoming disengaged from the family.

There is a tendency to regard the assumption of power over another as intrinsically rewarding. None of the four families however, took any pleasure in the increased dependence of the men, nor did they enjoy the power that it gave them. The resumption of a parent role can be a very uncomfortable, even a painful experience, especially when feeling obliged to make hateful decisions. Sometimes the family felt a need to take a position in opposition to the clinical team and were then put in the unfortunate position of debating about what was 'best' for an adult person, by weighing their perceived rights to personal control against their predicted failure and possible consequent feelings of shame and lessened self-esteem. The four families all showed a

tendency in such situations to be more protective of the person than the rehabilitation team and inclined to underestimate their ability to manage independently. Because they had the longer term commitment to the person, their beliefs in this regard could not be disregarded by the rehabilitation team and consequently they may all (except Bryce) have been deprived of (or at least delayed) in reaching their potential level of independence because of the feelings of protective love and the resumption of a parenting caring role.

Another characteristic the four men shared with children was the tendency to live in the present, with less ability to set goals or grasp a longer term perspective. This had a serious consequence for control over their own lives as they seemed reluctant to be involved in discussions about issues of planning and decision making concerning their own recovery. The family reluctantly made what arrangements and decisions could not be put off, such as the admission to Waimarie. Nevertheless, when suddenly confronted with decisions which affected their own future about which they had not been overtly consulted, all of them felt some degree of distress about having their lives arranged for them. Although they might have resisted making plans, it was not a solution in their eyes, to have others plan for them. In each case such occasions caused a feeling of disempowerment. Unfortunately the result of this was that each person had a very real sense of having a rehabilitation programme imposed upon him, of having been made to live in a residential setting rather than the ideal situation, where the person would be choosing to rehabilitate him or herself.

Clearly for each family, a new relationship needed to be forged, one which overcame and compensated for cognitive deficits without stripping the four men unnecessarily of what personal power they still had. Dependence, whether emotional, cognitive or physical turns relationships which were reciprocal into potentially duty bound and destructive ones, where one party continues because of a sense of obligation rather than choice. This matter of obligation cannot be glossed over as an issue in brain injury. In each case, the responsibility threatened to become a lifelong drain upon the emotional resources of the families who accepted the role. Perhaps it is for this reason that existing dependency roles within the family system have been shown in research to be the most successful (Panting and Merry 1972; Thomsen 1991:61). The needs of the person with TBI are lifelong, however and any person expected to resume and prolong such a traditionally temporary role indefinitely will require far more support from the wider community than is presently available.

Whether or not the person is regarded as having personality defects or cognitive deficits may have little bearing upon the longer term outcomes of brain injury. With both scenarios, they are often

no longer as capable of equal and mutually satisfying role relationships. In either case, therefore, it seems that there is a pattern of eventual rejection by friends and family. The implications of this tendency for long term quality of life are profound. As a policy, discharge back home or out into the wider community for any of these four men may be ill advised, as without the ability to maintain more equal adult reciprocal relationships, they are clearly very dependent upon the good will of other people. The experience of Rob and Max, who were left in their homes without appropriate support for a long period of time, suggests that the disintegration of the person's wider social support network is almost inevitable. This pattern was also discovered in other recent New Zealand research (Godfrey and Smith, 1993). As several researchers have pointed out[154], the sort of personality profile which requires such a level of support and which requires that others 'make allowances' and 'understand', places the person at considerable risk of losing the goodwill of those in their own family network as well as those employed to work with them. It is therefore necessary to provide those who deal with such a distorted and uneven relationship with continual back up and support to prevent the relationship from deteriorating.

SUMMARY

Crosson (1987:340-341) observed that "there were many different ways that premorbid personality adjustment enters into in-patient rehabilitation" and each of the four subjects of this study certainly showed evidence that their pre-accident habits and relationships continually influenced the course of recovery. Certain modes of thinking and feeling transferred into a compliance and so potential disempowerment in the recovery and rehabilitation situation, while other modes actively prevented the development of insight and adaptation to the changes brought about by brain injury. The evidence strongly suggests that the most effective recovery will require that the person incorporate some knowledge of disability into their self-understandings, reshaping their previous identity to account for the changes rather than discarding it entirely. This may require a supportive environment during a "liminal stage" (White and Epston, 1990:7; Turner, 1969), which fosters the positive resolution of those psychosocial and emotional crises that appear to be an implicit part of the recovery process. Some specific thinking and feeling strategies may need to be actively taught to overcome the use of now dysfunctional, habitual ways of defining situations. Effective rehabilitation should then, achieve the sense of integrity which Ben Yishay regards as an essential task of recovery from brain damage, as opposed to the frustration, stagnation and despair which is likely to dog the future of those who fail to manage this.

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[154] See Chapter 1, p.32, "Social Interaction".

Of course, throughout this chapter an assumption has been made that the person as a social being is recovering within an interactive context where the newly emerging ontology is shaped by the negotiation of symbols with others. The interpretive schemes and ontologies of the more significant of these others, therefore, will clearly have had a profound impact upon the recovery process. The experience of the four families involved has demonstrated that it was not just one person, but a whole family system which was experiencing a transformation as a result of the accident. Because this was not often fully acknowledged and understood by those involved in the acute medical and later rehabilitation stages, all the family members experienced feelings of alienation not only from the agencies whose job it was to support them, but also and more importantly, from the family member with the injury. How well family members resolved the crises they faced over this time could be seen as a crucial aspect in effective rehabilitation.

A lack of fit and failure to clarify the different definitions of staff, client and family in a rehabilitation programme is very common (Bray et al., 1987:33; Gans, 1983). Most situations where severe brain damage is encountered, there are complex reasons for the confusion, involving issues of interaction and relationship rather than just communication (Prigatano, 1991a; Gans, 1983). Firstly and most obviously, while the process of recovery is continuing, it is usually almost impossible to predict with any accuracy, what eventual level of ability or disability could be expected. Yet overlaying this, there were the differing emotions that the players in the drama of recovery were experiencing and the way in which they moulded what they said and did in order to resolve their own (and respond to others') inner feelings and fears. The family may unintentionally override and nullify the efforts of rehabilitation staff to clarify the nature of disabilities and discuss compensatory strategies, because of their own problems of denial and guilt have made it difficult for them to accept the new reality.

The points made in this chapter tend to confirm the findings of many studies which have focused particularly upon the consequences to families[155]; namely that there are functional and dysfunctional coping patterns in rearranging the family's interrelationships and in the building of shared interpretive schemes. Klonoff and Prigatano (1987) and Bray et al. (1987) suggest that if the family is to continue to function successfully, other family members must find ways to re-orient their lives and roles so as to encompass the traumatically brain-injured person with as little possible disruption. This research supports their conclusions. In order to recover well, it is clearly important for the person to feel a sense of belonging and participation, but this can quickly slip into a dysfunctional pattern of family relations if one person becomes too central a focus. It would

[155]See, for example, Bond (1983), Brooks et al., (1986), Lezak (1978), Gans (1983), Oddy et al., (1978), Panting & Merry (1972), Power (1985), Thomsen (1990), Weddell et al. (1980).

seem that the conscious intervention of staff with knowledge of the consequences of brain damage may be necessary in order for the pattern of family role relationships to be successfully rearranged. By supporting the families of patients, rehabilitation staff create a situation where it will be possible not just to restore skills and teach compensatory strategies but to encourage the return of the more subtle and interactive skills involved in relationships. It is only by drawing upon reciprocal and interdependent roles typical of one's close relationships that it is possible to work toward Prigatano's (1991a:2) ideal:

> **To help teach the patient how to make honest and fair commitments to work, interpersonal relationships and the development of what Carl Gustav Jung called "individuality".**

Only with this sort of "individuality" which involves team membership, can the person learn to take on emotional and social responsibilities toward other people and so achieve a recovery which could be described as holistic. This chapter has considered the influence of the larger, holistic situation surrounding each story of recovery. The person's characteristic ways of approaching situations and the response of the family within which they were placed at the time of their accident were found to play a significant role in recovery. This supports my initial hypothesis that rehabilitation must be regarded as an interactive process, strongly influenced by the interpersonal relationships within the setting of recovery.

If relationships are to become the focus for research, then it can be argued that interactive sequences become the data required rather than clinical definitions of deficit or disorder. The interactions studied should span the full range of people involved during the period of rehabilitation, not just the family or the clinical relationship. In the next chapter, some of the 38 behaviour exemplars, excerpts which represent and typify the experience of living with brain injury, are presented. These filmed segments are fragments of the interactions which occurred between each of the four men and the staff and other residents of Waimarie. They reveal in a dramatically different way to the theoretical discussion in this chapter, how clearly recovery was a process of re-negotiating the meaning of self and world through interpersonal exchanges.

CHAPTER 10

THE BEHAVIOUR EXEMPLARS

In this chapter an abridged version of the behaviour exemplars are presented. These short pieces of descriptive narrative seek to capture (as completely as words can) the actions, interactions, thoughts and feelings observed in selected segments of the filmed observation. Although the writing is chiefly descriptive, some inferences and assumptions have been incorporated into the text to recreate the scene clearly in the reader's mind. When feelings and motives (obviously not visible) were described, these have been confirmed in subsequent interviews with the interactants.

As explained in Chapter 4, the behaviour exemplars represent 10 percent of the filmed observation and they were chosen for further analysis because they revealed something of the themes and patterns in the experience of the four men during the eight weeks of filming. Only a representative sample of the complete behaviour exemplars used in this phase of the research is presented here because of constraints of space. Some have been abridged while others have been presented in summary form. These exemplars are presented in the order they were filmed and each cycle of film represents one week's observation, the second cycle in each case following a month after the first. The total filming period spanned the period from March 1994 until July 1995. Later, in Chapters 11, 12 and 13, a discussion and analysis of these behaviour exemplars is presented.

EXEMPLARS FROM ROB JOHNSON'S EXPERIENCE

CYCLE ONE

1. Doing Art

Setting: *The Smaller Occupational Therapy Activity Room. Seated at a table approximately 4 x 4 square. He has A4 paper and felt-tipped pens in front of him. There is music playing in the next door room, loud enough to be heard clearly.*
Present: *Esther, an Occupational Therapist, sits opposite him.*
Time: *Monday Afternoon, 7 March 1994. 1.17 pm until 1.24 pm.*
Duration: *7 minutes.*
Mood: *A timetabled session labelled "Art Group" has been in progress for four minutes, during which time Esther has described to Rob what he is to do today, a poster for his room. And they have begun work. Because Esther is new, Rob is feeling a little more keyed up than usual but appears to be enjoying himself, if anything more stimulated and more engaged than normal. Esther is relaxed and jovial, her usual manner.*

Rob has begun to pencil in the words on the poster ("Rob's Room"). Clearly, the tremor is making the task difficult. Esther, rather than watching him, begins to scribble industriously upon another sheet of paper in front of her. Rob relaxes and the two concentrate companionably upon their separate tasks as the tremor lessens but continues to impede his progress, making his lettering clumsy. Two minutes pass. Jill

(another occupational therapist) arrives in the doorway and excusing herself to Rob, launches into a conversation with Esther about whether or not she expects the people who usually do art in Don's room to attend her art group. Esther points out that it has been "written up" and that it is not "just art" but activities designed to address perceptual and motor difficulties. Jill suggests that she needs to explain this to everyone more clearly.

During this time, Rob has continued to work away at his lettering and there is no visible sign that he is listening in. After a while however, he pauses. He looks up anxiously, hesitates and appears to notice the intensity and tension. He seems to decide not to interrupt. Forced to act alone, he looks at first worried, then clearly making a decision, he casts aside his work, taking a fresh piece of paper and begins again. Jill leaves at this point, after Esther suggests she "read it again and then, if you still don't understand, come and ask me."

Esther turns back to Rob, seems to clear her mind of the irritation and switch back into the relaxed and friendly role of partnership she began the session with. "How'd you go?" She leans across the desk and notices that he has a blank page in front of him.

"Not good," he mutters hurriedly and reaches over to his right picking up the "messed up" page he had just discarded to start again. He looks ashamed, embarrassed.

"Oh!" Esther's tone sounds sympathetic. "This paper, is it not big enough Rob?"

Rob mutters something inaudible with his head down which it seems Esther does not understand. He concludes, "like this one I think?" offering it to her as if for her approval.

Esther looks at the work. "No, that's good." She nods, holding his work up and considering it objectively. "You gotta keep drawing."

Rob taps the pencil on the desk as he watches Esther and seems happy to submit to her judgement. He relaxes again.

"What was that?" he asks carefully, indicating the doorway through which Jill had just left. "Am I doing the wrong thing?"

"Oh no no!" Esther hastens to reassure him. She pauses as if thinking about how to put it, then launches in to her explanation. "What has happened is, - you know how there used to be the art group - for art?" Rob nods, uncertain. "Well we have started - we have changed it and I am going to be in charge of the art group for now and, I don't," she pauses to find a way to phrase this, "well, we don't want to have an art group where you go and do an activity for the sake of doing an activity? You know what I mean? I want it to be one staff and, then perhaps Catherine or I or Diane, or Mary, or Don, or someone to help just one to one with the person and, um, we are doing something with a purpose."

Rob watches Esther's face intently and nods regularly, she seems encouraged to continue elaborating. "See, what you are doing, it is good for your arms and it is good for you to have to concentrate on something for more than for one session, like, say, over a week?" Rob nods reassuringly. He understands. She continues, "- until you get it done? And it is good for you to remember for over a week, what we are doing?" He nods again cautiously and she checks out that he grasps this. "Yes?"

"Carrying on with it," he mutters agreeably, nodding.

"Yes - " Esther nods, pleased. "That is what I mean!" Rob nods again, as if glad to be useful. "And then, after a week we can come back -"

"Yes. That is the way I see it," Rob agrees approvingly. "If I am enjoying it today then I can come back and carry on - "

"Yes! And then next week maybe we can draw it on the Lino." Rob nods encouragingly, looking interested and Esther warms to her theme. "and then - yeah, maybe we can start cutting .. yeah! It is a *continuing* process," she summarises. "Does that sound all right?"

"I am on the right track," Rob responds, nodding quietly. He is pleased with himself. He understood the correct reply to make and because of this he has won her approval.

2. Discussing RHAs and CHEs[156]

Setting: *The Education Unit second classroom where the morning discussion group is held. The residents, are grouped in a circle and focused upon Linda who has a whiteboard beside her upon which is written "RHA" and "CHE" with some circles and arrows showing the relationships between them.*
Present: *Linda (Education Unit Tutor and Group leader) Tricia, Elspeth, Philip, Jane, (all residents from the "continuing care" side) and Rob.*
Time: *Tuesday Morning, 8 March 1993. 10.41 am*
Duration: *11 minutes*
Mood: *The group is an established Tuesday routine. Linda reads pieces from the weekly local paper and begins a discussion about them. The present discussion concerns the threatened closure of the local hospital and has just begun. As usual, it is taking considerable energy from Linda to get and keep a discussion going.*

Linda is reading from the paper about the range of hospital services available in the local town. Everyone is silent, watching her. Rob is fiddling with his left foot as he listens. The shoe will not stay on properly and it seems to be distracting him. Linda reads something about physiotherapy services and it catches his attention. He looks up still holding his shoe and asks, "is there physiotherapy there?" in polite interest. His manner suggests that he is trying to help her out by expressing an interest, rather than that he genuinely wishes to know. Linda turns toward him encouragingly. She nods and tells him the name of the physiotherapist, suggesting he may know her. Rob looks blank. "No," he answers, shaking his head.

This interchange appears to have engaged his attention and he forgets the problem with his shoe, shifts his position in his chair so that he is leaning forward focused upon Linda's face. Linda continues reading out a report of a public meeting and when she comes to a reference to the RHA she stops and explains, pointing to the whiteboard. "That is the group in charge of the health spending?" She checks out the faces surrounding her for signs of comprehension. Many, including Rob's, are a little blank.

"Like CHEs and other things," Elspeth chips in knowingly. Rob's cheek rests against his hand, he is concentrating hard but seems to feel a little out of his depth. Linda nods, looks around and seeing no other interest, she looks down and reads out the comments that were made by the mayor and the Director of the CHE. She pauses again, looks around and sees Rob looking blank.

"Is it making sense to you, Rob?" she asks.

"Mmm," Rob murmurs doubtfully.

"What they are saying," she elaborates, "is that there is still a lot of doubt about the future of health services."

"They are still thinking about it," Rob states quietly, not confident.

Linda nods. "Yes, still thinking about it," she agrees.

Rob's confidence grows. "There is still a lot of doubt," he ventures further.

Linda nods encouragingly and swings around, her gesture signalling the room to enter into the discussion. "Still a lot of doubt about its future," she agrees. "The hospital is thinking about the things it provides."

Rob looks more involved after the success of this small exchange. His hand is still on his cheek, but he is now thinking hard. "I think it is still needed," he offers. Linda turns back toward him and waits expectantly.

"You think it is needed?" she prompts.

He is forced to elaborate "There is a call for it," he adds uneasily. He stretches his hand in front of him. His voice becomes less audible, a mutter of words tumbled together in embarrassment, inaudible to the film and clearly Linda is only picking out the occasional word. He seems to be suggesting that if people

[156] The New Zealand health system is structured into 'Regional Health Authorities' (RHAs) which identify the health services required by the population and provide the *funding* for these services, and '*providers*' of these services which include 'Crown Health Enterprises' (CHEs), or government owned health organisations.

want the services they should stay. She nods encouragingly. He stops speaking. He continues to hold his hand, giving the impression he has not finished but although Linda continues to wait for him, nothing further is offered. She turns to look at the others.

"Rob says there is still a call for some hospital services here. Do you agree?"

"I think there should be a room for people who are recovering from their operations," Elspeth pronounces. "A special room for them." She pauses and seems less certain. " If they can get one that is," she amends.

"So correct me if I am wrong," summarises Linda, looking at Elspeth, "but you are saying that if our town doesn't retain a hospital for big operations and major surgery, but does stay there for the smaller type of things, then that will be all right. That people could go to Hathington[157] for bigger operations and come back to this area for the recovery? Is that what you are saying?"

Elspeth nods, uncertain. Rob's attention is caught. He now knows what the conversation is about again and wants to take part. He leans forward and ventures a remark but his voice is so quiet it is virtually impossible for anyone to hear it. Elspeth replies over the top of him. "There will be the room for them - - and they all want to be here," explains Elspeth gaining confidence in her position as she elaborates upon her plan, "so why not?"

"Getting back to the money," Rob speaks more loudly, almost interrupting Elspeth, "for the whanau." He stresses the Maori word, as the only Maori in the room, taking ownership of this aspect of health care. His hand gestures forward again confidently and his air becomes proprietal. He is now sure about the appropriateness of his remark. Linda nods approvingly.

"Good point Rob," she agrees, "and, it is not only the money, but the vehicle and the time," she elaborates.

He nods. "It is expensive to take buses for the whanau to visit." He is warming to his theme.

Linda too, is pleased with the direction, "and, is our public transport system suitable for visiting?" She adds, nodding enthusiastically.

"Yeah," Rob nods wisely. He is now very confident. "You gotta have money for those things, sure, sure." He looks around at Jane who is gesturing for Linda's attention. Linda tries to understand the arm movements which appear to be signalling something. Rob nods encouragingly at Jane, ceding the floor obligingly. Philip, sitting next to Jane has been getting restless at Rob's monopoly and jumps in, interrupting with his own comment.

"There is no use if you can't do operations," he suggests loudly, "the hospital is no use."

"So you think it is only valuable to have it, if it can do surgery," Linda clarifies carefully, doubtfully.

"Yes." Philip looks at Linda triumphantly. He looks over at Rob in satisfaction and perhaps challenge. Rob however, appears to be finding it difficult to understand what Philip is trying to say. Far from feeling challenged, the change of subject appears to have made his mind wander and his eyes survey the room.

Elspeth instead rises to the challenge. "There is the x-rays and the physio," she reminds Philip anxiously, one eye on Linda.

"Yes," Linda agrees, "and the laboratories and the other departments - "

Rob's attention is caught again. The mention of these departments reminds him of uses he has had for hospitals before his accident, in his sporting days. "Sprained arms, sprained legs" he offers, leaning forward, pleased.

"Minor surgery" Linda nods. Philip seems unsure now. He looks around belligerently, hunching his shoulders up and snorting. He asks a question of Linda which is inaudible to the camera and the rest of the room. Rob is watching carefully, as if eager to participate again. Linda's reply to Philip is clearly a summary of the supposed position of the rest of the room, " - on the importance of the minor services," she ends, looking around for support.

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[157] Nearest city, 35 minutes drive away.

"Minor services," Rob confirms nodding approvingly at her. He crosses his hands in his lap with an attitude of satisfaction and command.

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3. A Confusing Relationship (Summary only)

Nadine, a fellow resident, is attempting to compile 'the town list'. She approaches Rob in the passage and asks if he is going to town. It is difficult for Rob to understand Nadine as she has a speech disorder. He teases her in a 'flirtatious' way and although Nadine's manner appears discouraging to an observer, Rob appears unaware of annoying her.

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4. Needing Help (Summary only)

Rob enters the computer room and discovers that his computer has been returned after repairs but is still all packaged in tape and the cords are not connected. He does not know what to do and looks around for the staff, all of whom are busy. He waits and when Trudy, a tutor, passes near enough, he very submissively and apologetically asks for help. As she sets it up, he looks on, making anxious and apologetic remarks. When he is handed the bill, he does not know what it is or what he should do with it and does not ask but instead hands it back to Trudy.

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5. Relating to Staff. (Summary only)

During her morning tea break, Lisa, the speech therapist, attempts to engage Rob in friendly conversation about the computer game he is playing. Rob is initially unable to break his concentration in the game and later, he appears unfriendly, giving monosyllabic responses. Eventually, when Lisa persists with her attempts to discuss the programme he is playing, he offers her the mouse and is clearly prepared to surrender the computer to her. Lisa, who had wanted to 'take an interest', not take over, hastily withdraws and leaves him alone.

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6. Learning to be a Kaumatua[158]

Setting: *The Residents' Bar.*
Present: *Several residents are relaxing with drinks. Del and Charlotte (OT assistants) serving them.*
Time: *Thursday, 10.3.94. 3.30 pm - 3.45 pm.*
Duration: *fifteen minutes.*
Mood: *Relaxed, informal. The two OT assistants are moving about the room carrying drinks and arranging the less mobile people so that they can drink independently and working behind the counter, serving. Two residents are sitting in wheelchairs just below the high topped 'standing height' bar. Others are grouped around the four tables in the room.*

Rob wheels straight up to the counter, without acknowledging any of the other residents. He stops his chair under the high bar top, but cannot really interact with the two busy OT assistants from this position. He appears to wait and think about this and then carefully and slowly pulls himself upright, literally "propping himself up" on the bar. He is successful. He relaxes, looks around and smiles. Del, now level with him, looks up and smiles back. "Beer please," he asks.

Del goes to the fridge and pulls out a bottle. As she opens it she asks him "You learning your lines Rob?"

"What's that?" Rob looks worried.

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[158] Among the indigenous people of New Zealand, the Maori people, a *kaumatua* is a leader or an elder. The role requires oratorical skills, knowledge of the correct ceremonial procedure and the ability to guide others opinion.

"Remember what I wrote?" she tries to prompt him but his face still looks blank. "Tatou, tatou - " she starts it off encouragingly and waits.

Rob lets go of the bar and half falls, half sits, down into his chair again. "Tatou, - tena koe - kaumatua.." he offers slowly, uncertainly.

Del shakes her head vigorously "No," she says, her voice raising upwards to indicate that he should try again.

"Nga mai (tr) haremai te whare - " Rob continues, appearing to gain confidence. Del nods and then prompts.

"Roitau..(tr)."

"Roitau" he repeats and waits.

"Tatou.." she prompts again, continuing to bustle about at the bar, fetching a carrying as she listens.

"Tatou te whare," Rob stumbles through the words in a quiet voice.

Del nods noncommittal. "What do you say at the end?" her voice raises to prompt him again There is a silence. Rob concentrates without success. He remains silent. She continues on calmly prompting "Wakata (tr)..?"

"Tatou..," he tries nervously.

"No." she shakes her head without looking at him, carrying on working. "Kia ora..," she prompts further.

"Kia ora," he repeats. He waits expectantly.

"Good." Del comments, still preoccupied, not focused upon him. "I will start a bit early tomorrow," she continues.

"Five past nine," breaks in Charlotte (an occupational therapy aide), who has clearly been listening in.

"What time will he arrive?" asks Rob politely.

"Yes. He will be here by nine o'clock."

"Five past nine" Charlotte calls out, correcting her.

"And so I come around then?" Rob suggests nervously, uncertain. Del is wandering over towards the fridge again as she speaks and Rob's cranes to see over the top of the bar, tracking her movements.

"Yeah," she calls back, opening the fridge door. She gets out another beer for a resident and turns back toward Rob. " Just so that I can run through your speech - " Charlotte turns and looks at his face, seeing his uncertainty. "Do you want to write it down, Rob?" she asks him. Del pauses, watching to see his reaction too. "Do you?" she asks. Rob thinks for a moment. "Nah," he mutters. Del returns from the fridge back to the counter in front of him. She reaches under it and gets a pen and a clipboard. She is looking down at this, beginning to write busily. Rob struggles to his feet expectantly, her movement seeming to suggest to him that he is about to be needed, but she does not seem him. "Gee!" she comments in mild irritation as she writes, "I keep forgetting to bring in some Sellotape!"

Rob waits uncertainly and awkwardly for a moment, clinging to the bar top to keep his balance, clearly feeling unsure of her intentions. Then he slumps back in his seat, waiting and watching Del as she concentrates on her writing. A minute passes and she is still absorbed. He seems to feel called upon to do something else. He looks down and notices a racing form book in front of him. He turns to his left and for the first time notices Carson, another resident in a wheelchair who is parked alongside him at the bar. He grins at him, "This yours?" he asks. Carson cannot talk but demonstrates that it is with his jerky body movements. Rob begins to look through it in a desultory way.

(A page of interaction with staff and other residents as he drinks his beer is omitted at this point. The interaction is described again at a point where Rob has noticed a fellow resident whose company he enjoys.)

"Coming up?" he invites her, gesturing to the spot beside himself expansively.

"Nah," she replies. Rob has not realised that it is necessary for Betsy to have her drink set up for her on the table where she is sitting. She turns and drinks from it with a straw. Rob is silent. Because he is not looking at her, it is doubtful that he has grasped the reason for her refusal. He looks up at Del who is now free. He watches her for a while, taking a sip from his beer.

"Have you organised some kai for the powhare[159] tomorrow?" he asks her suddenly, his words a little slurred and inarticulate.

Del pauses in wiping the bench. "What?" she asks, tilting her head to concentrate upon his words when he repeats.

"Have you organised somebody to do the food for the powhare tomorrow?" he asks again, sounding less confident about his question.

"Oh!" Del nods, affirming him for his question, "No!" she grimaces. "I will tell you tomorrow. Every time I went past his door there was a notice on it saying, "back in ten minutes," and then, there was another notice saying "Back at one o'clock!" He nods in sympathy. "Then the next day I tried again and he did the same thing!"

Rob thinks about this and remarks, "he probably won't come back today. When he gets back you say, "hey hey see that notice, how come you didn't do what you said?" And he says, "what is the occasion, tell me," and "I will get you some food!"

Del nods "I will get hold of him and tell you tomorrow," she reassures him, not seeming to understand just what he means. She carries on working, putting chocolate bars away on a shelf behind Rob's back.

(A further page of this specimen omitted)

CYCLE TWO

1. Friend and Teacher

***Present**: Diane, Mark and Rob.*
***Setting:** The kitchen of the flat which Mark White and Rob Johnson share.*
***Time:** 8 4.94. Friday. 11.31 am - 11.37 am.*
***Duration:** Six minutes.*
***Mood:** Relaxed, informal. Preparing lunch together is a regular Friday activity. He has, with Diane standing over him and nodding and encouraging, already prepared and placed in the pot, the contents of the "boil up" he has chosen to make for lunch and placed it on the element.*

Rob goes to the drawer and takes out a big "stirring" spoon. As he tries to close the heavy wooden drawer while still holding it in the same hand, it catches in the drawer and is flicked across the room toward Diane. He looks distressed briefly then relaxes at Diane's laugh.

"Sorry, sorry." He grins at Diane, who grins back tolerantly.

"Trying to throw it at me?" she teases with pretended indignance. She folds her arms and waits, looking down at the spoon, to see what he will do next.

"It got stuck in the drawer," he explains still grinning and enjoying the joke. He swivels his chair and manoeuvring to the centre of the kitchen where it landed, stopping a little too late so that it is too close to his foot to be easy to retrieve. He stoops down, tries to pick it up and fails. He lifts his foot pedal, pulling his foot backward and tries again. This time he succeeds, although almost losing his balance in tipping far forward to reach under his seat.. Diane still watches without comment, a friendly smile on her face. He carefully manoeuvres his wheelchair back to the sink, puts down the spoon this time, to turn on the tap, picks up the spoon again and washes it. Clearly the stream of water seems too cold to him and he puts the spoon down again, adjusts the temperature of the water then raises the spoon again. After letting

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[159] *kai* is the Maori word for food, and *powhare* is the Maori word for a welcoming ceremony.

the water splash over it for a while longer, he puts it down again, pushes the tap levers to off, then picks up a teetowel hanging beside the sink, puts it on his lap, putting the spoon on top of it, he rubs at it one handed rather ineffectually, then carefully fumbles with the teetowel to remove it from his lap without dislodging the spoon, he puts the teetowel back on the sink bench. He moves back to the pot on the stove, lifts the lid of the pot and places it alongside, picks up the spoon from his lap again and stirs the contents once. Leaving the spoon in the pot, he bends down, opens a cupboard and takes out a frying pan, He puts it on the benchtop stove element and closes the cupboard. Throughout all these careful manoeuvres Diane has continued to watch without speaking. Rob does not look at her and knows not to expect any help from her. He seems to accept her 'watching' role philosophically although all the tasks he has just performed were made very difficult by his one handedness and her stationary presence underlines the unnatural 'therapeutic' intent of the scene.

Mark enters the kitchen and looking around, notices who is present. He then exaggeratedly ignores the other two, perhaps for the benefit of the camera[160]. He goes over to the fridge and takes out the rolls and other ingredients he needs to make his own lunch. Rob continues to stare ahead, not acknowledging Mark and idly looks around the bench space in front of him, picking up a bit of discarded plastic wrapping in a preoccupied way. Despite the cramped conditions and Mark's audible presence, Rob then backs in his wheelchair without checking behind him. Mark adapts his own movements, allowing Rob to throw the wrapping in a rubbish bag and then steer himself back forward again. Mark continues his own journey to the work bench to Rob's left. Rob does not appear to notice or acknowledge the concession made to him, not does he look over at Mark as he sets up his cheese and butter and rolls. He removes the pot lid and stirs again, staring at the pot which is at his eye level. Mark is now about four feet from him, standing at the bench, busily making his lunch. Both are silent, intent upon their tasks. There is a sound of boiling, copious steam is rising from the pot and clearly from Rob's arm movements, the contents are thick and heavy and are sticking a little to the bottom of the pot.

"Hot, Rob?" asks Diane casually after watching him continue to stir, oblivious of the boiling. "Do you think it's cooked?"

Rob cranes his neck, stirring as he examines the food in the pot. "Give it another five minutes," he mutters very quietly.

"Pardon?" Diane moves closer, leaning toward him.

"Give it five more minutes" he repeats, not much more loudly but this time, being closer, Diane hears.

"Five minutes?" She nods. "Okay." She turns away and then grins widely when she knows he cannot see her face. She moves away from him again, to her position in the corner of the kitchen where she can observe without getting in the way. Rob, having decided he has five minutes to spare, turns his wheelchair carefully so as to avoid Mark.

"I don't know what to do but just sit," Rob mutters almost inaudibly.

"Pardon?"

"I don't know what to do with that." Rob repeats, the words still very quiet and indistinct. It seems that Diane has not heard. Rob does not seem overly concerned. He begins to steer himself toward her on the way through into the living area.

"What do you have to do after you have eaten?" she asks him, seeming to want to get the subject on firmer ground.

"Wash," Rob replies promptly and more loudly.

"What?" Diane prompts him further.

"My spoons and my plate and fork," he recites, grinning at her.

"Yes." she approves.

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[160]Mark did not believe that the camera influenced his behaviour in the kitchen on this day. He said later that their deliberate lack of acknowledgment of each other, almost a pretence that the other was "not there" was typical.

"Clever, aren't I?" he teases her. She does not respond and seems a little disconcerted by the teasing. "If I don't do it, I get a bad mark," he continues, putting on a mock solemn voice. Still Diane is silent, determinedly expressionless, serious. "A bad mark," he repeats, as if to savour the sound of it, or to try again for the laugh he wants. Diane turns to me.

"Rob just loves doing dishes, eh Rob?"

"No! No!" he answers, starting up his movement toward the living area again. "That is one thing I hate doing eh?" he explains to me. He reaches the centre of the living area and turns his wheelchair in a circle so that he is facing the kitchen again. Diane remains in her corner of the kitchen and turns idly to look at what Mark is doing. Mark now seems to feel that he is free to chat.

"How are you today Diane?" he begins politely, even gallantly.

As Diane begins to answer him, turning away from Rob to face into the kitchen, Rob thinks of something he must ask her and the need is urgent enough to make him interrupt. He asks hesitantly "Diane?" he wheels himself forward toward her "do you think it would be all right if I had a cigarette?" the words are very indistinct, his mouth seems to be stiffer and less able to enunciate than usual. Diane, interrupted in her chat with Mark, does not understand him.

"What Rob?" she turns back to him.

"Do you think it would be all right if I had a cigarette?" He asks again more distinctly, but still rushing and stumbling over it. His eyes are not looking at her, but stare ahead in embarrassment. He has continued to wheel forward and so he is now back in the kitchen beside her. She hesitates, looking at him speculatively as if wondering what attitude she should take in responding. She decides on a reply.

"If you want to - " she pauses then adds warningly, "you better keep an eye on your lunch though. It will stick to the bottom. You will need to stir it."

"Do you want to stir it?" he asks her uncertainly, perhaps a little confused about how to manage both activities together.

Diane looks playfully indignant. "It is your lunch! I don't get to eat it so you should stir it!" she claims in a joking tone.

"Hard! Hard!" Rob exaggerates the shrugging shoulder movement which expresses his yielding. He wheels the chair forward, back to the stove again. "Gee! look what I have to put up with from this woman?" he reaches out for the spoon again.

"Why?" The laugh in her tone belies the pretended indignance.

"She just likes watching a man work!" he shakes his head, mock solemn as he stirs his pot.

(A further page of transcript has been omitted)

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2. Getting to Know a Flatmate

Setting: *Dining Area of the flat which Mark and Rob share.*
Present: *Rob and Mark.*
Time: *Friday 11.45 am, immediately after the previous behaviour exemplar.*
Duration: *4 minutes.*
Mood: *On Rob's part there appears to be an air of suffering the intrusion of Mark's presence. Mark seems oblivious of this.*

Mark sits down opposite Rob who is concentrating upon eating his lunch. This is a difficult task for him as his one handedness and his tremor both make getting the food from plate to mouth an ordeal. Often the food drops back onto the plate and splashes him. Mark appears totally oblivious of these difficulties however[161]. He is not concentrating upon the food but upon Rob's face. He does not pull the chair up to the table, instead he puts his hands in his lap and seems to settle himself into a posture for 'making conversation'. Looking up at Rob, he begins brightly.

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[161] Later in interviewing Mark about this session, I asked him about this and he seemed puzzled. Rob's difficulties with eating had not occurred to him.

"Okay, Rob. How is your family, good?"

Rob looks uncomfortable. He looks down at his meal, prodding at it with the knife-fork utensil he uses to eat. "All right," he growls in a voice so low Mark did not really hear him.

"Do you go home for the weekend?" Mark tries again. His face is politely eager and expectant. Rob looks unhappy, awkward. He shakes his head almost imperceptibly. After pausing for a while, Mark decides to continue. "I do," he offers brightly, "every weekend. I'm glad it's weekend. Once Mum and Dad come, I will be out of here!"

Rob seems to become resigned to making conversation and relaxes a little. "Where are you from?" he asks politely.

"Porterton," answers Mark, seeming pleased to have a personal question. "It is only 97 k," he adds, as if that explains why he is more likely to go home for the weekend.

"How far is that?" mutters Rob with his head down, resuming the struggle with his meal, but with a more relaxed manner.

"97k" Mark repeats in a tone of surprise.

"How far is that?" Rob asks again more loudly, but without any annoyance.

Mark grins. "97k," he says again more precisely and slowly, his voice expressing his amused incredulity.

"How far is that?" repeats Rob again without appearing to notice Mark's attitude. "How many hours?" he adds, at last clarifying his meaning.

"One and a half hours," Mark replies promptly, pleased to have grasped the problem. Rob nods and continues to eat. Mark waits expectantly for another question but Rob seems to be totally engaged in eating again. "How far away do you live Rob?" Mark prompts him after a pause.

"Wapatua[162]," he mutters.

"Wapatua," Mark prompts encouragingly, his tone expresses an intense interest in Rob's home. "There are some friends of mine on a farm up there - the Nawtons, I think they are farmers."

Rob nods, pauses in his eating and, head down, he seems to decide to think up a question to change the subject rather than to keep the conversation going. "What sort of sport do you play?"

"Rugby," Mark answers promptly, dropping his previous subject without hesitation. "I used to be in the first fifteen." He waits for a comment but gets none. Rob has continued to struggle with his next mouthful. "I was in the first fifteen and I was a lock." He waits again for a response but Rob seems content to nod and express a mild interest. "Vice captain," he continues, enjoying reminiscing, "I was so good that I - I," he pauses, and then his face adopts a solemn expression, "I - I got to play for the Matawauru Reps too." He waits for some sign of approval or admiration but when Rob continues to be silent he goes on. "Under Sixteens, Under Eighteens," he elaborates and then pauses with an expression of wistfulness, "I miss that sport now. Now I have changed quite a bit, because of my accident. - At first I found it pretty hard to talk. I couldn't talk - and now I can talk and eat and everything!" He ends triumphantly looking at Rob for approval.

"I played for Wapatua," offers Rob suddenly, raising his head and letting his fork-knife rest against the side of his plate.

"Did you?" Mark is surprised. "What did you play?"

"First five," Rob replies with a careful nonchalance.

"Oh!" Mark is amazed. "Rugby too!"

"Yeah. And I could box." Rob adds, as if pleased to have an audience now that he has accepted the inevitability of conversation.

"Mmm?" Mark is confused. His mind is still caught on rugby.

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[162]Rob here uses the name of the province within which his home town is located. Mark cannot know from his answer, how far away Rob's home really is.

"I box?" Rob tries again. Mark still looks lost. "I used to go boxing and play rugby." He rephrases it to make his remark clearer.

"Good for you man!" Mark says approvingly, "boxing is a violent sport!." He thinks for a moment. "Boxing would be a hard sport though, I reckon." He looks serious, concerned.

"Yeah it is," Rob agrees calmly, not inferring anything derogatory from Mark's comments. With his fork-knife he pushes and plays with his food, preoccupied, no longer really noticing it.

"What did you think of the rugby," Mark asks, "good sport?"

"Yeah" Rob is noncommittal, as if unsure how much he wants to share.

"Why's that?" Mark persists.

Rob capitulates. "I was in the Wapatua team?" he tells him proudly, "And I was only fourteen - in the under 21s?" He pauses and elaborates as if to underline the exceptional nature of his feat, "18 years olds, 20 year olds - "

Mark's face looks blank. "Oh yeah." He pauses. "Good team man?" Rob nods. He does not want to go any further. "So," Mark concludes in satisfaction, "we have both played rugby before."

Rob nods. "Yeah but I can't play now," he responds repressively.

"No!" Mark is emphatic, his tone important. "I won't play now that I am head injured." He looks across at Rob and continues tentatively. "So, you are a sports man are you Rob?"

"I used to be," Rob corrects him.

"You look pretty fit too," Mark continues, still considering him objectively as he sits hunched in his chair fiddling with his food.

"I was." Rob's voice is flat, emotionless.

"I was pretty fit too." Mark takes on the tone of reciting something he has been rehearsing for himself, "now, it is pretty more, the involvement I have got now is more - it has just changed, I don't know if I can explain it to you - but in days to come - " he pauses, then looks up and asks, "What was your accident Rob?" his face adopts an expression of polite interest.

Rob's face closes up, his head goes down "I don't want to talk about it." the words are rushed, inarticulate. Mark strains forward.

"Eh?"

"I don't want to talk about it."

Mark is taken back. "Oh!" he puts his head down, looking at his filled rolls. "Okay." He draws his chair forward and prepares to eat.

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3. Working Side by Side

Setting: *Computer room.*
Present: *Nadine (another resident) and Rob are alone in the computer room. Dierdre (tutorial assistant) is moving around in and out of the small office, organising resources.*
Time: *Tuesday morning. 9.23 am.*
Duration: *23 minutes.*
Mood: *The mood appears relaxed. Rob is playing patience on the computer. However, Nadine reported later that she was increasingly tense.*

(First three pages of this specimen have been excluded)

"You are going to miss me when I leave." she repeats.

"When are you leaving?" asks Rob in mild interest and surprise, still watching the screen and moving and clicking.

"Don't know when," Nadine replies.

"Want to get away from the ratbag, do you?" teases Rob. Nadine laughs explosively but does not reply. Rob turns briefly, grins at her and puts on his wheedling tone again. "We are not that bad are we?"

Nadine laughs again. "You thought I would be moving for your sake!"

"Exactly!" Rob replies, enjoying himself. "You are going to miss me!" he challenges daringly.

Nadine laughs again "Doubt it!" she exclaims.

"Come on Nadine," Rob puts on a mock pleading tone which makes her laugh in delight. He is still watching the screen and his own body language now suggests he is now 'going through the motions' of the role. He is barely aware of her reaction and continues to play. There is a silence. Rob finishes one game and clicks on "New Game" again automatically, staring at the screen as the new set of cards are laid out and then launching straight into playing without pausing. Nadine becomes engrossed in her own work. For six minutes the only sound in the room is the click of the keys.

At 9.37am, Rob's game has reached a point where he cannot move unless he finds a "Six" in the pack. He clicks quickly, turning the cards over rhythmically as he mutters "Six, six, I want a s-i-x." Suddenly the possibility for a little more teasing occurs to him and he repeats the word, changing the vowel sound slightly "s-i-e-x, s-i-e-x, I want a s-i-e-x" he looks eagerly over to Nadine to assure himself that she is listening but gets no response. She is still involved in her work. He pauses, considering her for a moment and then cannot resist "Sax eh Nadine?" he says, waiting and watching for a response.

"No! No!" Nadine replies sounding a little upset.

"Gee!" Rob is still grinning, delighted with his own joke, determined to make sure that Nadine has understood it "I say six and she says sex!" he says delightedly if inaccurately. Nadine is determinedly ignoring him still and so he continues "Hey! Do you want to get a sax!" he waits eagerly.

At this moment Linda enters the room and going up to Nadine she begins a conversation with her about the group session which is about to begin. Nadine is explaining that she must first talk to another staff member about the people for town. Rob listens in, still eager for some sort of interaction on the issue of sex.

"I'll come!" he suggests laughingly.

"No! No!" Nadine replies with clear agitation.

"What?" Rob is still not reading her distress over the word "sex" correctly and believes he is involved in a delightful game.

"Get off the grass," Nadine replies without much heat.

"What?" asks Rob. He seems bewildered by the expression, a new one to him.

"Get off the grass!" she repeats more loudly.

"I was only asking how's it going." Rob's tone is all injured innocence. "I can just ask can't I?" Rob watches her face as she determinedly ignores him and seems to decide he can push a little further. He purses up his lips, the tip of his tongue showing and makes a strange crooning noise "willawillawillawillawilla" he breaks off when Nadine still does not look at him "Nadine look! Look!" he urges her. Clearly it is important for her to see the facial contortion to understand the joke. He resumes again, this time pursing his mouth into a rounder vowel, "wollawollawollawolla!"

Nadine cannot resist looking. She watches his face for a moment and then an expression of disgust appears "Ohhhh!" she exclaims. Her anger is clear.

"You still there Nadine hey! Why, why??" Rob is getting really carried away now. He firmly believes that Nadine is secretly enjoying this and he is happy to oblige by prolonging the joke as long as possible.

"You are horrible," Nadine says explosively.

"Me? Why?" he replies, a cheeky grin on his face. She is silent. "No, I'm not" he prompts her further. Still she is ignoring him determinedly. "I know who I am and I like you." He tries again, putting a little more sincerity in his tone, conciliatory now, less sure of himself "I like you as a friend - " He seems to

sense a softening in her face and is encouraged to continue "as - tender - Nadine." Nadine cannot resist laughing and the two turn to each other and laugh companionably.

"Boy!" Nadine comments.

"Hey! I am a boy too!" Rob responds excitedly. Nadine seems to regret lowering her guard again and clams up. Rob watches her face uncertainly. "I tell the truth Nadine" he tries, watching for a response. Still there is not reply. He seems goaded by her silence now, determined to get a response "I'll be your boy, Nadine." Nadine lets out an embarrassed laugh. "I've got no-one," Rob continues, still grinning to show he is teasing. It seems to occur to him that the sexual innuendo may be disturbing her. "I've got no worries, Nadine, if I don't get what I want!" He laughs in delight at this joke. To him the idea of really making love to Nadine is funny. Still she is silent, stony-faced. He looks at her face and seems to try to think up something else that might get a response "Hey Nadine!" he tries to attract her attention, make her look then he purses up his mouth and makes loud kissing sounds. He breaks off to laugh in delight, partly at his own daring, partly at Nadine's expression of horror.

"Oh gee!" Nadine exclaims. Her voice is choked, but it is still difficult to tell whether it is distress or delight. "No!" she pronounces loudly, definitely. Rob only laughs, too carried away now to take in any but the most obvious of repressive signals. "You want to leave together Nadine?" He laughs in delighted amusement at the picture in his mind. "Leave together?" he repeats excitedly.

Nadine has had enough. She abruptly backs her chair out from the computer, swivels towards the door, turning her back to him.

"Come back! Come back!" Rob yells out laughing, "don't leave me!" Nadine can not resist laughing but continues to leave the room as she laughs. The laugh has relieved Rob of any lingering doubt that his behaviour could have been interpreted as offensive and he manages one passing shot "I know you want me!!" He laughs and Nadine's voice can be heard as she recedes down the passage, laughing too.

EXEMPLARS FROM MARK WHITE'S EXPERIENCE

CYCLE ONE

1. Being Filmed

Setting: *Oanau Flat No. 1.*
Present: *Mark and the researcher .*
Time: *11.7.94 at 9.00 am until 9.11 am.*
Duration: *11 minutes.*
Mood: *Mark is clearly self-conscious and excited about "performing" for the camera as this is the very first minutes of his experience of being filmed.*

(Initial page of transcript omitted)

Mark picks up wrappings and puts them in the bin. "I always do that," he explains, "because I am going to be more. - " he looks intent for a moment, "what is the word, um. - " The word clearly does not come into his mind and so instead he describes what he is picturing "tidy up my messes and - more - what is the word, I mean for that?"

"Conscientious?" I offer doubtfully.

"Conscientious" he repeats uncertainly and appears to consider it.

"Try harder?" I suggest.

"Yes. And conscientious," he elaborates, "try harder to be a clean kiwi." He seems satisfied he has captured his sentiments exactly.

"Care for your environment?" I check to clarify.

"Yes. Because I love it." He agrees eagerly, pleased to be on familiar ground. "I want to save it too," he adds. "Did you know that?"

"Yes I did." I nod.

"That is what I want to do for a job," he continues, "that is, if I can get it.." He turns back to the bench and solemnly and carefully tidies away the jars, butter, bread board, etc and wipes down the bench. For some reason his new glasses suddenly attract his attention, perhaps they move on his nose as he wipes with his head bent forward. "It is my new glasses I am just getting used to" he explains, fingering them for the camera.

"How come?" I ask.

"I have got some new ones this year - they go dark in the sun."

"Oh yes.Were you having trouble with the sun were you?"

"No" he replies blankly. "Mum just thought I needed different glasses." He continues with his shuffling around of jars and dishes and then adds as if reciting something learnt, "mums think of everything!" I do not reply, just smile and he continues on as if in a dramatic monologue. "Yes. I am proud of my family. The way they are supporting me. . Everything!" At last the bench is sufficiently tidy to satisfy him and he puts the pot of yoghurt and a banana beside the rolls on the plate. He picks up the plate and turns from the bench toward the fridge, looking pleased with the effect the food creates grouped on the plate. "You know, I have got dairy food, meat, veges, fruit." He indicates in turn each of these items on the proffered plate. "It should be a good balanced diet?" he asks rhetorically then as he moves towards the fridge he adds "I think!" to emphasise rather than to question and, opening the fridge door, he carefully puts the plate inside it.

"Do you usually do that this early?" I ask curiously.

"Yes!" he replies as if glad of the opening. "I come back up here now at 11.30, wash and sit down, turn on the TV, get them out and - eat them!"

"Mmm!" I comment noncommittally.

Mark has finished his task and looks uncertain for a moment. Then seeming to make a decision, he swings out of the kitchen and up the passage way to his bedroom and switches on the tape deck by his bed. He sits self consciously on the edge of the bed. I ask him whether he will let me set up the camera and leave it running and when he agrees, I begin the process of positioning it in preparation for leaving. He tries to assume a relaxed posture sitting on the bed, but clearly feels awkward about relaxing like this in front of the camera. He looks around, sees the soft toys on the TV and picks up a small blue teddy bear holding a sign saying "Get Well."

"Look what Mum gave me!" he exclaims his voice bursting with a euphoric emotion. I nod. "And my cousins!" he adds, putting down the first soft toy and picking up another. His voice is nearly breaking with the emotion of the remembered giving. He swiftly turns back and takes the third small toy. "This one too!!" He holds it out to me in eager delight and I laugh at his exaggerated pleasure. He laughs back his voice still so full of emotion it could almost be convulsive sob rather than a laugh. He continues. "I have decorated this room so that it is just like home" he pauses and gets his voice under control again, "it is just that, you know, I am going to be here for a while, so it is just everything that is - photographs [he indicates the photographs pinned on the large pin board], calendar, [he points to it], the staff I had in Porterton, [he points to a cartoon drawing done of the Porterton Rehabilitation Staff], the coach I had before my accident." He pauses then adds with significance, ."..and, he came to see me in hospital,"

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2. Scared about Moving into the Flat

Setting: *Social Work Counselling Room.*
Present: *Philippa (social worker) and Mark.*
Time: *10.30 am Monday, 11.7.94*
Duration: *Nine Minutes.*
Mood: *Mark regards his one-to-one session with Philippa as being a serious and a formal reporting of his feelings. The session began with Philippa reading out from a letter from Mark's mother, sharing the contents with Mark and periodically stopping to discuss them. The letter is in effect a report of Mark's weekend at home and it is an established practice for Mark and Philippa to spend a session on Monday*

morning going through such a letter together. His mother mentions in the letter, that he has some doubts about his ability to cope in the flat on his own and Philippa checks this out with him.

"I'm not sure," Mark says in a very quiet voice. "I am not sure of anything really."

"What aren't you sure about?" asks Philippa calmly.

"Taking responsibility of having the whole house to myself," explains Mark solemnly.

"Well," Phillippa reasons, her voice calm as if to counter-balance his intensely emotional tone, "that is part of the training, to see how you are getting on. With the cooking and cleaning and all that."

"Mmm." Mark nods, lightening his own tone a little. "I don't mind that but -" he pauses and eventually adds vaguely, "just being independent I suppose."

"So. Being independent." Philippa echoes him and pauses, waiting, "You think that's scary then?"

"No. Not scary - just, you know what I might find that I am not used to it and just and - having to adjust," he adds confusedly. He rubs his chin, strokes his hair back. He seems embarrassed by his own incoherence. He watches her reaction.

Philippa nods reassuringly. "Well to start with, you won't be all alone. There will be supports in place to help you look after yourself, there will be-" She seems about to launch herself into a list as Mark's eyes drop from her face and he interrupts her.

"Oh yeah," he nods casually and his eyes roam around the room, "so, lots of support when I need support." He yawns and leans back in the chair.

"Yeah." Philippa is not quite sure that the problem has been dealt with at all. "That's right. We are not just going to send you out there and leave you!"

"Dump me!" agrees Mark, grinning.

Philippa laughs. "Yes."

"Dump me in there," Mark repeats laughingly, as if to dwell on his joke. Philippa clearly wants to move on.

"So is that okay with you?" she asks.

"Yes." He nods graciously, "as long as you are not going to dump me in there without support. That is what I need." He nods in satisfaction.

"Has Valerie told you how they manage the rent?" asks Philippa, moving on.

"Don't tell me there is rent as well!" Mark reacts quickly. He is not pleased.

"Pardon?" asks Philippa.

He relaxes a little. "There is going to be rent there is there?" he asks in an irritated but resigned tone.

"You pay the rent," explains Philippa, "and so that you have to budget for it - as if you had rent?"

"Yep!" Mark answers brightly, magnanimous.

"- And, it goes into an account and goes to you when you leave," Philippa concludes her explanation. "Is that okay?"

"Yeah," Mark nods considering, "I might even be able to (inaudible) if I am going to do the shirts."

Philippa nods and waits a moment. "How is everything going?" She asks.

"Pretty good." He nods.

"And my goal, my role in that is to -" Philippa breaks off and starts again. "I think we probably need to have an arrangement like that to practise in, because, if you were living in Porterton, you are not going to have just a bedroom to look after, you are going to have a whole flat."

"Mmmmm" Mark nods in solemn agreement "I think I will need to too, because I have moved everything from my bedroom, up to my flat."

"You have?" Philippa encourages.

"I have six posters, two photos, one calendar, one sticker..," he pauses after each item, seeming to picture them in his mind and to savour each privately before carrying on. He looks up to the ceiling clearly trying to add to his list.

"You will have to look after the things in a whole house when you leave here." Philippa agrees.

"I have got two plants," continues Mark, nodding, "my plants need lots of looking after," he elaborates, "and-" Mark then launches into a long and detailed description of a wheat-man he has made, which should eventually grow "hair." Philippa listens and laughs with him as he jokes about its bald head and he becomes more excited and suddenly, jerks forward in the chair and suggests somewhat incomprehensibly in an artificially hushed, mocking tone, "it could poison me!"

"No, it won't poison you." She states firmly, repressively.

"I know," he replies in a more serious tone then yawns and shifts his position in his chair.

"What do you think will happen if it gets too hard?" asks Philippa.

Mark looks blank. "I am going to keep it up" he insists.

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3. The Notebook System

Setting: *Education Unit.*
Present*: Trudy (tutor) and Mark.*
Time: *12 July 94. 1.33 pm.*
Duration: *15 minutes.*
Mood: *Mark is eager and friendly. He has entered the room for a scheduled session and without any preliminaries launched straight into telling Trudy some information about his injury he has been given by his parents during the weekend.*

"Mum said -it was at the left side of the back of my head that I got hit," he explained eagerly, behaving as if he is giving Trudy the answer she has been waiting for. Trudy's confused look and hesitant response suggests however, that she is finding it difficult to orient herself.

"But that, would have been just where it hit," she says, slowly watching his face to see if he understands her inference " - it wouldn't have been just that part that got damaged."

Mark nods, pleased. "No" he agrees happily, "It went.. smack," he demonstrates with his hand against his head. "It was squashed up over on the other side of my brain too - on the other side."

Trudy nodded, watching him carefully. It is clear she has no idea what motivated him in initiating this conversation, but that she wants to make sure he has clarified whatever it was that bothered him. "Yeah," she comments casually "Do you think we can get somewhere with you?"

He grins "You can!." They laugh together.

"To Tiparary?" continues Trudy teasingly.

"Yes" agrees Mark seriously, then he falters and frowns. The humorous intent dawns upon him a little late but he is clearly eager to enjoy a shared joke. "Where's that?" he asks laughing.

"I don't know," Trudy grins, "somewhere near Taupo?" She is holding a paper and as she says this she moves out the door to give it to one of the students in the classroom. "I don't know where Tipparary is," she calls back at him casually. "Overseas, I think."

Mark's face breaks into a big grin. He is delighted for the opportunity to joke with someone but Trudy is not looking at him to see that he understands the joke. He follows her, his face lit up with excited delight as Trudy gives instructions to someone else about laminating. She then turns back toward him. "Near Hawaii I think," he says seriously.

"Oh is it?" she asks in surprise. "I was just thinking of the song in the war where they sing a long way to Tipparary," she explains as if to relieve him of the worry. "You are the traveller, not me." She enters

her office with him and takes her seat. He sits down at the desk beside her. "Have you got that notebook?" she asks briskly.

"No," he says, "no-one has given me one." (He has understood what notebook Trudy means[163]).

Trudy looks disapproving. "Nobody will give it to you. You will have to buy it," she continues in a lighter tone as she gets to her feet, "but, what I will do is, I will give you," she reaches into a cupboard and pulls out a new soft covered notebook of the sort used in schools, ."..this." He looks at it doubtfully. "It will probably be a bit bulky for you to carry," she suggests, "but you will be able to get started. Do you feel comfortable taking this around with you until you get your own smaller one?" She gestures at his top pocket. "You could keep it in there, say." He takes it and tries. It fits. He takes it out again and looks at it uncertainly. It is as if the idea of feeling uncomfortable about carrying a notebook had not occurred to him until this moment, but now he considers this seriously. "I suppose so," he replies grudgingly.

"Okay." Trudy says, satisfied, "so, what we will do, at the end of our session I will get you to write down what we have talked about." She waits for a response and does not feel that she gets sufficient evidence of understanding. "Do you remember what we talked about on Thursday?" she reminds him.

"Yes" he nods, pleased. "I just have to write down what I do in a notebook and I will get people to sign it too. I just talked about it with Philippa," he adds.

"Oh good." Trudy nods approvingly. "So, all right then. What we are going to do now is, nothing strict with your comprehension and all that jazz. What I want to do is think about the sort of questions that you want to ask .. what sort of job you want to do as a work experience job? Before you go to Workbridge you need to think about what you want to do."

"What's that?" asks Mark blankly. He looks lost, bewildered.

"They will help you to get jobs." Trudy explains economically, ."But, with Workbridge, they only come down once a month and so between their last visit and the next one we actually want you out working - just getting used to the idea of work - doing something?"

"Yeah." Mark nods cautiously.

"So I want to ask you," carries on Trudy, "what do you want to do? And we will try and find you something as close as possible. Do you want to find something close to your interests, or -" She waits, prompting him to respond with her questioning tone.

Mark thinks briefly. "I have quite a lot of interests." He begins uncertainly.

"This is not your career." Trudy explains further. "At the moment we are not really thinking about a career just something to interest you and give you some experience at working." She stops, clearly waiting again to allow him to think.

Mark jiggles his legs up and down under the desk.. He holds the pen poised, staring ahead, still. Then he puts his head down and begins to write busily. Trudy watches over his shoulder as he writes. There is a silence for a while.

"Are you?" Trudy asks suddenly, in response to something he has written about his interests. She reads on, then seems to decide it is time to elaborate further upon the plan. "Okay so, saving animals, making plants," she reads out. "Right, so you see that will help us to find something that will hold your interest like say - working in a vets?" She pauses to give him time to think, "Would you like that?"

"Conservation?" he says hesitantly, indicating the word he had written next on his list.

"I know," Trudy agrees. "But we can't do that we haven't got a Department of Conservation here. So we will just find something that would hold your interest, like for conservation, perhaps working on a farm? - or something outside, do you get the idea?"

"Yeah," he agrees, "and, maybe working on a farm." He writes it down.

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[163]During the previous week there was a family meeting at which it was agreed that Mark would carry a notebook so that he and the staff could record the weekly activities. There had been some problems caused by communication breakdown with Mark's parents and with such a system in place, when he returns home for weekends, his parents would be able to share in and support his recovery more fully.

"Yes. We are just looking at short term stuff - not a career," she explains, "just short term work experience." Mark is satisfied. He writes busily.

. "It's a bit like what I do for Dad," he suggests, looking up, "taking phone calls."

"Oh" Trudy is not sure at first. "Yes. That's right. All we are looking at is work experience so we can check for-" Trudy hesitates, her expression suggests she feels a bit uneasy about the next words, ."... appropriateness, and socialising."

"See if I can get up in the morning." Mark suggests.

"Yep. Yes that's right," Trudy agrees, "and also, how you take directions, what problems you have remembering how you fit in with the rest of the team and stuff like that that you need to get sorted out. Like, okay you might think, six instructions, I can only remember five so I will write down the sixth one, that sort of thing we are looking."

"Mum was telling me I might have trouble with that kind of thing," he agreed, his voice hushed and solemn and full of emotion. "She said I might need to have some work experience."

(Half a page of similar interaction with Trudy is omitted)

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4. The New Programme (Summary Only)

In their scheduled one-to-one session, Mark discusses his new 'flat-based' rehabilitation programme with Jill, his occupational therapist. They discuss how he has improved to a level where he needs to practice independent living with less one-to-one support and structuring. Mark is excited and pleased about the changes and comments upon how much he has improved. He also wants Jill to look at his notebook to see all the positive comments. Jill agrees with him that he is improving but appears to signal with her calmer responses that he should tone down the enthusiasm and that he does not need to aim for her approval, only his own.

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5. The Pool Game (Summary Only)

Mark is playing pool with Graeme, a visiting ex-resident who has become a friend. He is highly excited and seems to be eagerly looking for opportunities to make a joke, to react enthusiastically to anything Graeme does and to draw the attention of any passers-by to their game. His behaviour as a result takes on a rather clownish and exaggerated appearance. Graeme does not seem to understand why Mark is so excited and his own manner remains calm and matter-of-fact, providing a sharp contrast.

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6. Keeping Busy (Summary Only)

It is just after lunch and before the afternoon timetable commences at 1.00pm. Wearing a padded jacket, Mark goes through a brief exercise routine alone in the physiotherapy room. He lifts weights for a few seconds, counting each lift, then he cycles for two minutes, calling out "Heigh-oo Silver" and "Look no hands!." He then goes to the recreation room where the afternoon programme is about to begin. Don, the Recreation Room Director, is busy pushing people in wheelchairs over from the Terehi residential block, and there are several people sitting around a big table, waiting for the promised Car Racing Game to begin. Mark sits in the central position at the big table where the game will take place and waits passively without it occurring to him to help Don. While Don is out of the room another resident, Tom, is violent and abusive to a woman in a wheelchair who is unable to move, Mark initially tries to ignore the problem. He looks uneasily around for a staff member, but eventually he interrupts and, quietly and disapprovingly, tells Tom to leave the woman alone. He is still wearing the padded jacket although the heated buildings are very warm.

CYCLE TWO

1. Standardised Assessment (Summary only)

An occupational Therapy student, Dinah takes Mark through a 'COTNAB' Assessment test, under the supervision of Jill, his occupational therapist. Initially eager and enjoying the opportunity to demonstrate his improvement, Mark becomes progressively more irritable and disgruntled as he experiences small failures and as the two women in the room with him respond to his friendly and joking remarks in a quelling manner in an attempt to maintain the test conditions. He also seems disturbed by the presences of the stop watch and repeatedly asks not to be timed, a request which is denied. Eventually after two failed attempts to carry out a task he 'storms' out of the room, yelling at Jill.

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2. Mates

Setting: *passageway.*
Present: *Wayne, Mark, later Don.*
Time: *16 August 1994 ,10.30 am.*
Duration: *8 minutes.*
Mood: *Wayne, an ex resident, the same age as Mark has called to see everyone. Mark is very excited to see him again and they have just greeted each other. Wayne has made a joke about being emotional about seeing everyone and Mark clearly believes he is playing along with the joke.*

(The initial page of this interaction is omitted)

"Oh mate!" Mark, excited and grinning, puts his arm around Wayne's shoulders, "see!" he turns back in mock accusation, "you've made him cry!"

Wayne grins vaguely at this without turning to look at Mark. He has noticed another member of the staff approaching down the passage and walking towards him, he calls out to this man "Gidday John! How are you man?" Mark's smile fades. He looks around, his expression resentful. Seeing that no one else is observing him, he swings on his heel and marches sulkily toward the front entrance, through which he must go to reach his flat. Wayne's voice is loud and as he walks he can overhear the conversation with John that is continuing further up the corridor.

"Where's all the team?" Wayne suddenly asks to the passageway at large. Mark pauses, seems to consider a moment and then he turns. "I'll show you!" he calls brightly up the passage as he walks eagerly back. Wayne however, has now caught sight of Don, the Recreation Co-ordinator, pushing a wheelchair and does not seem to have heard Mark's offer. "Gidday Mate!" he shouts striding towards Don. Mark increases his pace clearly hoping to reach them both in time to join in the conversation. A big smile of anticipation breaks out on his face.

"Hello Wayne!" exclaims Don surprised "What are you doing here?"

"I have come to annoy you!" Wayne pronounces proudly to Don as Mark catches up with them and stands beside Wayne grinning proprietarily down at Don.

"That's good," Don encourages him grinning. "What are you doing now?"

"Being annoying!" Wayne replies and pleased with his joke he lets out a guffaw, hands in pockets.

Don grins and takes this as the end of the conversation he begins to push Rosemary on down the passage. "Oh good, I like to be annoyed from time to time!" he calls back as a parting rejoinder. Mark seems to decide to demonstrate that he too can be annoying. He leaps forward and vigorously rubs at Don's hair. Don, a little bewildered by this sudden development, responds valiantly to maintain the atmosphere of kidding. "Oh! Special annoyance eh?" He attempts to continue to walk down the passage, a mild smile on his face, but his remark has encouraged Mark to go to even greater lengths and he walks along beside him, rubbing Don's hair still harder and more enthusiastically. Don shakes his head as if to shrug him off and Mark immediately moves his hands to his shoulders and grips them roughly shaking Don's body. Don still shows no particular reaction but clearly Wayne is delighted with this development.

"Do it to Mark as well!" he calls out encouragingly. Mark turns back to Wayne and realises he has left him behind further down the passage, he gives up on Don and returns. "Hey Mark!" Wayne calls as he approaches, "come here!"

Mark comes up and stands expectantly in front of Wayne who, with another loud guffaw, begins to rub his hair even more roughly than the treatment given Don's. Mark stands grinning passively for a few seconds and then seems to decide that that this enough. "Leave it alone now," he says and falls into step beside Wayne. "Hair is hair and that is the way it stays," he adds.

Wayne responds by passing his hand through his own hair in an exaggeratedly feminine gesture. Mark grins "You should be a model!" he teases, as they walk on down the passage toward Terehi. Although they walk side by side, Mark is clearly following Wayne, like a puppy, while Wayne is looking around for more people to greet. "How are you anyway?" asks Wayne casually while there is no one else around.

"Good thanks, -" responds Mark, clearly intending to continue, but Wayne is not listening. He has seen another nurse. "Gidday! It's Evelyn isn't it?" he says, as if Mark was not there. Mark does not seem to mind. He seems glad to show off his friendship with this person.

"Gidday Wayne," answers Evelyn smiling, "That's right." She turns to enter the doorway of Terehi. Another nurse calls teasingly from inside the treatment room beside the entrance, "he knows your name does he Evelyn?"

"Just look out here!" Mark calls out excitedly as he and Wayne stand together proudly in the door way. Janey, a nurse aid emerges from the treatment room "Hurry up! What's my name first?" she teases him "You don't tell Evelyn hers and not know mine!"

Wayne steps forward chortling in delight. "Well see you later then!" he jokes. Janey and Evelyn laugh as he pretends to leave.

"You remembered mine" says Evelyn encouragingly.

"That's because you are better looking!" Mark chips in loudly. No one acknowledges him. There is a silence as everyone stands waiting for Wayne to remember.

"Joanna?" he tries tentatively.

Mark cannot contain himself "J-A-N -" he prompts.

"Janey!" Wayne calls out triumphantly. Janey grins and nods and he puts out his hand and shakes hers. "Took me a long time." he comments "But I got it! How are you?"

"Good, how are you?" asks Janey.

"Well, I have got to go now." Wayne says losing interest and he turns away, ignoring Mark who is standing beside him he walks out of Terihi again and back into the corridor. Mark quickly catches up with him again and turns to watch his face. He suddenly puts on a deep voice and swings his body from side to side in a parody of dancing. "Lets have fu-un!" .

Wayne continues to walk down the passage, not really watching. "Too right eh?" he agrees, casually preoccupied with his search for more staff to greet.

"Too right," Mark agrees again, "it is the key to life eh? To have fun." They reach an intersection in the passage way and Mark pulls back the plastic strips which screen off the way to physiotherapy. "Teresa's down here," he suggests, holding them for Wayne and making a mock bow. "Here you are matey!"

Wayne swaggered through the gap "thank you dude!." He strode on ahead. Mark dropped the curtain and rushed to catch up. "That's all right pal! Matey!" He grinned, walking sideways in his determination to elicit a response. He reaches up suddenly and messes up Wayne's hair in the way his own had just been messed. Wayne pulled away.

"Don't mess my hair!" he says, with pretend seriousness. He turns back and cocking his head at an angle to suggest he is pretending to be vain, "now where's the nearest mirror?" He carries on down the passage.

Abruptly Mark turns away. "I'm getting out. He is too poofy. He is a poofter, doing his hair all the time!" He storms down the passage in the other direction from Wayne who is too busy greeting the physiotherapist to notice his departure.

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3. Meal Planning with Jill

Setting: *Oanau Flat no. 2; kitchen and lounge area.*
Present: *Jill, Mark and intermittently, an occupational therapy student, Dinah.*
Time: *16 August, 1994. 11.15 am*
Duration: *10 minutes.*
Mood: *Mark is very positive and involved. He remains engaged throughout the session.*

For the last ten minutes Jill and Mark have together gone through cupboards, discussing what he will need to buy at the supermarket for the next week. Dinah, the OT student, is observing Jill and Mark from a distance of seven feet, standing out of the way of their activities in the kitchen, against a wall. Occasionally she will chip in with a tentative comment. This week, there is one special occasion to plan for; Mark has invited a friend to dinner on the Wednesday night. They have already planned what they will buy for the fridge and the pantry and are beginning to think about the frozen goods that will be needed.

"Okay Mark, lets see what you have got in the freezer for Wednesday" Jill says. Mark goes over and opening it, he bends down from the waist, legs spread, to look in. "Got lamb pie, two sets of chops," he calls out.

"Chops then?" suggests Jill.

He looks up and thinks. "I could also have hamburgers, there is one ham slice," he rummages further and corrects himself, no, it is half a ham slice." He pauses, clearly picturing in his mind the meal he will prepare for Graeme's visit. "Two hamburgers, chips.- coleslaw!" his face breaks into an elated grin. The imagined feast is just right.

"Is a quarter of a piece enough?" Jill hints.

"For one hamburger each, it is, yes," insists Mark.

"Is it?" repeats Jill mildly.

"Yes," says Mark firmly. There is a sense here in his expression of some doubt, but a resolve to hide it, a sense that he may feel it would suggest error and weakness to back down.

"Okay. If you think that will be enough?" Jill reframes her query, to offer him another opportunity to consider his judgment. "You don't need to buy another?" She waits a moment and then adds, "How many slices of this do you need for the pizza? Probably two, what do you think?"

"I thought just the same thing!" Mark nods again with exaggerated pleasure. He strides eagerly back to his seat and raises the pen.

"Okay, "Jill continues without further comment "we need to increase that. "

"Three ham" Mark reads out, as he writes it down.

"Chops for your other meal," reminds Jill, watching what he is writing. "Let's get all that down then." Mark stares ahead, thinking. "Chops if I have enough." He gets up again and lopes over to the freezer, peering in. "I have got one that is pretty big," he calls out, "so I could have half that for two meals."

"You reckon?" challenges Jill again.

"Yeah!!" Mark replies emphatically but not aggressively. This time he is prepared to stand by his initial judgment.

"Okay," Jill watches him write, ."... and what about some carrots?"

Mark thinks for a minute "They are a bit off," he decides.

"They'll be okay," Jill assures him.

"They have got a funny smell," he insists.

"They'll be okay," Jill repeats calmly. "Kumera?" she suggests after a pause. Mark looks doubtful.

"Corn on the cob, Mark?" Dinah offers.

Mark looks up with an exaggerated expression of delight and surprise. "That is a good idea!" he exclaims.

"You could try that" Dinah encourages in a more level but encouraging tone. "If you want some different vegetables." She turns to Jill. "What do you think?"

"Sounds good." Jill nods casually without looking at Dinah. She seems to be signalling to her student to keep it laid back, not to give the impression of 'telling' him what to eat. She turns back to Mark. "You could buy a wee bag with corn cobs in it," she suggests, "frozen ones. And then you just drop them into boiling water for about five minutes and it is cooked." Mark appears to be considering this and nods then writes. "And you can have that with your chops," continues Jill as he writes. Mark stops writing and looks puzzled.

"At home we have it just as a separate meal," he suggests.

"You could have it for lunch" Jill agrees, "But you probably wouldn't have just corn for tea, because it is not a very well balanced meal."

"Um, um, corn on the cob, - chips!" Mark reads out as he writes.

"Yes, and kumera," Jill reminds him as she watches him writing. Mark grins and screws up his face in disgust, then carries on writing. "That is for Tuesday. Okay?" she points out to him as he writes.

"Oh!" Mark says. "For Tuesday. I thought it was for this." He looks at his menu chart, confused for a moment. He then appears to grasp how the system works again and begins to write.

"So do you want to cross out that Thursday - just add corn on the cob to Wednesday's meal -" Jill prompts him as he reorganises his menu.

"I think that would be too much for me now," Mark says worriedly, he reads out the menu plan he has written. "Chops, corn on the cob and carrots?"

"We'll see how it goes," Jill replies noncommitally.

"Ooh!" Mark reacts with exasperation, his tone suggesting a warning to Jill.

"It is good to have variety," explains Jill quickly, "rather than a whole lot of one thing."

Mark relaxes suddenly and writes. "All right," he agrees. He drops his aggressive manner.

"Okay." Jill summarises for him. "So how many meals did we just plan Mark?"

"Three," Mark replies confidently.

"And what did you just tell me, what the other one was going to be?" She waits and Mark stares at her, clearly thinking hard without much result. "Hamburgers," she reminds him eventually.

"Oh yeah! That's right." He writes, pleased with himself.

"With coleslaw and what?" Jill prompts. Mark looks up from his plan and thinks, but with no answer coming to him.

"Chips" Jill reminds him.

"Those chip things," Mark corrects her, as if to assure himself that he is still controlling this session.

"You could put a bit of coleslaw in the bun if you are having hamburgers," Jill reminds him

"Would you like that?" asks Mark doubtfully.

"That is what they do in the shops or hamburger places," Jill assures him. "They usually put a bit of salad and vinegar." Mark nods, content to follow her lead on this one and writes it down. When he has

finished, Jill continues "Okay we just want to go through that plan and check that we have got everything we need."

Mark understands what is required immediately and takes charge. "Monday bacon and egg pie, that is all you need?"

"Yes" encourages Jill.

"Coleslaw. I have got to buy that."

"Yes you have got that written down.." Jill nods approvingly.

"I have got chips in the freezer."

"Mm-mm."

"Tuesday - corned beef and pizza and I have got all the ingredients for that -"

"Mm-mm," Jill murmurs encouragingly as he gets up speed and confidence with his checking off routine.

"Wednesday chops - and -," he looks down at his list, bewilderedly searching for chops and loses the rhythm.

"You have got the chops haven't you?" Jill reminds him.

"Oh! That's right yes -" he looks a little lost.

"Right what is next on your list?" Jill prompts, "chops, -"

Mark reads out what he has already done. "Monday, bacon and egg pie, pizza, lasagne -"

"Not lasagne," Jill interrupts "remember you decided on pizza."

"No." Mark insists unwilling to concede again, "Pizza OR lasagne I said."

Jill gave a little laugh "Okay." She backed down, "but, you are buying the things for the pizza though, so it will be pizza."

Mark's defence of his position on the lasagne was not overly important to him and he shrugged and dropped it. "Okay," reading "pizza, chops, corn on the cob, baked kumera -"

"Okay. Good," Jill encourages him. "Have you got all those things?"

There is a silence. Mark had forgotten in the pleasure of presenting his meal plan out loud, just why he was reading through them. He checks back quickly without admitting what he is doing. In the silence, Jill adds "corn, that's right and you have got the carrot and the kumera, we will come to the cost later."

"Just that hamburgers cost more than chips," interrupts Mark.

"Okay," Jill encourages him.

"That means I have got -" Mark seems to forget what he intended to say.

"Right," continues Jill after a pause to see if he was planning to say more. "Now what about your breakfast things - you have got enough cereal bread and toast?"

(Two further pages of meal planning and grocery list compiling are omitted at this point)

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4. Negotiation

Setting: *Oanau Flat No. 1, where Mark lives on his own but with support from Occupational Therapy staff.*
Present: *Trudy (tutor), Jill (Occupational Therapist) and Mark.*
Time: *. 17 August 94, 3.30 pm until 3.41 pm.*
Duration: *11 minutes.*
Mood: *Mark is a little on edge. He has been waiting for this meeting which has been arranged specifically to discuss problems that he has been having at his work placement.*

Trudy and Jill ring the doorbell and Mark goes down the passageway to the door, greets them solemnly and leads them back into the room. The women are clearly finishing a conversation they have been having as they walked together to the flat door and take little notice of the arrangements made as they enter, despite the fact that he and they are forced to manoeuvre around the side of the chairs blocking the doorway. They stand together in the middle of the room.

"Like a drink, a cracker?" asks Mark leaning over them with an eager, proprietal air.

"No thanks." Jill says.

"You sit there" Mark continues and he indicates the two chairs. Trudy and Jill obediently move over and settle into them. Mark looks pleased with himself. Trudy yawns as she sits down. "I have tired you out, have I?" Mark comments delightedly, opening the conversation.

He gets no response. Trudy and Jill are not amused about the wasted hour they spent trying to track him down earlier in the day, one of the intended topics of the meeting. To make light of this topic at this stage would clearly be a tactical blunder.

"Okay," Trudy takes the initiative "so where shall we start?" Mark looks blank as he takes a seat and faces them, waiting. "How are you feeling for a start?."

Mark folds his arms. "Okay." He pauses and then adds in a tone of warning, "now."

Trudy nods and continues in a conversational tone "If I sit here and you want to leave, I am right in your way." She points out. "Is that all right with you?" Her expression is bland, there is no suggestion on her face of sarcasm, despite the fact that Mark has twice already 'stormed off' when the issues that are about to be discussed were raised.

"Why would I want to leave?" Mark asks innocently. Trudy lets out a short bark of incredulous laughter.

"If you get angry" she suggests, dead-pan.

"I think I got angry this morning," Mark explains seriously, "because Diana was following me around."

Jill leaps in. "Mm-mm yes." She agrees, seeming glad of the opening he has offered her ."..and I can understand that to a point." She nods in sympathy but then carries on in a firm tone "But, your placement at the SPCA the people have said that they want you to be supervised Mark -"

"Bloody hell" breaks in Mark in an irritated tone.

"Okay?" continues Jill just as firmly and calmly despite the interruption, "Otherwise they won't have you down there." Mark looks extremely frustrated and his face expresses his need to argue, to protest at this decision she expects him to take as a given. "So I guess, since you have got to be supervised," Jill goes on confidently and firmly, "you need to perhaps improve your behaviour towards your supervisor and show to your employer and to yourself, that you don't need to resort to that abusive language."

Mark crossed his arms and closed his mouth into a tight line. "It was because she was there" he explains in a definite voice. "That was why."

"Yes okay" Jill nods and appears to concede but then continues "-and you let yourself down by doing that in front of your employer, that is the way I see it." She pauses. "do you think that is right?"

Mark is still suspicious. He pauses and considers. "Probably," he concedes, nodding warily, "that was the way it was this morning."

"Yes okay." Jill nods too, accepting of his feelings, waiting.

"I was really angry about it when I started this morning," he confides.

"Yes," agrees Jill, "-and you said you don't need a supervisor. Is that right?"

"No," Mark nods, "I don't even listen to her." he adds proudly.

"Okay" Jill nods, waiting.

"I just clean the cages out," he continues, "and - did the food.." she nods again. "-changed the bed roll, put in a new piece of paper, put the milk in the trays and did the water -"

"I heard that there was something that you didn't want to do with the dogs." Jill says suddenly, "That they were too vicious, or too mongrel,-"

"They are!" Mark informs her in indignation.

"Yes," Jill accepts his belief, but makes it clear he is missing the point, "but, you need to do as your employer directs you. Otherwise they can just fire you," she points out.

"Do you honestly think," chips in Trudy in a sympathetic voice, "that your employer would send you in to a cage full of vicious dogs?"

Mark hesitates, he scratches his nose and strokes his hair, then folds his arms again. "Probably," he decides.

"I honestly don't think they would," challenges Trudy. "They are legally bound to keep you safe. I don't think they would send you into a cage of vicious dogs."

"None of the dogs are very nice," he claims sulkily, "only the puppies are nice."

"Yes," protests Trudy, "but it doesn't matter if they are nice or not nice."

"It does!" Mark exclaims, clearly offended.

"The thing is," explains Trudy, "that you need to feed the animals." She looks at him and seeing his doubtful and argumentative expression, she continues. "They are animals that were just dumped - the job of the worker is to look after all animals, whether they are nice or not."

Mark appears unhappy. He leans back in his chair and rubs his chin, bringing his hand back to stroke his hair. He does not offer any response when Trudy pauses and so she continues with her line of persuasion, "I have to work with every client up here whether I like it or not" she points out, "it is part of the job."

"Even if they are pushing you!" Jill chips in grinning. Mark turns to her, looking delighted and laughs. Trudy continues, "because it is part of my job. I can't argue with my employers as far as that is concerned. They will say, 'You don't like it? that is fine! Resign!'."

"And that has already happened," Jill points out, assuming he understanding her switch back to him, "on Tuesday."

"50 percent of your employment has been cut," Trudy claims emphatically, "because they don't feel safe with you!"

"And they don't feel that they can ask you to do the job fairly," Jill adds. Mark tilts back the chair, backing away. "So," Jill summarises, "it sounds as though you don't want supervision, is that right?" Her tone is challenging. Mark nods carefully, putting his arms down to rest on the table and allowing his chair to fall forward.

(A page of further discussion of work skills is omitted)

EXEMPLARS FROM MAX KAVANAGH'S EXPERIENCE .

CYCLE ONE

1 Watching TV (Summary only)

Max watches television with a blank absorption. His facial expression and interest level does not seem to fluctuate when the advertisements come on. When a resident in the room becomes very verbally abusive to the staff, he does not turn his head, or respond in any visible way although the noise must have interfered with his ability to hear the television. When he is handed a cup of coffee, he thanks the nurse without looking at her, sips it carefully and then looks around as if to find someone to strike up a conversation with.

A fellow resident bangs his coffee cup up and down loudly on the table, spilling the coffee around him. Max looks over at this expressionlessly and then returns his attention to the television.

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2. Waiting for Lunch

Setting: *In the passage with Colleen and then in the dining room.*
Present: *Corinna (Occupational Therapists' Aide), Winston (Nurse Aide) , Hilda (Nurse) and Mark Hope (resident).*
Time: *Thursday, 22 September, 11.50 am.*
Duration: *10 minutes.*
Mood: *All participants are involved in everyday routine interactions. Max is relaxed, unselfconscious.*

After an unsuccessful attempt to attract attention[164], Max wheels himself out of Don's 'Recreation Room'. He wheels slowly up the passage, pauses at the toilet and appears to decide against entering it. He continues to wheel himself slowly down the long empty passage way without showing any interest in the activities going on in the rooms he passes or the other people who are coming and going in the passage. As he nears the dining area, Corinna, an occupational therapy aide he works with often, approaches from the opposite direction and says in passing "I will see you in crossword group on Monday." He mutters inaudibly. Corinna leans closer to him and repeats more loudly as if to someone who is deaf, "I will see you next Monday!." The increased volume has the effect of making Max lean forward and fix his gaze upon Corinna. He still does not appear to be quite sure what she is talking about however. "No, probably not" he replies. Corinna looks surprised. "Why, what's the problem Max?" She asks with a perplexed frown. Max mutters something to the effect that he doesn't like it. "You did enjoy it Max" says Corinna, confidently contradicting him. Max nods passively and appears content. He wheels on.

He enters the diningroom and sits waiting for his meal to arrive. He constantly establishes eye contact with Mark Hope, a new resident sitting opposite him at a neighbouring table, without attempting to acknowledge him in any other way, or without interacting with him. He looks down, fiddles, staying totally still for nearly five minutes.

Winston, a nurse aide, comes over with a plate of soup and says "soup" as he puts it down. Max explodes, shouting an incoherent stream of words and slamming his fist down again and again on the table, quite obviously expressing an uncontrollable rage. The words are short shouted comments, phrases and words, rather than sentences, including "Bad!" And "Shit!" Several times repeated. Winston's voice can be heard over the top of this incoherent stream of invective, expressing a sense of astonishment, of protest, and at the same time clearly an attempt to soothe, to calm, "Here, here, here, hey, here we go - you don't have to have it - here we go - here here."

The words seem to penetrate. As suddenly as it has begun, the anger attack is over and Max's body relaxes, visibly slumping as he calms down "Oh, I thought it was -" His words peter out in a quiet mutter. This angry outburst has disturbed the whole dining room. Heads are turned and several other staff have paused in their work and turned to watch. Hilda[165], the nearest nurse, now walks over, calmly and briskly. She stands beside Winston, looking down on Max frowningly. "You don't have to have it, you know." She points out carefully. "You can leave it. Would you like mince instead?"

"Yes" he mutters.

"You just have to ask!" scolds Hilda lightly.

"I'm sorry" he mutters, head down and ashamed now.

"Please don't jump up and down like that. It's not nice" continues Hilda primly, as if still not quite satisfied with his level of contrition.

"No, not at all" agrees Max.

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[164] He may either have wished to announce his intention to leave, or else, to ask for permission to do so. Characteristically, in such a situation, Max would have asked permission rather nervously, as if expecting a refusal, although Don had never denied him the right to come and go as he pleased.
[165] Staff nurse.

4. Word Attack (Summary only)_

Max is being taught to use a computer word game called "Solitile," which involves matching words and definitions to remove 'tiles' piled on top of each other, from the board on the screen. The aim of the game is to remove all the tiles from the game board. Deidre helps him learn it by using as few words and as much non-verbal 'scaffolding[166]" as she can. He is initially confused and comments that the game is too hard, but begins to grasp the rules as he plays it and by the end of the specimen, is confident of how to play.

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5. Walking with Joan

Setting: *Terehi lounge.*
Present: *Several residents and staff are present, none of whom Max is interacting with. Joan Naughton, the physiotherapist enters.*
Time: *Friday afternoon 24 September. 4.30 pm.*
Duration: *ten minutes.*
Mood: *passive and relaxed. Later however it becomes clear that he is looking forward to his evening meal, which is served at 5.00 pm. Usually he would leave to go up the hall to the dining area at about 4.45 pm.*

Joan, seeing the camera and perhaps feeling the need to clarify her actions, explains her intention to practise walking to me within Max's hearing and sight. He appears not to hear or comprehend this conversation at all. The fact that it is not directed at him appears to mean that he takes no interest in it. Joan then turns her attention to Max with a smile and looking down on him in his chair says brightly, "hi Max!"

Max smiles back peacefully and answers. "How are you going, all right?"

Joan, risking a repeat cycle of pleasantries checks out again, "all right?"

"Not bad at all," says Max comfortably.

"Would you go for a walk on your stick for me?" Joan asks in a bright and interested way.

"Yes please," he answers calmly.

Joan smiles approvingly, bending down toward his face. "If I go and get your stick from your room," she suggests encouragingly, "you can go and head for the dining room if you want to." She smiles expectantly.

"Dining room. Yes." Max nods, apparently pleased with the plan but making no move to carry it out.

"Would you go for a walk on your stick for me?" Joan repeats again.

"Yes please," responds Max again.

Joan disappears to get the stick and Max demonstrates that he has understood the plan as he unlocks the brakes of his wheel chair and moves slowly into the passage. There is no expression on his face and he moves in a calm and deliberate manner.

"All right?" he asks Joan as she returns.

"Good." Joan replies approvingly, her bright and enthusiastic manner is in sharp contrast to Max's placid and detached air. "Well, would you undo the brakes and just park up the road?" He appears a little nervous about Joan's intentions at this stage, perhaps fearing that he will be late for tea. "In here or around the corner a bit?" asks Joan, obviously meaning where Max should park his wheelchair before transferring.

"I'll ride around the pole," he replies as he wheels himself around the corner. "I use that for my tea" he explains, exposing something of his fear about the approaching meal time.

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[166]See Chapter 1, p.44 where scaffolding as a teaching strategy is described and discussed.

"Come along," responds Joan, grasping his concern. "We'll head you up the corridor towards tea." He relaxes and concentrates upon manoeuvring the chair in close to the wall. "Not too close to the wall," Joan warns him, "because we have to put the footplate down. All right?"

"No" he nods solemnly as he concentrates upon the task..

"Just a bit further, that'll do there because we are not going to block the corridor there," directs Joan. "On brakes!" she adds.

"On brakes," echoes Max.

One step of the plan accomplished, Joan is ready to prepare Max for stage two. She moves around in front of him, bends down a little and establishes eye contact. "Before you get up for a moment, can you remember what you are going to be doing with this leg?"

"Yes?" Max nods expectantly, waiting for more information.

"You are going to be bending at the hip and bending at the knee and you are going to make sure you put the foot down first."

"That's right, Prue," Max agrees, "get my foot to go hard."

"You are going to do that?" Joan questions him, ignoring his error in calling her by his wife's name.

"I am dragging it." Max agrees, making it clear that he understands the intent behind the preparatory lecture.

"Yes. Well, you are not going to drag it," Joan replies firmly. "You have to bend it there and bend it there." She touches his knee and his ankle respectively as she punctuates her instruction.

Max struggles to his feet and clutches the stick and begins to move forward slowly and deliberately, the left leg, the four pronged stick, then the right leg, over and over. Joan walks alongside, commenting "Good!" "The bend.. and.. the lift!" "Keep going.." "Oh yes, that's nice." "Yes." Take your time," and more quickly as he forgets, "bend the knee in!" "try not to scuff on the floor," "better," "that was better too," "that was rather nice also." With a less certain step from Max, she exclaims, "Oops!" followed by "not too bad" for the next step when he treads more confidently and "that was quite good" for the step that follows. There is a silence for two steps, then, "oops! You didn't bend at all, did you?" is followed by, "that was too fast"..

As the two of them make their slow way up and then down the passage of Terehi, Joan's commentary continues. Max makes no attempt to contribute to this one sided conversation. He is totally concentrated upon his walking. He appears to have a basic sense of trust in Joan and is relaxed. He quite clearly understands what is expected of him and appears to find the comments useful in monitoring and regulating his own walking. Although to an observer, Joan's approval seems exaggerated and overdone, it seems to have a positive effect upon Max who is quite stimulated and excited.

As the walking continues and Max has acquired an easy rhythm, Joan begins to relax and chat in a more general way. She suggests, "that's right, you are telling your leg what to do," and encourages him by suggesting that "Prue will be pleased to see your walking is improving," to which he responds "Prue is a wonderful girl" fairly automatically.

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6. Sunday Lunch (Summary only)

Max sits eating and drinking whatever is placed in front of him without acknowledging those who serve him, or those who are sitting around him eating their lunch also. He is asked how he will manage a bread roll and asks for it to be cut up, calling the nurse 'Prue'. He eats it and then waits for her to finish cutting up another roll, believing it is also for him. He thanks her as she finishes and when she explains it is for his neighbour, he shows no sign of annoyance or embarrassment at his mistake. When he looks blankly at the sealed yoghurt pottle which has been placed in front of him, the nurse tells him to look for the little 'lip' and tear it. He begins to search the middle turntable and she reaches over and points to the foil tab. He tears off the foil and continues to eat without acknowledging her.

7. Making a Toasted Cheese Sandwich

Setting: *Initially, Terehi Lounge, but after the first few minutes, Occupational Therapy Dept where a few other people are quietly engaged in other activities.*
Present: *Esther, an occupational therapist and Max.*
Time: *Monday 27th October 1995, 10.30am*
Duration: *12 Minutes.*
Mood: *Calm and relaxed.*

Esther walks into the lounge and approaches Max. "Want to come around Max?"

Max hesitates. "What time is it?" he asks as if for something to say to fill the gap while he thinks. When Esther tells him it is 10.30am, he asks "What do I have then?"

"You have me," Esther replies patiently. "Deb will be videoing us," she adds. "Is that all right?" Max nods. "I will just put those on the bench," continues Esther and then, as Max puts his glasses on in preparation for his session. "Good one. Glasses on."

They begin to walk down the passage together. "How was your weekend?" asks Esther casually as they walk along.

"Don't know at all," replies Max. And, after a pause, "I don't know at all, can't remember."

"Nothing at all?"

"Nothing at all," confirms Max. The conversation lapses for a while.

"Here's our Department," says Esther as they enter the double doors. "Okay, Max. Remember we have been doing snacks and stuff?"

"I can't remember," Max answers placidly, with no apparent concern.

"We can't use the kitchen today so I have set up our stuff over here." Esther indicates a bench where there is a bread board with a spike on it, butter, cheese, peanut butter, onion, tomato, jam, vegemite and pickle.

"Bad, yes. It is bad. Too much stuff" Max offers solemnly taking her cue. Esther keeps her tone warm and positive, coaxing him brightly. "Yes, I have got some stuff out for us here." She points as she lists the items in front of them. "Bread, pickle, tomato relish., I thought we would make some sandwiches."

"Sounds good," responds Max compliantly.

"Sounds good?" prompts Esther seeming to want to elicit more comment.

"Yes it does," Max responds solemnly, now sure that he has made the right response.

Esther asks him to choose which sort of sandwich he wishes to make, peanut butter or cheese and he says, "both" with prompt certainty. She grimaces, startled and suggests that that would be a yucky sandwich. She then suggests that if he selects the cheese he could have onion as well with the cheese and adds "that would make you fart, Max!" Max explodes with delighted laughter and says, "that would be too much!"

"You want to use some cheese as well?" she asks.

"Yes I do." He nods consideringly.

Esther nods back and then turns her attention to the board. "Okay, what do you do first?" she asks him briskly.

Max stares blankly at the variety of items confronting him. "Put some tomato on there?" he ventures uncertainly, pointing to the bread.

"Some what?" coaxes Esther.

"Straw - some oat - ah" Max becomes quite literally lost for words. He clearly knows what he means but is unable to produce a word for it.

"Butter?" asks Esther.

"Butter." Max concentrates, thinking about it, but cannot decide. "No?" he shakes his head.

"No?" says Esther. "Remember we just said before we were going to butter this top side so then it gets toasted in there?" She elaborates for him in the hope that he will remember the process from their session last week.

Esther is standing very close to Max. The body space arrangement is different from normal because the focus of interest in a practical task calls for a closeness without it implying a higher level of intimacy. The closeness appears to give him a feeling of a partnership.

"Okay?" says Esther giving up on her hope that Max would independently carry out the next step, "so what we need to do is butter two bits of bread."

Immediately, Max picks up the knife, grips it like a pen, looks round at the items in front of him searching for something to use with it.

"Stick it on there" Esther prompts, pointing.

"Yes please" says Max, continuing to hold the knife incorrectly.

"Are you up close enough to the bench?" asks Esther, perhaps hoping to cue him into thinking of how well he has arranged himself for the task. He does not alter the grip on the knife however.

"Yes I am," he answers calmly and butters the bread.

As he works, Esther watches him and chats. "You can do lots of snack things by yourself," she suggests and, as he finishes buttering the first slice "Okay. are you ready to try the next slice?"

"Fair enough too," agrees Max and, as he puts down the knife to take the bread and then as he picks it up again, he at last changes his grip on the knife to one more appropriate for buttering. Esther then explains the use of the spike after he has already started using it, so reinforcing with words the actions he is taking as he is taking them, reminding him of the reasons and the cause effect relationship. Next Max moves the cheese over to place it on the bread.

"Remember it will melt a bit so just move it in slightly." Esther watches silently to ensure he carries this out successfully and then takes the pickle jar and opens the lid. Meanwhile, the effort of placing the cheese accurately on the bread causes Max to pant a little.

"Are you puffed out already Max!" teases Esther.

"Buggered!" says Max grinning as he puts the pickle on. The air of partnership and companionable sharing in their conversation is reinforced by this interchange and by their close body language.

"Good Max. Look all right to you?" Esther asks having thus cued him as to the correct response.

"It does good," Max responds peacefully.

"Do you want to put the lid back on the jar?" Esther asks.

"I'm sorry Prue," Max answers, correctly perceiving the underlying correctional nature of this hint.

"That's all right," says Esther casually, neither reinforcing nor disapproving.

CYCLE TWO

1. A Perfect Day

Setting: *Education Unit office with Trudy, a session is just beginning.*
Present: *Trudy, Education Unit Tutor and Max.*
Time: *Monday 27th October, 1.30 pm.*
Duration: *11 minutes.*
Mood: *relaxed and informal.*

Trudy offers Max a red pen having failed to find a blue one. "Is it all right if you write in red pen?"

"Yes. Good." Max replies, seeming quite pleased by the idea.

"Are you sure?" checks Trudy and, as he nods, "Okay then, head the date up."

Max checks his watch. "Twenty ninth of the sixth," he says as he writes.

"It is actually the twenty-sixth of the ninth," corrects Trudy and pauses as he starts to change it. "You got it fack to bront there," she teases lightly. Max turns to her with an expression of delight and laughs, enjoying the joke and understanding the humour. Trudy grins back at him. "One out of three ain't bad!" she adds, referring to the rest of his heading.

Max appears to misunderstand this attempt to make light of his mistake and he begins to make some calculations on the paper. "Three plus six that's nine - let me see - four days following that - ah that's," he mutters inaudibly to himself as he calculates, "four days to go.. that's five." He looks up expectantly at a bewildered Trudy.

"You have lost me Max" she admits.

"The month must be only ah - I see - the month is the ninth month September, 31 days?" He looks at Trudy hesitantly seeking approval and confirmation of the direction he has taken.

"Only got 30 days," offers Trudy helpfully, still not sure what his problem is. "Four days until October."

"It goes like hell," Max tells her solemnly.

"Time flies when you are having fun," Trudy jokes.

"Yes it is," says Max, apparently calmly accepting the remark as a truth. "That's my birthday," he adds.

"October?" asks Trudy.

"Yes."

"What date?"

Max looks up and thinks. "Don't remember the time at all," he admits.

"Don't you remember what the date is?" asks Trudy. "Is that your birthday?" she points, "the seventeenth?" He nods and she attempts another joke. "Will you be twenty one again?"

"I think I will be 31," Max replies seriously and then after some thought adds, "about sixty."

"About 60?" asks Trudy doubtfully.

"Yes," agrees Max, "sounds terrible!"

Trudy pauses, looking at his rather blank face, then leans across and writes in front of him as she speaks, "When were you born, what year?"

"42," he replies correctly.

"So" she writes as he watches, "Nine take away four is? - five - so - you see? You will be 52 this year."

"Sounds terrible!" says Max frowning.

"Certainly not in your thirties," agrees Trudy and then moves quickly on to the day's exercise. She places a printed sheet in front on him and, indicating the heading says, "Okay. I thought we might work on this one today and see if we can develop your planning skills. So it says, 'Use your imagination in planning the perfect day'."

Max's face drops. "I can't do that. I am not sure at all."

"Just think," Trudy responds, putting on a more encouraging and enthusiastic tone, "you have got all the money in the world."

"My mother is not there either," comments Max rather inconsequentially. "I have got to take her as well."

"No," says Trudy, obviously a little startled. It can be anyone and anywhere." She turns her attention back to the worksheet. "Now, where do you want this perfect place to be?"

"I don't know" mutters Max, head down, in a low voice. His posture suggests a feeling of inadequacy, a lost emptiness.

"You have got to use your imagination. It might be.-"

"King Country. Ashton," says Max firmly, as if taking an opportunity to place the situation upon more familiar ground.

"Whereabouts in Ashton?" asks Trudy.

"Ashton" repeats Max with more certainty. "Ashton is a perfect place, I belong there too. Been there about 40 years." He is warming to the idea now, quite obviously his memories are pleasant and comforting and he continues to speak as if to prolong the feelings.

"But you don't live there now, do you?" Trudy reminds him.

"No" he agrees sadly. He thinks for a while and continues. "They got killed, they died." He thinks a little more and unaccountably laughs as he adds, "Got married .. Stupid." and then, in a calm and unconcerned voice, "She died too."

Trudy seems confused by these remarks. She pauses, then seems to decide to centre upon the issue of the "dead" wife.

"What is your wife's name?"

"Prue" replies Max calmly.

"Prue is well and truly alive." Trudy reassures him. Max looks up at Trudy with a mild interest as if at some unimportant fact.

"Is she? Where is she?" he asks.

"23 Natuch Tce, Limmerton," replies Trudy solemnly. Max nods wisely and chats away in a long monologue about Prue, much of which is either incoherent or inaudible to her. He seems to be suggesting that Prue helped him with a science exam and also that she has a child and then that she is "nice." Trudy nods and looks mildly interested and then summarises when he pauses.

"Yes. So she is not dead."

"No. So it was," Max agrees peacefully, "she's nice too."

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3. Going to Limmerton

Setting: *Initially the dining room and then Philippa's room.*
Present*: Philippa (Social Worker) and Max.*
Time: *3.30 Thursday. 20th October 1995.*
Duration: *20 minutes.*
Mood: *Reflective and quiet.*

(A page of interaction is omitted)

"How has your day been?" she ventures in a casual tone.

"No. Not at all," replies Max, concentrating upon his wheelchair.

"You don't know?" asks Philippa.

"I don't know if I am," explains Max, he makes a couple of incoherent queries of Philippa which quite clearly she does not understand. When she does not answer immediately he continues on placidly, "- nice people, nice kids too."

"Are these the people you need to work with?" asks Philippa, grasping for something to help him clarify his own meaning.

"I think so, yes," he answers solemnly. Philippa seems to give up on this topic at this point and choose another; commenting with a voice that is raised at the end to prompt a response, "Nice sunny day."

"Yes" agrees Max in a preoccupied way. His attention had been diverted by the open door to the Occupational Therapy Recreation room, "Do we go in here?"

"No." Philippa informs him "My room is around the corner. That is where you go with Don. But Don's gone home."

"That's terrible," Max says solemnly.

"You like it in his room, don't you," Philippa comments sympathetically, correctly interpreting his meaning.

"Yes it's nice," agrees Max calmly, looking straight ahead down the passage again.

"You do some great pictures," she continues and so incited a stream of confused monologue about doing a job well where he appears to conclude "Now nowhere to go at all to work hard, now nowhere to go at all.." Although the exact sense is difficult to follow there is a clear theme expressed in the words he chose and in the manner he expresses them, that he is distressed and depressed by his current circumstances and that he would like to be creative or productive but is at a loss to know how to please people in this way any more. As they continue slowly Philippa murmurs sympathetic encouragements to him to continue and although she can not follow his words, it is clear she understands the underlying emotionality and that her responses make him feel supported and understood. When he slowly runs out of words, Philippa brings him back to the present

"My name is Philippa, Max.. Did you know that?"

"No. I'm sorry," he replies, but it is unclear whether he is sorry for not knowing, or for his long monologue.

"I am the social worker."

"That's nice," he comments politely.

"And you and I often have chats," she continues.

"Do we?" he asks in mild surprise, "that's good too."

"Good?" questions Philippa.

"Yes. That's good too." He smiles vaguely.

"Do you want me to push you around to my room?" she continues.

"Yes please," he nods happily.

" Put your feet up..," she instructs him as she bends to flip down the foot plates for him to rest his feet on.

"Yes, I'm sorry," he says calmly as he lifts them out of the way.

"The other one," she instructs.

"I'm sorry too," he repeats

"Don't be sorry," says Philippa as she straightened and moved behind him to push.

"It makes me feel useless," he explains, "buggered too."

(At this point there is a gap in the tape when the battery ran out and the conversation resumes as they have settled into a conventional counselling position at right angles to each other in the quiet and privacy of Philippa's room. Philippa has introduced the topic of "Edenton," the home that there is a plan for him to move to)

"Rest home?" asks Max gloomily.

Philippa reassures him quickly, "Not for old people, Max - for people who need help getting around."

"Sounds terrible," he comments sadly.

"Terrible?" asks Philippa.

"Terrible," he confirms. "Does."

"What's terrible?" asks Philippa.

"People going around doing things for you. That's bad." he explains. "Sounds bad" he clarifies more exactly for himself. Then he nods. "Yes. I used to and now we don't talk. I have said to myself and now I am too much trouble." He looked depressed as he grieved for his lost independence.

"You feel bad having people looking after you?"

"Yes it does" he agrees ignoring the second person format of the inquiry. "It is terrible and it stays terrible" he elaborates further as he explored his feelings.

Philippa appears to pick her words carefully. "These people at this home, they will let you do everything that you can for yourself Max," she insists. She seems to search for word pictures which will clarify for him this imagined situation and make it more desirable. "You can dress yourself, feed yourself, shower yourself."

"That's nice," he agrees nodding placidly. Although he is reassured, there is no real expression of relief. His face remains impassive, unconvinced in anything good in his future. It was rather as if he is resigned to 'being good', to putting up with this plan, so as not to be 'too much trouble'.

" - and hopefully by then there will be a programme set up and you will still be able to do the woodwork and the group sessions and those sort of things -" she continues.

"Sounds good," he agrees cooperatively.

"-And Prue will be able to visit you -"

His attention is caught by this point and he looks more alert. "That would be nice. Don't mind at all," he agrees graciously.

"Yes. You will only be ten minutes away from where Prue lives," Philippa continues.

"That's quick, very quick indeed," Max comments interestedly.

"Yes," agrees Philippa, warming to her theme. "It is nice and she would like to visit you too."

"Fair enough too," he agrees as if conceding her right to an opinion. After a moment he adds, "I didn't see Prue at all. She is a missing girl. That is bad."

"Yes." Philippa nods in sympathy. "It is hard for her to visit."

"So it is yes," Max agrees wisely.

"It's is too far away here."

"Yes." He echoes, "too far. That's bad." He holds out his hand toward Philippa in the gesture of an actor about to deliver a soliloquy.

"Yes it is bad. And hopefully you will move back to Limmerton and she will be able to see you more often," continues Philippa.

"Dead right. I don't mind at all" Max agrees, nodding as he lets his hand drop back into his lap. "How many days - how many times?" he asks more hesitantly

"This is not for a holiday we are talking about Max. This is for ever."

"Will I be going home?" he asks uncertainly, clearly confused again about the situation.

"Well at the moment" says Philippa carefully "Prue has to work," she seems to pick her words with care, intent upon avoiding any possible connotation of rejection, "and so she thinks it will be better for you to live somewhere else. And she will visit."

Max calmly accepts this, nodding in a matter of fact manner. He begins to speak but his words are not very coherent. It is clear he is telling stories from his memories of Prue however ".. and what was her name?" he suddenly ends with a question.

"Prue's surname before she got married?" checks Philippa bewildered. He nods "I wouldn't know that Max."

"Dempsey? Martin?" he asks.[167]

"I wouldn't know that Max."

He nods and lapses back, accepting that he can not explore and elaborate his thoughts alone and that Philippa can not help him with this.

"Silly" he mutters.

"What's that Max?"

"Don't like it at all," he mutters angrily.

"It wasn't silly at all Max" Philippa tries to reassure him firmly.

He smiles peacefully, "I'm sorry dear." He points to his head. "Doesn't stay. That's bad."

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4. Dining With Ginny

Setting: *Dining Room*
Present: *Most residents and Nursing staff*
Time: *Thursday afternoon. 30 October 1994, 4.45 pm*
Duration: *30 minutes*
Mood: *The Waimarie dining room is not always a very convivial place. Although there were many people about, the staff were busy serving and feeding and the other residents around Max were silent and seemed disengaged.*

Max wheels himself slowly and placidly down the long passageway from Terehi, into the diningroom. As he approaches his usual table, he pauses, watching it expressionlessly from a distance of two or three feet. His usual neighbour at the table is a man called Rick, who is unable to move or speak and uses a very long wheelchair more like a tilted bed on wheels. This had been parked rather carelessly on this afternoon and is jutting out into the area that Max would usually park in. He seems to consider the situation for a while and then, making a decision, he turns away, wheeling himself to the adjacent table and parking his chair there. A minute passes as he sits placidly. Ginny, a nurse aide whose job it is to serve both he and Rick comes over.

"Max, do you want to sit there today?" She asks casually in passing without implying any approval or disapproval. Max points rather agitatedly at his usual seat. "There is someone in my seat there," he accuses.

"No, Rick is not in your place," Ginny responds, understanding the confusion immediately. "Do you want to sit here?" Max looks frustrated, not ready to be convinced that his place is vacant. He gestures at it again. "It's all right Max, you can go in your place" Ginny reassures him. Without expression, he wheels himself slowly to his usual place.

The staff are chatting with each other and two of them are reading a family letter out to a young girl resident opposite and exclaiming over the news, trying to drag responses from her. Max seems uncertain whether or not he should listen in to this conversation and looks around uneasily. He sees the camera pointing at him and stares at it blankly for a while. He then seems to decide to demonstrate physically that he is not interested in the conversations around him, that he is preoccupied, busy. He moves the blue sticky mat (which holds a plate firmly in place for a one handed person) into a straight position, looks around, checks that his brakes are on and fiddles with them. He reaches down and adjusts his shoe and then turns back to look at the camera again. He gets down a desert spoon from the pile of cutlery on the turntable in the centre of his table. He appears to run out of things to do to look occupied and clasping his hands together, stares blandly at the camera.

Seven minutes after his arrival in the dining room, Ginny appears behind him again, carrying two plates of food. She puts one down in front of him saying "There you go Max." She moves straight on to

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[167] Prue was later able to tell me that both these surnames were of people from his distant past in Ashton, well before he met her. It is likely he was confusing her with his first wife, although neither was her maiden name either.

deliver the second one without waiting for a response. Max was unconcerned by this, incurious about the manner of arrival of his food, or its source, and did not seem to feel any response was called for. He does not look up at Ginny at all but immediately picks up his spoon and begins to scoop up a mouthful of mashed potato. Ginny returns and, seeing him with the spoon, she picks up a knife and fork in a business like way from the turntable and stood over him. He reacted by pulling the spoon back towards him and looking up at her passively, so gesturing clearly that he was yielding up his meal to be cut up. Ginny begins to cut in a brisk fashion, watching the meal not Max.

"So what have you done today?" she asks casually as if making conversation rather than with any real desire to know.

"I have been quite busy," returns Max absently, watching his meal.

"You have?" She asks still without any deep interest implied, but as if to keep the chat going.

"Yes," placidly, still intent upon the meal.

"Do you know where you are?" asks Ginny suddenly, still chopping briskly and still in a conversational unconcerned way.

"Yes," replies Max.

"You are at Waimarie, Max," continues Ginny.

"Why?" asks Max, beginning to get more interested in this conversation.

"Why?" responds Ginny, "because you had a head injury," she explains matter of factly.

"How did I get in?" perseveres Max.

"You had an accident," Ginny repeats, still cutting busily.

"Did I?" asks Max surprised.

"Yes. Do you remember?" Ginny pauses looking uncertain now about her conversation. She seems to feel suddenly on difficult territory.

"No not at all," he replies placidly. Ginny finishes cutting up his food. "Here you go," she says briskly, "eat up!" and she swings away without looking at him, seeming to want to escape the situation she finds herself in.

Max's attention immediately returns to the food. There is no visible sign that he is dwelling upon his accident or his situation as a patient until Ginny passes two minutes later. He catches her attention with more sense of purpose than he usually showed; "How many - how much do I have to do?" He asks anxiously. Ginny is understandably confused and asks him "What?"

"Did I have a car accident?" Max tries again.

"What?" Ginny had still not made the connection with the previous conversation.

"Did I have a car accident?" repeats Max more clearly.

"Yes," says Ginny.

"Did my wife bring me here or did I come in here by myself?" he continues.

"No, your wife Prue brought you," Ginny answers.

"I can't remember," Max explains as if to apologise for his interest. "I don't remember at all."

"I will get someone to tell you," says Ginny.

"That will be nice. Thank you" says Max apparently satisfied with this solution "I'm sorry" he adds.

He turns back to his meal and continues to eat with an apparent lack of further concern or interest in this topic, or in whether or not Ginny carries out her promise. After two more minutes Ginny returns and, finding Hilda, a staff nurse, standing nearby, asks her to tell Max about his accident. Hilda turns around to look at him, surprise on her face.

"Who's asking? Max?" her voice expresses her surprise.

"I can't remember," Max chips in apologetically.

"Fell off a ladder?" asks Hilda uncertainly, obviously searching her mind for more detail. Max seems to feel that she is asking him rather than herself.

"No I don't know," he answers uncertainly, "I can't remember." He pauses as if to consider the possibility. "When?"

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5. Relaxing in the Evening (Summary)

Max believes the toilet is engaged and does not know what to do. He waits passively without asking. A nurse eventually notices and tells him it is vacant. When he wheels himself back into the passage a moment later another nurse who is passing, Olwyn, notices that he is in a slumped position and prompts him to push himself back in the seat. She asks him if he wishes to stay up late to watch the rugby game which everyone has been talking about. He is very bewildered and suggests it might be like squash and that he might have to have a shower. The nurses find him amusing and laugh with each other but he is unaware of having provoked their amusement. He returns to the lounge and watches 'Wheel of Fortune' on the television, companionably suggesting possible answers to the word puzzle to the nurse.

EXEMPLARS FROM BRYCE LAWSON'S EXPERIENCE

CYCLE ONE

1. Getting Lunch (Summary)

Sid is in the lounge area of the flat, eating his lunch. Bryce enters and goes about making himself lunch without acknowledging Sid at all. He cooks in a deliberate manner, never taking his eyes from the cooking food and performing each task sequentially rather than performing several operations simultaneously. His attention remains fixed on the demands of his task and he does not allow himself to be distracted. Once the meal is cooked and placed on his plate, he spends a considerable length of time searching the cupboards and fridge for the tomato sauce. Eventually it occurs to him to ask Sid if he knows where it is. Sid tells him he has it. He sits at the table with his food and strikes up a conversation with Syd.

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2. Before the Polytech Students' Visit

Time: *Tuesday, 9 May, 1995, 10.39 am - 10.57 am.*
Duration: *14 minutes.*
Present*: Bryce and Syd, his flatmate.*
Setting: *The lounge of Bryce and Syd's flat at morning tea time.*
Mood: *Informal but not really relaxed because of the heightened sense of expectation and a consequent heightened self consciousness.*

Loud heavy metal music (Metallica) plays. Sid is at the sink, washing a mug. Bryce walks over and leans himself casually one hand up against the fridge, the other resting on the edge of the bench.

"It shouldn't be long before they get here," he comments in pretended nonchalance. Sid seems unimpressed. He continues fiddling with the cup. Bryce observes him for a while, seeming to be looking for something to say. "Did anyone ever tell you you are a funny guy?" he asks.

Sid grins up at him from the wheelchair. "Yes," he agrees.

"Did you tell them they were right?" Bryce persists, grinning also.

The mug suddenly slips inside the tea towel Sid is using to dry it. "Oh shit!" he mutters.

"Don't swear, you will get me in trouble by the way!" Bryce gestures dramatically toward the door where the camera is positioned. Sid turns and notices the camera. He grins at it mockingly.

"Oh - Hello!" he calls and then turns back to Bryce. "Well, I don't know what the hell I am doing here."

Bryce laughs at Syd's confusion. "You are putting coffee in your cup," he suggests.

"I am doing the talking and then I don't know what I am doing!" Sid exclaims seeming amused at his own confusion.

"They are not too far away," Bryce comments. In changing the subject he reveals his own preoccupation. "They are just going around, oh," he looks up thinking, "what is that place called?"

Sid is busy concentrating upon wiping a mug, head down. "You are hoping you are going to get a bang are you?" he teases. Bryce lets out an pleased laugh and then puts on a pretence of worry.

"Hey Syd, remember Deb!"

"You get sucked in easily!" Sid teases him still rubbing at the mug.

Bryce explodes in a forced and artificial sounding chuckle. "Oh! That was funny!"

There is a silence as they both recover their composure the Bryce continues as if he had not alluded to the camera. "Oh! they are just going around Tatou, tatou."

"What?" Sid has not followed the swing in the topic.

"Tatou Tatou," repeats Bryce. "The polytech students," he explains further when Sid still looks bewildered.

"The polytech students going around tatou tatou?!" Syd's voice expressed his bewildered incredulity.

"Yeah." Bryce nods, "you don't even know what that is do you?" he taunts.

"No, I don't," agrees Sid calmly.

"Head injuries!" Bryce comments teasingly.

"I know what Tatou tatou is - it is some Maori word," Sid defends himself without heat.

(A few minutes of interaction is omitted during which Sid and Bryce continue a similar light banter with each other as they await the arrival of the visiting students. The specimen is resumed at a point when they are reminded of their shared difficulties with memory.)

"What's today," he asks. "Thursday eh?"

"Ah, yeah, Tuesday I think," Sid replies.

Bryce inspects his timetable. "Oh yeah it is too" he agrees.

"I thought it was Thursday this morning," Sid confides without any sign of embarrassment.

"I thought it was Friday," Bryce replies as if not to be outdone. "Oh! Brain injuries! - you don't know anything!" He pauses and then adds in mock seriousness "I know how to crash cars and write them off!"

"Eh?" asks Syd.

"I know how to crash cars and write them off," he repeats.

"I know how to crash motorbikes!" Sid replies[168] as he stirs his coffee and then puts the teaspoon in Bryce's tea. Bryce has been watching this manoeuvre.

"Why did you just stir your coffee and then put it in my tea?" he asks in pretended horror. Sid laughed. "Yuk!" he continues, still grinning.

"I thought you would need to get that tea bag in there," he explains.

"Oh what!" Bryce replies, still pretending to be annoyed, "I'm driving!"

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[168] Syd's head injury is the result of a motorbike accident.

They both take their mugs from the bench top and take a sip. "Now, don't do a Bryce and spill it all over your wheelchair" Bryce warns him laughing. They both take a sip.

"So what are you doing after you have had your morning tea?" asks Bryce conversationally.

"Go and see Philippa," answers Syd, then adds "Aaaagh!" Bryce laughs at him obviously understanding the reason for the pretended anxiety about this appointment. "Is she here?" Sid adds.

"I don't know" Bryce answers.

"Probably not," Sid continues gloomily, "because I will be there!"

"She doesn't like you any more does she?" Bryce taunts him "Because you tried to take a photo of her."

"Yeah," Sid agrees consideringly, "that is probably why."

"I want a photo of her face," Bryce comments. "There will be no show of getting that! No show in shit show."

"Yes you have!" Sid thinks about it. "Just go round there and go 'Philippa!'"

"Hey! I told you that!" Bryce objects, "I told you how to get it!" Sid does not challenge this assertion and there is a silence for a moment. "I had a good way of moving the trailer, until I crashed into Dad's car," Bryce continues in an apparent non sequitur. "It wasn't the trailer of course!" he adds.

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3. Recreating (Summary only)

Bryce is one of a group of residents playing a board game with Don, the recreation room director and Diane, an occupational therapy aide. As the game ends, he tries to tease Diane and Don, as if to develop a sense of teamship, but they do not really reciprocate. He notices some men in the passage and pretends to be anxious that they are 'Mormons' seeming to want others in the group to ask him why he is concerned about Mormons, but again, no one takes his lead. When Don suggests people make a poster of their own profiles, Bryce eagerly reminds everyone that he has recently shorn his head of hair. When Don suggests that he could make a poster using the name of a music group, he suggests that it will have to be ABBA because Metallica and ACDC are too long.

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4. Sharing the Learning

Setting: *Education Unit Office.*
Present*: Linda, Education Unit Tutor, and Bryce.*
Date*: Friday, 31 March 1995. 10.03 - 10.10 am.*
Duration: *8 minutes.*
Mood: *Formal and structured "work" orientation. The beginning of a 30 minute one to one session.*

"Hi Bryce," says Linda, quickly looking up from the papers she is checking.

"Hi." Bryce answers, drawing up a chair and seating himself at the desk he always works at.

Linda pulls up a chair alongside him. "Will it disturb you to have the door open?" she asks.

"No," Bryce answers calmly. His attention is on the pieces of paper Linda is putting on the desk.

"Right," Linda begins, indicating the paper in front of him, "put the date on top, Bryce."

Bryce hesitates, then begins writing. Linda watches and then comments casually, "gosh, April tomorrow!"

Bryce pauses, looks upward, seeming to think. "Aah, what is that the fourth month, ah March, No.." He looks a bit confused.

"It's April tomorrow," Linda continues smoothly, "do you know what day that is?"

"The first of April."

"And what is the first of April, do you know?"

"April Fools Day!" Bryce is pleased to be reminded.

Linda nods, smiling. "Got anything up your sleeve?"

"It's not that, it's what other people have for me up their sleeve!" Bryce replies eagerly.

"Oh well. Keep your eyes open."

"Thank goodness it's a weekend!" Bryce continues. "Sid is going away."

Linda smiles but does not take up the cue to explore what Sid would do. "Okay," she says briskly, turning her eyes back to the photocopied worksheet on the desk, "can you read what you have to do?"

Bryce seems happy to drop the chat and begin work. He bends his head down, concentrating. His brows draw together, the pencil clutched in his hand is held up against his cheek. Linda watches, her body still, back a little from the table so that he can be totally unaware of her. After 30 seconds, Bryce looks up.

"I don't know what that word is," he says, pointing. Linda leans forward, reads.

"Substitute" she tells him. He nods and reads on. Linda withdraws again out of his visual range. Six seconds pass and then Bryce looks up from the paper, staring straight ahead.

"So," Linda says, taking her cue, "what do you have to do?"

"Get rid of - no,that's right, I've got to write down a word here for another word"

"You are on the right track," Linda approves, "lets look in the example, substitute 'a' for 'the' and 'box' for 'space'. Linda is pointing to the words on the paper as she speaks and both heads are close together bent over the worksheet, concentrating. "Put 'a' in there instead of the and 'a hat' there and 'a shoe' there , okay?" Bryce nods slowly, uncertainly, " Okay. So space is changed to?" she pauses, looking at him.

"Box." Bryce answers firmly and his face seems to clear in understanding.

"Right, so there there and there you would put box," Linda agrees, pointing and nodding.

"There is one and a half lines here, right?" Bryce asks suddenly. Linda pauses, turns to look at him, waiting for him to explain further. "And my writing might be bigger."

"That's okay, just squeeze it in as best you can," Linda reassures him, turning back at the same time to the worksheet. "Right. Number One. When you read spring, you are going to put summer -"

Bryce writes busily and Linda leans back again and stares out the window. After a few seconds she looks over Bryce's shoulder at his work but remains so still that he would not have been aware of this. As she reads, it occurs to her that he is not managing alone. She leans forward. "You don't need to write," she points to the words on the worksheet that Bryce has been copying out, "that's the instructions Bryce."

"Ooh! Ooops." Bryce sounds a little disconcerted, but quickly switches to a resigned amusement. "I stuffed that up!'

"Nothing that can't be fixed up," Linda replies calmly. "Now, for this sentence, you are supposed to write summer in where it says spring."

"Okay." Bryce leans forward and carries on writing, his concentration expressed in the frown on his face. Linda watches what he is writing carefully this time and has moved her body forwards so that he is conscious of her gaze. "Garden," she prompts and watches as he puts it in, "such a-"

"Such a delightful - place," Bryce finishes for her.

"Right," Linda straightens, sounding satisfied that he understands, "so every time it says spring it would read," she watches him write, "good!" she remarks as he obviously manages the next substitution without any more direct help.

He finishes writing and as he puts the full stop, Lee says in a satisfied tone, "right. So. If every spring was summer, it would read 'In the garden -" she pauses signalling for him to take over.

"Right now if instead of garden," Linda points to the sheet, "you will be putting?"

"and - in - the - summer - the.-"

"It says garden, so what are you going to write down?"

"Ohh! Yes ah - pool.."

"Good."

"Pool - is - such - a - delightful - place," he finishes the sentence with a look of satisfaction.

"Good" Linda nods calmly, "so would you like to write that down now?" Again there is silence as Bryce writes busily and again Linda, by pulling herself back a little in her chair and gazing out the window, gives the impression of 'leaving him alone'. After a few seconds however she glances over his shoulder and clearly notices that he is not managing the next sentence alone after all. She does not interrupt him however but watches carefully, what happens next. He continues without making the correct substitutions however and after 40 seconds of watching him fail to notice his errors, she speaks quietly from behind him. "Can you read it all right?"

Bryce pauses, "Yes I can read it all right."

"What were you supposed to do?" she prompts.

"I was supposed to change it."

"Yes."

They are interrupted by a person knocking at the door. Linda turns and speaks to the social worker about arrangements for a meeting later in the day. Bryce looks over, then, seeing they are not talking about him, he turns back to his work sheet and works on solidly alone. When Linda's conversation finishes after one minute, she turns back and noticing Bryce is absorbed, she waits, watching what he is writing, nodding approvingly as he clearly manages without further assistance.

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5. Cup of Tea with Syd

Setting: *Bryce is in the lounge watching TV (children's programmes). Syd, enters and goes directly to the kitchen area, at the other end of the rectangular living/kitchen room, approximately 10 metres away.*
Time: *Friday, 31 March 1995 10.37-10.51 am.*
Duration: *14 minutes*
Mood: *Relaxed and informal. Bryce perhaps has a slightly increased self-consciousness as he is awaiting Philippa's phone call and probably thinking about what he will be saying to her.*

Sid enters, barely glancing at Bryce who is sitting in the lounge area, staring at a children's programme on TV. He wheels on through to the kitchen end of the room. Despite the noise of clattering in the kitchen as Sid begins to make himself morning tea, Bryce also seems oblivious of another's presence. A minute passes. "Do you want a cup of tea?" Sid calls.

Bryce still stares at the screen. "Yeah," he replies in a bored sounding voice. As Sid wheels himself around preparing the mugs and the kettle, Bryce continues to watch TV without showing any interest.

"You want coffee do you?" Bryce suddenly calls out to him from the lounge area, without moving his eyes from the screen.

"That's why I am here," Sid answers, unimpressed.

Bryce's interest in what he is watching begins to wane. He starts fiddling with the remote control in his hand and then, looking over to the kitchen area, calls out to Syd, "give me your camera and I will take a photo of Philippa for you." He pauses and, getting no reply from Syd, who continues to make the coffee and tea without pausing, he turns back to the TV, as he explains further. "I've got her next. She is going to ring me as soon as her meeting is finished."

"Don't say it's mine," Sid calls back.

"I won't say it's anyone's, I will just take it." Bryce is nonchalant, watching TV with a studied disinterest.

"She's got a short mini-skirt on today too," Sid comments, perhaps thinking of the photo.

Bryce grins and looks up again. "Ohh!" he pretends excitement.

"What time have you got her?" Sid asks.

"When she rings." He has become absorbed in the TV again and answers absently.

"She is not in a good mood today," Sid warns teasingly.

"Why?" Bryce answers, looking a little more interested, but still staring at the screen.

"Ask her what Henderson said," Sid suggests.

Bryce agrees to without asking Sid what he means, although this was quite clearly an invitation or a prompt and Bryce has no idea who Henderson is. The conversation lapses for a few minutes and Bryce starts to sing along in a jeering voice with the children's nursery rhyme on the TV. Sid makes no response.

There is hair still lying on the kitchen floor from when Sid cut Bryce's hair the night before. Sid notices it as he wheels around in the kitchen, fetching the milk. "We ought to get rid of that," he comments.

Bryce looks down at it expressionlessly. "Have we got some newspaper?" he asks casually without moving. He looks back to the TV and then after a moment without a response from Syd, he adds resignedly, "I'll do it."

"Nah. We could just get a broom to suck it up with I suppose." Sid replies.[169]

'Happy Birthday' is being sung brightly on the Children's TV programme that Bryce is watching. He looks up at Sid still working in the kitchen and sings out raucously, jeeringly, "squashed bananas and stew, he looks like a monkey and he acts like one too!"

Sid does not seem amused. "I don't mind looks like but not acts like," he complains without heat.

Bryce looks back at the screen in exaggerated nonchalance. "Okay, he acts like a virgin," he drawls in a bored voice.

"What brought that up?" Sid asks, bewildered.

"Shut up!" replies Bryce his eyes still fixed on the screen. There is a silence for a few seconds which Bryce breaks, asking, "when are you leaving for the weekend, before or after tea?"

"Before," says Syd, wheeling back to get the second mug from the bench, "then you will be all alone for the weekend," he jeers.

"Shut up," Bryce says again but without any heat. He is staring at the screen again and yet it is increasingly clear that he is not really interested in this programme any more. After a short silence, he suddenly remarks, "I bet when you come back I am going to have two black eyes." He waits.

"Why?" Sid obligingly but a little reluctantly, asks him.

"I am going to come on smart to my old man." His voice, is belligerent, as if rehearsing for this encounter. "I will let him hit me a couple of times then I will give him hell." He pauses but when Sid says nothing he continues. "He thinks he is tough because he used to be a boxer, but martial arts is the best, it would beat boxing any day."

"Why?" Sid responds grudgingly to Bryce's cue again.

"Because in boxing you don't use your feet," he explains confidently.

Sid is silent, unimpressed. After a moment he comments of the coffee cup he is attempting to carry. "Shit, that is the wrong way round."

Bryce looks up, his face expressionless. "I will come and get it in a moment," he responds. He looks over at the screen and calls out "shut up you dork!" to the character on the screen, as he presses the 'off' button on the remote.. "I'se a coming!" pulling himself to his feet and strolling over to take the two mugs. He takes them through to the living area, putting one beside his chair and the other on the small

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[169] Neither man thought of, or noticed this hair again although there was a large pile of it right in the middle of the kitchen floor throughout the day. Later it was cleaned up by an occupational therapy aide.

coffee table, ready for Syd, who positions himself in the other corner of the small lounge beside the table. These movements have the look of well established habit.

"Hey," says Syd, "I told my old man I had a crush on Philippa."

Bryce lets out a bark of excited laughter. "What did he say?" he asks eagerly.

"I could tell that!" Sid answers, laughing.

"Does your mum know?"

"I've told her, but she's got 'Alzheimers'," Sid answers casually.

Bryce looks startled. "Has she?" he asks.

"Not really but I tell her that," Sid explains, "because she forgets everything."

Bryce gets out his tobacco and begins to roll a cigarette. "Shit, I forget everything too," he offers casually.

"Dan's[170] got Alzheimers," Sid comments.

"Yeah, I know. Dan's got this real stink disease. Well no, he has got two real stink diseases." He licks his cigarette paper and pauses as he concentrates on sealing it. "He is stupid and he is ugly. He doesn't think he is but I know he is." He puts his cigarette in his mouth and looks for a lighter, "he's bloody mental" he finishes, in a mock-anxious voice.

CYCLE TWO.

1. A Session on Sequencing (Summary only)

Having worked together through an exercise which involved putting pictures in the correct sequence to create a logical story, Linda (The Education Unit tutor) remarks to Bryce that he found this difficult and he agrees. They then discuss the purpose of such exercises, Linda explaining that the skill of working logically step by step through tasks, applies to most everyday experiences he would need to cope with. Bryce agrees, saying he understands his cognitive difficulties a lot better now and so feels ready to leave Waimarie and attempt to manage in the community.

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2. Future Plans

Setting: *Social Worker's Office. The camera is on a tripod in the corner.*
Present: *Bryce, Philippa.*
Time: *Friday 12 May 1995 9.30 am - 9.35 am.*
Duration: *5 minutes.*
Mood: *Formal counselling session. Weekly timetabled space which Bryce understands to be for expressing his thoughts and feelings. He is slumped comfortably in an armchair.*

"How's it going Bryce?" asks Philippa as she settled into the chair opposite him.

"Good."

"Good?" she ignores the casual tone and asks with serious concern.

"As well as can be expected," he modifies, "having no friends here - because Sid has gone and he was my only friend and, yeah. I am just looking forward to leaving."

"Did you decide that?" asks Philippa.

"Yes" he answers definitely, "and, yes. I have told Aroha" he adds teasingly. He seems to be waiting, expecting, perhaps even hoping, for a protest. Philippa just nods calmly.

"Yes I know. I read it somewhere that you had done that."

"Yes" Bryce speaks lightly but wears a guarded look.

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[170] Dan, a fellow resident, has very severe memory problems.

"You think you are finished here really," Philippa states flatly.

"Yes I do, Because -" he hesitates. "Don't laugh because, everyone sort of laughs - well like everyone I knew before - because I worked on a friend Sue's car and killed it and it cost her three and a half grand to get it on the road again and all that needed doing was the clutch needed oil!." He laughs at the memory and then continues, "-but I am going to be a mechanic."

"Okay," Philippa replies, "how are you going to get that set up?"

"Well, next year probably, cos, this year probably say I am going to do a course at the community college on motorbikes. Then I will advertise in the paper saying I have done a course and I am looking for an apprenticeship." He pauses briefly and then adds, "it is the best way to go about it I would say."

" Do you know the course is there?"

"Well, yes I do." Taken aback he has to think a bit more, "but of course, I don't know if it has already started or not. But I don't suppose it starts until January or February."

"Peta[171] is trying to set up a work assessment for you - are you going to wait here until it happens?"

"Depends," he answers, guardedly.

"If it is not done before your review, are you going to wait until it happens?" Philippa persists.

He hesitates and then reluctantly admits, "probably not." He pauses, as if listening to himself making the statement and considering its impact. Then he adds "no."

"No?" Philippa encourages him to continue.

"I take a stand now," he says more firmly and certainly. He laughs. "I say this is going to happen at this time and this is going to happen at this time," he pauses and then adds, "but yeah, it probably won't. Because," he pauses again, "I know that you are going to disagree with this and, probably everyone that works here will disagree with it, but in July there is going to be Stella and Sally and me and we are going to have a big big huge party and we will probably all get drunk. And no one will be driving so it will probably be a long walk from one side of town to the other side-"

"Mmm" Phillippa contributes reflectively "In Wimberley?"

"In Wimberley. I am never going to live in the country again."

"I just need to remind you about head injury and drinking."

"Yes I know," Bryce interrupts in a mock bored tone, "and I have still got that thing you gave me," he continued ."... and I haven't read it" he concludes proudly.

"I think you need to think about it if you are thinking of getting drunk," Philippa continues in a quiet but uncompromising voice.

"Yes," Bryce protests, "but are you saying that I can't really drink heavily for the rest of my life?"

"No," Philippa responds.

"Good."

"But what do you think it would be the wisest thing to do?" Philippa continues after a pause.

"Not drink," Bryce comes back with immediately. He pauses, then adds, "but, too bad, I am going to."

"Get drunk?"

"No! Not get drunk," Bryce begins to get tangled between his original attempt to project a 'devil-may-care' image and his wish to explore the issue more seriously. "You know, just have three or four cans or something like that?" He watches Philippa's face for her response, "and about once a month, go to the pub and get really sloshed and -"

"Get really drunk?"

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[171] Peta, a new occupational therapist had just begun work at Waimarie at the time I was filming Bryce. She replaced Jill, who was in several earlier behaviour exemplars and Bryce was assigned to her caseload.

"Yeah. Find a way of getting really drunk - same as before. Like the last time there was Sally, Jenny, Mike and I and I got really sloshed and jumped in my car and we were going to Sue's house and we were going past and Sally said to me :"Ah, just past this street and I go "I know that" and she says "Oh," cos Dad lives just past her and I went up to his place and did heaps of burn outs on the front lawn and went out and got stuck and they thought I was pulling their legs and I said "Nah, get out and push man" and then he turned his lights on and they ran out of the car and pushed me out we were off!"

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3. Alcohol, Love and Emotion

Setting: *Social Worker's Office*
Present*: Philippa (social worker) and Bryce.*
Time: *Friday 12 May 1995 9.45 am - 9.50 am (Shortly after the previous excerpt)*
Duration: *5 minutes*
Mood: *Formal counselling session. At the point this segment begins, Bryce has dropped his usual flippancy and is beginning to explore feelings more honestly. He is talking about his accident.*

"..Everyone in the car reckons I wasn't drunk, but I know I was. I must have been eh? Because, as soon as I would finish a can, I would open another can!" He pauses and seemed to be thinking of his past. "Man! I went through some money!" He jerks himself out of his reverie, "anyway, it has happened."

"Don't you really think about changing since you have had the accident?" Philippa asks.

"Drinking?" Bryce asks.

"Mm-mm" she nods, "-drinking and driving."

He grins cheekily "Talk to my father!"

"No, I don't need to talk to your father."

Bryce perseveres. "Well he is stuck in the mud anyway."

"What do you mean?"

"He thinks I am a perfect boy and, you know," Bryce thinks about his father's attitude and his voices becomes more emotional, upset. "He is dead against me drinking again and dead against me driving and all this." He launches into a story from the past, concluding. "and I said "Oh well, get over it," and he said, "are you going to drink and drive again?" and I said, "yeah, probably. I have got to have some way to get home from the pub!" He pauses for a reaction, gets none and, giving a small laugh, he carries on, "and he says, 'Well, what about a taxi?' and I said, "cos I spend all my money at the pub!"

"And what do you think you will do?" Philippa asks quietly.

He seems to give up, relax his attempt at impressing, drop the attempt to build up this image. He speaks more quietly, levelly. "Probably be like that til the day I die. Probably the day after I leave."

"Why do you want to do that?"

"What, dying? or being like that? No it is definitely going to slow down because I have got a baby to think about now - I am going to live with the mum and we are going to get married. And well, she had a child before Joshua, so I have got them to think about now too so, unless you can find a very good babysitter than can stay the night. I am in the shit to put it nicely"

Philippa nods. "Mmm. But I still don't think you are thinking about your brain injury enough"

"Yeah, but I reckon, if I don't think about it I will forget about it and it will just go away."

"It is not going to go away," Philippa reminds him. "It happened"

"Well I know," he pauses. "I know I am stuck with it for life, but ," He stops, lost for words.

"Hopefully," Phillippa perseveres, "you will keep improving and compensating for anything that doesn't improve, but there are some changes you will have to make."

"Yeah. I know that!" He is grinning in mock protest, "But you know I am twenty. I have got another two years to think about that! Because I count on being dead by the time I am twenty four. The way I look at it." he pauses then watching her hesitation adds, "true!"

"What do you want to be dead for?"

"Die?" he asks.

"Mmm."

"What's the world got for me?" he challenges, then adds quickly ."... and don't say cows!"

"You tell me what the world has," she answers.

He lowers his head and speaks quietly, seriously "It has got two kids."

"Mm."

He puts his head up, smiling. "And I want another one, but Stella doesn't want another one. Mind you, she is only nineteen, and so maybe that will change by the time she is nineteen and a half - hopefully it will change - but I don't know. Not this week but the week after I will find out because I am going to stay with her for a week." Clearly by now Bryce was no longer in the social work room - in his mind he was in Wimberley with his fiancee and son. "So, that is cool. I am going to see my baby - it's funny. Only three or four times I have seen him when Stella and Joshua came down. Last weekend or the weekend before took me back to Sally's place and she took me to see Stella the next day and she went to her mother's to use the phone and Joshua was sort of moaning just like waking up and I thought "Oh! What do I do - can't breast feed him!" So I was just like rocking on his crib and I started crying! Is that stink or is that stink?"

"Why do you think you were crying?"

"Because I love him!"

"What's wrong with that?"

"I mean I am a guy, I don't cry."

"You feel emotion though."

"Yeah I know but I mean, the only time that was - last weekend or the weekend before - and the only time I cried before that is when Stella kicked me out of her house because I got up her nose and I cried then - because I was sleeping in my car the night," he laughs as he remembers. "She came out, at quarter to four and woke me up and said go to work...."

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4. Othello (Summary only)

Bryce is using an unfamiliar computer game which requires strategy and visual processing. He makes repeated errors and the computer continually advises him of his error and prompts him to make a new move. Bryce instead repeats the same error. When the computer asks him if he wants instructions, he says without heat, "shut up!" He continues, but appears to be making the first move he thinks of, rather than attempting to devise a strategy. He whispers "Yes!" in a pleased voice when the computer accepts his moves and "Oh you Dork!" when the computer's moves show him he has lost pieces unnecessarily. He continues to make several more illegal moves without reflecting overly when the computer continually rejects them and asks for a different move. When a tutor approaches and asks how he is going he tells her he is "getting there" and she moves away after by chance, he makes one correct move.

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5. Work Experience at the SPCA

Setting: *SPCA grounds.*
Present*: Caroline, the SPCA President and Bryce. Later, Jillian, another SPCA volunteer.*
Time: *9.57 am . Tuesday Morning. 16 May, 1995.*
Duration: *15 minutes*

Mood: *Bryce was dropped off by the Waimarie Van at 10.45. He has been kept waiting by Caroline who has only just arrived. She is very rushed and apologetic and races around letting animals out for a run, checking kennels and pens and feeding. Bryce seems awkward, unsure what to do. He has his hands in his pockets.*

(Initial page omitted. The specimen begins at a point where Bryce, having completed a task he was given, stands idle.)

His posture is slouched, relaxed, immobile, suggesting that he too is passive, waiting to be told what to do.

"We will need some hot water this morning, Bryce," Caroline says, handing him an electric kettle. "Fill that up eh?" Bryce takes it and turns to the sink, just inside the shed. "It's a bit cold today to use cold water," she suggests. There is no response. Bryce plugs the kettle in and he is again at a loose end. Caroline cleans out a kennel and asks if he will do the dishes. With a studied casualness he takes on a longer task, seeming more relaxed again now that he is busy. There is a silence as she and Bryce both carry out their respective tasks. The goat seems interested in what Bryce is doing at the sink and pushes his nose in, under his arm.

"Sick of living?" asks Bryce in a exaggerated pose of casual disinterest, without looking at the goat. He carries on working, intent upon the dishes. Two minutes pass.

"Bureaucrats!" Caroline suddenly comments to the room at large. There is no interest from Bryce. She waits and then turns to me.

"I am arguing with the council at the moment," she explains as she moves into a large pen for cats beside us.

"Yes?" I ask.

"Yes," she replies, clearly building up to a story as she begins briskly to move around the pen cleaning and organising the inside.. "Well, these are the pound's kennels, eh Bryce?" she turns to him, casually including him again in her "team." He nods uneasily. "Yeah" she continues, satisfied and turning back to her work as she talks, "And they came down with a gun - and shot one of our beautiful dogs in our kennel here!" while I look concerned, Bryce shows no further interest in this conversation. He does not appear to believe that it involves him in any way. Caroline is busy in the cats' pen and does not notice this. She finishes her job and picking up a sand tray calls to him. "Okay, I'll pass them out to you Bryce. Put the dirty sawdust in the drums over there please" she instructs pointing. Bryce looks around uncertain "Down there? by the office?" she explains checking his face to ensure he understands." Bryce takes the tray, deadpan "see over there? The scrubbing brushes" she elaborates and he seems to grasp the task expected of him and is immediately relaxed. He saunters off with his trays towards the bins. "Are you any good at fixing hoses Bryce?" Caroline calls after him.

"If you have got the stuff I will do it," Bryce calls back casually.

"That one going fast enough?" she asks as he turns on a hose and prepares to begin scrubbing out the trays.

"Yes," he calls back confidently. He happily scrubs trays for four minutes from 11.04 to 11.08. He makes no attempt to interact with Caroline during this time and shows no interest in anything around him. He is intent upon his work. Caroline however, likes to chat as she works and after a time she calls out to him from the cats' pen. "It is no good for your business if you want to go back to work on a dairy farm, Bryce!"

"Guess what?" Bryce answers.

"This milk is giving these cats a tummy ache," Caroline continues, unaware of Bryce's interjection. "Not very good business for dairy farmers!"

"I am not going to be a dairy farmer now!" Bryce replies ignoring the cats' tummies.

"Aren't you?" Caroline shows a friendly interest. "What are you going to do?"

"Be a mechanic." He replies and before she has a chance to respond he adds, "Don't laugh!" He pauses, but when she does not react at all, he continues "because a friend of mine, Sally, well she was my girlfriend but anyway, I decided that I was going to be a dairy farmer -" he pauses.

"Oh yeah" Caroline offers.

"And about a year ago I went to fix her car because the clutch was stuffed - I took the whole motor out with the clutch..." he continues on the well worn track of the familiar story.

"Yeah?" encourages Caroline obligingly

"And that cost her three and a half grand to get it fixed!" he finishes with his punch line.

"Holy!" Caroline exclaims.

"So she said, 'well if you want a reference, don't come and see me!" He concludes the story and then seeming to feel that he hasn't quite told the story clearly enough to reveal the point, "so I don't think I will ask her for a reference!"

INTERACTION. INTRA-ACTION AND INTERVENTION: A DISCUSSION OF THE BEHAVIOUR EXEMPLARS

CHAPTER 11

A PSYCHOLOGICAL SELF

The behaviour exemplars in the preceding chapter provide fragments of the typical experience of four people recovering from brain injury. They rely upon description rather than interpretation to create an understanding of the different world the four inhabited. In this chapter, these scenes are examined in more depth in order to move from description to analysis of the interactive processes underlying that description. The purpose of introducing this hermeneutic step to the inquiry is to examine how changes in brain behaviour were transformed into changes in awareness and then how these changes in awareness altered the relationships the four people had with others. It will be shown how these cumulative changes within their relationships determined the future of the four men, as much as, if not more than, the underlying cognitive and perceptual damage.

Because of this focus upon interaction and relationships, this chapter constantly seeks to separate out the role of the person's inner cognitive and perceptual processes from that of the interactive dynamics which both shape and are shaped by them. Interactive dynamics are a two-way phenomenon, determined as much by the other people in the filmed scenes as by the four men. These people all, in varying degrees, adapted their own interpretations and interactions to account for the changes they perceived in the person. The way in which they approached, interpreted and responded to them was very significant in determining the quality of the relationships developing. A case is made for understanding recovery as an interactive process which requires the careful manipulation of setting, task and relationship in order to maximise recovery of an adaptive, purposeful and independent selfhood.

This analysis uses an interpretive scheme focused upon what van Manen (1990:101) calls the "corporeality" of the four people, or the way in which they were, at the time of the research, "bodily in the world". The physical and sensory experience could easily be overlooked in a discussion such as this which primarily examines the relationship between the cognitive processes and social behaviour. However, sensation is inextricably linked with feeling and feeling is just as strongly linked with interpretation. The physical body is also the means and mode of acting and it is actions that determine the roles and status we are accorded by others. At every level of experience therefore, the sensory and physical experience of the four men was implicated in the interactions.

To separate these two aspects of the body as experiencer and as actor, the themes and issues which arise in the interactions of the four people will be arranged according to the four levels of the body described by Denzin (1984:105-28), as "the sensate body, the phenomenological body, the body-for-the-person and the body-for-others". The nature of the relationship between these levels will also be drawn out and described in order to explore the types of breakdown that occur as a result of brain damage, the manner in which each of the four was responding to these breakdowns and the way therapeutic interaction was assisting or thwarting their process of recovery of self directed and purposeful living. In this chapter, the first three of Denzin's levels will be considered.

SENSATE EXPERIENCE

For most of us, physical sensation is taken for granted. Feelings such as pain, heat or cold, which are not under our conscious control, act as a source of information, both about the state of our own comfort and also about the nature of the world around us. Damage to the brain can dramatically alter the nature of sense perception and it was shown in at least three of the four cases that the sensate experience which was available to the interpreting consciousness was already altered or impaired in varying degrees.

TOUCH

The loss or even the lessening of the sense of touch was shown to have a considerable impact upon the lived experience of at least two of the four people. The filmed observation and interviews suggested that this change, although apparently physical in nature, profoundly affected the person's sense of interpersonal power. Rob's difficulty detecting by touch, for example, translated into a certain clumsiness and incompetence to his way of doing things. He needed to look down to know if his shoe was on or not and then had difficulty pushing it back on ("Discussing RHAs & CHEs", RJ Cycle One. No. 2)[172]; he dropped the soup spoon and then, because he needed to keep his eye upon it as he fumbled to find it ("Friend & Teacher", RJ Cycle Two, No. 1), he had to pull up his footplate and manoeuvre his chair into just the right spot. He could not tell if objects were hot or wet and so put away damp clothes in his drawer and took a still cool pie from the microwave.

Staff and other residents, (whether because they forgot, or were unaware of his sensory disability), frequently interpreted these situations in ways which converted what was a disability

[172] Throughout the next three chapters, this method will be used to reference the behaviour exemplars. The initials (RJ) denote which subject is involved, the cycle number indicates whether it is the first or second

into a negative character judgement. Diane, the occupational therapy aide who most frequently assisted Rob, had become aware that he often failed to dry his clothes properly:

> **DIANE: Mm - if you leave it to him to dry it he will put it in his drawers all wet! - so I try to make sure he gets it in if I can because I have got other people to get organised -**

Diane's attitude to Rob and her manner of making remarks like the above, was one of tolerant amusement, implying a friendly tolerance for someone who could not be trusted to do a job properly if left to his own devices. Upon reflection, she agreed that it was very likely that sensory deficits were responsible for some of his difficulties with performing the tasks of daily living, and yet despite this, her relationship with him was coloured by a prevailing impression that such incidents sprang from personality traits.

Max's experience showed a similar link between sensory deprivation and interpersonal experience. Like Rob, he had difficulty keeping his shoes on and was not always aware when they fell off. He would complain vaguely that his clothes were uncomfortable without being able to isolate where the sense of friction or tightness emanated from. Nursing staff, unable to clarify what his problems were, tended to conclude he just needed a little attention and, adopted a cheerful bracing manner to tease him out of his discomforts and jolly him into feeling comfortable again. They gradually began to regard themselves as more accurate judges of his body's well-being and would make unilateral decisions about what he needed. The two nurses, for example in "Relaxing in the Evening"(MK Cycle Two, No. 5), examined Max's posture in his wheelchair critically and then firmly managed his repositioning without consulting him.

Because of this loss of sensation, many situations occurred each day where the staff had little other option than to take over decisions about comfort and safety. To minister to what they saw as needs, rather than relying upon Max and Rob to articulate them, was the only way they could fulfil their mission to care. However, Max's experience provides a good example of the inherent risk in such a solution. He had a fixed dilated pupil which made light painful to his eye and yet he was unable to sense, understand or articulate this feeling to staff. Instead a vague belief that he liked to wear sunglasses occurred to him only when he saw a pair and he would put them on regardless of whether or not they were his. The oversensitivity immediately rectified, he would be determined then to keep the sunglasses, resisting any attempts to restore them to their rightful owner and replace them with his own. As with Diane and the wet clothes, the result was a response from others of amused tolerance and a mistaken assumption that he was too confused to 'know his own mind'.

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month of filming for that person, and the Arabic numeral indicates which of the excerpts from that cycle it is. These behaviour exemplars can quickly be accessed by referring to the table of contents, p. v.

OLWYN: Yes ...I don't know whether it was vanity, or what, but now that he has got into it - yes - it seems to be a security blanket.

A sensory loss, when combined with a lack of the ability to put it into words, can be converted into something quite different, a loss of the ability to influence the shared 'definition of the situation'. The problem with language whether in recovery from brain injury or not, is that what is not felt, is not as likely to be put into words as easily as what *is* felt. As a result it is very possible that others (such as Mark and Bryce) experienced sensory loss without being able to define the change for themselves, let alone articulate it to others. Unrecognised changes to sensible feelings may have created some of the 'differentness' they both demonstrated. An obvious example was offered by Mark when he wore a thick padded jacket inside a heated building while doing vigorous exercises ("Keeping Busy", MW Cycle One, No. 6). Mark and Bryce both made several remarks during the filming periods which suggested that they felt ill at ease in their bodies, without being able to elaborate. This could be irritating for staff who, wishing to help the person explore their difficulties, regarded such remarks as a "cop out":

TRUDY (speaking of Mark): Exactly! - "I feel uncomfortable", .. why? - he can't comprehend why!

It appears likely that this sense of being alienated was related to a change in bodily sensation. Because others around the four men took their own sense of touch for granted, it was unlikely to be taken into account in interactions and the oddness or clumsiness they all displayed was often seen as a 'silliness' or 'laziness'.

In an extreme situation a loss of self-perception can mean a loss of a sense of being in the world at all. Sacks (1985:42) mentions a woman client who suffered such a total loss of physical sensation that he described her as only "haunting" her own body. To lose sensation in this way is to lose the ability to interact and engage unconsciously with the world in quite the same way again. It is also certainly considerably more difficult to feel 'in control' and competent.

ANOSAGNOSIA AND NEGLECT

Perhaps the most striking and bizarre consequence of brain injury is "anosagnosia" (Babinski 1914) or 'neglect', similar in effect if not neurological basis, to lessened proprioception. Max was the one to exhibit the most noticeable neglect. He did not seem to be aware of his own body in the same way as others and so used one hand clumsily in tasks which with two could have been easy, or walked with one leg, 'forgetting' as Joan the physiotherapist put it, to take the other leg along[173]. This change in awareness affected not only his competence in everyday living, but also

[173] See Chapter 6, p. 225.

his involvement in it. When only half his body was involved in his activity, it seemed to engage only half of his mind as well.

As we discussed her actions in "Making a toasted Cheese sandwich" (MK Cycle One. No. 7), Esther, the occupational therapist, explained that she consciously chose activities and strategies which would promote two-handedness.

> **DS: There** *[pointing to filmed incident on p.389]*. **You tell him to put the lid on.**
> **ESTHER: Yes, I try to introduce bilateral stuff all the time.**

It was at this point in her session that Max began to include the second hand and with its introduction his ability level seemed to lift. It was as if that hand brought in the part of his consciousness that had earlier lain dormant. Once he had involved the left side of his body it became available to him again. She had discovered that both arms were more often used when an activity particularly appealed to him, or when it called upon past habits. An activity without a personal purpose, designed instead to promote an abstract therapeutic goal, was less likely to engage him in this way and as a result, he had a tendency to perform badly.

> **ESTHER: I have had him in my office sometimes where the whole way through I will be badgering him to use two hands. And he will sit here, one handed. And I look at him over there** [*pointing to the sheltered workshop*] **and he will use two hands the whole way through and I will think "Oh God, what does that say?**

While familiar activities encouraged the use of both hands, this knowledge had a limited use for Esther in a rehabilitation situation. There was no guaranteed transfer of bilateral involvement to newly developing and unfamiliar skills. Because she wished to extend his repertoire of skills to increase his independence and because she needed to teach him to use new adaptive strategies to overcome his disabilities, Esther could not just arrange a programme for Max full of woodwork, crosswords and board games. She needed to assist him in developing new daily living skills. By consciously prompting the use of his second hand therefore, she appeared to create, from the outside-inwards, the ideal inner state of consciousness for Max; one where he was able to draw upon both hemispheres and to maintain the state of productive enterprise he found so pleasing. This method of working to promote two-handedness therefore, was vastly preferable to assuming (as many others did), that inability to perceive a limb translated into an inability to manage it. Many staff interacted in ways which effectively denied him the use of his left side because they were accepted his neglect of it. In the behaviour exemplars "Walking with Joan" (MK Cycle One, No. 5) and "Making a Toasted Cheese Sandwich" (MK Cycle One, No. 7) it can be seen that by prompting bilateral involvement and by remaining alongside to encourage it, Esther and Joan (at least partially) overcame the more negative lived effects of his anosagnosia for Max.

SPATIAL ORIENTATION

Although he suffered damage to the right hemisphere of the brain, Mark appeared to have no left-sided neglect. However, a closer examination of his interactions suggested that some related change in body-awareness may have occurred. He regularly invaded people's personal space without realising it and he was impervious to the non-verbal signals of others about this behaviour. His body language in "Mates" (MW Cycle Two, No. 2) offers the most obvious example, but these traits are typical of much of the film. His "corporeal schema" had altered, as Merleau Ponty (1953) and Sullivan, (1996) would say, and as a result he had become less able to judge his impact upon others.

> **JOAN [*The physiotherapist*]:... he is not too hot on the personal space bit. He tends to stand right in front of you rather than standing a bit to one side - he comes hooning up to you and stands four square in front of you -**

A similar, more subtle change in body-awareness may have influenced Bryce's interactions. Although he initially experienced some disturbance to his spatial orientation and sensory perception, by the time of the research, the only apparent sensory loss involved his vision. This 'heminopia' however, may indirectly have disturbed his idea of what was happening in a variety of subtle ways, affecting his comprehension of social and interactional situations, as much as it affected his ability to read or drive. Because of the serious effect such self-readings have upon effective reciprocal relationships such a possibility should not be underestimated.

Invading the space around a person, or misinterpreting the meaning of others' non-verbal signals, is discomforting enough for others in social situations, but Mark and Rob had another problem with judgment of spatial relationships with (potentially) a more serious effect. They both sometimes misused touch, threatening others unintentionally by breaking normal social rules of acceptable physical contact. Rob touched women without invitation and was misunderstood. This had bred in Nadine such a climate of fear that she turned her motorchair and rushed away down the passage ("A Confusing Relationship", RJ Cycle One. No 3) leaving Rob startled and bewildered. In Phillip, a male resident with cerebral palsy, Rob's physical invasiveness was less open to misinterpretation and fear, but still caused a sense of discomfort and unease of which Rob was oblivious. I asked Phillip why his manner in the group session was hostile toward Rob:

> **PHILLIP: Sometimes he annoys me and I don't like being annoyed.**
> **DS: Oh? how would he annoy you?**
> **PHILLIP: This [*Touching his own arm*] - touching me with his shoulder.**
> **DS: Touching you?**
> **PHILLIP: Yes - and I don't like people doing that.**

A loss of spatial orientation may, therefore, whether directly or indirectly, create problems within interpersonal relationships; problems which deserve a greater consideration as a target of

therapeutic intervention. Nadine, Phillip and Joan were not the only people at Waimarie who had converted what was initially a sense of unease into an aversion for, or other negative judgement, about a resident.

In summary, various forms of neglect and agnosia can be seen to have altered the lived experience of the four men in several ways. The consequences to both their interpretive and their interactive power were not always recognised. Many of the misunderstandings and misinterpretations which occurred in their relationships may have been directly or indirectly attributable to these changes. It appears that rehabilitation staff need to adapt their intervention strategies to account for a possible loss of innate body awareness and they needed to ensure that all other interactants become and remain mindful of this invisible and perhaps underestimated aspect of lived experience.

SENSORY PERCEPTION AND COMFORT

Despite this loss of awareness of sensible feelings, for three of the four men, sensory comfort appeared to have become more of an issue in lived experience, perhaps because it was less under their control. Several people remarked that Max had become less able to screen out or disregard the everyday irritations of living. He spoke worriedly and seriously about difficulties with urinating ("Relaxing in the Evening", MK Cycle two, No. 5); the threat of a draught from an open door was one of the few things which could break into his concentration upon a TV programme ("Watching TV", MK Cycle One, No.1); and noise was very distressing for him, clearly contributing to moments when he became distressed or uneasy.

Perhaps as a result of the loss of conscious control, sensory stimulation in general had assumed a much more central place.

> **GINNY** *(nurse aide in Terehi House):* **We have all encountered it. One thing he doesn't like is noise. He hates noise. He hates Nita...**[174]

Perhaps the most obvious example of the loss of control over sensible feelings was the changed attitude toward eating which three of the four men showed. All four had gained weight during the period of their recovery and although at first perhaps they needed to replace body fat lost during the period of coma, by the time of the research three of them, Max, Rob and Mark, had reached a point where staff and family were concerned about overeating and encouraging them to control their diet. This was proving easier said than done however, as they enjoyed eating and the staff, because of their genuine wish to comfort and nurture, sometimes worked surreptitiously against their clients' best long term interests.

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[174] Nita, another resident, often made loud moaning noises.

OLWYN: Yes I have given him little treats...probably because he is meant to be on a diet and, it's terrible, but we cheat all the time ...

Even when they were not openly acknowledged, the staff were often intuitively aware of food as a motivator and were taking into account in their interactions. Joan reassured Max when asking him to do some walking ("Walking with Joan", MK Cycle One, No. 5), that he would not be late for tea. Winston and Hilda both understood immediately when Max exploded in fury ("Waiting for Lunch", MK Cycle One, No.2) that he was disappointed with the lunch presented to him that day. Because of this tacit awareness, they were able to manipulate Max's attitudes and actions more effectively.

This loss of self-discipline over sensory pleasure appeared to be a result of a changed temporal relationship as much as a sensory one. None of the four men seemed able to control their behaviour on the basis of more abstract future outcome. Although their self-concept was probably even more important to them than to those who were not recovering from brain injury, they were more likely to act in ways which were destructive of this emerging self-image:

DS: Do you think if you gave him the choice, "Max, you can have this icecream, but you don't like being fat, so you might choose not to have it", something like that, do you think he might decide not to have the icecream?
OLWYN: I think he might eat the icecream and then think about it afterwards - he really loves that food...and that is great that he has got that pleasure. But when he has had it, he probably does think like that.

Of course, an inability to deprive oneself of a sensory pleasure for the sake of longer-term goal is not a phenomenon exclusive to people with brain damage. It is especially difficult for anyone to be self-disciplined when the lived present is stressful and overwhelming. Sensory solutions to stress are often the most simple and effective strategies available and, as such, perhaps should be encouraged rather than discouraged during this stage of recovery. Mark for example, discovered the power of a child's swing, of stroking his hair, rubbing his chin and similar motions tended to occur during difficult moments in his day making him appear abnormally nervous, or ill at ease:

TRUDY:... he tries so hard and I am sure that the stroking, I think he strokes his head just to placate it and, it's nice stroking it here and he just does that to take some time out....

Mark alleviated his discomfort, just as Max in losing his temper, wanted only to remove the noise, or the draught, or any other disturbing "immediately given sense impression" (Goldstein 1952:251). Neither was aware of presenting an impression. After brain injury it may become more difficult to counteract sensory problems with the more cognitive means of controlling them and as a result there is a pronounced increase in the use of more visible sensory techniques creating an appearance of oddness or childishness to a casual observer. Put simply, the lessened cognitive control made it sometimes impossible for them to discipline and control their experience of their own body as effectively and completely as others. Ginny clearly believed that this

explained much of Max's supposedly problematic behaviour and this allowed her to empathise with him rather than judge him:

> **GINNY: ... But if you were sitting there yourself. That noise. That would upset me too. Like Nita's noise, that drives you up the wall! I get irritable but I can get away from it....**

Max, Rob and Mark had all discovered the power of physical sensation to comfort and reassure them. Such measures, if they produced a sense of being 'in touch with' one's inner self again, however transitory, become valuable tool of their recovery. The process of recovery can be seen as the replacing, or augmenting of these self-nurturing strategies, with more cognitively-based coping skills which would assist the four in their progress toward a more 'normal' interactive presence and appearance. All four people, seemed to have lost a measure of control over the sensate in their experience and this loss was reflected not only in short term behaviour change but also in the loss of a longer term 'delayed gratification' dimension to sensory experience. As a result, goal directed planning and programmes which relied upon vague abstract notions of 'health' and 'fitness' lost something of their persuasive power. Until sensory experience could be reintegrated with inner ontology there was little incentive for any of these four to control and limit their use of sensory stimulation for comfort so that it remained socially appropriate and allowed them to live a purposeful, adaptive and independent life.

SUMMARY

Taken together, anosagnosia, spatial orientation and altered sensory awareness are aspects of lived consciousness after brain injury which can profoundly affect recovery. Changes in the physical experience of living, whether caused directly by the loss of sensation, or more indirectly by the cognitive and interactional response to such losses are not always integrated into the setting of rehabilitation in a coherent way although they are clearly central to recovery.

Examining the effect of disturbances to sensory and physical awareness in this more interactive way has revealed the shortcomings of a mechanistic approach to understanding disability. The body is not a machine which functions under the direction of the mind, but instead, as the stories of these four men show, the body and its senses form the bases of mind. In contrast to a mechanistic approach, Heidegger's (1967) conceptions of Dasein as "inhabiting itself", offer a much more accurate understanding of the meaning of consciousness. Max, Bryce, Rob and Mark, in as much as they had lost the power to 'feel themselves' competently, had become separated out from and less available to their own minds. This change in consciousness reduced them to a relationship where the body, now "outside of central consciousness" (Gerstmann, 1942:901), became the clumsy and disabled tool of a mind adrift without perception to guide it.

There is a powerful message in the evidence of the four lives therefore, that sensation unleashed from cognition can become an alienating and hostile force which can work against the rebuilding of a coherent sense of self.

PHENOMENOLOGICAL EXPERIENCE

Of course, the inner sensate experience of the four men was never directly available for study, but only inferred. Because of this, a clear theoretical distinction can not always be maintained between the 'sensate' and the next level of Denzin's typology of feeling, the "phenomenological body" (Denzin 1984:119). Feelings clearly entered into and pervaded their interactional relationships[175]. Max, when he exploded with anger ("Waiting for Lunch" MK Cycle One, No. 2), was expressing himself as an extension of the phenomenological body. Rob was, when he reached out and touched another instinctively or affectionately; and Mark too, when he abruptly curtailed a new friendship ("Mates" MW Cycle Two, No. 2). It is in recognising and exploring the characteristics of this unreflective feeling level of consciousness that Heidegger (1967) offers a useful new dimension for understanding the experience of brain injury.

On this phenomenological level there is no sense of 'intentionality'. Expression precedes thought. It was only later that Mark found ways to justify his sometimes precipitate actions, stating that he had acted because he felt tired, weak and angry ("Mates" MW Cycle two, No. 2 and "Negotiation" MW Cycle Two, No. 4). Sometimes, in fact, actions based upon phenomenological experience seemed completely alien to and unconnected with these men's more intentional and reasoned acts, causing them to feel a disturbing sense of fracturedness. Max and Rob, for example, were often unable to explain moments where they lost emotional control suggesting there was total absence of any mental organising of their experience. They were pure feeling in motion, reacting to what Denzin (1984:116) calls the "psychic sounding board".

At first therefore, it may seem that this level of embodied experience is not relevant to an inquiry which addresses symbolic interaction. We are talking here of something which lies underneath the symbolic consciousness. Denzin (1984) has demonstrated however, how important it is to acknowledge the embodied nature of experience in symbolic interaction inquiry because it is at this level the body furnishes the foundations for the socially shared feelings (Scheler 1973:338-9) providing the "peculiar value content in her [or his] lifeworld" (Scheler 1973:339). In this section, the phenomenological level of experience receives further exploration. It will be shown how much of what was considered different about the four men may have stemmed from a change in the relationship between the phenomenological body and the self as expressed at other

levels of experience. Outbursts, euphoria and petulant childish emotional reactions all suggest that an uncontrolled 'feeling' body was playing a greater role in their lives after their accidents than it would have before. Paradoxically, the same sets of behaviour exemplars and interviews reveal what at first seems to be a diametrically opposite set of emotional characteristics, emotional blankness, repetitive stereotypical habits and perseveration. Using Heidegger's (1967) notions of Dasein, transparency, manipulation and disturbances, Gadamer's (1975:91) concept of "play" and Gross's (1987) theory about altered opponence, an interpretive framework is constructed here which demonstrates how these contradictory personality traits have developed from the same basic change in the experiencing of one's own body.

TRANSPARENCY AND ABSORBED COPING

According to Heidegger (1967:78-85), our everyday way of life is usually lived at the transparent level of awareness he called "being-in". We are far more often living in this unself-conscious mode than as the self-conscious actor which psychology tends to assume. As Gadamer (1975:94) points out, it is in this state that we experience "play' which fulfils its purpose only when we become lost within it. All play is a "being-played" (Gadamer 1975:95). Without an ability to be 'in' or absorbed by our bodies in this way, life would become arduous and task oriented and relaxation, creativity and recreation would disappear from our experience.

All four people showed many moments of such absorption. Max in the workshop was lost to awareness of the outside world, while Rob's mind and body seemed locked to his computer when playing Tetris and Patience ("Relating to the Staff", RJ Cycle One, No. 4). With Mark, it was anything rhythmic and repetitive (so long as it did not involve physical exertion) which absorbed him, lulling him into unconscious 'at homeness' with his body. Bryce stared blankly at children's TV programmes ("Cup of Tea with Syd" BL Cycle One. No. 5), or played aimlessly with coloured styrofoam shapes. Whether or not these activities had any clinical purpose or value, the four people could have been described as 'happy', or 'in tune' with themselves while absorbed in these ways. To encourage such qualities in anyone's existence seems an appropriate goal for rehabilitation.

These were the same activities however, which were responsible for the more inactive, stereotyped and repetitive moments of the day, the very behaviour which most marked them out as 'different'. There was something about the manner of their absorbed intentness which seemed to signal their 'brain damage' or suggest they were becoming 'institutionalised'. They could remain totally engaged and absorbed in something monotonous without looking around for

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[175] See Chapter 2, p. 72 where Denzin's four-fold typology of 'Emotion's Body' is explained.

something more stimulating. Their minds seemed blank and empty. Both staff and family members seemed to feel, therefore, that stereotyped behaviour and long periods of doing nothing were to be discouraged. There was a feeling that what skills remained needed to be used to avoid stagnation and decay and that a setting which encouraged activity and stimulation was desirable.

For all four then, Dasein might be described as having become too "transparent" (Heidegger, 1967:186) to itself. "Disturbances" did not occur to switch being into a contemplative mode. Habits acquired a 'mindless' quality. The body no longer monitored sensations, movements and feelings with the same discrimination and so the "unavailable and occurrent" (Heidegger, 1967:102-3; Dreyfus, 1991:85) did not act upon consciousness as a disturbance. Because they were not easily thrust into a more conscious awareness, they were less able to manipulate their reality by reorganising it cognitively. They became subject to their habit rather than in control of it. Max, the least conscious, demonstrated moments of perseveration, Bryce, in playing a game requiring strategy and information processing skills ("Othello" BL Cycle Two, No. 4) calmly entered incorrect responses without appearing to be cued by the computer feedback, to reflect upon his error, while for Rob and Mark the problems were more usually described as forgetfulness and of problems with prospective memory which made their lives unidimensional and locked into the present.

DISTRACTABILITY

Alongside this tendency to inactivity, however, was a parallel and contradictory tendency to be easily distracted. There were occasions when, far from failing to be disturbed, the four men were distracted from their focus too easily. Mark in particular had difficulty screening out extraneous information and reacted to it in the phased manner which Luria (1987:113) describes.

> **TRUDY: He got into this jerky movement of the head today. I was talking about something and the smoke alarm went beep - it means that you need a new battery - well, he has bought a new battery and all of a sudden his head is going around like one of those meer cats on the telecom ad - very jerkily - like those puppets on thunderbirds - and I looked at him and he looked at me and he could see me looking "Mark I was half way through a conversation and you are looking like a silly meerkat -.. what are you doing?" and he said, "I heard a beep..."**

Although more noticeable in Mark, this sort of distracted and tangential logic was also evident in Bryce. For both men, what began as a change to a more sequential thinking style, then appeared to translate in action into an equally jerky and distracting interactive style. Mark seemed to feel obliged to reflect with his actions, every fleeting thought, every slight emotional change. He leapt at Don, messing up his hair when he felt the slightest encouragement ("Mates" MW Cycle Two No. 2); he eagerly and enthusiastically responded to the most casual and mundane of comments in sessions with Trudy, Philippa and Jill. (MW Cycle one Nos. 2,3 and Cycle two No. 3), leaning forward or leaping up from a chair. His whole manner was constantly bouncy and energetic, but

easily distracted as when he heard the beep of a low battery signal on his smoke alarm in the flat. There appeared to be no sustained mood or orientation.

Gross's (1987) remarks regarding concretic personality syndrome encompass not only thought, it seems, but also interaction and relationships. A more stimulus bound and impulsive response to the immediate environment became in an interpersonal sense, a loss of ability to keep track of the central theme of a conversation, or to bear in mind the nature of a particular relationship. As a result conversations and relationships were not shaped to fit a 'whole'. There was less ability to counteract the "immediately given sense impression" (Goldstein, 1952:251), simply because there was no general, guiding 'definition of the situation' available to the person's consciousness. Effectively, therefore, the loss of guiding schemes to interpret situations, to relate them logically to each other, caused a change in the phenomenological experience of living. Less likely to distinguish between the relevant and the irrelevant in the cues their setting offered, the four men were equally less likely to switch from transparency when the occasion demanded it and more likely to when the occasion did not demand it. They were "being played" rather than "playing" (Gadamer, 1975:94). As they were not prompted by situations into a more intense engagement, they were unlikely to build stimulus-response behaviour into something which heightened the level of their consciousness. They could no longer "reverberate and build upon the emotionality that is felt" (Denzin, 1984:116).

AROUSAL

After brain injury the integration between a feeling body and an interpreting mind can no longer be assumed. Divorced from an ontological core, the phenomenological body lost its power as a "sounding board" (Denzin, 1984:116) of inner feelings. Emotion was set free of cognitive constraints and at times the person seemed more emotional and out of control as a result. However, there were other times when without the conscious mind to direct and extend what the body felt, a more intense stimulation or arousal had become beyond the four men. Even when they reacted to feelings, there was less intense and sustained emotion.

Goldstein (1952) regards the ability to extend and develop emotional states as essential to quality of life. Certainly the story of these four lives confirms his view. Without a sustained and coherent emotionality the interpersonal interactions and developing relationships of Rob, Max, Bryce and Mark were distorted and unequal. Following Gross's (1987:102) extension of Goldstein's theory, it might be said that when opponence dynamics diminish, so too does the quality of personal relationships. Without "reafference", without adequate stimulus to conscious

reflection, a person may become more stereotyped and habitual, less 'open'[176] and so less likely to independently seek out and maintain an "optimal level of arousal" (Mirenda, 1994). If a physiological brain process is interfering with something innately human, then it seems important for the therapeutic process to build in compensatory strategies to counteract the effects of the damage sufficiently to allow the person to function as an open system again.

Gross and Goldstein demonstrated how implicit drive and self-actualisation processes are to brain functioning and how after a brain injury, they can not be assumed as a given, nor left to reoccur naturally. When considered in the light of the symbolic interactionist perspective of the person as the meaning creator, Gross's work upon opponence, suggests that a key focus for any rehabilitation programme must be how and when to stimulate conscious reflection in order to allow the sensate and the feeling to be integrated more effectively with the symbolic.

Thus, in order to stimulate self-directed and purposeful activity, it may be necessary to prompt excitation and inhibition processes. This may sometimes mean the purposeful inducing of stress in order to initiate an energy flow. When Sacks, in *Awakenings* (Parkes and Lasker, 1989) describes people who 'take their energy from the ball', he would have struck a chord in many people who work or live with someone with frontal lobe syndrome[177] or confined to concrete thought. While it appeared that there was no self directed energy, there was a form of energy which was a response or reaction to an impetus. This could be maintained with a sensitive adapting of one's own interacting style. By creating an energy imbalance, or by providing the reafferent stress, another person may excite autonomic activity, hypothalamic activity and related hormonal secretions which have a profound influence upon the dynamic and interactive brain. It was remarkable how regularly the times identified by all four as the most meaningful and important were those when the others, (usually therapeutic staff), were 'proactive' rather than 'reactive' in their approach to their interactions, acting as a motivator and energiser. The film shows continual situations where staff, in being over-directive, risked taking away some autonomy (or independent control and choice) in order to ensure that the character of the session was active, involved and valuable.

Many of the people who worked in this way as energy providers did so without full consciousness or understanding of the role they were taking. When asked to view film where they were behaving like this, they frequently became almost apologetic about the amount of direction they

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[176] The open system view of human beings recognises the human innate needs for action, stimulation, creation and production (Kielhofner, 1985:3).

[177] See Chapter 1, p. 13 for a description of frontal lobe syndrome.

were using. They tended to explain their actions in terms of intuitive feelings they had at the time, rather than theory.

> **ESTHER: Looking at it again, maybe I was doing too much for Rob and yet ideally you want Rob to want to come back and do it again and looking at it in that way, then maybe I didn't do too much.**

It became clear as I talked to the staff that many were aware of and monitoring the four men almost *physically*, fashioning their role as an energy source to suit an intuitive sense of the person's need for either excitation or inhibition:

> **LINDA: Yes I do - often he will slump back as if it's an effort- then getting towards the end he was getting really tired and I could feel that and I knew I was really pushing him. And he was wanting to stick with it but finding the concentration really difficult.**
> **DS: The energy from you is massive isn't it? To keep him going?**
> **LINDA: It is. And to do it without actually *doing* the work.**

To provide for this group of people then, may mean the fashioning of an environment capable of "inspiring and persuading" (Ben Yishay, 1985:256), at the same time as it is capable of soothing and calming. This asks a considerable intuitive skill of the staff and family who surround the person. Relationships which rely upon one side more than the other for energy and direction are also not as reciprocal as they should be. The fact that the four people all required a greater commitment of energy from the other interactants meant that for the staff and family there was a need to fashion and manipulate their own emotional consciousness to provide for these needs. The emotional 'nourishment' in such situations is clearly one way, ultimately very draining for the family and staff. Trudy, speaking of managing a group, suggested she sometimes felt like a juggler, trying to keep several plates spinning at the same time. Don, the recreation room director, agreed he was constantly bright and breezy, trying to draw in people who were uninvolved, using his 'this is fun' tone.

> **DON: Right. Yeah - because you can sense, like, if you come in and you are lacking energy, or you are angry or depressed about something, then you can feel it right through the whole group and I don't think it is really fair to put your problems onto them.**

As Don pointed out, the distinctive difference between a group of people with brain damage and a group without, was their dependence upon others for the feelings of energy and stimulation. The ideal relationship compensated for this difference by intuitively manipulating awareness levels. The requirement or goal, as Keilhofner (1985:61) described it, was:

> **To create a setting that is optimally arousing to clients, one may need to create conditions that will either decrease or increase the person's arousal level. Removing distractions, simplifying tasks, lowering criteria for success and decreasing the number of people in the setting are ways to lower arousal. Providing a variety of activities to choose from, increasing task complexity, increasing interactions with other people and setting higher criteria for success are all approaches to raising arousal.**

Keilhofner's goal might be reframed at this point, in terms of Denzin's four levels of 'emotion's body'. He is advocating the conscious monitoring and manipulation of the phenomenological

body to ensure that optimal arousal is maintained. Such a goal ensures that adaptive, purposeful and autonomous consciousness is encouraged, while stereotyped, distracted or in other ways dysfunctional forms of relating to the world are diminished. By fostering appropriate levels of arousal, other people may be better able to support the recovery of a more adaptive consciousness.

PHYSICAL DISABILITY AND ALIENATION

Artificial manipulation of the level of consciousness by alternately disturbing and righting balances then, has a potentially important role in maximising recovery. However, before proceeding any further with this theme, it is important to consider the role physical disability played alongside changes in consciousness in the changing relationship of the four men to their phenomenological body.

As far the physical body was concerned, the accustomed 'balance' of all four people was very seriously disturbed as a consequence of their accidents. There can be no more disturbing change in the relationship one has with one's own body than to lose the ability to control its movement. To some extent, this occurred in all four cases, but in Max and Rob's case, the physical disability was most profound. Neither was able to control his limbs effectively enough either to walk unaided, or to manipulate equipment or objects in order to carry out the simplest of daily tasks of living.

Madjar (1991:123-33), in her study of the experience of pain, makes several remarks about the changing relationship pain can cause to the phenomenological body and her observations appear just as relevant to this issue of physical disability. She suggests a person may lose a sense of his or her own bodily boundaries. What was once a known and predictable entity, may come to feel hostile and alien. As a result, anger at not being able to escape or control the situation often emerges (Madjar, 1991:123), as well as a feeling of being overwhelmed, of having lost a previously known and predictable physical reality.

Max and Rob both often made remarks which suggested they felt just such a changed sense of embodiment and alienation from their own bodies, a sense of being trapped within them:

> **MAX: To me, I was on one foot. And I was on two. Now I know it's buggered, I am actually buggered because now it's joined up to two legs. At times I won't walk at all. At times I can walk no trouble at all. Can't get out of bed and walk - too long. Can't talk bad neither. Because I do that sometimes because of (inaudible). And I walk along then I talk later because I have to, my feet. Sometimes I roll around - others, good as gold. Sometimes I will be 'had it', I can't walk at all although I try to.**

Although in Bryce and Mark the physical change was less dramatic, there still occurred a similar alienation from their own bodies and a sense in which they had come to feel what Denzin (1984:117) and Heidegger (1967:233) describe as awe, dread or "not-me" feelings. The disability had acquired an "uncanny animism" (Sartre, 1978:441-2) of its own.

Such alienating experiences of one's own physical body might be interpreted according to Heidegger (1967), to mean that, in becoming conscious of or disturbed by his body, each entered sometimes into a more "manipulative" relationship with it. Physical disability interrupted the everyday "in itself" quality to Dasein, caused an unavailableness, or occurrentness (Heidegger, 1967:102-103; Dreyfus, 1991:85) between self and body and forcing a switch to a subject/object intentionality in order to regain control over and reincorporate a change to experience. Max, for example, talked as if he was attempting and failing to 'communicate' with his body, puzzling over the inexplicable communication breakdown ("Walking with Joan" MK Cycle One, No. 5). Rob felt shame and attempted to hide his tremor as if it was some nasty trick his body was playing upon him ("Doing Art" RJ Cycle One, No. 1). The same process was evident to a lesser extent in the interactions observed of Mark and Bryce. In fact, all the people, presumably as a consequence of their physical and cognitive damage, thought and spoke as if they were acting upon an alien and uncontrolled body so often in the behaviour exemplars, it is impossible to detail them all here.

It appears then, that when switched to the manipulative reflective mode by the experience of disability, much of the energy of each of the four people was diverted from 'feeling' to a cognitive separating out and 'analysing' of their own capability and changed sense of embodiment. They became in varying degrees absorbed by their concern to cognitively interpret the loss of physical abilities, using objectifying processes in an attempt to regain what was once taken for granted and habitual.

Conceptualising and analysing in this way is, of course, a verbal and symbolic process. It was evident in the talk of the four, rather than in their action. Making sense of their feelings by talking about them was a strategy all four used (although with varying success and enthusiasm) during the research period and conversations of this nature are well represented in the behaviour exemplars. Each man seemed to find this sort of framing, or reframing of phenomenological experience useful. To a symbolic interactionist, of course, this sort of talk is central to the recovery process as without it, there can be no negotiating of shared meaning.

Cognitive rationalisation of inner feeling states proved almost impossible for all four to manage however. Repeatedly, the behaviour exemplars revealed inauthenticity and contradiction in the

explanatory schemes they created. Real "emotional understanding", Denzin's (1984:112) term for the authentic sharing of emotional experience, eluded them all. In talking about physical feelings, they appeared to be forced by the limitations of language in explaining consciousness, to adopt a mechanistic approach to their own bodies. Most noticeably with Max, but also with the other three, there seemed to be a separating out of mind and body running throughout the interactions and intra-actions in the behaviour exemplars. Physical abilities and disabilities were often spoken about by the person themselves, by their family and by the staff, as a separate entity with a life of its own and as a result there was a strong emphasis upon mastering and controlling the body. When Joan spoke of his 'forgetting to take his left leg along' she bought into this 'divide and rule' philosophy, however lightly and it was equally apparent in so many of the other conversations and interactions, colouring the attitude to goals and needs assessment strategies.

This psychology of body/mind separation is, of course, a characteristic and endemic feature of rehabilitation (Sullivan, 1996). 'Acting upon' and 'treating' the body was the prevailing framework of Waimarie, which encouraged and promoted a belief that objectifying and managing one's own physical body is a necessary part of recovery. After brain injury however, as an epistemic framework the use of this model causes some interesting difficulties, more evident from the perspective of Heideggerian theory. While it may be useful to regard a limb as a separate entity, objectifying the mind and the brain processes in order to manage them can cause some peculiar cognitive constructions and epistemological inconsistencies. Bryce for example, transferred responsibility away from himself when he spoke in a way which suggested he had managed to disassociate himself from his own brain:

> **BRYCE: No the trouble I have got is that my brain ain't accepting messages from my eyes and I can't see it properly.**

Similarly, Mark's remark about his vocabulary ("The New Programme", MWCycle One, No. 4) demonstrated how physical a concept of memory he had developed:

> **"Yes" Mark nods "It is getting better." He holds his finger and thumb. "My word group used to be about, this big" he holds them an inch from each other, "and now," he brings up his other hand and draws them wide apart "to about this big!" He grins expectantly.**
> **Jill considers his extended hands seriously and, as he drops them says calmly, "I know it has improved, I am not sure it is that much though."**
>
> **(The New Programme, MW Cycle two no. 4)**

While it may have had some value as a heuristic device, adopting this framework established a mentality which effectively 'disconnected' the four people from their own minds. In interaction, this essentially diminished their interpretive power. To a symbolic interactionist, the only available truths are the interpreted realities negotiated in interaction and the four, in buying into such a mechanistic approach, effectively denied themselves the central role in creating meaning about their own disabilities. The degree to which they had discarded inner phenomenological sources

of self-understanding, translated into the degree to which they denied themselves an inner-centred ontology. Without definitions which relinked the physical body to the interpretive frameworks upon which action was based, the development of self-directed and adaptive independence would be limited and even thwarted by the rehabilitation process.

While in managing a broken leg it may be more important to listen to the knowledgeable doctor or physiotherapist than to listen to one's own inner thoughts, personal interpretive control over such fluid and responsive cognitive disabilities as sense perception and information processing is far more indispensable. While a brain is regarded as separate from the person, it is no longer so open to the self-directed experimental manipulation of consciousness. Until Bryce was able to return to a more personalised version of his problem, he was unable to see a role for himself in the healing of his body and the visual difficulty became a concrete and fixed barrier rather than a difficulty which would require him to learn compensatory techniques and to work in partnership with therapists to improve his reading. The expert consultant in Bryce's case, could only assess, he could not prescribe a drug or a lens, which resolved it mechanistically. Any solution to the lived experience of this disability would therefore rely upon the cooperation and partnership of a body and mind and perhaps also, therapist and patient. Similarly, even if it was possible to add a dictionary full of words to Mark's mind, they would be no more available to his information processing skills than all the other words in his memory, without support and encouragement in the practising of interactive communication.

Solutions to the disabilities of brain damage therefore, even those most clearly consequent upon neurological damage, could only be found in manipulating interpersonal experiences.

EFFORT

A less effective relationship with a phenomenological body appears to have been responsible for yet a further change in the way the four men interacted with their world. Because more conscious effort was necessary to carry out what was once automatic, the mind was monopolised by the mundane actions usually taken for granted or "transparent" (Heidegger, 1967:186). Transferring what is usually unconscious or procedural knowledge, into a conscious performance may have meant the task was completed, but while it was being carried out, mental processes were unable to be used for anything else. Bryce could not talk to Sid while he cooked ("Getting Lunch", BL Cycle One, No. 1), Rob could not chat while he ate ("Getting to Know a flatmate", RJ Cycle Two, No. 2) and in Max's case, walking so dominated his thoughts that he was incapable of managing a conversation ("Walking with Joan" Cycle One, No. 5). Joan adapted the manner in which she instructed him to account for this, no longer trying to chat as she walked and then

gradually introducing conversation once the habit of walking was established to help him learn it. She regarded this as the main reason that Max would never accomplish independence in walking; something which might seem to the uninitiated, to be a strictly physical rehabilitation task.

Sometimes the real disability, therefore, was the loss of unconscious performance. The problem was not that their minds could not direct action, but rather that they needed to keep directing it. To regain independence, they needed to switch more effortlessly between transparency and manipulation and to learn to tap procedural knowledge without the prompting of others. Perseveration[178], rigidity and irrational action are inevitable in anyone who cannot switch effectively between these styles of living; to encourage someone to be more consciously aware may encourage a sense of alienation from the phenomenological experience and the wealth of procedural competence available at a less conscious level.

TEMPORALITY

Related to this issue of conscious effort, was an apparent change in the perception of time. One of Mark's often stated goals, for example, was 'to become fit'. He referred constantly to this wish, stressing how important it was. In "Getting to know a Flatmate" (RJ Cycle Two, No. 2), he spoke yearningly of the feeling of reaching a peak of sporting excellence and seemed prepared to go to extreme lengths to experience fitness again. In practice however, he demonstrated remarkably little energy for any sustained physical activity.

When confronted by this paradox he frequently blamed his own body for his difficulties. He insisted it was no longer under his control. In particular, he described it as feeling 'weak' or 'uncomfortable' . Staff generally found these vague descriptions difficult to work with and responded by attempting to clarify more exactly what the difficulty was.

> **JOAN:... yesterday -in the pool, he said he wouldn't do any lengths because he felt weak. Now, I don't know why he feels weak - I think he latches on to convenient excuses for not doing things.**

In Mark's case therefore, when he was striving, he seemed to lose the ability to monitor how long the effort had been made. He could not keep track of how much time or effort had been expended. He did not seem able to rely upon physiological signs either:

> **JOAN: ... he was not even pink, he was not sweating, I don't know that his pulse rate is up that much - he is certainly not working hard - he is not pushing himself as hard as he says he wants to be pushed.**

It was not only the switch to more effortful and conscious modes which interfered with the smooth marking of time however, but also the change to more concrete and sequential thinking

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[178] See Chapter 1, p. 18 for an explanation of this term.

styles. Rob seemed content with a very slow, plodding existence; one where he was forced to deal with things sequentially and so sit passively for long periods.

> **DS: So there you are waiting for the microwave to cook it- you spend quite a bit of time waiting.**
> **ROB: It is the story of my life, waiting.**

This pattern of waiting, whether for a microwave, an outing, or a visitor, rather than carrying on with something else simultaneously, was a characteristic of all four men. As Madjar (1991:61) has noted:

> **In health we experience our embodied selves in an unselfconscious way, taking for granted and paying little attention to processes such as breathing... in illness there is a breakdown - sensations draw attention to themselves, make one's being in the world unpredictable and effortful.**

Unable to just 'be' as Dasein, the person was switched by their disability into a state of mind where time appeared to creep past, out of tune with the temporal step of others. Again, the response of the person was often to feel as if considerably more energy had been expended than had:

> **JOAN:... he actually also says that he is riding bikes for 20 minutes and he really has only ridden it for three or four, those sorts of things.**

The loss of a "sense of connectedness" (Reed 1992:350) with a phenomenological level of experience is therefore shown in the four lives to have a profound impact upon the meanings they were creating. As a result there was a marked change in the way they experienced their own bodies and located themselves in time and place. These changes also altered their power over the shared definition of what the problems and needs of recovery were.

To recover a sense of wholeness or intactness appears to require of the rehabilitation setting that it foster a better awareness of inner sensation and feelings. It is this faculty of initiating, noticing and responding to disturbances, therefore, which separates out the adaptive and independent phenomenological body from that which has become stereotyped, phased, overreactive, or in other ways dysfunctional. The quality of adaptivity which I suggested earlier was an ideal toward which rehabilitation programmes strive, has been shown in this context to require the manipulation of the level of consciousness. Looking at the four people as Heidegger (1967) or Gadamer (1975) would, it might be said that because each of them was less able to manipulate his level of consciousness appropriately, his relationship to his body became more 'separated out' and consequently there was a loss of the sense of intactness.

INTENTIONAL CONSCIOUSNESS

The *Body-for-the-Person* is Denzin's (1984:110) term for more intentional and conscious experience of being. This is the level at which the person, having interpreted his or her situation,

adopts a specific orientation or attitude and acts accordingly. According to Denzin (1984:121), all feelings are given intentional meaning when they are reflected upon and having attributed meaning, action and behaviour is shaped in ways which express, extend or communicate these ideas. It is at the levels of the enacted body-for-the-person and its counterpart, the enacted body-for-others that Denzin (1984:124-7) using symbolic interactionism, demonstrates the complex interplay between self and other in building a notion of identity.

The experience of the four people suggests there is a risk that brain damage may prevent a person experiencing this sort of inner-directed lifestyle. This happens when cognitive disorders alienate a person from an inner phenomenological stream of experience and disrupt any pre-existing ontology as well as making it difficult to process new information effectively. There was a risk that the four people, while acting as a body-for-the-person, actively thwarted their own recovery because they felt obliged to adopt a personal attitude without the means or self-knowledge to do so.

LINKING FEELING TO SYMBOL

The most striking first impression the four men offered in their many hours of filmed interaction, was a certain 'differentness' in their gestures and 'body language'. Without any knowledge of their brain injury, anyone watching the film would probably identify each as unusual, as 'disabled' in some way, although they might have difficulty in expressing exactly how.

For Max and Rob, the severe loss of physical control might make this remark seem a statement of the obvious. However, Bryce and Mark's presentation of self was also regarded as unusual, despite the very minor loss of physical control they experienced. It was confirmed by families and friends that they had become more stiff, awkward and contrived in manner. Mark was like a coiled spring, excitable, jerky, overly talkative and constantly bending at his waist, tipping his upper body forward and from side to side in clownish antics (perhaps most evident in "The Pool Game" Cycle One, No.5;, "Meal Planning with Jill" Cycle Two, No. 2; "Mates" Cycle Two, No. 3, because he was moving around more often than in the other behaviour exemplars). Bryce in contrast, had acquired a strange studied deliberateness which made his actions seem self conscious pose more than simple movement. With his arms held out slightly too far away from his body, his legs set slightly too wide apart, he seemed to 'swagger' around the buildings and grounds of Waimarie or 'sprawl' in a chair rather than sit in it. Although they had not lost as much physical control as Rob and Max, their actions no longer seemed to 'fit' them. They were overstated, too deliberate, or they lacked a synechdochic responsibility (Goffman 1969:44) because there was a disparity between the "given" and the "given off".

It is self evident that our bodies are important tools for self-expression. With gesture and facial expression we illustrate the words we speak and sometimes dispensing with the words altogether, convey our meaning clearly with physical signs and signals. Denzin (1984:108) points out that as an "expressive gestural system", our bodies allow us to be defined (and to define ourselves) from the outside (Denzin, 1984:109). It is important to explore how the loss of ability to 'present a front' affected the four men's interactions.

Max again represents one extreme. In the behaviour exemplars which included Max, the words impassive and unresponsive were constantly in use. He seemed to be able and inclined to 'switch off' his awareness of other people and exist quite literally in a 'world of his own'. He watched television for long periods without altering his fixed and blank gaze ("Watching TV", MK Cycle One, No. 1), he would respond to requests or instructions compliantly without reflecting any feeling about what he was doing (all twelve behaviour exemplars), even when in a state of pleasurable anticipation as he usually felt at meal times, he expressed nothing in his actions to differentiate this from boredom or even dread.

Yet there were times when Max appeared to illustrate with action, feelings he was not capable of putting into words. In "Going to Limmerton" (MK Cycle Two. No. 2), for example, he stretched out his hand in an oratorical gesture while his speech showed a clear confusion about whether or what he felt at all.

> **"It is too far away here [for Prue to visit]."**
> **"Yes." He echoes, "Too far. That's bad" He held out his hand toward Philippa in the gesture of an actor about to deliver a soliloquy.**
> **"Yes it is bad. And hopefully you will move back to Limmerton and she will be able to see you more often." Continues Philippa.**
> **"Dead right. I don't mind at all" Max agrees nodding as he let his hand drop back into his lap.**
> **"How many days - how many times?" he asks more hesitantly.**
>
> **("Going To Limmerton", MK Cycle Two. No 2.)**

Although Max knew he felt strongly about his separation from Prue he could not clearly establish within his mind what attitude he wanted to take. In terms of symbolic interactionism this appears to be a very important distinction. The ability to convert feeling into symbolic meaning, is a prerequisite for effective negotiation of ideas. What Max did when he stretched out his hand palm up must be seen therefore, as a profoundly important attempt to communicate on a physical level, an important feeling he could not express with words.

It is extremely important then to understand how others respond to the sort of vague gesturing I have described. Philippa (the social worker) appeared to recognise his confusion and adapted her response to give him the information he needed to make more sense of his situation. As a visual

statement therefore, this gesture was more effective than it might have been, but only because the person with whom he interacted had a deeper understanding of his needs and could interpret the significance of his gestures in the light of this knowledge.

Mark's problems in projecting impressions were not usually ones of deficit so much as of excess. Nevertheless, in terms of symbols, he was just as ineffective at signalling clear meaning with word or action. There are many occasions during the filming for example, when he waved his hands about as he spoke[179]. This 'flapping', giving him a clownish and awkward appearance, which could be very distracting. A wariness soon crept over the faces of those who encountered him for the first time and it was clear, having labelled him as 'different', they altered their expectations and attitude toward him accordingly. This troubled both his staff and family who could see that until he learnt to tone down his gesturing he was unlikely to be accepted as 'normal' or 'equal' by his former peers. Trudy, the tutor in the Education Unit, after watching him over the course of many sessions, concluded that the oddness in his body movements was connected with the same loss of symbolic organisation as that ascribed to Max above.

> **TRUDY: I think he really uses his hands in a really flat way and that they are almost used as verbal expression. He has problems finding the words verbally and his hands actually have problems finding the words also in the movement and so, his hands actually just are sort of waving from side to side in** *[demonstrates with her hands]* **trying to remember them.**

From a symbolic interactionist position, any loss of ability to communicate a clear definition of the situation will have considerable impact upon recovery. A disturbance in the link between meaning and symbols would be catastrophic for ontological reconstruction. A 'symbolic anomie' would cause a loss of the facility to clarify one's own meaning, let alone communicate it to someone else. This implies that it is an important role of therapeutic situation, to provide symbols for feeling states, helping the person identify and communicate their inner experience more clearly. Taking account of the more concrete nature of information processing, it seems that there is a place for coaching people who have had a brain injury into using appropriate gestures and words which accurately communicate an inner thought.

Symbolic interactionism as theory assumes that there is in each of us a fundamental need to express and communicate meaning to others in order to clarify our own ideas and negotiate a shared reality. Once the link between feeling and symbol (whether gesture or word) could be made stronger, the four people were more able to mediate the feeling in interaction. This sort of coaching appears to offer a powerful way of controlling through symbolic means, potentially overwhelming inner feeling states. A good example of how effective this form of coaching can be occurred in the first of

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[179] see the examples cited above.

Mark's behaviour exemplars. Mark's family, recognising how a high pitch indicated extreme excitement, had taught him to understand and identify this for himself and he demonstrated how useful this was as a self-controlling strategy.

> **"Yes." He answers casually "I do cleaning duties and wash my own clothes." he indicates a basket "Here is my washing basket which I got for my birthday."**
> **"Mm" I comment.**
> **"Yes and I feel," his voice becomes choked with an emotional intensity which could be equally joy or anguish "excuse me" he coughs, puts his head down and pauses then continues in a more subdued and calm tone "when I get excited my voice goes high., I have got a wash basket, a tiger picture down in the dining room and, two plants and I have got a few plants."**
> **("Being Filmed" MW Cycle One Tape 1 No. 1)**

In stark contrast to the polite pretence of 'not noticing' inappropriate body language, the family's approach allowed Mark to reestablish a useful level of metacognitive appraisal of his own body. This allowed him to work towards a more authentic relationship with the "body-for-the-person".

COMMUNICATING

Audibility

Of course, if like Max and Rob, you can only use one hand to gesture and if like Rob, that hand has a tremor when you are self conscious, this will affect how well you communicate. Both these men were now much more reliant upon speech than gesture and action to share their meanings. However, as a result of his injuries, Rob had less volume to his voice. This had an important impact upon his relationships.

The most serious consequence of reduced audibility was the misinterpretations it caused. His failure to communicate loudly enough sometimes made others feel angry, suspicious or resentful. One woman resident, Elspeth, refused to attend a group session again while Rob was there, saying he 'put down everything I said', despite the fact that he never directly commented upon any remark she made during the discussion ("Discussing RHAs and CHEs", RJ Cycle One, No. 2) while many of his difficulties with Nadine ("A Confusing relationship" RJ Cycle One, No.3 and "Working Side by Side" RJ Cycle Two, No. 3) sprang from similar misunderstandings, many of which arose simply because she did not hear him fully and fell back upon her assumptions about what he might have said, based upon her rather negative view of his character.

Rather than being a sign of aggression, however, the lower voice volume appeared to happen most for Rob in times when he felt a sense of lowered status, when he was made to feel either a nonperson (Goffman 1969) or a 'subject' of others assessment and treatment ("Needing Help" RJ Cycle One, No. 4; "Learning to Be a Kaumatua" RJ Cycle One, No. 6 and several other

occasions). When there was no sense of self conscious and intentional projection, when he was relaxed, teasing, or joking as he did with Diane ("Friend & Teacher", RJ Cycle 2, No. 1), his voice came through much more loudly and clearly.

There were several occasions when both Max and Rob's overly quiet remarks seem to have been intentionally ignored. At other times, there was insufficient attempt to clarify what they meant. The result was that others often misinterpreted them. They learned to accept beliefs, ideas, or remarks as their own which in fact had been the creation of anothers' mind, in order to avoid the painful repetitions.

> **DS: It seems there are places where you've got the general idea but then you don't hear exactly what he says. Then you sort of half guess what he said and half answer vaguely enough so that it doesn't matter. would that be right?**
>
> **ESTHER: Yes Mm-mm - I don't like doing that to him but yes I did. I don't like asking him to repeat himself too much because the whole roles change. I remember when I was little and I spoke too fast and my mother used to tell me to slow down and say it again more clearly and it used to make me so angry that I just went away and didn't say it and I don't want to do that to him, to make him stop - it is hard to know what to do.**

Esther was not being insensitive here. She was caught in what is a constant and very real dilemma for those who wish to model an equal partnership and maintain the flow of continuous backward and forward energy which is the normal patterning of a conversation. She was quite right in guessing that asking him to repeat himself too often would destroy the 'smoothness' and directedness of their session. There were several moments on the film when this inaudibility effectively killed interactions which Rob was trying to conduct, particularly with other residents, many of who have similar communicative difficulties.

Just about all the staff observed with Rob behaved much as Esther did in this example. Their actions reflected the implicit moral code noted by Goffman (1969) in his dramaturgical analysis, to protect the stability of others' images in order to maintain the commonly shared definition of the situation. Although it was obviously well meant, effectively this convention changed what was a minor physical deficit into a much more major interactional one; a loss of control over the choice and direction of the conversation.

Some modes of communication are clearly easier to ignore than others. A lower tone of voice can be as catastrophic to personal power as the more obviously disadvantageous modes of communication seen at Waimarie. Within an institution used to dealing with the various forms of aphasia and the electronic aids and alphabet boards used to overcome them this problem may not be very evident. However, when Rob left Waimarie and returned to community settings where all those around them exercised a relatively more equal power over the control of speech, it is likely this would have serious implications for the microdynamics of power within his interactions. As

Goffman (1969:208) said, a person may feel shame for honest acts if the performance goes wrong.

Words

Communicative power of course, is not just a matter of mechanistic control, but also the facility of expressing meaning with a vocabulary of apt words. The power of self expression is the power of word skills and quick witted information processing skills. I have already demonstrated how, for both Max and Mark and to a lesser extent Bryce and Rob, these word skills had become restricted to more concrete concepts and simple, sequential rather than integrative constructs. In terms of their competence in acting as a body-for-the-person, such restrictions upon the words available to them, will have an obvious impact upon their relative power within interactive situations. There are several moments upon the videotape where all four, having difficulty finding the correct word, reached blindly for some approximation which would allow the flow of the conversation to continue. Mark was at the time of the research, perhaps the most conscious of this difficulty:

> **MARK: If I am with my best friend I knew and we were talking to a couple of other people and I couldn't think of the word that we were talking about - say it was the word for female, I would lean over to my friend and say "What's another word for girls like male?"**

Words represent meaning and so are abstract by nature and require some pattern recognition. As Goldstein (1952:248) points out, in a normal brain an object or a situation becomes a "mere accidental representative of the category to which it belongs" and, as such, previously processed ontological appraisals or evaluations can be applied to it. For these four people, however, each situation was now new and separate and experience had less pattern. Without the ability to see patterns in problems they were unable to categorise them and so 'own' them fully. Disabilities were reduced in their mind to isolated difficulties, with no real relevance to their goals.

The key to recovering a sense of self-direction, therefore, may be in a more accurate and efficient blending of the functions of the left and right hemisphere of the brain, or, the linking the sensory and phenomenological experience of living with conceptual and mental interpretations of it. After brain damage, the usually smooth interaction of the hemispheres can be disrupted causing a sense of hemispheric disconnection that Geschwind (1965:398) noted. Both interaction and intra-action are altered as a result. According to symbolic interaction principles, people shape and are shaped by these interpreting processes. Sensation and imagination, the right brain qualities, need to be given form and expression by the left brain. With symbols, this constructing-oriented left brain 'disciplines' the more creative and intuitive right brain impulses, imposing rationality and logic upon it. Without such a disciplining process, these feeling experiences are dissipated. Several staff

appeared to see their role as in 'putting words' to the problems and words which allowed the specific a more general application.

> **"You don't need, to actually do this exercise, you don't need to use the sledge, or clean the shoes or make the cheese on toast," Linda pointed out.**
> **"That's good." Bryce nods warily, not sure where this is heading.**
> **"The reason I have got you to do this exercise," she continues, "is not in case you need to use a sledge down a hill at some time in your life. That is not the important issue. The reason that we did this exercise is to actually help you work processes out in your life?"**
> **(A Session on Sequencing, BL Cycle Two, No.1)**

Without words to operate as abstract concepts, linking past experience logically to new situations, communication as a means of clarifying meaning is impoverished. Without some abstraction of meaning there can be no mediating or negotiating of symbols. Our chances of being social beings become seriously limited. Many people with brain damage suffer just this fate. To address it requires a more interactive conceptualisation of consciousness.

Emotional Management

Not only was it more difficult to find symbolic expression for feelings it was also more difficult to manage emotional extremes. Excessive overexcited behaviour regularly overwhelmed Mark's attempts to hold conversations, particularly at moments of embarrassment and confusion ("The Notebook System" MW Cycle One, No.3), or when the response he had received seemed to him to be negative or rejecting ("Mates" MW Cycle Two, No. 2). Mark's fury with Jill ("Standardised Assessment" MW Cycle Two, No.1) and his friend ("Mates") suggest that the sense of being rejected was so distressing that any attempts he was making at "intentional value feeling" (Denzin, 1984:120) were abruptly discarded. Max experienced even more dramatic extremes, his customary stoic acceptance being punctuated by unpredictable outbursts of raw emotion. These moments of fury were clearly unintentional and painful experiences ("Waiting for lunch" MK cycle One No. 2), as frightening for him as for others. Along side the sudden fury was another less obtrusive emotional theme just as out of his control, one of depression and despair.

Called variously "catastrophic reactions" (Goldstein 1942), impulsivity and emotional lability, uncontrolled emotion severely hampered self-presentations of the four men. The disturbing level of violence and threat also affected the response of others around them who became wary and ill at ease. Until the four men could learn to control their emotional extremes they would be considered dangerous and alien outside an institutional setting. Nothing threatened smooth reintegration into the community more. The staff, aware of this, had developed several interesting practices which together might be described as manipulating the person's emotional tone for them until they were capable of taking back control of emotion themselves. It seemed also that it was

necessary to pitch this 'scaffolding' of emotional control at the cognitive level the person was capable of, only attempting to communicate calming and soothing messages when the emotion was extreme rather than using reason and promoting a better understanding. In the following excerpt from Max's experience, Winston repeated words rhythmically while standing as still as he could beside Max. He left it to another staff member to find out the problem leaving time for Max to recover.

> **Winston's voice can be heard over the top of this incoherent stream of invective, expressing a sense of astonishment, of protest, and at the same time clearly an attempt to soothe, to calm, "Here, here, here, hey, here we go - you don't have to have it - here we go - here here..".**
> **The words seem to penetrate. As suddenly as it has begun, the anger attack is over and Max relaxes, visibly slumping as he calms down. "Oh, I thought it was," his words peter out in a quiet mutter. This angry outburst has disturbed the whole dining room. Heads are turned and several other staff have paused in their work and turned to watch. Hilda, the nearest nurse, now walks over, calmly and briskly. She stands beside Winston, looking down on Max frowningly. "You don't have to have it, you know." She points out carefully. "You can leave it. Would you like mince instead?"**
> **"Yes" he mutters.**
> **"You just have to ask!" scolds Hilda lightly.**
> **"I'm sorry" he mutters, head down and ashamed now.**
> **("Waiting for Lunch" MK Cycle One. No. 2)**

Winston was attempting only to ease an immediate situation and as soon as Max switched back to his usual calm the staff allowed the matter to drop. With Mark however, because he was able to manage a higher level of interpretive control, more effort was made to address the matter of anger management further but still with a 'scaffolding' of emotional support. The behaviour exemplar "Negotiation" (MW Cycle Two No. 5) is a good example of how staff, attempting to confront Mark with the consequences of his aggression, carefully regulate and manipulate the emotional tone of the conversation so that Mark is able to reflect upon his own role in causing his employer to become frightened by him. In effect, he learned in this interaction to "take the role of the other' but only because of the intuitive blending of humour or light teasing and serious confrontational remarks which monitored and adapted constantly for his own erratic emotional control.

Crosson et al.'s (1989) remarks about the level of awareness are as relevant to this issue of control over emotion, therefore, as they are to self-perception of other disorders. The different way in which the staff dealt with anger in these two men reveal their assumption that Max was not likely to manage a level of emergent or anticipatory awareness even with therapeutic support. To attempt to instil within him the compensatory strategies commensurate with these higher levels of awareness would be demeaning to him and a pointless waste of energy. Instead, staff reacted with a situational level of compensation, providing a soothing environment. In contrast Mark was encouraged to take back adaptive control of himself in interpersonal situations by rehearsing strategies at an anticipatory level of compensation.

While Mark was encouraged to develop abstract ontologically based "feeling rules", Max was only asked for a crude form of "emotion work" (Hochschild, 1979:557-61). The staff's efforts with Mark were an important contribution to the development of a new ontology. The more able he became at re-establishing clear feeling rules, the more likely he was to reconstruct firm principles upon which to base his future behaviour.

Linge (n.d.:8)[180] regards this loss of emotional control as a significant problem in his own recovery. He experienced a gradual return to control, but it was never again as effortless and automatic as before his accident and he had to adapt his interactions to account for this:

> **I have to recognise however that a problem still remains in this area. I cannot cope with anger as well as I was able to before my accident. Rage, related to my losses, does not lie just under the surface waiting to explode as it did earlier in my recovery. Yet, like any other person living in the real world, situations arise which make me justifiably angry. Before my accident it took a lot to make me angry and I am still today slow to anger. The difference is that now, once I become angry, I find it impossible to 'put the brakes on' and I attribute this directly to my brain damage. It is extremely frightening to me to find myself in this state and I still have not worked out a truly satisfactory solution except in so far as I try to avoid anger provoking situations and try to deal with them before they become too provoking.**

Like the four people studied at Waimarie, Linge learnt more appropriate emotional control by consciously explaining himself to himself. This was an important part of his recovery and it clearly requires the sensitive and intuitive intervention of other people; people prepared to manipulate their own interactive style during an intermediate period to foster such a resolution.

In sharp contrast to this externally managed emotion, there were occasions when the person, trying out newly developing "intentional value" positions (Denzin, 1984:120), appeared to deny and distort their own inner needs. For example, Mark, when trying out roles, was inclined to accept wholesale the value positions which he believed related to them and 'perform' feeling positions enthusiastically but without any authenticity. He seemed to be learning to mould his feelings into whatever shape he felt would attract others' approval. The result could be a somewhat cloying sentimentality or absurd rationalisations and justifications after the event. It was as if, unable to understand his own inner feelings when he tried to explain himself to himself, he used what existing knowledge he had of relationships. This strategy lead him to grasp at theoretical reasons for his problems and become excited with their explanatory power.

> **"I'm not sure," Mark says in a very quiet voice. "I am not sure of anything really."**
> **"What aren't you sure about?" asks Philippa calmly.**
> **"Taking responsibility of having the whole house to myself," explains Mark solemnly.**
> **"Well," Phillippa reasons, her voice matter of fact and calm as if to counter-balance his intensely emotional tone, "that is part of the training, to see how you are getting on. With the cooking and cleaning and all that."**

[180] Linge (nd) is a psychologist who wrote workshop material which drew upon his personal experience of brain injury.

"Mmm" Mark nods in agreement, lightening his own tone a little. He seems unsure for a moment and then continues. "I don't mind that but," he pauses and eventually adds vaguely, "just being independent I suppose."
"So. Being independent." Philippa echoes him and pauses, waiting, "You think that's scary then?"
"No. Not scary, just, you know what I might find that I am not used to it and just and having to adjust." He adds confusedly. He rubs his chin, strokes his hair back. He seems embarrassed by his own incoherence. He watches her reaction.

("Moving into the Flat." MWCycle One No. 2)

This was confusing for those whose job it is to counsel him as these ideas of his lacked any authenticity yet seemed to be necessary to him.

PHILIPPA: It is really frustrating - especially when he picks up on a 'theme for the week' and it will influence everything he says and he does.
DS: And you can feel that this is not real, this is something he has just latched on to?
PHILIPPA: Yes. But in social work I feel like I have got to be able to just sit and accept it and work through it when he comes up against a problem.

A very similar process of role and "intentional value feeling" (Denzin, 1984:120) experimentation appeared to be occurring in Bryce's interactions. He seemed more sure about the image he wished to project and the problems of impression management were caused largely by his failure to find credible performances. He seemed to look around for ideas and feelings to copy in those he admired. Once adopted as his own, he seemed to have had no idea of the original source of his thoughts, sincerely believing in his ownership of them. When Sid joked about having a crush on his social worker, for example, Bryce initially played along, teasing him, pretending to further his case ("Cup of Tea with Syd" BL Cycle One, No. 5). Within a day or two, however, he had convinced himself that it was he who was in love with Philippa.

DS: I thought it was Sid who had a crush on Philippa though?
BRYCE: No it is me - I have got a crush on Philippa. Yeah! But nothing will ever happen that is for sure.

This borrowing of others' feelings extended even to matters of taste and interest, giving him a strangely diverse and erratic set of likes and dislikes. He insisted upon playing only loud heavy metal music when flatting with Syd, for example, and then, having listened to ABBA with another resident who liked this band, he was determined that this sort of music was his preference. Although an inner Bryce was not totally absent it took some detective work to discover the real person beneath such confusing variety.

Because they were 'adopted' not felt, Bryce and Mark's ideas often contradicted each other and the roles they presented themselves within did not fit together logically into a coherent ontological scheme. Although some looseness of identity is necessary to allow elaboration and "constructive alternativism" (Kelly, 1955:3-46) any role and idea experimentation needs to be sufficiently contained to prevent a "fragmentation corollary state" within which "a person may successively employ a variety of construction systems which are inferentially incompatible with each other"

(Kelly, 1955:83). Mahoney (1985:19) suggests that the experience of fragmentation is inevitable when one's world view is cut loose from an interdependent and coherent ideology. In an extreme case, a multiple personality may emerge.

In a small community such as Waimarie borrowed identities were quickly recognised as such and there was a tendency to discount what Mark and Bryce said when it was 'flavour of the week'. However, although the staff may have privately found them less than credible, no attempt was made to strip away their pretensions to authenticity. There was a sympathetic cynicism, for example, in the following remarks Don made about Bryce's 'real' music taste.

> **DON: He likes Metallica because Sid liked it when he was up here.**
> **DS: So you get the feeling sometimes with these sorts of conversations you have with him that he is trying to work out what he feels and thinks? You know, give himself an identity?**
> **DON: Yes. He is. I wondered whether the ACDC thing, I remember telling him that my brother played with ACDC in Australia and so whether to score a point with me he mentions that he likes ACDC too but then again ACDC was very popular with guys his age.**

While he was allowed to perpetuate a myth of independence in thought, Bryce's pretence was obvious to others. The staff were motivated to foster this 'idea experimentation' because their role was to encourage positive attitudes to the future and they did not expect or demand fully reciprocal relationships. The behaviour patterns which were acceptable and which worked within this closed and caring community, therefore, would not necessarily transfer to the outside community. Remarks by Sid about Bryce confirm this fear.

> **SYD: I don't mind. He is always doing it so I just sort of ignore him. He's a bit pathetic really - so I just forget it, I am used to it because it is his head injury.**
> **DS: So if you weren't living at Waimarie, if you were in a flat out there and you had a flatmate like that.**
> **SYD: I wouldn't.**
> **DS: You wouldn't have a flat mate like that?**
> **SYD: No.**
> **DS: And yet you seem to get on okay.**
> **SYD: Yeah cos I - I have had a whack on the head and he has had one so I know.**
> **DS: But when you leave here you wouldn't flat with him?**
> **SYD: No.**

Although the four men appear to have acquired a sense of acceptance within Waimarie, the many similar remarks of residents and staff suggest the relationships each was building were conditional ones, established because of brain injury rather than in spite of it. In a setting where the other interactants were unaware of the brain injury, or where there was no knowledge or understanding of the likely effects upon interaction, such terms would not be available to them and rejection and alienation seemed almost inevitable.

FEEDBACK

Even if the four managed to link feeling, image, sense and symbol more effectively and authentically, social interaction requires yet a further level of sophistication of the processing

brain: the ability to perceive and integrate the response of others. The four people had all become less competent in their ability to monitor and adapt to external feedback.

External feedback, according to symbolic interactionist principles, allows people to regulate their performances adapting them to fit changing situations. Without good regulating skills the performances of the four people sometimes became like caricatures. Bryce, determined to impress others with his relaxed self-sufficiency, slumped against a bench ("Before the Polytech Students' visit" (BL Cycle One, No. 2), or sprawled in a chair (BL Cycle Two, Nos. 2 and 3). His voice was a complacent drawl, his only subject matter his own interests and history. Rob and Mark too, tended to 'act at' people without noticing and adjusting their behaviour, for any response they received. This made their actions seem stereotyped, one dimensional and self conscious. Not surprisingly, others found this compulsive and excessive self-presentation approach to interpersonal situations irritating.

Egocentrism is often listed as a consequence of brain injury (Pepping & Roueche 1991). It may be more accurate, however, to define egocentrism not as a cognitive deficit, but rather as an interactive deficit which gives a one-way quality to interpersonal exchanges. Even the more caring, altruistic or selfless transactions can be seen as fitting this same general pattern in relating to others. Rob, for example, frequently adopted the role of the "kaumatua", recently acquired at the time of the research[181] in his relations with other residents. In "Discussing RHAs & CHEs" (RJ Cycle One, No.2) when he became confident of his ground in a group discussion, he adopted a slightly avuncular air and put out his hand, holding it in the air to illustrate his point in a stylised oratorical manner. Later in the same session, when Kristen, a rather frail fellow resident, entered and seemed cold, he eloquently expressed his concern in a paternalistic or protective gesture. However, this performance of community leadership was just as onesided as was a more self-centred role because the other members of the group did not acknowledge his right to guide or interrupt proceedings. Because of his failure to notice the reaction of the others in the room, ultimately his attempt at the leadership role was doomed to failure.

PHILIP: I was trying to answer Linda and he was interrupting.
DS: Was he trying to help?
PHILIP: No he doesn't help.
DS: What was he trying to do then if he wasn't trying to help?
PHILIP: Get my attention - my eyes off Linda.
DS: Trying to take your eyes from Linda and look at him?
PHILIP: Yes.

[181] "Tatou Tatou" is a room at Waimarie recently dedicated as a marae. Rob, as a long term resident of Maori descent was offered the role of kaumatua for ceremonial purposes. He was extremely proud of this role and took it very seriously, trying hard to remember the words of his short speeches in which Del coached him (See RJ Cycle One, No. 6 "Learning to Be a Kaumatua").

Roles are social phenomena and so they exist only in sets and relationships. They complement each other, fitting together to give commonly understood rhythms to interaction. Mark's and Rob's attempts at friendship or partnership often failed ("Mates" MW Cycle Two, No. 2; "Friend and Teacher" RJ Cycle One, No.1; and "A Confusing Relationship" RJ Cycle One, No. 3) simply because they did not recognise this. They seemed to realise that their interaction had lost its accustomed rhythm but without the capacity to identify and respond to feedback. Their own performances became uncertain, faltering as they found it increasingly difficult to fit themselves expressively into the current social 'scene'. According to Duncan (1968:7-8), ambiguity is " kind of bridge which we run backward and forward across from one kind of meaning to another until we make a firm resolve to cross the bridge into new and fixed meaning". Without the ability to adapt to feedback, they would be unable to fine tune their definitions of what 'was happening' and so adjust their role presentations to account for the responses they were receiving.

Habits

Of course, as well as being performances and projections, much of what is ontic and everyday embodied action is a part of what Keilhofner (1985:24) refers to as the "habituation Subsystem" and describes as "a collection of images which trigger and guide the performance of routine patterns of behaviour." I have used the term "procedural knowledge" (Willingham et al., 1989:1049) elsewhere to describe this same general function of a 'less-conscious' consciousness.

In relation to the phenomenological body, I have already described much that is habitual, that has an "in itself" quality, as "transparency" (Heidegger, 1967:186). I have suggested that the symbolic and deliberative modes of consciousness, those which convert action into a conscious subject/object intentionality, are engaged at times when transparency is disturbed. In this earlier discussion I was also particularly concerned to understand how transparency was altered by and itself altered, the process of arousal and stimulation. Now however, in relation to this intentional 'body-for-the-person', it is necessary to revisit the notion of habit in order to understand how procedural knowledge can either contribute to or thwart the recovery of a sense of self-directedness.

The habitual subsystem according to Kielhofner (1985:32), contains within it a wealth of important unconscious knowledge built into an inner hierarchy of subroutines, configured so that they no longer exist as separate parts. Each of these subroutines involves a "complex interplay of musculoskeletal, neurological and symbolic phenomena" (Keilhofner 1985:32) and as such can be seen as a prepackaged, pre-integrated 'unit' of the very physical, perceptual and symbolic processes which (as I have just demonstrated) have become alienated from each other by brain

injury. It is this very unitary nature of habits which makes them so invaluable for this group of people for whom integrative processing has become so difficult. Not only do habits free up conscious processing space in those for whom it has become limited, but also once triggered, according to Keilhofner, they can be adapted so as to be performed under varying conditions. It is no wonder then, that so many researchers and practitioners have urged the tapping of this inner resource of knowledge and skills. Goldstein (1952) and Gross (1987) for example, both suggest that with a more limited cognitive capacity, habit is even more essential to people with brain damage that those without.

Before their brain injury, each of the four people had an extensive habitual repertoire upon which to draw and this made up a large, if unconscious and taken-for-granted, part of what they all thought of as their identity. With Max there was a vast body of carpentry and building skills, as well as those which he used in fishing, squash and other recreational pursuits. For Rob and Mark, sporting skills provided a considerable proportion of self esteem, while for Bryce, knowing all about dairy farming was an important part of who he was. Of course, in addition to these skills which were most central to their identity, each had also acquired, before their accident, a range of taken-for-granted everyday practices such as making a coffee, dressing oneself, socialising with friends and managing the subtleties of interaction in informal and formal exchanges which they had been able to perform without thinking. Although physical and cognitive disabilities cut across and disturbed this body of knowledge and skill and although there were many habits which the four people would never use again independently and productively, each, given the right circumstances, demonstrated that much of these 'chunks' of ability were still available to them.

> **PRUE: He has talked to my father at times about it because my dad was a builder as well. ... Dad would ask him specifically about things, about mixing concrete and if I remember rightly and, Max would still reel off the quantity and stuff and say, you know, you stick it in the wheelbarrow and....**

It was because of the loss of these more fluid information processing skills that the crystallised knowledge was not being used appropriately. Habits were triggered which did not fit situations, as when Max called everyone Prue ("Relaxing in the Evening" MK Cycle One, No. 5; "Walking with Joan" MK Cycle Two, No. 5), or Rob continually drove past his destination and needed to make u-turns or, using the wrong day's programme, failed to meet his commitments. Although former skills and habits were available to them, to be useful they needed to be adapted to fit situations involving a less able body and a mind with cognitive difficulties.

Kielhofner (1985:33), Norman (1981) and Reason (1977) all point out, there are several possible ways that a habit could fail to function effectively, related to selection, storage and discrimination. Habits, once a powerful tool of the unconscious mind, became more susceptible to all three of

these errors when the "supervisory attentional system" was disturbed[182] and as a result they became maladaptive and rigid, discrediting rather than strengthening performance. Dogged performance of inappropriate habits revealed the loss of self-regulation and demoted them in others' estimation and expectations, to the role of non-person (Goffman, 1969:137) or to a "sick" or "invalid" role (Keilhofner, 1985:26).

Without the ability to accommodate for change, the establishing of new adaptive habits was beyond the reach of the men. Although they were all capable of performing the tasks of rehabilitation with deliberation and effort, none had reached Ben Yishay et al.'s (1985:255) "control" stage, where as they could concentrate upon the "idea behind the act" as a habitual lived body. If a habitual subsystem is again to become an intrinsic part of a lifestyle, therapeutic styles clearly needed to be adapted to acknowledge the difficulty these men had switching in and out of this less conscious experience of being. To maximise recovery will require that each is supported in learning to adapt whole gestalt units to fit new situations through the sensitive coordinating of transparent consciousness and manipulation of 'disturbances' so as to allow them to manage the necessary symbolic reordering which will allow them to tap into habits and skills appropriately again.

Dreyfus, H. and Dreyfus, S. (1986:50) suggest that there are five stages of skill acquisition, during which new learning progresses from analytical and conscious to intuitive and unconscious processing. When knowledge becomes intuitive, it requires less of the conceptualising processes, but while the new skill is being learned a person needs to consciously supply habits with symbolic referents which allow its effective storage, retrieval and adaptive functioning. Without such a reconstruction of an adaptive habitual subsystem notions like autonomy and empowerment become hollow and meaningless as independent life becomes an effortful performance. This process which moves knowledge from the conscious to the unconscious can not be charted objectively by a clinical assessment process and so there is a lack of recognition in rehabilitation settings of the need for the larger proportion of living to be effortless and habitual, governed by an unobtrusive metacognitive "monitoring" which activates a more deliberative approach only at moments of conflict or disturbance. Not alerted by the cues of others, too concerned with the management of their own impressions, the attempts of the four men to perform roles were causing them to act laboriously 'at' and not 'with' those around them.

[182] See Chapter 1, p. 18 for a discussion of the supervisory attentional system as an executive function.

THERAPY AS A SPECIFIC STYLE OF SYMBOLIC INTERACTION

Because disability after brain injury is not only the result of cognitive, perceptual or physical damage but also (and perhaps more importantly) the interaction of these three, the more successful therapeutic endeavours observed during the process of the research were those which fostered participation and partnership. When other interactants were able to monitor and regulate the flow of an activity to ensure the person remained engaged, contributing to and 'keeping up' with the changing 'definition of the situation', this scaffolding of the outer interactive process, appeared to encourage a more efficient 'intra-active' process. Although sometimes direct, honest feedback was used to help the person improve his interaction skills, at other times more subtle forms of behaviour shaping were occurring with adaptations to interactive styles.

The Focus of Interest and the Level of Consciousness

One of the more notable features of the weeks of film was how often successful and positive sessions focused upon something other than treatment or rehabilitation. The staff member designed a project with a goal which appeared unrelated to physical and cognitive recovery, upon which the people, alone or alongside other residents, worked as a 'team member' or in 'partnership' with the staff member. While the project could be (and frequently was) justified according to some therapeutic function, for the participants there was also some more immediate and concrete product toward which they worked. Rob was making a poster ("Doing Art" RJ Cycle One, No. 1) and cooking lunch ("Friend and Teacher", RJ Cycle Two, No. 1), Max was making a toasted sandwich (MK Cycle One, No. 7), Bryce was making patterns ("Don and Patterns", BL Cycle One, No.3).

When staff appeared to help too much and even take over the task, it was often in order to protect the integrity of this goal or project, to ensure that the person did not go 'off the track' and was going to produce a satisfactory finished product. For example, Del ("Learning to be a Kaumatua", RJ Cycle One, No. 6) was perhaps over directive in her tutoring of Rob's welcome speech, telling him what to say, making him repeat after her and going over and over instructions as to how and when to say it.

> **DEL: Really what happens is that I do the planning and then I say, "What do you think?" and try to bring him into it.**
> **DS: So you are trying to make it as if you were a team?**
> **DEL: Yes.**
> **DS: But really you are doing most of the thinking, making the decisions?**
> **DEL: Yes. I keep trying to make it that he doesn't realise that and he does feel like he is joining in. If he disagrees with something, he will say.**

Linda, helping Rob to construct a crossword for the morning education group, all but made up the crossword herself. She explained that her reason for contributing more than usual on this occasion was to ensure that the product was 'real' and important.

> **LINDA: If it could just go away in his folder and never be seen again it wouldn't have mattered. Instead, it was going to be used for the group and so it had to be up to a certain level.**

Similarly, when Esther co-produced a poster ("Doing Art", RJ Cycle One, No. 1), using the string, scissors and glue as often as (if not more than) Rob, she rationalised her actions in terms of ensuring an outcome which would provide Rob with pride and motivation.

> **ESTHER: Ideally you want a session that is one that is going to be part of a series - that Rob wants to come back and do it again and looking at it in that way then maybe I didn't do too much...**

This 'team' approach to learning had several advantages for those who had damaged cognition. Verbal instruction, because it relied upon now difficult symbol/object linking skills, often confused them, or failed to clarify a task. This approach allowed the therapist instead to demonstrate in action, by working alongside a person, providing an unthreatening opportunities to imitate and 'join in' without the necessity to comprehend an overall purpose, or conceptualise what they were doing in a more abstract way. This 'learn by doing' approach also allowed the use of multi-modal instruction. In "Word Attack" (MK Cycle One, No. 4) for example, Dierdre, a tutorial assistant in the education unit, enticed Max's involvement in an activity by playing it with him. She demonstrated as she spoke, guiding his hand and at the same time he was able to watch the result of moving and clicking the mouse on the screen. He could not have grasped the idea with a verbal explanation and yet he learnt in this session, to play a game which he afterwards received many hours of pleasure in playing alone, as well as rehearsing word skills which would clearly have improved his vocabulary. As demonstration was combined with words, Max had the opportunity to rehearse symbol/idea referencing. Adaptations of such a style as this allowed the teaching of abstract concepts and ideas to those still confined largely to the concrete and immediate sense impressions. In "Othello" (BL Cycle Two, No. 4) for example, Bryce used the computer's feedback to grasp rules in a process of stimulus-response shaping rather than relying upon declarative learning. Although he could probably not have articulated the rules, after several sessions of such a trial and error method, the number of incorrect moves slowly reduced. The repetitive nature of such a game also allowed the acquisition of habit and skill in a pre-integrated unitary form which required less of Max's concentration.

Quite apart from the learning of a habit unit and the sense of competence produced by the completion of a task, these moments were valuable because of the sense of fellowship they produced. To spend several minutes colouring, or stirring, clicking with a mouse together with

another person, allowed people the opportunity to relax and enjoy a rhythmic and soothing activity. As it became more automatic, conversations were often initiated and these were moments of relaxed and unself-conscious discussion. Whether it was a timetabled session as in "Doing Art" (RJ Cycle One, No. 1) and "Recreating" (BL Cycle Two, No. 3), or informal interactions between fellow residents as in "Working Side by Side" (RJ Cycle Two, No. 3), there was noticeably less strained role playing during moments of absorption in some common project, as compared with the more formal occasions such as "Future Plans" (BL cycle Two, No. 2)., "Alcohol, Love & Emotion" (BL Cycle Two No. 3) and perhaps most obviously in "Scared about Moving into the Flat" (MW Cycle One, No. 2) when the focus was turned directly onto the person.

If the nature of the activity has such a powerful influence upon the degree of learning and the level of therapeutic partnership which can be attained after a brain injury, it makes sense to plan rehabilitation around projects which allow the joint involvement of therapist and client. While non-brain-injured people might be expected to engage an appropriate degree of mental energy in a task designed for one, an examination of the behaviour exemplars suggested that no such assumption should be made of a person with brain damage. Therapeutic objectives may be better reached when they take a back seat; when some shared enterprise can be developed in which the person feels a genuine interest, shifting their attention from the disability to the project's goal.

By intuitively adapting their own interactions therefore, the staff members observed during the filmed interaction usually appeared to manipulate the level of awareness, engagement and metacognitive monitoring that was occurring, so providing with their actions whatever appeared to be lacking. Because they accomplished this by moulding their interactive styles to draw out in response the most effective consciousness, they were able to avoid the sense of objectifying and disciplining their client, so injurious to a sense of self-direction, or control and power. In terms of Heidegger's (1967) conception of being and time, it might be said that such styles of interaction "call Dasein back from its alienation in the they-self" (Lacan, 1968:181) in that they make use of "shifters" (Wilder, 1966:183) or re-assign "dasein designations" so as to allow a more comfortable relationship to self to be operating, producing a greater sense of alliance and so empathy on the part of both participants in a shared scene. Madjar (1991:241) illustrates this strategy very well in relation to the changing of dressings in burn treatment, demonstrating how the manner of the more sensitive and intuitive nurse allowed the person in a sense almost to share their body's sensations with the staff member, offering up their experience of their own bodies in a partnership which reduced the level of pain they experienced.

Dreyfus, H. and Dreyfus, S. (1986:64), speaking of the learning process, pointed to the power of tapping other levels of consciousness than the intentional, suggesting the importance of "quieting the analytic mind and letting the emotional, involved holistic right brain do its work." They point out the importance of drawing upon holistic as well as analytic styles of processing to develop new skills. After a brain injury it may be that a person requires help in switching between and in integrating these two modes of consciousness more effectively to promote effective skill learning.

SUMMARY

Using symbolic interactionist principles the experience of living with and recovering from brain injury was explored through the medium of film and interview. In order to organise the observations, a typology of awareness levels described by Denzin (1984) was used which divided them according to the level of physical and sensate information as opposed to cognitively contrived understanding which was involved in the interpreting and interacting process.

In this chapter, three of the four levels of consciousness described by Denzin were examined. It was found that at each of these levels - the sensate body, the phenomenological body and the body-for-the-person - the experience of 'being' after brain injury had been profoundly altered. The differences were very evident in the interactions the four men had with others in the setting and they affected the nature and success of the therapeutic relationships being created. The four people were clearly less able to manage equal, reciprocal and mutually rewarding relationships and they were less able to manage an adaptive, autonomous and purposeful lifestyle. There was one main underlying cause for these alterations wrought by brain damage: a lessened ability to make the authentic connections between inner sensations and feelings and the symbols which allow them to be communicated, clarified and resolved through interaction.

As I have already commented during the separate discussion of the four lives, the medical and mechanistic orientation toward human functioning drives conventional rehabilitation philosophy. This sometimes inclined all those within the setting to think in terms of recovery or healing of damage, rather than adapting to an altered awareness and reshaping interactions to help the person account and adapt for the changes. The examination of these exemplars suggested that because the problem was with making connections that allowed the communicating and negotiating of shared symbols, it is the *relationships* and *interactions* which are the more proper focus of any therapeutic enterprise. The findings of this chapter suggest that the most effective ways of supporting recovery involved an adapting of one's own interaction style so as to account and compensate for the changes in the person with brain injury, allowing him or her to continue to make meaning out of the world.

Symbolic interactionism however, goes a step further than the discussion thus far has taken us. As well as recognising the importance of interpreting and communicating one's own inner meanings, symbolic interactionist principles suggest human existence is inherently social, that true quality of living can only be recovered when the person is also able to take the 'perspective of the other' and fashion his or her responses and interpretations in response to the inner social 'me' as well as the knowing 'I'. In the next chapter, the final level of awareness as described by Denzin will be explored in relation to the lived experience of the four men, that of the body-for-others, living according to the feelings of the moral person

CHAPTER 12

A MORAL SELF

In the preceding chapter, the experience of living with an awareness altered by brain damage was explored as it affected the individual or 'psychological' aspects of consciousness. It was established that recovery required the integration of feeling and sensation with meaning and that the person was likely to require particular styles of intervention during the rehabilitation process in order to accomplish this. To become adaptive, purposeful and autonomous however, requires something more than just the reintegration and mastery over mental and physical skills. It also requires more than just a 'psychological' recovery. A person is a social being and recovery can only be fully understood when it is placed in the context of the person's roles and social identity. A sense of self cannot redevelop in isolation and any new purpose or goals the person developed would be meaningless outside this network of relationships and structures which make up an inner as well as an outer world. The focus of this discussion therefore moves on from performance and competence to the reconstruction of these inner self-understandings which provide motivation and direction.

I have referred regularly in exploring the sensate, phenomenological and intentional levels of experience, to concepts of feedback, both internal and external and to the adaptation or accommodation which responds to and accounts for such feedback. I have also stressed how central to symbolic interactionism is the notion of self as a process with a dynamic, emerging and interactive nature. In doing so I have sometimes touched in passing upon elements of Denzin's final hypothesised level of experience at which he suggested, we experience our selves as a body-for-others (Denzin, 1984:110). Denzin suggests that it is at this 'other-centred' level of experience that a person is inclined to make moral judgments about him or herself and to appraise situations according to the feelings of a "moral self" (Denzin, 1984:124). This chapter will examine the possibility that this inner conjured audience is responsible for much of the divergent and problematic beliefs and behaviour observed in the behaviour exemplars. This chapter will focus upon the role of such an 'inferred perspective' in the observed interaction and describe the way the relationship between an inner self and a projected 'other' influenced emotion, ontology, motivation and interpersonal power.

PHYSICAL DISABILITY AND THE VIEW FROM THE OTHER

It has been suggested that in Western culture the most superior minds are regarded as those that suffer least from the intrusions of the body (Gatens, 1992:62). None of the four participants was

immune from such innate cultural definitions. Rob and Max, who had suffered the greatest loss of physical control, were the two who had the most severe loss of self-esteem. Not only were their bodies more dependent on others to meet basic needs, they were also more intrusive, with such problems as a tremor ("Doing Art" RJ Cycle One, No. 1) or a dangling foot ("Walking with Joan" MK Cycle One, No. 5), thrusting them into a self-conscious awareness. At such times, they both tended to assume a submissive and apologetic manner suggesting a sense of personal responsibility for the loss of physical control.

> **" Put your feet up..," she instructs Max as she bends to flip down the foot plates for him to rest his feet on.**
> **"Yes, I'm sorry," he says calmly as he lifts them out of the way.**
> **"The other one," she instructs.**
> **"I'm sorry too," he repeats.**
> **"Don't be sorry," says Philippa as she straightens and moves behind him to push.**
> **"It makes me feel useless," he explains, "buggered too."**
>
> **("Going to Limmerton" MK cycle Two, No. 3.)**

Rob Johnson was the most vulnerable to these feelings of diminished worth. He had grown up with such a pronounced gift of physical power and skill that the cognitive disabilities caused by his accident seemed insignificant in comparison to the physical change. His body, once a source of pride had become an embarrassing nuisance and when he imagined himself from the perspective of another, he saw someone unworthy of respect. At an interpretive and interactive level therefore, this initially physical change created a change in his interpersonal style (e.g. "Needing Help", RJ Cycle One, No 2). Once assertive and self-assured, he was now passive and ashamed.

> **TRUDY: I don't think he feels strong enough, because he is in a wheel chair, to stand up for himself. Before, I remember ages ago when we were talking, I said to him, "I'm sure you and I would never have got to know one another if you hadn't had your accident." And he said, "No, there is just no way." I look at him and see a real cool dude. But, he has lost all that - he has lost that sort of mana, that power, because he is in a wheelchair and he feels a bit broken and he feels a bit "stink" - he often uses the word "stink."**

This shame, as well as causing both Rob and Max to deny themselves equality, diverted a great deal of energy into attempts to make the disability less visible. Personal feelings about one's own status and moral worth came to have a direct relationship to the ability to manage an impression, something which now required physical motor control as much as, if not more than, any more subtle interpersonal skills. Controlling and restraining their bodies (Gatens, 1992:62) appeared to dominate their minds on several occasions in the filmed observation, including careful and secretive attempts to replace a shoe that was falling off without being noticed ("Discussing RHAs and CHEs" RJ Cycle One, No. 2) and waiting until no-one was looking before fixing the position of a piece of clothing, or taking a sip of coffee ("Getting to Know a Flatmate" RJ Cycle Two, No. 2). It meant worrying about needing to use a toilet when in an environment where it may not be accessible without help; it meant doing without a cigarette because of the awkward fumbling

involved ("Friend and Teacher" RJ Cycle Two, No. 1) and the need to use the one good hand. As Keilhofner (1985:20) remarks:

> **Physically disabled adults may put as much effort into appearing to sit and hold their extremities in a natural position as they put into efficient performance of motor behaviours, sometimes sacrificing the latter to maintain the former.**

Subterfuge though it may be, the film suggested that these efforts were worthwhile. 'Looking normal' really did seem to promote and encourage more equal encounters at Waimarie. Just being at the same eye level, for example, could be worth the effort to struggle and prop one's body in a pose of confidence. Sadly however, this sort of front maintenance took too much effort to be sustained when attention was diverted.

> **He stops his chair under the high bar top, but cannot really interact with the two busy OT assistants from this position. He appears to wait and think about this and then carefully and slowly pulls himself upright, literally propping himself up on the bar. He is successful. He relaxes, looks around. Smiles. Del, now level with him, looks up and smiles back. "Beer please," he asks.**
> **Del goes to the fridge and pulls out a bottle. As she opens it she asks him casually, "You learning your lines Rob?"**
> **"What's that?" Rob looks worried.**
> **"Remember what I wrote?" She tries to prompt him but his face still looks blank. "Tatou, tatou," she starts it off encouragingly and waits.**
> **Rob lets go of the bar and half falls, half sits, down into his chair again. "Tatou, tena koe, kaumatua.." he offers slowly, uncertainly.**
>
> **("Learning to Be a Kaumatua", RJ Cycle One, No. 5)**

As Goffman (1968:19-30) understands and describes, a loss of physical control can translate into a loss of ability to manage coherent performances. When a performance is discredited in this way, an "other consciousness" (Goffman, 1968:30) can prevail and (more aware of their changed persona) people become uncertain of their moral status. Because of this, the attempts Rob made to present an able image were ultimately destructive of his developing new self. It threatened the process of becoming accustomed to a new body schema and thereby regaining a sense of a habitual body (Madjar, 1991:134).

Making a connection between acquiring a disability and feeling a sense of inferiority is hardly new or startling. Whether from inner or outer sources of appraisal, stigma has long been understood as having serious consequences for perceived social status (Goffman 1968). What makes the acquisition of stigma have a different character in the case of a person with brain injury however, is the uneven nature of the assumed inferiority. Each of the four men experienced feelings of diminished worth but the idea of being less worthy and less powerful came and went erratically, giving their interactions an uneven flavour. Less efficient perception and information processing made it more difficult to incorporate a new self-image into an ontology. As a result, it was only in reaction to a specific situation that the disability became a part of the person's consciousness, causing considerable oscillations in manner. This variability was very apparent in rehabilitation

sessions. In "Doing Art" (RJ Cycle One, No. 1), for example, Rob was drawing happily until Esther returned her attention to him.

> **Esther turns back to Rob, seems to clear her mind of the irritation and switch back into the relaxed and friendly role of partnership she began the session with. "How'd you go?" She leans across the desk and notices that he has a blank page in front of him.**
> **"Not good," he mutters hurriedly and reaches over to his right picking up the messed up page he had just discarded to start again. He looks ashamed, embarrassed.**
> **"Oh!" Esther tone sounds sympathetic. "This paper, is it not big enough Rob?"**

Esther's inquiry recalled him to painful self-consciousness and he slipped into a subservient relationship to her. As Esther chatted to Jill just before the above moment, Rob was no longer the object of her attention and so, despite the difficulties he was experiencing in drawing, he did not objectify himself. His body and the art materials were "transparent" (Heidegger 1967:186) to him and he was in a "circumspect" (Heidegger, 1967:66) mode of existence. The disturbance of this state re-installed the inner audience and along with it the sense of shame. From enjoying the opportunity to draw, he switched suddenly to an awareness of being looked at and judged when Esther wanted to see his work. This "examination" is a powerful mechanism for controlling bodies (Munford, 1989:35). At that moment he quickly dropped any pretensions to equality and her assessment of the art product was more important than his pleasure in the art process. The next moments in this interactive sequence revealed even more clearly how significant the manner or style of intervention can be in determining mood and attitude. Esther, apparently sensitive to Rob's unease, began to draw herself.

> **DS: You drew yourself. You actually say at one stage, "I am going to do some myself". Can you explain why you did that?**
>
> **ESTHER: Because then Rob would see me more as an equal, because we are doing this together and like, a lot of people have a big hang up about art, I can't do it and just seeing someone doing it sitting right next to you, it sort of breaks the ice and makes the whole thing much more relaxed.**

By clearly indicating that she was shifting her focus of attention from Rob to her own sheet of paper, Esther allowed Rob to release himself from the awkwardness of self-conscious awareness and concentrate his mind upon the artwork he was producing. As the session continued in a mood of relaxed fellowship, Rob controlled his tremor and increased the volume of his voice by the simple means of forgetting both.

These moments of absorbed consciousness then, offered the four people a valuable freedom from the constraining and demeaning potential of a 'spoiled identity'. All four sets of film show extended periods of relaxed unselfconscious pleasure when the men were totally absorbed in a computer game, art, or music and when engaged in convivial or playful interaction. Whatever the role of absorbed consciousness in eventual recovery, there is no doubt that it has an important contribution to make to quality of life, feelings of self-esteem and so by implication to the feelings

of the "moral self" (Denzin, 1984:124-8). Interactive strategies which switch people out of 'other-consciousness' clearly have a very important role in therapeutic settings.

PERCEPTUAL AND COGNITIVE DISABILITIES AND THE VIEW FROM THE OTHER

For Mark and Bryce, who retained physical expressive control, the dynamic created by an inner audience was qualitatively different. Their disabilities, more cognitive and perceptual in manner, affected role and relationship more than physical presentation of a self and so were not obvious to them when they took the perspective of the 'other'. As a result they appeared to believe it was necessary to consciously draw attention to difficulties they wished others to take into account, while at the same time they seemed less self-critical, lacking an accurate inner voice of self-regulation. While Rob and Max were too harsh as self-critics, these two were sometimes too complacent, believing that the images they conveyed was more coherent and competent than they seemed to the others around them. No knowing 'I' challenged the performing 'me' and tempered and moderated performances. As a result, they were sometimes rather excessive caricatures of the personae they believed themselves to be presenting[183] and a distinctive 'lack of fit' appeared between their projected impression and the perceptions of others.

Whether physical or relational in nature therefore, all four men had become less able to adapt and accommodate for the impression they created in interaction. Their experience was a one-way projection punctuated by moments of sudden confrontation with their own shortcomings. When their "vaunted selves" (Goffman, 1969:181) were thwarted they could not negotiate the necessary shifts and instead swung wildly as they tried out and discarded positions. For example, in "Getting to know a flatmate" (RJ Cycle Two, No. 2) Rob and Mark swung between confident assertion and submissive muttering, while in "Working Side by Side" (RJ Cycle Two. No. 3), Rob was expansive and outgoing as the young male hopeful yet quickly discarded this impression, becoming submissive and apologetic when he needed help ("Needing Help", RJ Cycle One, No. 4).

What this concept of an inner audience adds is a clearer understanding of how inseparable and enmeshed are the terms 'intrinsic' and 'extrinsic' when considering human social behaviour. A sense of sanction, whether reinforcing or discouraging, is ultimately never external, but totally dependent upon the inner interpretive processes of the person as actor. These interpretive processes include memory, attention, information processing, sensory perception, all of which I

[183] See "Mates", MW Cycle Two, No.2; "The Pool Game", MW Cycle One, No. 5; "Cup of Tea with Syd", BL Cycle One, No. 5; etc.

have already demonstrated had been profoundly altered by the brain damage. The way in which each of these elements of cognition affect the role of the inner audience will be dealt with in turn.

SELF-DEFINITION AND THE LOSS OF THE PHENOMENOLOGICAL BODY

> **MARK: I'm not really sure how I feel any more. I wish I knew how I felt. I find it hard to find out how I feel.**

A changing sense of embodiment (Madjar, 1991:106) had deprived all four men of a familiar habitual relationship to the world. They had, to a greater or lesser degree, become alienated from their physical and phenomenological self-feelings and as a result they faltered in their attempts to construct self-definitions and project a coherent image. Now, at this level of the body-for-others, it can be seen that these problems translated into a tendency to hand over to others the right to define not only their new situation but also their innermost feelings. In the filmed sessions the four men regularly deferred to the expert staff in the reconstructing ideas about their inner volition.

> **"Why, what's the problem Max?" she asks with a perplexed frown. Max mutters something to the effect that he doesn't like it. "You did enjoy it Max," says Corinna, confidently contradicting him. Max nods passively and appears content to accept this definition of his feelings... .**
>
> **("Waiting for Lunch." MK Cycle One, No.2)**

Max's passive acceptance of another defining his emotions in this excerpt is typical. Many of the staff at Waimarie constantly told or 'reminded' people what they thought or felt. Usually like Max, the resident concerned would accept the information peaceably. Unable to call upon an inner feeling resource, they apparently accepted pronouncements on their emotional state by others.

It seems that without a phenomenological intactness, the 'inner audience' of the four people may have become too powerful, shifting the locus of control from inner to outer sources of self-definition. Inevitably, spurious forms of emotionality (Denzin, 1984:153-6) resulted which compounded the sense of self-alienation. Even some of the most personal feelings and ideas expressed by the four men were found later to have been adopted or imitated. For example, in the following excerpt Bryce begins by teasing Sid about the 'crush' he had on his social worker and then adopts the feelings as his own:

> **"She doesn't like you any more does she?" Bryce taunts him. "Because you tried to take a photo of her."**
> **"Yeah," Sid agrees consideringly, "that is probably why."**
> **"I want a photo of her face," Bryce comments. "There will be no show of getting that! No show in shit show."**
> **"Yes you have!" Sid thinks about it. "Just go round there and go 'Philippa!'"**
> **"Hey! I told you that!" Bryce objects. "I told you how to get it!" Sid does not challenge this assertion and there is a silence for a moment.**
>
> **("Before the Polytech Students' visit" Cycle One. No.2)**

Denzin (1984:149-156) describes how through "spurious emotionality", "emotional identification" and "emotional infection", a false self-system can be created as a result of the submersion of the self in the other. He warns that a person risks becoming 'lost' to himself or divided against himself in drawing upon and adopting inauthentic forms of emotionality. In attempting to own the feelings of others, the four men distanced themselves progressively from their own ontological core. The more alien their inner feelings became, the more reliant they were upon cues from others to direct their own self-ideas.

Mark's story in particular demonstrated how, unable to tap a deeper sense of self-directed energy, he looked for approval instead of contentment and so did not develop a real sense of concern or engagement in his own recovery. His occupational therapist sometimes became bewildered about what her role should be in helping him learn independent living skills, simply because he didn't seem to have the concept of "feeling like" something.

> **JILLIAN: ... we started making the odd other thing for lunch- like, he had nachos once and pie and coleslaw and chips or something but his mother was worried he was having too many calories and so he went back to all bread rolls for lunch every day of the week and said "I don't mind, I don't care." .. And, he doesn't seem to have a concept of getting bored with the same thing. I am sure he would have chops, or drumsticks every night if we let him...**

While it might seem 'useful' to have a client group who readily accepted imposed definitions, the staff knew there was no sense of victory or accomplishment in telling someone with brain injury what to think. Compliance did not bring about a recovery of autonomy, purpose and adaptivity. Without an inner self-directed motivation, the adherence to a rehabilitation regime frequently seemed mechanical and meaningless; disempowering rather than re-empowering. While the staff all tried desperately to promote self-directed action, they were constantly confronted and thwarted by this feeling limitation. For example, in "Meal Planning with Jill" (Cycle Two No. 3) a session where ideally Jill and Dinah supported Mark as he planned what he wanted to eat for the week, slipped perilously close to dictatorial instruction as Mark was unable to relax and call upon inner, personal memory of pleasure.

> **"Kumera?" she suggests after a pause. Mark looks doubtful, thinking.**
> **"Corn on the cob, Mark?" Dinah offers eventually.**
> **Mark looks up with an exaggerated expression of delight and surprise. "That is a good idea!" he exclaims.**
> **"You could try that" Dinah encourages in a more level but encouraging tone. "If you want some different vegetables." She turns to Jill. "What do you think?"**
> **"Sounds good." Jill nods casually without looking at Dinah. She seems to be signalling to her student to keep it laid back, not to give the impression of "telling" him what to eat. She turns back to Mark "You could buy a wee bag with corn cobs in it," she suggests.**

As well as causing a greater reliance upon cues from others, the absence of feelings could cause a greater reliance upon cognition. Attempting to understand themselves, Mark and Bryce turned to

analysing and quantifying the unquantifiable and a peculiar form of self-accounting took over. Mark, for example, when asked for his favourite meal replied that it was chops, because of the 'bone' and when Philippa asked him how he liked living in the flat, he felt called upon to itemise everything, as if listing experiences could make them become more real.

> **"I have six posters, two photos, one calendar, one sticker..."**
> **("Scared About Moving into the Flat.", MW Cycle One, No. 2)**

Alienated from feeling, they were still driven to make sense of their changed life and so turned to dehumanising analytic principles. Personality qualities became concrete and almost physical properties which could be counted.

> **MARK: I had three goals when I came to Waimarie and I have already done two.**
> **DS: What were the three goals?**
> **MARK: Control my anger, work hard to build my fitness up. Before I came here I was really weak and the third goal was learning how to consider others and be in a group.**
> **DS: And which two do you think you have "done" and which is the one that you are still working on?**
> **MARK: Controlling my anger, being in a group - that is my third goal.**
> **DS: So it is just the fitness left is it building up the fitness?**
> **MARK: Yes. I do do that but I find that hard.**

Attempts to explain his situation such as this example above, made Mark seem odd or different to most people, who found it difficult to discuss such intangible qualities of living as concrete, fixed quantities. His family and the staff both tended to discourage this strategy and he was trying to stop.

> **MARK: I know it is not something that's normal and it annoys Mum and Dad.**
> **DS: Counting things?**
> **MARK: Yes Trucks and that. "Jeez!" Dad says "seventeen trucks, So what Mark!" - because it is not normal behaviour - I have adjusted and I am not doing it so much now really.**

It is remarkably difficult to learn by way of such an objectifying "top down method" (Cicerone and Tupper 1991: 287) how to relax and be oneself again. No matter how much he wanted to 'adjust', when Mark described himself relaxing he revealed anything but restfulness.

> **MARK: Each morning and each night I play tapes while I sleep and I have to rewind them and then just play them - play cassette one, forwards, cassette two, forwards, then that's good and I just come back to press forwards again - five hours of music - reminds me about the fifth tape and then I wake up and look around and then I get out of bed.**

Madjar (1991) observed a similar sense of alienation from the physical body in people with painful burns or cancer and she suggests recovery from these conditions requires an inner acceptance of a changed state. She found that the return to a sense of bodily intactness, control and safety is fostered by the development of intersubjective relationships with the treatment staff (Madjar, 1991:134-5). By creating a sense of alliance and shared purpose, she found that the staff were able to support the process of regaining a sense of the habitual body. Although her findings may be equally relevant to the field of brain injury, there are clearly some problems in creating an authentic partnership with a person for whom rational problem solving has become difficult.

Observation of interactions at Waimarie suggested that a sense of authentic intersubjectivity was only achieved when the other interactants (whether staff, residents or family) adapted their interacting style, consciously guiding the person into a relaxed climate of partnership. Usually the techniques were deceptively simple and often the person concerned was acting without a conscious awareness. Esther decided to do her own poster ("Doing Art" RJ Cycle One, No. 1); Philippa slipped further back in her chair, almost supine in her signal to relax ("Scared about moving into the flat", MW Cycle One No.2); While Trudy just handed Max a pen ("A Perfect Day" MK Cycle Two, No. 1).

> **TRUDY: Oh he likes it. Max likes writing down. I think it is the old builder thing. A pen or a pencil in your hand and you can do anything. He is really good with a pen - he actually expresses a lot better with a pen than with his words. He is very comfortable like that [***Nodding to the screen where Max is busily writing].*

This emotional intersubjectivity appears to be the key element in successful therapeutic relationships. It was occurring beneath the intentional consciousness and appeared to tap into the phenomenological level of awareness. There was many occasions filmed when staff perceived and responded so instinctively to signals of stress that, although they adapted their own mannerisms to counteract it, they had no knowledge of the role they played. Philippa, the social worker, was horrified to see (on the film of her session) how excessively relaxed she appeared, almost to the point of disinterest ("Scared about Moving into the flat." MW cycle One, No. 2). Yet, upon reflection, she believed that her physical attitude was a response to the tense nervousness she was picking up from him, evident in his tense forward sitting posture on the film. Trudy too ("The Notebook system", MW Cycle One No. 3) only noticed in viewing the film later, how important it was for Mark that she attune her body language to his, suppressing the sometimes destructive level of anxiety by fashioning her own responses to project calmness. In this excerpt, hypothesising a "feeling of knowing" sensation (Shimamura and Squire 1986), she suggested her own calming response helped him eventually find the answer he sought.

> **TRUDY: He looks frustrated and he acts frustrated, agitated, he gets all the body movement and his hands and his arms become very , gross in movement, and he will lean forward close to me and really he is just wanting to drag the answer out, we almost crack heads! He will just think, think, think - and he still can't get it and he leans forward and "I can't get it" and his legs are going. I wait and help him feel he can take his time.**

With a damaged consciousness the film clearly shows, the four people were unlikely to regain an authentic sense of a habitual body if left to their own resources. A lack of ability to align an inner feeling self with an inferred attitude of the other left them vulnerable to a variety of distorting self-interpretations. A metacognitive or analytic approach exacerbated rather than resolved this problem, creating the climate for a divided self and a spurious emotionality. In such a situation, there is a strong need for the development of empathic therapeutic relationships which foster the development of authentic emotionality through a sensitive partnership in the process of change.

Such a relationship requires non-verbal as much as, or even more than, verbal techniques in order to diminish the power of the external audience to a point where the inner voices become audible again.

SEQUENTIAL THINKING AND THE BODY-FOR-OTHERS

Information processing styles play an important mediating role in self-recreation. Change to cognition will, by implication, become change in the nature of self-awareness. It is very difficult to objectify oneself or consider oneself from the perspective of the other without the cognitive capacity for metacognition. Another very significant common theme therefore, was the more sequential and relational nature of thinking processes. As explained by Goldstein (1942,1952) and Gross (1987), after a brain injury, schemata may not be available simultaneously and so cannot always be processed in relation to each other. Instead, thinking proceeds as a reaction to the immediate moment, less influenced by wider and abstract implications and considerations.

As I have already demonstrated[184], this change in cognition changed the relationship each had with time. Despite the wide difference in their personalities, a sense of 'waiting' as well as a contentedness to engage in boring and repetitive activities, pervaded all four sets of filmed data. Bryce stood by the stove, staring at his lunch as it cooked ("Getting Lunch", BL Cycle One, No. 1), or sat in the lounge of his flat with his eyes fixed intently to a children's television program ("Cup of Tea with Syd", BL Cycle One, No. 5). Mark sat watching the countryside for long periods, idly tossing pebbles and counting the number of cars that passed. Despite the awkwardness of manoeuvring his motorchair in his small bedroom cubicle, Rob put away items of clothing one by one, returning each time back to the pile on his bed without thinking of sorting through and grouping the individual items.

Anyone versed in literature about total institutions will be familiar with descriptions such as these above. There is a considerable body of research which demonstrates how institutionalisation of human beings will induce these apparently mindless or repetitive activities without any signs of irritation or frustration. Most caring health professionals would regard this sort of behaviour abhorrently, as evidence of negative and disempowering states of mind. They would see their role as one of returning the control to the person and avoiding the development of a "learned helplessness" (Bray et al., 1987:65) which can be created by the structures and relationships in a formal institution.

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[184] See "Temporality" P.427.

However, control implies power over decisions and to make effective decisions requires a metacognitive and abstract level of information processing. As Crosson et al. (1989) point out, this level of awareness is beyond many who have experienced severe brain damage. It is very evident in the filmed interactions that whenever confronted by tasks requiring metacognitive or conceptual levels of consciousness all four of the men disengaged, deferring to the other in an acceptance that the demands for abstract reflective information processing were beyond them. Their interactions and remarks also showed a tendency to misunderstand the meaning of their own experience at any more abstract level. For example, at the beginning of her art session with Rob ("Doing Art" RJ Cycle One. No. 1), Esther explained that the purpose of the art program was to extend concentration span, to increase the control of the arm movements, to practise planning and organising of a long term project and to put some continuity into his life by having activities which are carried on from one week to the next. When she asked Rob if he understood however, he demonstrated that it was only one of the several aspects which he had understood and incorporated into his understanding.

> **"Carrying on with it" he mutters agreeably, nodding.**
> **"Yes," Esther clearly feels affirmed by Rob's understanding of her purpose "that is what I mean!" Rob nods again, pleased to be useful "- and then, after a week we can come back -"**
> **"Yes. That is the way I see it," Rob agrees approvingly. "If I am enjoying it today then I can come back and carry on."[185].**

Although Esther was content on this occasion to concentrate upon the element of her explanation that Rob did understand, the development of a sense of purpose and self-direction in it can be to return the power over living to a person for whom a metacognitive perspective has become so difficult. In the film the staff constantly attributed underlying theoretical reasons for the activities they had organised, despite knowing how fruitless such an exercise was likely to be.

> **ESTHER: I didn't want to treat him like an idiot. I didn't want to go in there with my goals for Rob and not let him in on it because I don't think he responds as well unless he knows what is going on and that is good from then on - and,, just build trust and rapport and things like that.**

Esther, like all the staff, had to accept that no matter how often she articulated goals, no matter how much she promoted a sense of partnership, there was an underlying element of deceit in her method of therapeutic practice. She knew but he did not, how unrealistic many of his self-ideas were. Much of her practice was directed toward bringing her clients at their own pace to realisations which her testing and experience had clarified for her in the initial stages of their relationship; a realisation of the full impact of the disabilities. Living with this uneven arrangement of knowledge was disquieting and stressful for many of the staff, particularly those whose ideal was to re-empower and create a sense of shared purpose and they seemed to respond by creating

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[185] When shown film of this conversation later, Rob again identified the idea of a long term ongoing project as being the only goal which Esther had discussed with him.

a climate which softened the impact of the dawning knowledge. By sharing in the activity in this way, the encountering of a difficulty allowed joint confrontation and joint reflection about it and furthered a more realistic discussion about the future .

> **ESTHER: The other thing I think about what was happening is that Rob wants to do bone carving and I don't think that physically he is capable of doing that and I want him to be able to build up to having a go at it. I don't want to say, "I'm sorry Rob, you can't do it." I want him to have a try and I want him to be able to come back and make some decisions.**

By creating a situation here where Rob would discover bone carving was too difficult while he was working alongside her, Esther ensured that his confrontation with a loss would be followed by a more realistic discussion of possible leisure activities, based upon concrete evidence, not theory. This maintained the focus upon compensatory strategies and compromises rather than negative revisions of his own character.

Not only the relationship but also the structure of sessions appeared to be adapted to accommodate this change in thinking style. The clarification of the goals was not introduced at the beginning of the session but happened in response to situations and was regularly referred to and reintroduced whenever the situation provided reinforcing evidence. In this way Esther provided a learning situation for Rob where physical concrete evidence was paired with verbal explanation. If it is only possible to "construe" (Kelly 1955:36) in concrete and sequential ways, the abstract relationships and themes which give order and coherence, or a 'wider picture' of a life, will not necessarily be grasped. It becomes impossible to "put one's psychological space in order and plot the varying courses of action" (Kelly, 1955:36) alone. A different type of helping relationship may be necessary, in such a situation, to guide the return to self-directed and autonomous living. The filmed interactions in Waimarie suggest that just urging a person with cognitive damage to take back control over his own life without adapting for the loss of an abstracting ability, may incite the very sort of anxiety and passivity associated more with the deprivation of control. Oppression and disempowerment may occur in this particular group because the people interacting with them have failed to adapt their expectations and to compensate for the loss of construing ability.

'Learned helplessness', therefore, does not emerge from a particular type of place, nor from a hierarchical structuring of roles, but rather from an imbalance in the construing process in interactive arrangements. Until some abstraction is possible, re-empowering requires special types of relationships.

IDENTITY AND PICTURING

To symbolic interactionists fantasy has always been understood to have a central role in meaning creation. Through imagining oneself in a role and then through interactive play and rehearsal,

identifying oneself more firmly with that role, new attitudes and behaviours are learnt and a greater sense of alignment between the outer performing person and the inner ontological self is attained.

None of these four men had yet managed to create a coherent, consistent and realistic new image of himself and perhaps as a result, they became rather erratic in their self-presentation, sometimes seeming to adapt their actions for their new situation and sometimes slipping into habitual ways of relating. This gave an unusual lack of form to their personality, most noticeable in Max. As Prue Kavanagh put it, Max was like 'a radio that kept going slightly off the station'. When relaxed and less self-conscious he appeared to slip into relationship styles characteristic of him before his accident, yet he was rudely awakened from these easy habitual interaction patterns when something in his encounters reminded them of his new and changed identity:

> **"I think I will be 31," Max replies seriously and then after some thought "about sixty."**
> **"About 60?" asks Trudy doubtfully.**
> **"Yes," agrees Max "sounds terrible!"**
> **She writes down for him as she says, "When were you born, what year?"**
> **"42" he replies correctly.**
> **"So" she writes as he watches, "Nine take away four is?- five - so- you see? You will be 52 this year."**
> **"Sounds terrible!" says Max frowning.**
> **"Certainly not in your thirties," agrees Trudy and then moves quickly[186] on to the day's exercise. She places a printed sheet in front on him and, indicating the heading says, "Okay. I thought we might work on this one today."**
>
> **(A Perfect Day. MK Cycle Two, No. 1)**

As part of their recovery then, each needed to rebuild a picture of themselves as they were to others. Moments of self revelation like this one above became moments of "disturbance" (Heidegger, 1967:105) triggering an inner audience to appraise and judge the identity they could once have taken for granted. The judgement was often severe, particularly for Max and Rob and at such moments all four men seemed peculiarly vulnerable and sensitive. To encourage recovery of a sense of self, it seems it is necessary to encourage the imagining of new and positive self-images. However, after a brain injury as I have already demonstrated[187] imagination can be let loose from the constraints of reason and frustrate the recovery of a shared social reality rather than support it. As a result, mental pictures can sometimes be helpful and yet at other times destructive. Exploring the use of fantasy in the four sets of filmed observation suggested that, although there are several caveats to bear in mind when fostering the use of imagination after a brain injury, it is too powerful a tool not to use to support and maximise recovery.

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[186] Trudy explained when I interviewed her about this interaction, that she diverted Max's attention to the work she had planned because she felt the discussion about his age was painful and upsetting for him.
[187] See Chapter 8, p. 290.

Firstly, there is the strong connection between motivation, goal directedness and imagination. An image of a possible future could act as a powerful motivator. For example, Mark imagining his eventual role as a competent worker:

> **DS: So when you are feeling good about yourself, you think about the future.. What sort of things do you think about when you are picturing it?**
> **MARK: Well, I do work and the boss says "Mark, you are doing so well, you are going so well."**

'Picturing oneself' in a successful future was an influential and powerful mind-game used by all four men. It appeared to turn appealing possibilities into goals. Bryce created in his mind, the possibility of being a responsible father, Rob imagined living at home and being surrounded by admiring children to whom he could teach his rugby and boxing skills, Max imagined himself in his workshop again and Mark imagined the return of at least some of his former social skills and ability.

However, on numerous occasions in the filmed observations, ideal mental pictures threatened the rational and considered planning process which the staff were attempting to engage the four men within: images could be so attractive and they could be produced so instantaneously. The improbable could become the possible and then the easily attainable within a day. Flimsy evidence became firm proof, as indicated in this conversation with Mark:

> **MARK: They did a book about that Deb, do you remember? A boy who had some sort of illness and he was a kid, eight years old when he got the illness and when he was 17 he got rid of the illness and he was in hospital for four years and he came out and he said, "the world is mine! "And then he started to play basketball and stuff - and he got grades, got A grades, at school.**
> **DS: Is that how you see your own recovery? what you imagine will happen?**
> **MARK: It is not what I imagine will happen - it is what is going to happen!**

This sort of psychology sometimes made images extremely dysfunctional. The careful planning, the sustained effort which the staff and family could see would really be necessary to achieve a goal, was disregarded with an impatient nod. When he decided upon an abrupt career change from dairying to mechanics during the second cycle of filming, for example, ("Work Experience" and "Future Plans" BL cycle Two. Nos 2 and 5), Bryce did not take into account that he had visual heminopia, that he was unable to read, that he would not be allowed a driver's licence or that his memory difficulties made learning new information a slow and repetitive process. He also managed to picture himself simultaneously as supporting his family and earning money and as being a polytech student without the contradiction occurring to him.

This lack of realism was equally evident in the imagining of interpersonal relationships, where there was an expectation of instant friendship occurring when they pictured their lives after discharge. Mark's mental picture of striking up a relationship is revealing:

MARK: I would go up to someone and you know after some time I could see myself having a conversation and I would tell her about my accident - [She would say]"Can I buy you a beer?" and I say, "no thanks, I am not allowed to drink any more." And she goes, "why not?" And I tell her it is because I have had a head injury and she goes, "God, Mark you are a miracle!"

Reality could never quite match these instant and perfect images. Sometimes, it seemed that once Mark, Bryce or Rob had a picture in his mind of what could happen if he worked toward it he lost the impetus to do so. The picture itself was so much more satisfying for a person with several disabilities than the experience could ever be. Sometimes it seemed that it might became sufficient by itself and the person would become consigned to a fantasy world, composed of past memories and images from such impoverished sources as television soap operas. The problem with such self-images is the inability to demonstrate them.

ROB: I can't prove that I was and you mix with the guys and, "he's lying, ah, he's lying". (silence) I'm the kind of fella that can show you that I was good at something, but now I can't and you might say, "what you fellas doing?" But, I know for myself I was good at sport ... Someone might tell someone and someone might tell you, but if they can't see for themselves, I can't show them anything. I've got trophies and that to prove it. They're proof. (silence) Anyway my word's good enough.

In order to maintain such aspects of their identity which they could no longer demonstrate, Rob as well as Mark and Bryce, needed to tell people, particularly new people, about their past successes. The egocentricity often attributed to this group of people may stem in part from this concern to influence the 'picture' the other formed and a feeling of powerlessness to demonstrate it in any more subtle way. Rob's sporting success was such a central part of his identity and yet he could no longer act this role. Bryce was proud of his reckless and carefree lifestyle, yet now he was unable to drive a car, or drink alcohol. Mark had regarded himself as competent and popular and now his friends were beginning to avoid him and he was having difficulty forming successful new relationships.

Without support in modifying them, 'mind pictures' may prevent a person from maximising their recovery. It is not being adaptive, purposeful or independent to leap from one fantasy to another and avoid rational planning and sustained effort. With the use of thoughtful counteracting responses however, appropriate images of succeeding were sometimes instilled which fostered a more gradual notion of recovery and which reinforced images of working hard. Joan, for example, attempted to reframe Mark's idea about his timetabled swimming session, as 'training' not 'rehabilitation'. Having made this transition verbally, he and Joan could begin to work together toward a goal of fitness which satisfied his mentally pictured ideal.

JOAN:... so, instead of doing this plain 'swimming', he is actually lined up to do "swimming training". So we are going to have to have some discussion and I think he is actually capable of having a set target of ten lengths. Of three in freestyle and three in backstroke and three in breaststroke and he can do one other length in any other stroke that he likes and he can do

either one length at a time or three lengths at a time and I am going to bring the stopwatch and time him.

In a similar manner, Philippa instilled in Max ("Going to Limmerton" MK Cycle Two. No 2), a picture of himself as living independently of Prue and being visited by her. Because she had first built a picture in his mind of a man capable of managing alone in a supported environment he had managed to dispel his image of being a helpless and passive patient. In this light, the prospect of living apart from her could be viewed positively and it is even suggested by his manner in the following excerpt ("Going To Limmerton" MK Cycle Two, No. 2) that he was imagining a more equal relationship with her, with less emotional dependence upon her presence.

"-And Prue will be able to visit you -"
His attention was caught by this point and he looked more alert. "That would be nice. Don't mind at all," he agreed graciously.
"Yes. You will only be ten minutes away from where Prue lives," Philippa continued.
"That's quick, very quick indeed," Max commented interestedly.
"Yes", agreed Philippa warming to her theme, "it is nice and she would like to visit you too."
"Fair enough too," he agreed as if conceding her right to such a feeling.

Such conversations can adapt potentially harmful and unrealistic self-images, building new ones which foster notions of succeeding by effort, by the learning of compensatory strategies, by reorganising the environment to overcome difficulties. This image of oneself as becoming competent through careful planning and effort is difficult but necessary for all four of these people to grasp if they are to make realistic choices again. Only then can fantasy empower rather than thwart recovery.

As well as reshaping the images their clients had, staff were frequently seen to use their own images to strengthen the message of recovery they were promoting. Sometimes the picture was not only offered but also acted out. This physical demonstration seemed to be instinctive and unconscious and caused some of the staff some embarrassment when seen later in the film. They had not realised how much they had been acting out what they were talking about.

TRUDY: ...so I was trying to give him an example of me, saying, "Well, I work all day and I don't have a drier," In fact, I actually even mimicked a washing machine at one stage, I thought it was a very good impression of a washing machine!
DS: You are very expressive with your body.
TRUDY: Yes!
DS: Did you realise?
TRUDY: No. Not until I saw the film. I had no idea that I use my hands that much!

Sometimes rather than offer new images, the staff member concentrated upon challenging the existing image, negotiating for something more probable; something others could support and encourage. It is interesting to see how, when Bryce was imagining himself in a reckless role he adopted an equally reckless mode of thought and arguing.

"[We will] party and we will probably all get drunk. And no-one will be driving so it will probably be a long walk from one side of town to the other side."
"Mmm" Phillippa contributed reflectively. "In Wimberley?"

"In Wimberley. I am never going to live in the country again."
"I just need to remind you about head injury and drinking."
"Yes I know," Bryce interrupted in a mock bored tone. "And I have still got that thing you gave me," he continued "and I haven't read it", he concluded proudly.
("Future Plans. BL Cycle Two. No. 2)

Philippa's strategy at this point was to switch Bryce from 'imagining' to a more verbal 'conceptualising' where a deductive form of rational information processing made the conclusion unavoidable, that to drink was unwise. Like Joan above, therefore, she reframed an image by switching from picture to concept and introducing a new possible interpretive scheme, the PCT[188] technique of "constructive alternativism" (R. Neimeyer, 1987a:4). Forced to acknowledge at least with the verbal and rational part of his consciousness, that Phillippa was making a valid case, Bryce tempered his image and played with a less extreme version of the party-going image, coming eventually to a compromise with which both felt content. Although he might still have lapsed into heavy drinking after he left Waimarie, there is no doubt that conversations like this allowed him to imagine alternative roles and unless this imagining process was possible, personality changes which accommodate for the effect of the brain damage were unlikely to be effective.

MEMORY DIFFICULTIES AND THE PERSPECTIVE OF THE OTHER

Rebuilding an inner 'knowing I' would have been difficult enough for this group without the added disadvantage of memory problems. Whether or not memory is a passive store or an active (or interactive) system, all four men found that it failed sometimes to provide an accurate resource. This loss had a huge impact upon their reforming notions of identity.

Although thought processes are vulnerable in all of us to the vagaries of memory and association, the memories of these four people all failed more often to provide a self-regulating inner audience. Most significantly, they all experienced at least one occasion where they had no memory of decisions they had made about their own future and were thus forced to rely upon the accounts of others. In these circumstances, it would not have been at all surprising if Mark, Rob, Max and Bryce had lost any belief in their ability to direct their own future. Yet it appears this did not happen. As Mark demonstrated here, in talking about his new program (see MW Cycle One, Nos. 3 and 4), despite not remembering many of the negotiations he had been involved in, he had developed a sense of ownership and participation.

MARK: Yes - I feel like I am really involved in this new timetable.
DS: You have? And you feel you have got what you want?
MARK: Golf lessons man, I am damn lucky.

[188] Personal Construct Therapy. The Framework for Therapeutic intervention devised by Kelly (1955). See Chapter 1, p. 62.

DS: Right. The golf lessons and the job, that really pleased you. Do you remember it coming out of that meeting between the staff and you and your family?
MARK: *(shaking his head)* **I don't remember it.**

It is important, therefore, to understand how they became infused with a sense of self-direction during the rehabilitation process, despite the problems they had with memory.

Firstly, each person had developed a sense of trust in the staff and their family. Because of this, they were able to adopt another's version of a conference or experience they had been involved in. This trust appeared to have developed in part because any information given to them could be 'triangulated', or confirmed by several people, an aspect of residential living which is perhaps undervalued as a component of rehabilitation. Doubt could be dispelled and stories confirmed by approaching several people and comparing their different versions. As I followed the four men with a camera, I was particularly struck by the number of times they needed to hear the same story from each of the different participants within it. With each retelling it seemed that repetition reinforced the sense of ownership as well as adding to the store of facts.

Sometimes too, this often repeated story had the power to cue their own memory traces. Mark in particular had learnt, that while he might not recall an incident he could recognise it in its retelling.

DS: So when somebody says to you "Do you remember that meeting on Thursday?" What are you likely to do?
MARK: I say, "Could you just say what happened so that -"
DS: and that helps?
MARK: If the cues are there I will remember.

Secondly, as Denzin (1987b:165) demonstrated in his research with alcoholics, the four men could rebuild more effective memories through the recounted stories they heard. Gradually as they relived their experiences through the accounts of others, picturing what must have happened, they seemed able to internalise the forgotten memory. From feeling driven by others' ideas and goals, they moved toward understanding themselves from the perspective of the other by repetitive story-telling.

Of course, this way of remembering allowed the staff an interesting and perhaps disturbing opportunity. They could mould the recreated memories to suggest the person was more in control, more self-directed than had in fact been the case. This slanting of memories so that they furthered the cause of autonomy was often evident. Trudy, Jill and Phillippa so convinced Mark of his participation in the New Program that he was extremely committed to it ("The Notebook System", The New Program", "Scared about Moving into the Flat" MW Cycle One, Nos. 2,3 and 4). Linda in "A Session on Sequencing"(BL Cycle Two, No.1) recapped the course of Bryce's cognitive recovery in such a way as to suggest his active participation. Del, as she reminded Rob of the need for catering arrangements, deferred to him as she would have to a kaumatua

("Learning to be a Kaumatua" RJ Cycle One, No. 6). Such excerpts show that what was important was not always so much the *detail* of the process as to infuse it with an appropriate valorisation, a prevailing *mood*. This mood influences the attitude and determines the approach taken as a moral self in a body-for-others.

Thirdly, by recounting the stories and recovering and clarifying the meaning, the staff and family fostered a "semantic awareness" (Tulving, 1972) of partnership and shared purpose for which the "episodic memory" was now unavailable. Although they had lost the occasion, they managed to incorporate something of its quality into their developing ontology. As Philippa reflected upon her session with Max ("Going to Limmerton" MK Cycle Two. No 2) she revealed her belief that at some less conscious level, Max was absorbing and incorporating these meanings they created together.

> **PHILIPPA: I don't know. I have always wondered if you can work through it unconsciously ... like Don[189], who actually has no memory - whether it is worth starting.... It is something I have just started thinking about. That is why I have started trying to work with these people on things like grieving. I have just started with talking about grief and even if they forget what they talk about - maybe unconsciously they are dealing with it.**

The story of these four men suggests that where memory is impaired it may be necessary for others to act as and consciously reimpose the 'perspective of the other' in order to help the person feel a sense of participation in recovery. Although it might seem that such practices verge upon an unethical colonising of another's mind, observation of the film and of the course of recovery over the months of the research, suggests that these are instances where the ends justified the means. The developing sense of partnership and shared goals was clearly essential to successful recovery of purpose, autonomy and adaptation and yet as Gans (1983) points out, memory problems discourage such relationships developing as a matter of course.

EMOTIONAL INTERSUBJECTIVITY, EMOTIONAL SURVEILLANCE AND AN INNER AUDIENCE

A great deal of the discussion thus far has concerned building self awareness or insight. In theory (particularly symbolic interactionists' and constructivist theory), if the four people could be brought to even just an intellectual level of awareness (Crosson et al., 1989:47) of their altered consciousness they would come to a better control of its impact upon their life. If the level of awareness could be improved to an "emergent" or "anticipatory" (Crosson et al., 1989:48-9) level, the odds for recovery of a self-directed, purposeful future increase enormously. However,

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[189] Another resident with very severe memory difficulties. Also referred to by Syd (Chapter 10, p. 402). All the people at Waimarie, both staff and residents, frequently compared and contrasted the cognitive disabilities of the residents in an effort to rank them for severity and so organise their understanding about the impact of a specific deficit.. Several people seemed to regard Don as the most extreme example of memory deficit.

it was clear in the filmed observations that motivation and self-direction did not automatically follow upon cognitive awareness for any of these men. As well as understanding what was happening to them, it was also necessary for them to discover an effective emotional attitude toward their new situation. A loss of control over their emotional reactions quite clearly thwarted the recovery of purpose after brain injury, whether the problem was impulsivity and over-reaction, or its opposite, a 'lack of affect'.

It was not surprising therefore, that staff who had positive and effective relationships regularly used the word 'balance' to explain their interactions with their clients to me.

> **LINDA: I suppose to get the balance, with Rob - because he does lose his concentration, mind you we had a long session. He just gets tired and I suppose, I am aware and I don't want to push him too much -but I knew we had to get it finished.**

Many staff were revealed in the filmed observations as adapting their own transactions in response to their feelings about their clients' emotional state, often without fully acknowledging or understanding their own motives. They seemed to be intuitively monitoring the climate and either dampening excessive emotional reactions or heightening engagement and stimulation with their replies. As Mirenda (1994) would say, they took responsibility for maintaining an "optimum level of arousal" by promoting a positive mood or tone.

> **DEL: He gets, when I look at him sometimes and I am trying to tell him something he gets that I am growling him-I say, "I am not growling you - I am teaching you" and so sometimes I can feel it that it will make him go down, so making a joke sort of stops that. He's got a great sense of humour when he wants - trying to take the mickey, something like, when he said "Ta ta" and I say "no, tatou."**

The lack of ability to identify what they felt which I discussed earlier[190] made these men very open to such emotional 'guidance'. Trudy in "A Perfect Day" (MK Cycle Two, No.1) had not been prepared for the writing of the date to incite so many personal issues and quickly acted to divert the flow of the conversation from them. Although she presented to Max at the time as relaxed and accepting, her teasing responses to the more emotionally intense remarks he made suggest that she chose to manipulate her session so as to maintain a light-hearted mood. Released from a harsh and overly critical inner audience he could look at the change in his relationship with less pain.

> **"You don't get mad do you?" She asks lightly, seeming to want a less gloomy tone.**
> **"No" agrees Max placidly.**
> **"Ooh, I don't know," teases Trudy, "that ginger hair!"**
> **Max enjoys the joke. In laughing, the sorrow he showed as he told the story vanishes and the relationship is restored to an easy relaxed one.**
>
> **("A Perfect Day". MK Cycle Two, No. 1)**

It was not so much depression as overexcitement and getting 'carried away' which had an unfortunate effect upon the developing relationships of the younger three men. It often caused

their rejection by those they most wished to impress. For example, Bryce's use of mocking and insult irritated Sid ("Cup of Tea with Syd" BL Cycle One, No. 5) and when Mark messed up Don's hair excitedly believing he was being witty, Don moved away hurriedly ("Mates" MW Cycle Two, No. 2). Similarly, when Rob was spurred on by Nadine's embarrassment to greater heights in daring sexual innuendo, he had no idea that Nadine was becoming distressed until she abruptly left the room ("Working Side by Side", RJ Cycle Two No. 3). It was important that such difficulties with interactions could be righted without stripping away the dignity of the person.

Whether their inner audience was too positive or too negative in its self-appraisal was not the issue therefore, but instead, whether or not an authentic emotional intersubjectivity (Denzin, 1984:146-58) was occurring. When a spurious emotionality prevailed, the interactions were unlikely to be as effective for the person. To assist them in mediating their emotion, the other interactants appeared to consciously monitor and shape the interpretation of emotion. Bear (1982), who understands emotional problems as caused by a disturbance of the integration of feeling and thought, recommends forms of therapy which 'tell' the verbal left hemisphere, what the right hemisphere feels. Phillippa, in her role as a counsellor, regularly put feelings into words for Max. In doing so, she demonstrated for him how feelings of helplessness and despair could be replaced with feelings of hope and independence. It was not the label "Rest home" which was disturbing for Max but the image of himself as helpless and useless.

> **Philippa reassures him quickly. "Not for old people, Max - for people who need help getting around."**
> **"Sounds terrible," he comments sadly.**
> **"Terrible?" asks Philippa.**
> **"Terrible," he confirms. "Does."**
> **"What's terrible?" asks Philippa.**
> **"People going around doing things for you. That's bad," he explains. "Sounds bad," he clarifies more exactly for himself. Then he nods. "Yes. I used to and now we don't talk. I have said to myself, and now I am too much trouble." He looks depressed, grieving for his lost independence.**
> **"You feel bad having people looking after you?"**
> **"Yes it does," he agrees ignoring the second person format of the inquiry. "It is terrible and it stays terrible," he elaborates further as he explores his feelings.**
>
> **("Going to Limmerton" MK cycle Two, No. 3.)**

The power of words to not only interpret but also change an emotional attitude was equally evident in her interactions with Bryce. Philippa had to tread carefully as she negotiated with him for a version which retained some of his ideal of recklessness and bravado and yet tempered this with the awareness of the effect of alcohol upon a brain no longer 'normal' ("Alcohol, Love and Emotion", BL Cycle Two, No. 3).

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[190] See Chapter 11, p. 417.

A key skill in promoting emotional intersubjectivity, therefore, appears to be supporting more positive re-interpretations. In this way, situations which were too distressing or destructive to incorporate into the developing new self-image could be assimilated and solutions could be negotiated which allowed the person to channel the emotion into a self-directed and self-motivated energy. Mark's family discovered the power of reinterpreting activities such as this early on in his recovery.

> **JULIET WHITE: He is very fond of walking and to try to get him to rationalise what was happening at the rehab here and at home, we would call our walk and our ball games, physio. "Lets go out and do our physio," [we would say]. So then he started to see that what he was doing as part of getting better. When we played games, we called it occupational therapy and then he actually started to see that and he himself changed the label for speech therapy. "I can speak perfectly all right," [he said] and so we changed the name to 'communication'. And he went back and he told her that he was going to communication now and she accepted that -and so that is what it was called and he worked on letter writing and synonyms and all of these sorts of things, but that were to do with speech but that was a label he didn't feel was attached to him.**

It is not suggested here that calling a perfectly ordinary everyday activity by a clinical name will always encourage self-motivation and a sense of ownership. For some people quite the opposite may result from such a strategy. What such examples do make clear, however, is that each person's interpretive framework of his or her recovery is unique and understanding these inner personal meaning systems of the person and adapting one's own use of words to suit, is a powerful strategy. When the more sensitive people around the four discovered the words which were the most powerful motivators and used them in discussions, they were able to manipulate the four men into a more positive, involved and self-directed approach to their own rehabilitation regime.

What mattered was not the words but the feeling they conveyed. As Mark progressed with his recovery the way he conceptualised his progress changed and it became important for him to regard it as 'normal' activity rather than therapeutic activity. During the second cycle of film in the process of supporting this shift in thinking, the staff cause Mark to feel considerably more enthusiastic and involved by the reverse of these strategies, calling the sessions in the therapy pool 'swimming training', finding activities which removed him totally from the clinical one to one situation and which imitated the life he would be expected to live in the community, allowing him to rehearse, evaluate and modify his self-presentations.

This technique of providing interpretive assistance to promote a positive intersubjectivity was equally powerful in dealing with what could have been threatening confrontation with cognitive deficits. In "A Session on Sequencing" (BL Cycle Two, No. 1) after they had worked together through an exercise, Linda spent some time explaining to Bryce why she had selected it and what use she imagined it might have for him. When I discussed this with her, she explained that she

wanted to encourage Bryce to see himself as a 'client' using a service designed to assist him in his efforts to recover; a far more powerful role than the one of patient subjected to treatment. She was effectively coaching him in a new and more powerful role. That she succeeded in handing back to Bryce the interpretive power over his life, at least temporarily, is evident in the tenor and direction of the conversation as it continued.

As described earlier in relation to fostering the return of a phenomenological self, the staff can be seen as consciously manipulating the emotional climate with their interactive responses. In this way they moved their clients progressively from a phenomenological to a cognitive and finally to a metacognitive level of experiencing feeling. An inner audience was reestablished from the *inside outward* at the same time as from the *outside inward.* This strategy allowed the four people to progressively monitor and control more of the flow of their own feeling state. Again, the implications of this observation are far-reaching: other interactants, whether staff, family or friends, are in a position to influence even that innermost experience of consciousness: the feelings and (in particular) the feelings of the moral self.

EMOTION WORK, FEELING RULES AND SELF TALK STRATEGIES

As the focus shifted from attributes such as 'lack of affect' to issues of changed relationships, emotional difficulties appeared to be more related to a loss of an ontological core or 'self' with which to interpret the world than to any loss of chemically induced sensation. How to promote a successful return of emotional control becomes an issue which concerns interactions and relationships rather than treatment. Once this is established, Hochschild's (1979) concepts of "emotion work" and "feeling rules" can be seen to provide a conceptual link between inner emotional streams of consciousness and the outer social drama.

If "feeling rules are the underside to our ideology" (Hochschild, 1979:566) they are clearly also the building blocks of an ontology. In order to establish self-directed grounds for action, the four people needed to develop new feeling rules. From Hochschild's (1979) perspective, the staff and family could be described as assisting this process by manipulating the emotional dynamics of their encounters. I do not imply with the word manipulation that the feeling rules were imposed on an unwilling recipient, however. The behaviour of these four men suggests that any clues as to what to feel will be eagerly seized upon. This may be why a backward and forward justifying and temporising process appeared sometimes to fuel actions, giving a contrived and inauthentic appearance to the explanations they gave for their actions. Discussing teasing for example, lead Mark to make a solemn statement about the importance of laughter.

MARK: I love laughter. And you know, sometimes laughter makes a friendship.

The significance of role coaching and self-talk strategies is also illuminated by this conceptualisation of inner feeling rules as the building blocks of an ontology. It allows the relationships to be drawn between the person as an actor in the world and the person as an inner stream of consciousness or ontological core. Symbolic interactionists such as Duncan (1968) and Goffman (1968;1969) understand that 'surface levels of conduct' are an important part of social experience. To understand how inauthentic and destructive relationships and structures occur, it is necessary to understand the tensions between these inner and outer dimensions of human experience. Using the dramatic metaphor, they suggest better self-knowledge and more authentic emotionality require an integration of the needs of the outer actor or the inner person. Effective change may occur just as much, if not more, because of the refashioning of outer actions and interactions as because of manipulation of an inner ontological stream.

Mark's mother and father have been openly coaching him into the use of self-talk as I described earlier[191]. As a result, some self-regulation was emerging.

> **MARK: Yes that is what Mum says to me she says "Mark, you are [*making a high pitched voice*] talking like this."**
> **DS: And she taught you to recognise that?**
> **MARK: Yes she taught me to do that and I do but not all the time.**
> **DS: But you can recognise it and alter it sometimes - you did that time - you picked that up very well - do you do it very much?**
> **MARK: No I don't - My Mum - it is when I am feeling excited-I can feel my neck going really tight..**
> **DS: And you feel like that about the duties you do in the flat?**
> **MARK: Yes. All of them - keeping my eye on my watch -because I don't want to miss out anything - I am going to have a flat one day.**

Don ("Recreating" BL Cycle One, No. 3) and Diane ("Friend and Teacher", RJ Cycle Two, No. 1 and "Recreating" BL Cycle One, No. 3) both demonstrated more subtle methods of shaping feeling rules to promote positive but realistic self-appraisal. This 'emotion-fashioning' was typical of many interactions between staff and resident at Waimarie, suggesting that moulding feelings and relationships was as important to them as supporting the skill-learning, the ostensible purpose of the sessions.

> **DS: Do you think that you take any other responsibility though? Do you try and shape the conversation at all?**
> **DON: yes some conversations. ... we have gone through the stage where he was really all out to impress me with smashing up cars and girls and all that sort of stuff and he knows now that that doesn't impress me that much.**
> **DS: How do you show that?**
> **DON: I say "Yeah I have done that before" and grin and that, and "It was fun then but I look back on it now and think how stupid I was". That sort of thing with a bit of humour I guess - and not placing too much importance on it.**
> **DS: Do you feel a responsibility to do this for him?**
> **DON: yes.**

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[191] See Chapter 11, p. 195.

This coaching metaphor can be extended using the dramaturgical analogy, to an understanding of how prior rehearsals could assist these people in establishing coherent feeling rules. When he had the opportunity to 'prepare' himself emotionally, for example ("The Notebook System" (MW Cycle One, No. 3), Mark had a heightened sense of surety and self-confidence in an important interview. In retrospect he could also appreciate how this strategy had helped him.

> **DS:** *(pointing to film)* **Do you remember this? Trudy had a conversation with you about what sort of jobs you would like.**
> **MARK: Yes. I remember.**
> **DS: Do you know why she did that?**
> **MARK: Because she was going to coordinate with Workbridge.**
> **DS: And as she said to you, Workbridge only comes once a month and it is important that you know what you want before the meeting. Do you think that when you had that meeting you did know what you wanted?**
> **MARK: Yes. Because Trudy helped me figure out what I wanted to do. [She said] "When this lady comes, what are you going to do."**

In as much as they worked by reframing the definitions of their clients, the therapists could be said to have been moving beyond therapy as recovery or restoration of function, into the arena of creating new directions and a new future. It was not only feeling rules in which the four men were coached therefore, but also emotion work. An experience is an emotion reflected upon (Denzin 1984:69) and it is by reflection that meaning is attached to experience. One of the main principles of symbolic interactionism is that 'meaning-making' is a processual emerging phenomenon.

The most important implication of this for rehabilitation practitioners, relates again to the issue of temporality. Planning and goal directedness is an explicit part of the rehabilitation ethos. The person, to feel a sense of achievement, is usually regarded as needing to 'improve' on some quantitative measure of recovery, measures which can be plotted in graphs and charts. This ethos ignores the need of the person to work with the flow of their recovering emotional consciousness and learn to attain an optimum level of arousal without the pressure to 'perform'. As Diane understood, the steps toward recovery did not fit neatly into a pre-ordained treatment plan and required of the therapist, the ability to respond spontaneously, adapting the session to move onwards as the person was capable of it, not when any plan dictated.

> **DS: So it is spur of the moment - it is not planned?**
> **DIANE: No.**
> **DS: So you will suddenly think, oh, he's pretty good form today, why don't we try?**
> **DIANE: Yes. I think so. Well, it is pointless trying to push something a bit more difficult on someone at the wrong time.**

Clearly therefore, what was happening at Waimarie in therapeutic relationships was not really as focused upon treatment and restoration issues as it might have seemed. The central theme of recovery was far more emotional in tone than it was practical and skill based learning. Hochschild's (1979) concept of emotion work and feeling rules offers a much more accurate conception of the sort of rehabilitation that was occurring. In a partnership with the rehabilitation

team, the four people were each refashioning their emotional attitudes to their lives and practising appropriate feeling coached by other people who were more able to appreciate the changes in emotional attitude which would help them find 'quality of life'..

Prigatano (1989a; 1989b; 1991a; 1991b), Willer (1994) and Ben Yishay (1985) have all become recognised for developing a more holistic approach to rehabilitation after brain injury. They have stressed the importance of moving beyond the more mechanistic and medically oriented notions of recovery and adopting a teaching role in supporting the person as they resolve the emotional and interpersonal issues raised by the changes in brain function. With educational strategies, the therapists in the filmed observations often shifted the focus of attention from the behaviour defined as a problem, to the intrinsic meaning structures underlying it and in this way they could be seen to engage the person in an emancipatory (Carr and Kemmis 1983:131) practice directed at self-reflective understanding.

EGOCENTRICITY AND RECIPROCITY

People with brain damage are often regarded as having become more egocentric[192]. There is often a loss of consideration or interest in anything or anyone except themselves. For obvious reasons, an egocentric attitude can become a major concern for family and friends. Even people who completely recover former cognitive and perceptual skills will fail to reintegrate into their community of family and friends if they are unable to reestablish reciprocal and mutually rewarding relationships. A rehabilitation program which does not recognise and address this issue therefore fails the people it professes to serve.

At first, it seemed that the four people studied were atypical in this regard. Rob was considered by his family to be 'just the same Rob' as far as his relationships with others were concerned. Prue, in fact, wished Max were *less* caring and sensitive, believing that he was distressed largely because he felt he was a problem to others. Bryce was also regarded as in some ways 'more caring' than before. Mark was the only one seen as having become more self-centred and even in his case, the egocentrism appeared to be caused by his obsession to win approval and to rehabilitate himself as well as possible - arguably an unselfish underlying motive which had developed from his sense of being a burden upon his family. However, a closer examination of the filmed interaction suggests that despite these signs of caring for others, cognitive and perceptual change had made each of the men less capable of understanding accurately how another might be feeling.

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[192] See Chapter 1, p. 33.

The mental taking of "the role of the other" is implicit within the notion of empathy, reciprocity and caring. Although it was not for the lack of trying, on the occasions when any of the four people attempted to defer to another, or to imagine how the other might be feeling, they were at their least effective and their most clumsy and inappropriate. In "Getting to Know a Flatmate" (RJ Cycle Two, No. 2), for example, Mark tried conscientiously for some time to establish himself as caring and interested, but was thwarted by his inability to attune his mood and tone effectively to Rob's. Eventually, he fell back on more egocentric subject matter and paradoxically, at last discovered a way of connecting with his new flatmate. What to Mark seemed like interest, to Rob seemed a patronising self-importance. His unenthusiastic demeanour and non-committal responses would have alerted most fellow interactants to their failure to establish an effective start to their conversation. Mark, however, so enjoyed talking about himself that he failed to notice the lack of encouraging feedback and did not reflect how it might have felt to listen to this conversation from Rob's point of view. Although he began with the intention of striking up a friendship therefore, he failed to do so.

In Mark this change in his perception translated into a quite subtle change in interpersonal style, while in Max a change similar in nature, was taken to a much more extreme degree in action. His interactions suggested a near total loss of ability to perceive and respond to others' feelings. During the week I filmed his daily life, he seemed unaware of even the most intense displays of emotionality (eg "Watching TV" MK Cycle One, No. 1). When shown film later of his interactions, he made several comments which suggested that his lack of reaction was caused by his inability to judge the emotionality within a social situation and so understand what role it would be appropriate to take.

> **MAX: Yes it does - you know sometimes people speak to me and I want to say something back and I think I don't like the look of that fellow and then I can't speak at all.**

Unable to appraise others' behaviour and make sense of it, he was clearly guided by others' indications and in each of the filmed instances of intense emotionality, the staff, intent upon signalling calmness to counter any distress the scene might be creating, were modelling a remarkable *lack* of reaction. Max was learning an abnormal social response or at least having his existing abnormality affirmed.

Perhaps as a result of this one-sided view of interactive situations, the four men also had a tendency to resort to rather empty, mechanical social conventions (e.g. "Walking with Joan" MK Cycle One, No. 5; Work Experience at the SPCA BL, Cycle Two, No. 5). Social habits remained, but, detached from a more other-perceptive self, they revealed their limitations. Without any firm underlying ontology or finer perception of interpersonal dynamics, the social personae they

presented became stereotyped, unable to extend or develop beyond an initial opening comment or two. Joan could have prolonged the greeting pleasantries indefinitely if she had waited for Max to initiate anything ("Walking with Joan" MK Cycle One, No. 5), as he seemed totally incurious about her purpose and content to confine himself to meaningless niceties. Mark, Rob and Bryce's attempts at initiating conversations also seemed stilted and artificial (e.g. "Getting to Know a Flatmate", RJ Cycle Two, No. 2).

After the initial introductory stages, people usually begin to inject a little more of themselves into their conversations: adopting a role, considering a proposition, furthering a personal agenda. To move beyond habit and reaction however, we need to draw upon an awareness of ourselves as a body-for-others. Because these men could not establish a stable image of themselves and of how they fitted into the setting, they could not direct conversations to serve their own ends while still deferring to the other and observing the conventions of politeness. They remained (unless supported onwards by the other interactants) stuck in a perpetual acting out of habit. The effect upon their relationships was profound. Slowly self-sovereignty slipped away and a passive persona was being installed and they were more at ease in situations where others defined the scene and structured their contribution for them.

> **His drink arrives and is placed in front of him. He doesn't notice or acknowledge the staff member who places it down, focusing only upon the drink. Rachel puts the roll back in front of him and he eats it without thanking her.**
>
> **("Dining with Ginny", MK Cycle Two. No. 4)**

They were all progressively less likely to take the initiative on another's behalf, even Mark, who clearly wished to be seen as a caring and considerate person and yet took no action to prevent Rosemary being frightened by another resident ("Keeping Busy", MW Cycle One, No. 6).

Recognising a sense of mutual obligation and developing a consideration for the thoughts and feelings of others are important elements of the feelings of the moral self. These characteristics cannot be recovered in isolation from interactive experience. It is very probable that this process of disengagement from the 'body-for-others' began long ago, when in the early days of recovery in hospital they learnt to hand over their suddenly helpless body to others. A passive acceptance of their own loss of power which may have been appropriate back then, but it became less functional in the later recovery. Unless the interactive relationships encouraged a progressively more equal contribution during a post-acute stage therefore, they would be progressively more deprived by this habit, of future reciprocal and interdependent relationships so necessary to achieving a quality to living.

To foster a return of other-consideration however, proved easier said than done. Instruction and direction did not appear to be effective. Constantly criticising or correcting another's social

behaviour was more likely to induce shame than reciprocity, thrusting them further into an inferior position. Max and Rob particularly had a tendency to assume, given the slightest opportunity, that they have done something wrong and apology had become a habit. Both may well have developed this strategy because of the generally positive and reassuring reaction they received for it.

> **Nadine is silent, her mouth suddenly closed tightly. Rob looks at her speculatively for a moment. "Sorry" he offers suddenly.**
> **She relaxes. "That's all right" she concedes, continuing with her work.**
> **"Just wanted to understand what you are doing." Explains Rob further.**
>
> **("Working Side by Side" RJ Cycle Two. No. 3)**

Each time they apologised for themselves, the people, building from the outside in (Goffman, 1969:31), were developing more powerless and diminished personae, easy for others to disregard and dismiss. Each time they failed to apologise, however, the habit of disregarding others' needs was further ingrained. It becomes important for those who worked alongside them to find ways of preventing this front slippage, or to help them "maintain expressive control" (Goffman, 1969:44) by 'hinting' or by modelling what was appropriate, prompting more effective reciprocity without seeming judgmental or critical. Esther, in this excerpt, attempted casually to reinstill in Max a sense of obligation through companionable partnership. Although it might seem at first that she inspired only a slight sense of shame, repeated such instances prompted a more caring and reciprocal approach to others by the medium of adapting existing habits.

> **"Good Max, look all right to you?" Esther asks (having thus cued him as to the correct response).**
> **"It does good," Max responds peacefully.**
> **"Do you want to put the lid back on the jar?" Esther asks.**
> **"I'm sorry Prue," Max answers, correctly perceiving the underlying correctional nature of this hint.**
> **"That's all right", says Esther casually, neither reinforcing nor disapproving.**
>
> **("Making a Toasted Cheese Sandwich", MK Cycle One, No. 7)**

Implicit within this interaction, as with many others where reciprocal responsibility was encouraged, there was the sense of a shared purpose. Throughout the process of recovery, the staff had frequent opportunities to manipulate the setting so that the person was brought to realise the value and importance of his contribution. By such means the person was brought to an awareness of himself not as an object of treatment but as an equally contributing participant within it. From this perspective it was possible for people to achieve an emotional intersubjectivity even when cognitive constraints limited their planning and projecting ability, through the moulding of situations to produce a sense of shared purpose. This therapeutic skill deserves a greater acknowledgment for the role it plays in recreating an effective self.

What is usually described as 'egocentricity' therefore, is much more accurately explained with reference to Mead's (1934) two-level 'intra-active' concept of self. From this perspective it appeared that the 'I' and 'me' were no longer dynamic counterparts, but instead had become merged. The person had effectively become more trapped within a one-dimensional or egocentric perspective and needed special types of relationship to be freed from this restricted world view. Only then were they able to rediscover the rich quality of reciprocal and authentic relationships.

SELF-AWARENESS AND THE USE OF FILM

In regard to this discussion of self-image and experiencing oneself as a body-for-others, the use of film as a research tool became especially relevant. It seemed that seeing oneself on film actively promoted the development of a more effective and competent inner audience.

The four people as well as those they interacted with, watched film of themselves in everyday situations. They were interviewed as they watched about what was going through their minds at the time. These interview questions, designed to yield information about what the person was thinking and feeling at the time for the purposes of the research, appeared to elicit something more as well. People (with brain damage and without), reflecting objectively upon their own actions some days after they occurred, seemed more able to understand why they had responded in a certain way, and to explain their actions to themselves as well as others.

> **DON:** [*watching film of himself, working alongside Bryce without looking directly at him*]**It is interesting looking at it from this perspective, because I am trying not to look at him when he is actually doing something with them so that I don't make him self conscious..**

While it was useful for the staff to reflect upon their practice in this way, the film offered something even more valuable to the four people with the head injury. It gave them a unique opportunity to observe themselves dispassionately as many times as they wished, to explore and attempt to build a picture of how they presented to 'the other'. This dynamic was demonstrated in a conversation I had with Rob about the behaviour exemplar entitled ("Getting to know a Flatmate" RJ Cycle Two, No. 2).

> **DS: What do you think he is trying to do when he sits down at that table and starts talking about where you come from and rugby and girlfriends?**
> **ROB: He is trying to see if we could be friends.**
> **DS: And it doesn't really come off?**
> **ROB: No. My friends, they give me a hand. They don't look to me as more friends, they give me a hand AS friends? But Mark, he does that to his friends. That is the difference between Mark and me?** [*imitating Mark's action in holding out his hand]* **"Give me your hand" and he grabs my hand and then he says "we will be good friends". "Out!" [I reply], "Taking my hand doesn't make you my friend - keep on the straight and narrow and you will be my friend!"**

While in this excerpt, an objective backward reflection allowed Rob to articulate why he rejected Mark's attempts at friendship. He managed to use this experience to develop his self-knowledge also and at a much deeper and more ontological level than the lived experience had offered him.

As well as providing time to reflect and develop a clearer understanding of one's inner feelings, film allowed the person to 'take the role of the other' more accurately than imagination had. Freed of their projected feelings at that time, they were sometimes able to empathise in ways beyond them during the moment of action. Mark, looking at the same piece of film, was able to understand more clearly how his actions might have appeared to another. He realised that his intentions were not translated clearly into his manner and it occurred to him how easily others could misinterpret him.

> **MARK: I think I sound pretty - I don't know how to say it - pretty serious.**
> **DS: So you were coming across like this is all really important.**
> **MARK: Yes. Especially when I talk about the rugby. Now I see it I can understand how Rob felt.**
> **DS: Pretty overpowered?**
> **MARK: Mmm.**
> **DS: Did you pick that up from the film rather than realising it at the time?**
> **MARK: I sure did.**
> **DS: It's almost like, - too much interest in him?**
> **MARK: Yes - shocking.**

Rob and Max both demonstrated here that film could compensate for memory and information processing disorders, by providing a slower and more visual method of developing insight or self-perception. In this way they were able to understand how they had appeared to others and why their attempts to interact had been less successful than they expected. Such reflection was a useful base for involving them in compensatory planning. When Rob saw himself on the film reluctant to be distracted by someone who wished him to stop and talk he remarked:

> **ROB: [***nodding to himself]* **I don't like stopping when I am travelling because it takes me a long time to get somewhere I want to get.**
> **DS: It's just the time? You just don't want to stop?.**
> **ROB: Mmm [***begin to show the film again but stop it almost immediately because Rob, watching himself motoring alone down the passage and reflecting upon the above, interrupts***] When I get to that place I am likely to forget what I was doing there?**

Film also allowed them to understand confusing interpersonal dynamics, particularly those involved in sexual or power manoeuvres, which can be extremely complex. There were several opportunities during the research process for all four men to understand the difference between playful exchanges and intrusive rudeness. Rob, watching "Working Side by Side", (RJ Cycle One, No.3) 'took the role of' Nadine quite explicitly and from this position assessed his own behaviour in a way he could not as he lived these moments.

> **DS: Do you think she meant it when she says "you are horrible"?**
> **ROB: No she is playing along with the game [***show more film from 9.41 to 9.42*[193]**] Gee cheeky bugger! *[laugh with delight].*Confident eh? Confident!**

[193] The transcribed film shown at this point: "Me? Why?" he replies, a cheeky grin on his face. She is silent. "No I'm not" he prompts her further. Still she is ignoring him determinedly. "I know who I am and I like you," he tries again, putting a little more sincerity in his tone, conciliatory now, less sure of himself. "I like you as a friend..." He seems to sense a softening in her face and is encouraged to continue in a 'wheedling' tone. "as..tender... Nadine." Nadine cannot resist laughing and the two turn to each other and laugh companionably.

It is extremely difficult to arrange an artificial forum to practise such interpersonal exchanges and yet the film constantly revealed how much the four men needed feedback on how they appeared to others. Once they were made more aware of the probable attitude of others toward them, they could understand how to temper and adapt their own performances. Allowing them the opportunity to observe themselves in this way therefore proved invaluable to the research process, but equally invaluable to the rehabilitation process. The use of film removed the necessity for the therapist or interviewer to make and express intrusive value judgements about appropriate conduct in an area where individual differences in approach must be respected and encouraged. Because of the presence of the film, Rob was able to assess his behaviour and reflect upon it purely from the point of his own value framework and cultural/social position.

SUMMARY

In this chapter, the physical, phenomenological, imaginal and emotional experience of the men was considered at the level or dimension of consciousness which Denzin (1984:110) calls the "body-for-others". The evidence of the filmed interactions and relationships suggested that disturbances to cognition and perception will have their most devastating effect at this level and none of the men was managing to live according to an authentic and coherent ontology.

Because of a loss of the ability to adopt the attitude of the other, the four men were unable to develop an effective inner audience. As a consequence, they were less able to conduct interactions appropriately and adapt to allow for the projected attitudes of others, negotiating shared understandings. Without "feelings of the self and the moral person" (Denzin, 1984:124-8) to guide them, the four men required particular styles of relationship to develop feeling rules and other-centred strategies with which to manage their life again. Until they were capable of a more authentic emotional intersubjectivity, they appeared to need this form of support to pursue a recovery of purpose, autonomy and adaptivity.

Nothing more profoundly illustrates the essentially social nature of consciousness than this examination of the dimension Denzin called the body-for-others. It demonstrates conclusively that power over oneself and authentic re-empowerment, requires at its most sophisticated level, that we are intersubjective and interdependent, rather than objective and independent. Recognising this, the final chapter of analysis of the filmed interactions will concentrate upon the impact of the setting upon the recovery process. Using symbolic interactionist techniques, the

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"Boy!" Nadine comments.

person's experience of living in a particular type of community will be examined and the impact of an institutional lifestyle assessed as an important element in their recovery process.

CHAPTER 13

WAIMARIE AS A THERAPEUTIC SETTING

In the previous chapter it was established that Max, Bryce, Mark and Rob had a less effective 'intra-active' dynamic as a result of their brain injuries and because of this, it was difficult for them to monitor and supervise their actions from the perspective of 'the other'. While this projected perspective is the dimension of consciousness stressed by symbolic interactionists, there is considerable literature in the field of brain injury rehabilitation which recognises the loss of something very similar: a supervisory, or 'self-objectifying' level of awareness. Both symbolic interactionists and rehabilitation practitioners would agree therefore, that recovery required the return of a more effective and objective self-awareness.

In circumstances where there is a less effective meta-awareness and self-regulation, the environment within which recovery takes place assumes a particular significance. With less volitional control over action, behaviour becomes more environmentally dependent (Cicerone and Tupper 1991:282). In order to be successful, the setting and style of rehabilitation practised would seem to need to adapt and compensate for this change in functioning. In this chapter, Waimarie is evaluated as a setting within which the four people lived as they dealt with the issues which arose from their accident. It will be shown how an institutional setting contributed much that was valuable and important to an effective recovery of a sense of self.

MEMORY

The establishing of a sense of 'community' where they were known as a "whole man" (Plant, 1974:23) appeared to be an important element in the recovery of past memories for the four men. Their past life and in particular their accidents, about which they had no personal memories at all, had assumed a central importance as they worked toward new self-definitions. When circumstances confronted them with their ignorance about the past, people who knew them well enough to explain the gaps in their past became extremely important. The formal relationships found in a more clinical rehabilitation setting, those which addressed only one aspect of the person's experience, were inadequate for this need.

At Waimarie, the environment could function for the four people as a built in memory provider. In "Dining with Ginny"(MK Cycle Two, No. 4) for example, the nurse who was unable to give Max the information he needed, sought out the answer from another nurse. Incidents such as this clearly demonstrated the advantage to Max of a closed and small community where, without

limiting the people around him to the immediate family and so still offering a number of diverse perspectives, he could trust those in his environment to provide him with necessary details of his life history. This allowed him to function with a consciousness of his past which would not be possible in a more open environment. Many instances were provided in the previous chapter, of how this allowed them to feel a sense of direction.

However, relying upon such memory techniques upon a long term basis would severely limit the potential to become future-directed. If they did not have an environment capable of reminding them of their experiences and helping them interpret them, each of these men might (it could be argued) fail to incorporate new experience and information as effectively into their self-understandings. It was important therefore, that the environment of therapy address the issue of future memory as well as past memory.

PLANNING, PURPOSE AND PROSPECTIVE MEMORY

Perhaps the most disempowering aspect of their memory impairment was the loss of a future or "prospective memory" (Sohlberg and Mateer 1989:151). Finding ways to recover independence despite the loss of ability to anticipate and plan was a primary concern at Waimarie. For a number of reasons, this setting was more effective than a more open social community would have been, in supporting such a goal.

In a relatively closed community it was possible to adapt the whole environment so that the objects, people and places that Mark, Max, Bryce and Rob encountered during the day offered constant and consistent feedback. Adaptive and purposeful behaviour could be moulded from the "bottom up" when it was impossible for the person to impose new behaviours upon themselves from the "top down"(Cicerone and Tupper, 1991:272). This behaviour shaping included not just the more rigid skills and tasks of a formal rehabilitation training, but a wide range of social skills. The particular physical prompts used effectively with the four men in this study included Max's electronic watch, Mark's lists, Rob and Bryce's use of notes and notices and the written timetable they all used during formal program hours. The signs, labels and mirrors which were strategically placed around the buildings, while not specifically for their benefit, could also be said to have prompted them. The more interpersonal and social behaviour shaping observed included role rehearsal and coaching, the development of new procedural skills in quasi-flatting situations and the use of forms of emotional intersubjectivity to foster more inner-directed and appropriate social behaviour[194]. Not only was it easier in Waimarie to establish adaptive change in these area

[194] Examples of all these strategies are well represented in the behaviour exemplars and already discussed in Chapters 11 and 12.

of living, it was also easier to regulate the removal of the 'scaffolding' within which they had been established. Compensatory techniques such as prompting, could be carefully reduced in frequency and size and the process of moving from outer to inner sources of feedback carefully monitored. All these strategies required people who worked together in a team approach with goals shared not just with the person but also with each other. It also required a degree of control over and modifying of the physical setting which would have been difficult to accomplish in a wider community.

Because they lacked sufficient metacognition, the four men would have found it difficult to redevelop the daily living skills that they mastered at Waimarie without this form of environmental scaffolding. Yet the filmed observations suggested that it was not as a memory prompt it was most useful but as an opportunity to become purposeful and self-directed. Whenever they looked at their program, whenever they responded to the beep of a watch, whenever they inspected the meal plan they had prepared, the men were able to feel a sense of continuity and forward momentum. Whenever they were encouraged by positive encounters with team members to interpret their situation more hopefully or purposefully, they developed a greater commitment to their goals. These experiences together affirmed their actions, putting them in a context of working (albeit slowly) toward their own recovery and future goals. This allowed them to sustain an interest in those items in their day designed to facilitate future intrinsic reward, rather than present satisfaction. For example, in the following excerpt Jill uses the compiling of a list (essentially a memory aid) to promote in Mark a sense of control and order in his life:

> **"How many slices of this do you need for the pizza? Probably two, what do you think?"**
> **"I thought just the same thing," Mark nods again. He strides eagerly back to his seat and raises the pen.**
> **"Okay, "Jill continues without further comment "we need to increase that."**
> **"Three ham," Mark reads out, as he writes it down.**
> **"Chops for your other meal," reminds Jill, watching what he is writing, "lets get all that down then." Mark stares ahead, thinking. "Chops if I have enough." He gets up again and lopes over to the freezer, peering in. "I have got one that is pretty big," he calls out. "So I could have half that for two meals."**
> **"You reckon?" challenges Jill again.**
> **"Yeah!!" Mark replies emphatically.**
>
> **("Meal Planning with Jill" MW Cycle Two, No. 3)**

Imposing structure appeared to encourage self-directed action, however much of a paradox this may seem. An environment manipulated to foster recovery could become an artificial metacognitive dimension of consciousness. The written timetable each person carried appeared to be a particularly powerful way to provide a sense of order and purpose. The activities and behaviour of the men outside program hours and in weekends contrasted markedly with that spent during the 9.00 am to 4.00 pm routines. They all became remarkably inactive when nothing had been arranged for them and despite expressing a sense of boredom, no activity seemed

worthwhile unless it offered an immediate sensory reward. Activities only assumed meaning and importance as a part of their program and this was compounded as they were able to see signs of progress and improvement. On a Monday, they were often unable to remember what they had done in the weekend, whereas, after a weekday, a quick glance at the program allowed them to recall the day's achievements. Without having to identify long-term goals, without having to initiate action to realise them, they were able to live a present-oriented existence in the comfortable knowledge of meeting their long-term interests. A sense of being supervised then, was a comforting presence in a world where one felt alien and anomic:

ROB: Yeah.. It is better to have somebody watch.
DS: Watching you or telling you?
RJ; Depends if I know what I am doing really.
DS: Watching you if you seem to know what you are doing?
ROB: Yeah.

However, an ongoing problem for staff at Waimarie and also for those families who were involved with them in the recovery process, was the essential conflict between compensating for losses with environmental adaptation and re-establishing a sense of sovereignty over self. The same range of compensatory strategies that empowered by overcoming memory and information processing problems could be potentially just as disempowering as the deficit they addressed. By regulating the environment and the setting the staff imposed a pre-ordained control over the daily life and behaviour of the person, inadvertently stripping them of the opportunity to practise the very initiation and self-direction skills which they most needed to rediscover. Several of the staff expressed a sense of unease about encouraging too much compliance to such compensatory devices.

The most satisfactory way to understand cognitive recovery therefore, may be to recognise a *progression*, over time and through interaction, toward self-awareness, and so a need to provide 'a scaffolding' of metacognition at earlier stages on this path. Ben Yishay et al. (1985), Crosson (1989), Goldstein (1952), Gordon and Hibberd (1992), Prigatano (1991a) and Cicerone and Tupper (1991) all suggest some such hierarchical ordering of intervention styles was necessary. While externally imposed organisation and appraisal systems may provide an important intermediate step, longer-term, the goals and strategies must encourage self-direction. New habits might manage everyday physical needs, but they can not address what Maslow (1958) terms the higher order needs. The social, aesthetic and self-actualising needs which Goldstein (1952) identifies have no other referent or purpose than intrinsic pleasure. They deal not with mechanistic skill performance, but with the intangible qualities which give meaning and purpose to living.

Supporting the recovery of these more qualitative dimensions of being appears to require emotionally intersubjective relationships. Staff working in a stable closed community setting had a distinct advantage in this area. They were able to develop a heightened understanding of and sensitivity to their clients' feelings and could then provide appropriate affirmation and encouragement of self-direction. Over time, the initially clinical and formal relationships matured into something more reciprocal, where issues could be resolved in creative individual ways. In regard to the written timetable, for example, it was the joint attitudes developed toward it which determined its significance, not its ability to prompt memory. Those staff who were eager to encourage independence demonstrated that it was possible to use such a memory aid while preventing it becoming a rigid and controlling mechanism. By encouraging self-monitoring and negotiation, they helped clients learn to create and modify social arrangements to suit their own needs. As a result at the same time as they supported the adherence to the program structure there was a constant message of flexibility. For example, Philippa the social worker had a time-tabled session with Max, but clearly indicated his right to choose whether or not he attended; Diane and Gillian both made clear to Rob and Mark that they should choose what to cook to please themselves, not to earn approval ("Friend and Teacher" RJ Cycle Two, No. 1; "Meal Planning with Jill" MW Cycle Two, No. 3). Clearly the goal of eventual self-directedness was never far from their consciousness, even and perhaps particularly when they were at their most 'pushy'. As Trudy explained:

> **TRUDY: I mean it is important I think. Mark has the potential to actually gain a lot of Mark back.**

The lack of 'Markness' which she felt but could not name, made Trudy uneasy and instinctively she, like many others at Waimarie, adapted her own interactions to prompt and challenge behaviour which seemed 'odd' and inappropriate. Again, the concept of an inner audience regulating actions and feelings, so central to symbolic interactionism, can be seen to offer a way to distinguish between controlling and self-control. In the process of reintroducing inner directedness, it may perhaps, after a brain injury, be necessary to provide a temporary objective audience, controlling for a while what should be self-directed, but only so as to encourage the re-development of an effective and appropriate inner audience. Many interactions described in the behaviour exemplars show how the use of interactive styles promoted choice and so autonomy, at the same time as it encouraged the establishment of habit and routine to overcome memory difficulties. To introduce the one aspect without the other would have been disempowering, to introduce the two together furthered the habit of negotiation, the key to reestablishing an effective and useful inner audience and in so doing the use potentially rigid devices such as a timetable became empowering.

FEELINGS OF THE SELF AND MORAL PERSON

Denzin's (1987a; 1987b) studies of the AA[195] programme suggest that a residential community very similar to Waimarie offers the alcoholic a unique opportunity to begin his or her life again and construct a new and more effective sense of identity. Denzin feels that to do this a person needs to step outside normal time and in a sense step outside him or her self, in order to reflect upon the future objectively. A community with a common ideology and purpose seems to him essential in breaking down the previous way of being-in-the-world and in establishing a new relationship where an emotional intersubjectivity prevails. A further concept from symbolic interactionism, that of 'role' now allows the tracing of this new relationship.

Relationship and role are interdependent concepts. In establishing new roles for themselves, the four men needed to understand the expectations and rights others would assume. This required considerable skill in interpreting interpersonal situations as they occurred, skills largely beyond people with brain damage and perhaps this was why all of the four men clung to past roles, even when (as with sporting achievements) they were now beyond their capability. There were some signs in each set of filmed observation however, of a new moral self emerging, as well as some attempts to adapt existing roles. Most of this role development appeared to require a stable and safe small community which would allow some experimentation. Rob was discovering the responsibilities of behaving as a kaumatua ("Learning to be a Kaumatua", RJ Cycle One. No. 6) for example and Mark had added to his repertoire, the part of a conscientious rehabilitatee, enjoying demonstrating to himself and others, how much effort and application he could give (if erratically) to his rehabilitation. Max was learning ways to accept support from others and retain his sense of personal power by working in a partnership rather than an independent way toward accomplishing tasks.

Max, Rob and Mark envisaged themselves in ways which promoted behaviour the staff and family would be pleased by. Bryce in contrast, was trialing more negative self-images ("Getting Lunch", "Cup of Tea with Syd", BL Cycle One, Nos. 1 and 5 and "Future Plans", "Work Experience at SPCA, "Alcohol, Love and Emotion" BL Cycle Two, Nos. 2,3 and 5). He appeared to be risking becoming 'divided against himself' in his efforts to discover new roles and relationships.

> **... I count on being dead by the time I am twenty four. The way I look at it," he explained. He pauses, then watching her hesitation adds, "true!"**
> **"What do you want to be dead for?" asked Philippa.**
> **"Die?" he asked.**
> **"Mmm."**
> **"What's the world got for me?" He challenged her and then added quickly " and don't say cows!"**

[195] Alcoholics' Anonymous

("Alcohol, Love and Emotion" BL Cycle Two, No. 3)

To understand this need of Bryce's to appear so 'tough', it seemed necessary to understand his pre-accident history as much as if not more than the effect of the brain damage upon his interaction. Bryce's story was a complex one, revealing two diametrically opposed personae; the diligent dairy farm worker made a stark contrast with the irresponsible drinker and party-goer who barged through life leaving a trail of unwed mothers and drinking and driving convictions. In describing his life story earlier (See Chapter 8), I suggested that in striving to create a life from chaotic beginnings, he had moulded himself to fit the different expectations of those around him. In order to maintain some coherence therefore, he had needed to keep his audiences separate from each other and to make fresh starts in new locations. At the time of the research, his fear of being exposed to ridicule appeared to have put him in danger of discarding the more competent, rational and successful roles he had been developing. He seemed bent upon portraying someone completely reckless and feckless. Simultaneously however, because he had the opportunity to try out this role in a safe setting, he appeared to be developing some unease about how he was casting himself. When Philippa mildly suggested he think about changing his lifestyle ("Alcohol, Love and Emotion" BL Cycle Two, No. 3), he seemed to prompt and encourage her challenge, making it clear as he threw in his father's viewpoint, that he welcomed encouragement to try out more authentic roles. An inner audience developed from these trials, one which could imagine rejecting destructive behaviour and abstaining from alcohol.

How positive Bryce felt about the role trials probably depended as much upon outer as inner sources of affirmation. There seems no doubt that he was watching for reactions as he acted, whether with staff, family or fellow residents and that he would not have reconsidered his position on alcohol so seriously in this excerpt above if Philippa had responded to him differently. The attitude portrayed by others therefore, appears crucial in the negotiating of new roles and by implication, the ethos and attitudes promoted with the setting of rehabilitation were crucial. In this excerpt, for example, if Philippa had set up too challenging an opposition to his drinking, she may have encouraged him to fall into his well rehearsed role as a rebel, just as his father's attitude had clearly done. Instead, she ignored his offer to set up a united opposition and continually prompted him to work upon his own critical inner audience rather than relying upon this external and easily rejected one. As she resisted his attempts to offer her the role of critical parent, he was gradually forced to take it on himself. As the conversation moved on he could be seen to redefine his inner audience, drawing his sense of pride from an image of his new role as a father, he developed a much more rounded, less one dimensional role to project:

> **He put his head up, smiling. "And I want another one, but Stella doesn't want another one.." He paused and then continued brightly, "Mind you, she is only nineteen and so maybe that will**

change by the time she is nineteen and a half - hopefully it will change- but I don't know.... Last weekend or the weekend before Dad took me back to Sally's place and Jursain was sort of moaning, just like waking up and I thought 'Oh! What do I do, can't breast feed him!' So I was just like rocking on his crib and I started crying! Is that stink or is that stink?"
"Why do you think you were crying?" asked Philippa.
"Because I love him!"

("Alcohol, Love and Emotion" BL Cycle Two, No. 3)

From the perspective of the role of new father, a quite different style of future image was possible. When he thought of himself as a father, Bryce felt free to confess to feelings of pride and love and to feel emotion. Perhaps this was because the baby was a undeniable fact and did not require skill or competence from him.

Film such as this excerpt, which showed personae being trialed and adapted, suggests that there may be an intermediate stage in this process of new role construction, when it is necessary to 'perform' for the benefit of others and to concentrate upon the external signals of approval or rejection rather than any inner satisfaction. It seemed that there were times when the staff and other residents were turning themselves into 'sounding boards' for the four people, offering forms of feedback which allowed the fleshing out of roles which initially seemed inauthentic and approval-seeking rather than genuine. Mark provided the most obvious example with his role of 'the good rehabilitatee', which so motivated him to be seen as working and trying that succeeding at rehabilitation activities had become an end in itself. In being filmed, Mark grasped any opportunity which allowed him to display his improving skill and especially if a score would be recorded ("Standardised Assessment", MW Cycle Two, No. 1). Suddenly just eating a muesli bar assumed an importance which delighted him ("Being Filmed" MW Cycle One No. 1).

Unfortunately, this image of himself as conscientiously applying himself to his rehabilitation required constant fuelling and his eagerness to perform became excessive, making him seem peculiar. To counteract this, at the time of the filming, much of the staff's energy was becoming devoted to encouraging a more habitual, less effortful and less self-conscious approach to living. As he considered beginning work experience, he and Trudy together defined his role in a way which blended the rehabilitatee with the worker, setting up a transitional image with which to align himself ("The Notebook System." MW Cycle One, No. 2). For someone at Mark's stage of recovery such an intermediate step seemed to be necessary. During the time he spent at his work experience Mark needed to work hard at adjusting his ideas of appropriate behaviour. The content of the Behaviour exemplar "Negotiation" (MW Cycle Two, No. 3) reveals how many difficulties he was having understanding how he appeared to others in a normal work situation. By allowing him to try out this role in a sheltered setting, Mark was able to work through the issues that arose without jeopardising a real work opportunity.

Again in this area of role therefore, it can be seen that there were many benefits for the four people in a residential program. In a sheltered setting where staff knew their story and understood their needs, attempts to develop new roles or adapt existing ones were more likely to be treated sympathetically. Residents could try out leadership roles which may not have been available to them in other settings. Seeing themselves in such roles allowed the development of self-esteem and higher self-expectations. In this regard the most dramatic example from the research was Rob's role as kaumatua. When he was feeling at his most confident, the kaumatua role altered his personality dramatically.

> **"Getting back to the money," Rob speaks more loudly, almost interrupting Elspeth, "for the whanau." He stresses the Maori word, as the only Maori in the room, taking ownership of this aspect of health care. His hand gestures forward again confidently and his air becomes proprietal. He is now sure about the appropriateness of his remark. Linda nods approvingly.**
> **"Good point Rob," she agrees. "And, it is not only the money, but the vehicle and the time."**
> **He nods. "It is expensive to take buses for the whanau to visit." He is warming to his theme.**
> **Linda too, is pleased with the direction. "And, is our public transport system suitable for visiting?", she adds in a minatory tone, nodding enthusiastically.**
> **"Yeah." Rob nods wisely. He is now very confident of having a useful position in this conversation "You gotta have money for those things, sure, sure." He looks around at Jane who is gesturing for Linda's attention. Linda tries to understand the arm movements which appear to be signalling something. Rob nods encouragingly at Jane, ceding the floor obligingly. Philip, sitting next to Jane, has been getting restless at Rob's monopoly and jumps in, interrupting with his own comment.**
> **"There is no use if you can't do operations", he suggests loudly. "The hospital is no use."**
> **("Discussing RHAs and CHEs" RJ Cycle One. No. 3)**

While he was being a kaumatua, Rob became concerned for the feelings and state of comfort of the other residents and even attempted to draw them into whatever activity was going on, ceding centre stage to them with the proud air of the parent. He tended to have very expressive use of his one able hand when in an expansive 'host' mood, using it in the manner of an orator upon the marae, to punctuate, elaborate, to draw word pictures and give them more power and presence. Once again therefore, by providing a setting which was a microcosm of social life and which offered the social equivalent of 'safety nets', the four people were able to develop a greater awareness of new possible roles and relationships with others, without exposing themselves to those within their own family and community who would be expected to accept them as they had re-created their identity.

HUMOUR

As Symbolic Interaction theory demonstrates, to recreate oneself in a new image is a very threatening process. Alienation, frustration, despair and depression were constantly kept at bay, waiting to overwhelm the four men, to thwart many of the brave attempts to recover at least a

semblance of normality. The most important strategies for all those who work and live with this group may be those which soften the impact of the losses and deficits, without encouraging

unrealistic notions about the future. Perhaps the most powerful tool that the staff and residents shared, was humour. Humour was used regularly in the behaviour exemplars and appeared to serve several functions, some positive and some negative.

> **Diane looks playfully indignant. "It is your lunch! I don't get to eat it so you should stir it!" she claims in a joking tone.**
> **"Hard! Hard!" Rob exaggerates the shrugging shoulder movement which expresses his yielding. He wheels the chair forward, back to the stove again. "Gee! Look what I have to put up with from this woman?" he reaches out for the spoon again.**
> **"Why?" The laugh in her tone belies the pretended indignation.**
> **"She just likes watching a man work!" He shakes his head, mock solemn, as he stirs his pot.**
>
> **("Friend and Teacher." RJ Cycle Two, No. 1)**

Rob's manner in this excerpt was far more assertive and confident than was characteristic of him. He was grinning, alert and happy. His relationship with Diane suggested an equality he did not often achieve with a staff member, allowing him to play the part of a flatmate or a brother, rather than a patient. Goffman explored how in normal social situations (those which exist outside an institutional structure or therapeutic arrangement of roles) "convivial interaction is used as a sanctioned occurrence for the realigning of definitions" (Goffman, 1969:181). Flirting, getting drunk, mock collusive alignments, sparring conversation, sanctioned non-serious aggression, playing games and practical jokes are all recognised by Goffman as having this function. Similarly, Denzin notes the power of comedy and humour in the experience of the alcoholic, to allow a distancing out from one's old self and so a neutralising of the guilt and fear associated with changing (Denzin, 1987b:163). With the judicious use of humour, a person may rehearse the switching process involved in 'taking the attitude of the other' with impunity. Provided it is clearly presented as a joke, there is no obligation to adopt a position more permanently and no shame in impersonating or pretending.

This has a very obvious relevance to the experience of recovery observed in the four men. Rather than risk failing and so being thrust into shame, Bryce developed a story line which made a joke of his ambition to be a mechanic, which ridiculed it before he had even begun his attempt. Preparing the way with self-denigration allowed him then to try out a role and examine himself within it from the perspective of the other, without letting the 'other' know whether or not he was serious. During the second filming period he told his story about destroying the motor of a friend's car upon four different occasions (Two examples are available in the behaviour exemplars, "Work Experience" BL Cycle Two, No.5 and "Alcohol, Love and Emotion" BL Cycle Two, No. 3).

Goffman (1968) also points out how situations can arise where it is necessary to acknowledge a disabled state which both parties have been politely ignoring. At such times, he suggested, humour can be valuable, allowing a smooth integration of this fact without humiliating.

"Ah, yeah, Tuesday I think," Sid replies.
Bryce inspects his timetable. "Oh yeah it is too," he agrees.
"I thought it was Thursday this morning," Sid confides without any sign of embarrassment.
"I thought it was Friday" Bryce replies as if not to be outdone. "Oh! Brain injuries! - you don't know anything!" He pauses and then adds in mock seriousness, "I know how to crash cars and write them off!"
"Eh?" asks Syd.
"I know how to crash cars and write them off," he repeats.

("Before the Polytech Students' Visit." BL Cycle One No. 2)

In a similar way, Max managed to laugh at himself rather than feel embarrassed at making an inappropriate choice, because of Esther's contrived use of humour to distract him. With this teasing approach, he could learn to laugh at the image of himself as being a little foolish without feeling any pain.

Esther asks him to choose which sort of sandwich he wishes to make, peanut butter or cheese and he says, "Both." She grimaces, suggesting that that would be a yucky sandwich. She then suggests that if he selects the cheese he could have onion as well with the cheese and adds, "That would make you fart, Max!" Max explodes with delighted laughter and says, "That would be too much!"

("Making a Toasted Cheese Sandwich". MK Cycle One. No.2)

As well as allowing the person to "try out vaunted selves" (Goffman, 1969:181) without having to take responsibility to commit himself permanently, humour also allowed the person to learn to manipulate and influence others' attitudes, an essential and perhaps underrated human social skill. The frequent use of interactive games provided all four of the men with opportunities to practise a range of different styles of strategic interaction. The therapists were just as inclined to initiate or encourage this strategy as the residents were. Trudy agreed that she quite consciously manipulated the tone of the conversation in this way, to coach people while avoiding the power imbalance endemic in their teacher/student relationship.

TRUDY: I think it challenges him, I think it makes him not so serious - that here is a "therapist" who is going to test him to bits. It gives me a bit of real face value in that he can actually see me as a person .

To learn to joke and tease appropriately is essential to developing effective friendships again. The obligations as well as the rights which are implicit in any relationship could be conveyed. Several of the therapists seemed to understand this and set up situations that allowed two way practice of such relationship skills.

Mood setting was not just an exercise in power equalisation however. In "The Notebook System" (MW Cycle One. No. 2) and "A Perfect Day" (MK Cycle Two, No.1), for example, the atmosphere created had other benefits. Creating a relaxed attitude, with a lowered self-awareness, seemed to maximise learning. In this 'frame of mind' both hemispheres were tapped and so a holistic style of perception and interpretation operated. Observation of the film suggests

that several staff used humour quite consciously to manipulate the learning process in this way[196] so managing to establish a shared interest in what they were to do together and to hint that they need not approach the activity too solemnly, that enjoying life was the real underlying aim.

There were several occasions observed however when the use of humour prompted just the sort of inappropriate and odd behaviour which most marked these four people out as different. As many have commented (Pepping and Roueche, 1991:229-230), a "silliness and euphoria" is a common characteristic of people who have brain damage and one which will seriously affect their chances of a return to normality.

> **"Happy Birthday" is being sung brightly on the Children's TV program that Bryce is watching. As Sid hands him his coffee, Bryce, reaches up, grins and sings loudly at Sid "He looks like a monkey and he acts like one too!"**
>
> **("Cup of Tea With Syd". BL Cycle One, No. 5)**

And

> **Wayne swaggers through the gap. "Thank you dude!" he strides on ahead. Mark drops the curtain and rushed to catch up. "That's all right pal! Matey!" he grins, walking sideways in his determination to elicit a response. He reaches up suddenly and messes up Wayne's hair in the way his own has just been messed. Wayne pulls away.**
> **"Don't mess my hair!" he says, with pretend seriousness.**
>
> **("Mates." MW Cycle Two, No. 2)**

In these two examples as in many other occasions in the filmed observation, Mark and Bryce both tried to establish a reciprocal camaraderie and became disconcerted when the other person failed to respond as they expected. They each reacted to this by rejecting the other person and cutting off further interaction, in order of course, to salvage their pride, but also to avoid confronting the meaning of the failed projection for their inner developing self-image. Unfortunately, in both the above cases as in many others, this deprived them of the very negotiative processes they needed in order to develop a more accurate and more appropriate persona.

With this particular group then, humour must be used with caution. None of the four men seemed able to regulate their forays into humour effectively enough and frequently became 'carried away' as a result. For example, a light hearted joke could trigger an embarrassingly excessive response, invasive of other people's dignity. With a less sophisticated interpersonal perception accommodating and adapting processes operated too crudely to allow a smooth imperceptible adjusting of the tone. As a consequence there was often a clumsy lack of balance, sometimes too enthusiastically pursuing one direction despite quelling responses, at other times abruptly breaking off, crushed by the mildest negative response. This oscillation was just as pronounced in the peer relationships being negotiated, as in the more formal and treatment oriented ones. Less competent

[196] Further examples include "A session on Sequencing", "Friend and Teacher" and "Doing Art".

at predicting 'the attitude of the other', teasing and ridicule became potentially dangerous threats to successful interaction.

This problem with humour can not be solved by abstaining from its use, but suggests rather that some instruction in the use of humour, followed by controlled practice, should be necessary components of any program which encourages more successful and 'normal' interpersonal exchange. Although honest feedback might seem a useful beginning point to deal with situations like those cited above, as Crosson (1987:343) observes:

> **Our own learned social behaviour teaches us to minimise or cover up awkward, embarrassing behaviour for our family or our friends and it is natural to apply our social learning in this respect to the rehabilitation setting even though minimising or covering up inappropriate social behaviour is counter-therapeutic. It is necessary for therapists to unlearn such responses in the rehabilitation setting before they can learn to address interpersonal deficits.**

Instead of open feedback, staff often used humour to recover the lead and so direct conversation into safer channels. Trudy, like several others at Waimarie, could signal affirmation of what was acceptable and quell what was 'over the top' without overly bruising the very sensitive emerging egos. Mark showed that he understood this intention and appreciated her efforts to relax him.

> **DS: Right so there is Trudy and you are solemnly saying how you are going to work hard and get somewhere today and Trudy says "Oh, where are you going to get, to Tipperary?"**
> **MARK: (Laughs loudly).**
> **DS: You weren't expecting that were you?**
> **MARK: No!**
> **DS: Do you notice that Trudy often does that?**
> **MARK: Oh yeah. She does everything possible really - that is how I feel she is.**
> **DS: You enjoy that joking?**
> **MARK: Yeah.**
> **DS: What do you think it does for you?**
> **MARK: I don't know. It makes me feel comfortable I reckon, not pressured or anything.**
> **DS: When do you think she does it? Have you noticed?**
> **MARK: With things like - when I have feelings about how hard it is.**

Whenever the staff took back the lead in this way however, the conversation risked becoming less equal. The incidences of an adult to adult exchange dropped. It was only when they felt some interactive power that the four people were in a position to learn to regulate their own interaction. As the more passive recipient of a clinical session, the opportunity to contribute was reduced. For this reason it was equally significant that humour was observed in the interactions to shift the power balance back to the client.

> **DS: Okay. Now. you seem to tease Trudy, would that be right?**
> **MARK: (Nodding enthusiastically) She teases me, I tease her!**

Although humour revealed as positive in several ways, it is equally obvious that it was responsible for some of the misunderstandings and confusions in the lives of the men. By making a joke of themselves, they all sometimes concealed their feelings and so risked denying their real needs. In the "Work Experience at The SPCA" (BL Cycle Two, No. 5) specimen, for example, sharing real and meaningful work allowed Bryce to develop a spirit of teamship and encouraged him to

confide in Caroline confidently. Yet then, slipping into his habit of self ridicule, he denied himself an opportunity to share a more genuine discussion of a career:

> **"So what sort of mechanic are you going to be?" asks Caroline "Car, bike, what?"**
> **"Ah, car" says Bryce, pleased with the new opening "yeah. The only thing I know about motorbikes is how to fall off them and how to ride them so I don't think.."**
> **("Work Experience at the SPCA" BL Cycle Two, No.5)**

This type of interaction sequence had the unfortunate effect of reducing the person in the other's and so by implication, his own eyes, to the status of what Mark called a "Wally". Although in the following excerpt he revealed that he had adopted this style in order to earn friendship, he could see for himself how, in order to protect himself from ridicule, he had voluntarily abdicated his right to be taken seriously:

> **DS: How do you feel when people are calling you a Wally?**
> **MARK: It makes me laugh so I am not really fussed.**
> **DS: Do you sometimes think there is some truth in it?**
> **MARK: Yes. Sometimes I make a fool of myself.**

In conclusion, humour in this rehabilitation setting will only work when it is authentically interactive. Unless both people involved are enjoying the playing with the realities that occur humour may be destructive of the developing self. One way humour is not humour at all, but patronising, ridicule or scorn. Two-way humour which equalises the power dynamics within a therapeutic relationship offers the person back some of the power. Success in building effective relationships in a rehabilitation setting might best be measured by signs of reciprocal humour.

TEAMSHIP

Another interesting aspect of life at Waimarie was the capacity it had for promoting team membership. Using an extended dramatic metaphor, Goffman (1969) and Duncan (1968) point out the importance of teams within which there is the trust and skill to present a common 'front'. Without team membership, role relationships become more superficial and one dimensional and do not promote the same sense of belonging and fellowship. None of the four had been able to re-create this quality in their social interaction at the time of the study, either with staff, or with other residents, although they were not always aware of their own loss. For example, Bryce's relationship with Sid was more superficial than he realised,

> **SYD: I don't say anything real personal to him. ..**

and several staff were observed 'going along with' presentations of self about which they were in reality, quite cynical.

> **DON: I think he really did like ABBA but I don't know that he actually did like ACDC.**
> **DS: right. So that might have been acting?**
> **DON: yes.**

There were several ways that the dynamics of institutional life developed team membership skills. The filmed observation include many interactions which suggest Waimarie provided an ideal environment for people to rehearse of the dynamics of teamship, without needing to meet the same standards of consistency and reciprocity which are usually expected within teams.. The filmed observation also suggested that, as the person began to recover a more assured and coherent self-hood, the environment was capable of offering a subtle progression of teamship demands, slowly moving toward a more authentic and shared fellowship.

Firstly, a residential program seemed to promote constancy over inconstancy. In any small closely knit community, there is an expectation of conveying (across the available range of relationships), the same basic ideas and behaviours (Plant 1974:23). Because everyone knew each other, opportunities for deceit as well as for a sense of anomie or role confusion to prevail, were minimised. Reforming identities could be supported in their consistency and coherency. There were many occasions when a person who stepped out of role was reminded of the expectations others had of him, sometimes subtly and at other times openly. When Max lost his temper for example, Hilda pointed out to him, how he should have handled this matter:

> **"You can leave it. Would you like mince instead?"**
> **"Yes," he mutters.**
> **"You just have to ask!" scolds Hilda lightly.**
> **"I'm sorry," he mutters, head down and ashamed now.**
> **"Please don't jump up and down like that. It's not nice," continues Hilda primly, as if still not quite satisfied with his level of contrition.**
> **"No, not at all" agrees Max.**
>
> **("Waiting for Lunch" MK Cycle One, No 2)**

As well as providing help with the expectations they should place upon themselves, this setting offered support for learning what expectations they could place upon others. This quality was evident when residents sanctioned each other.

> **Tom turns to his other side, where Rosemary is seated. He looks at her then with a large grin on his face. He lets out a loud bark of laughter then suddenly slams his open palm down hard on the table in front of her. She is startled, even a little frightened[197]. Mark looks concerned. He looks between Rosemary and Tom and then seems to feel morally obliged to make a stand. In a very quiet and serious voice he says, "You shouldn't do that Tom".**
> **Tom has got a reaction. He jumps at the opportunity, laughing out loud in delight, "Why's that?" He challenges, a big grin on his face.**
> **"I am not going to talk to you. That was dangerous." Mark answers very low voice, He lowers his head staring at the table and bringing his hand up, fiddles with his glasses.**
>
> **("Keeping Busy" MW Cycle One. No. 5)**

Of course, although they could be critical of each other, the residents of Waimarie were aware that they shared a very important common experience: brain injury. This knowledge appeared to provide a powerful sense of teamship. Bryce, Rob and Mark all seemed to enjoy occasions which

allowed them to present a team front as fellow 'rehabilitatees'. Just before the Polytech students' visit (BL Cycle Two, No. 2) for example, Bryce, delighted with the prospect of their visiting his flat, began to chat with Sid in a more self-conscious and contrived way, as if suddenly more aware of how he and Sid might seem from another's perspective. It seemed to occur to him that they should pair up and present a common impression. He then turned his attention to his unsuspecting flatmate and began to establish a tone of casual fellowship. Sid seemed happy to oblige. The sudden need to develop a common team front raised Bryce's awareness of himself as a part of a gestalt system, a pair with common interests and agenda, rather than just two separate people with brain injury. Later, when the students arrived, Bryce revealed how completely he had assumed this joint identity when he made an impromptu speech. In the process he divulged as much if not more information about Syd's disabilities and problems as his own, perhaps for the first time identifying himself eagerly as a 'person with a brain injury' because of his pleasure in being a subject if it meant receiving the interest and attention of an audience predominantly young, single and female.

Team membership is implicit within the concept of friendship and no recovery could be considered complete unless this quality of friendship could be returned to lived experience. Opportunities to practise a variety of forms of emotional intersubjectivity occurred, as well as opportunities to differentiate between degrees of friendship[198]. These experiences with fellow residents were more important than their informal 'off-duty' nature might suggest. Because there were a range of people with whom to associate, some of whom they enjoyed and others of whom they avoided, the four people were constantly required to make interactive choices, switching their manner and tone to suit the degree of intimacy felt.

Fellow residents, once established as members of a team, served a further purpose. They could, from this privileged position, be a more critical audience than the clinical team without causing as much distress or offence. Graeme, a friend of Mark's who also had brain damage ("The Pool Game" MW Cycle One, No. 5), Syd, Bryce's flatmate ("Cup of Tea with Syd" and "Before the Polytech Students Visit" BL Cycle One Nos. 2 and 5) and Rob in response to Mark ("Getting to Know a Flatmate" RJ Cycle Two, No. 2), made no allowances for the altered cognitive state and were sometimes extremely critical or rejecting in their responses. Sid was very cynical about Bryce's blase overly relaxed stance behind his back and Phillip and Nadine were suspicious and wary of Rob's attempts to play a leadership role. As all these people were obliged to continue interacting with each other, there was an ongoing negotiating process built into the daily routine

[197] Tom could be unpredictable and his erratic behaviour made the other residents nervous. He seemed to delight in creating situations which incited fear.

giving the four men the opportunity to deal with conflict and challenge within a range of settings, both formal and informal, group and one-to-one.

Max of the four men, was the one for whom a sense of teamship had become most elusive. He lived in almost total isolation from the residents who surrounded him, only noticing them when prompted to. His more profound brain damage had so alienated him from himself that he had lost an effective inner audience and with it, any sense of how he fitted or 'belonged' in a scene at all. In his case, the residential setting could be seen to perform a different role again: one which softened the impact of this loss and compensated for it. Seen in the light of this concept of audience, much of the staff members' 'bossier' more controlling tactics could be seen as determined attempts to include him within a teamship, prompting and cueing him to join in and be part of their group. This was particularly obvious with informal interactions with the nurses in Terehi House, such as when two nurses wanted Max to stay up and watch the rugby with them.

> **"You want to watch the rugby," Olwyn tells him reassuringly. "You go in the lounge, go past Maria there." she continues as Max looks vaguely around, not quite sure where she means to direct him.**
> **"That's right Prue," Max murmurs contentedly steering his chair slowly toward the lounge again.**
> **"No," corrects Olwyn sternly, "that's Maria, not Prue - and I am not Prue, either, I'm Olwyn."**
> **("Relaxing in the Evening." MK Cycle Two, No. 5)**

At such times, Olwyn, Joan and others like them appeared to be motivated to create within Max and his fellow residents, a sense of being at ease and at home. They clearly believed that by reminding him how to enjoy these forms of relaxed conviviality, he would come to understand his own role and identity more fully and consistently. Interactions like this one had little to do with purposeful goal reaching, nor did they cater to any physical need. They were totally motivated by a sense of human fellowship. Recognising that for Max, the inner audience would always be a transitory experience, only present when prompted by interaction with someone else, they appeared to see their own role as to manipulate his level of self-consciousness in order to enrich his quality of life.

Unfortunately however, the work requirements placed upon the staff and the formal division of labour at Waimarie made it difficult for them to maintain this 'team building' style of role coaching consistently and as a result, Max clearly found it difficult to know to what team he now belonged. In "Watching TV" (MK Cycle One, No. 1) for example, when the staff were talking about domestic matters related to the running of the unit, he, a resident, could no longer be involved in the "backstage" management (Goffman, 1969:86) and as a result the normal conventions of team membership did not seem to apply.

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[198] There are so many examples of this in the behaviour exemplars that I have not referred to any specifically.

During this sip, which is about the third he has taken, it seems to occur to him that drinking coffee is a social activity. He lifts his head up and looks around the room in mild interest as if to find the opening for conversation. He watches a woman visitor move about the room as if waiting for her to approach and initiate something. When she sits down again somewhere else, he looks over at the two staff members in the kitchen. They are also drinking coffee and engrossed in a conversation. He appears to try to follow it, a look of preparedness to become engaged appears. They do not notice his mild hint however and after a moment he turns back to the TV discarding his attempt to become social.

("Watching TV". MK Cycle One. No. 1)

In Max the habit of deference and respect for others' privacy was well entrenched. Fearing his listening was regarded as an intrusion, he seemed to turn back to the television out of politeness, rather than any wish to watch it. The TV provided him with a prop which gave him the appearance of having something to do with his time. For Winston and Marie, however, the staff who chatted with each other, the signal was taken at face value and he was left alone to watch.

Of course, these instances of tact, deference and exclusion of some people from full team membership, are not exclusively institutional characteristics. In fact, in areas such as the lounge of Terehi, the relations between staff and residents often reflected relationships more typical of family or flatmates rather than clinical settings. Because the residential nature of this setting created this experience, they were able to rehearse group living skills. While their control and influence over the tone and topic may have been greater than is usual in a household, staff constantly provided opportunities to rehearse these sort of family relationships. When I asked Winston how he regarded his relationship with the residents, his response, like that of most of the staff I spoke to who worked in Terehi House, supported this finding.

WINSTON: It is just the experiences that I have had in my life coming through. Things that have happened to my own family. It has just sort of made it easier. For me it is like that. It is more than a job.

As they became more independent and moved into the transitional flats, the residents needed to develop similar relationships with their flat mates, but without the same level of guidance and scaffolding as the staff had provided. As with other strategies, this induction into team membership roles could be seen therefore, to follow logical 'steps'. In later stages of rehabilitation, reliable team membership became an expectation staff placed on people and this was particularly evident in the staffs' interactions with Rob. At the time of the research, Rob was about to be discharged from Waimarie after a six-year stay. The staff did not see him as a client and the film revealed how the original treatment orientation had been overlaid by the genuine friendships which had developed with specific staff.

TRUDY: Rob and I haven't worked together formally for a while now and I quite like the guy so I don't see him as someone I have to put heaps and heaps of energy into -I don't have to work at it. I can just chat with him and say "Oh, Rob, no, I don't want to talk about that just now," you know, "leave it alone and come and have a coffee," or, "come on out and have a smoke." Quite casual I suppose.

Such a change in the nature of his audience ensured that Waimarie provided a very effective preparation for discharge, blending what were originally formal and one-dimensional roles into more complex and reciprocal relationships. In this way he was provided with opportunities to experience the teamship, intimacy and backstage collusion which others such as Bryce and Sid reserved for fellow residents. A process of disengaging from Waimarie and the status of "patient" was occurring quite naturally in preparation for living again in the community.

OWNERSHIP

The real danger of such a setting for rehabilitation is perhaps that the four men could feel no sense of ownership of the space they were inhabiting during their recovery. Because of this, all deferred to the staff whenever an issue concerning the resources or buildings arose. While no staff appeared to demand this sort of deference and submission, there appeared to be something about the structural arrangements which fostered and encouraged it. Particularly evident in this regard, was the different use of language within Waimarie, as compared to outside it. The office worker running the canteen, for example, when Rob asked for his canteen account, informed him that "it has all been taken out of your trust account". By using the passive voice in this way, she (albeit unintentionally) denied Rob the right to know who was managing his finances and at the same time she implied that the control over his money was legitimately the role of the institution. Allowing residents the right to purchase items in the canteen and bar without cash may have been the most convenient arrangement earlier in his recovery, but at the time he was being filmed, Rob needed to take back the management of such details of his living and this response thrust him into a disempowering dependence upon others to arrange these personal resources.

These ways of defining were insidious, creeping into the relationships in ways which it was difficult to counteract. The three tutors in the Education Unit, for example, found themselves unable to change Rob's habit of asking permission to use the computers, although they have repeatedly begged him to use them when he wishes. Rob justifies his continued permission seeking by explaining:

> **ROB: You say how I use them. I don't want to please myself . It wouldn't be there if it wasn't for you fellas, so you guys get more right to say about it, I think.**

Remarks such as this one concerned those staff who felt thrust into a role they did not want:

> **TRUDY:... he sees me as an authoritarian role because I always, he always asks for permission to use his computer and it drives me bonkers. It's his computer and he doesn't need to ask all the time. But I have told him that every day and he still does it.... he often asks me for permission to do other things too.**

Recognising this disadvantage of the setting, several initiatives were put in place to counteract it. It was stressed, for example, that the transitional living flats were the residents' own territory. They carried a key to the door and anyone who called first rang the door bell and waited. They were encouraged to bring their own possessions and to arrange the furniture as they wished it to be. Mark in "Negotiation" (MW Cycle Two, No.5) demonstrated how powerful this symbolic ownership could be when he carefully arranged the chairs before a session with Trudy and Jill that he felt very nervous about. Similarly, in several of the work areas, most notably 'Tatou Tatou', the decisions about use and control were explicitly shared with the residents and Rob revealed in his chatting with Del ("Learning to be a Kaumatua" RJ Cycle One, No. 6), how much satisfaction this gave him.

It was not always so easy to transfer the ownership of institutionally structured space with these strategies however and several of the interactions in the film suggest that as a result the person regarded themselves as having no real power or rights within another's territory. Faced with such evidence of self-disempowering ontological schemes, the staff could be observed to respond by engaging in the sort of playful interactive dynamics common between family and friends (e.g. Friend and Teacher, RJ Cycle Two, No. 1), so effectively cutting across and contradicting the more conventional roles set in place by the hierarchical structure of the institution and the formal treatment roles. In this way, the residents were offered back their sense of ownership and given opportunities to learn to co-operate and to demand the support they needed from those important to them. In effect they developed their ability to manipulate others.

DS: Do you try to get Esther to do things for you?
ROB: Yeah.
DS: How? Do you ask, or -?
ROB: Yeah, I ask to get her to do it.
DS: Any other ways you get her to do things for you besides straight asking?
ROB: Some of the time I make out I can't do it and then I get her to do it (breaks into laughter).
DS: (laugh) I know your secret now Rob Johnson.
ROB: You caught me out! You caught me out!

I do not intend to imply, with the use of the word 'manipulation', that role play of this sort was always surreptitious or underhand. It appeared, in fact, that a range of different levels of self-consciousness was involved and that the more conscious of the playful nature of roles the person was, the more competent they were at reciprocal affectionate relationships.

DS: Do you think Esther knows that, that you con her into doing things?
ROB: I think so, yeah, I think they all know.
DS: So you are not really fooling anyone with this then?
ROB: Just myself I think!

This role coaching may be managed overtly of course, but there was then a danger of slipping again into the patronising teaching role. When Del was teaching Rob how to be the Kaumatua for Waimarie's new 'Tatou Tatou Whare'[199], she provided a good example of how carefully intuitive staff were maintaining a balance between teaching and prompting through interactive role play.

> **DEL: It is actually because we told him "you are our kaumatua- kaumatua for our whare and that is a big honour," and he sort of looks proud and he said, "My head is big." And sometimes he can get a bit bossy with it.**
> **DS: How do you handle it?**
> **DEL: I say, "Hey kaumatua!" and laugh aloud. And I say, "You be rude to your iwi[200] and your iwi won't come back!"**
> **DS: That's one way of getting the message across!**
> **DEL: And he laughs, he laughs at that!**

Ownership of space is clearly a serious issue for any residential treatment setting. However, with the careful use of such counteracting techniques, the formal structure of treatment can be overlaid and superseded by the more powerful, more manipulable informal modes of relating to each other.

A MORAL CAREER

Of course, it is not only over physical property that we exert or cede ownership but also over roles. There is one disadvantage of a residential medical setting related to role ownership, which deserves particular attention in this discussion, because of its potential to deny autonomy and purpose to the recovering person. There is a risk, when putting together groups of people with similar disabilities, that coping with their injury might become a "moral career" (Goffman 1968:45).

All the people surrounding each of the four men, whether family or staff, knew and related to them as a 'person with a head injury'. There was an implicit message in many of their dealings with others that they were now only interesting and important because of their injury. They were talked of, recorded, reported on and measured. They became the subject of intense meetings between their family members and the medical team because of their disability not their ability. While these roles made them feel important and gave them others' attention and interest, for as long as they played them they would be acted 'upon' rather than with and 'treated' rather than interacted with on equal terms. As Keilhofner (1985:26) points out, in assuming sick or invalid roles, people risk their right to participate equally in a community again. There is no doubt therefore, that an environment that risked even some degree of induction into a moral career,

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[199] Whare is the Maori word for a house. Tatou Tatou Whare was a room recently set up as a whare for the residents who were involved in the Maori culture group.
[200] The tribal unit of the Maori people.

risked self-limiting resolutions of identity. Using Goffman's dramaturgical metaphor, the dynamics which created this situation and the effect it had upon lived experience, are examined further.

Firstly, the brain injury, followed by the process of recovering from it, had effectively merged the 'audiences' usually available to the men. Each before his accident, was active in a number of separate arenas; each was a worker, a sportsman, a member of a family and a friend. By keeping audiences separated from each other they maintained not only definitional control, but also expressive control (Goffman, 1969:44). It was possible for them to 'wear different hats' without conflict and contradiction. With the admission to an institution, they lost choice and control over the audiences they presented their performances to however and it became impossible for them to maintain "synecdochic responsibility" (Goffman, 1969:43). The person running the bar was also helping them with their laundry, the person they flirted with saw them struggle in an occupational therapy activity. They were exposed as weak to those who had known them as strong and self-sufficient, as pathetic and dependent to those who regarded them as socially skilled, as physically helpless to those who had known them as strong and able. Stripped of their masks (Park, 1950), they felt a consequent loss of character and lost faith in their ability to maintain any previous "deceit" (Goffman, 1969:15). Max was clearly the most totally defeated by this new situation. He seemed unable to distinguish between audiences at all. His solution was to assume in everyone, a personal knowledge of his life that very few had and as a result he was seen not just as an 'invalid', but also as invalid. Each of the other three showed some signs of attempting to shape new roles for themselves and try them out only to discover how little ability they retained to manage and impressions effectively.

If we do need, as Goffman (1969:31) suggests, to "train ourselves from the outside inward" then to deprive a person of a variety of audiences, both formal and informal, who could be deceived and who allowed dramatic realisation of new self-images, would be a serious error. However, returning people into their pre-accident setting where they were accustomed to roles and relationships they could no longer manage could be seen as equally destructive. Some form of middle ground seems necessary, where a new life career can be forged in interaction with a sympathetic audience, capable of adapting its manner progressively as the person re-developed a sense of selfhood. The interactions in these behaviour exemplars suggest that some such process was occurring at Waimarie. People who had difficulty with self-monitoring could receive feedback and open and frank discussion about interaction failures which are usually tactfully ignored. This allowed them to develop more appropriate and accurate ideas about their roles and relationships. Because having a disability was the norm at Waimarie, they could live without fearing front slippage and exposure.

However, even with a supportive audience, the residents still found it difficult to escape from roles where their disability figured as a central theme. The place existed because of brain injuries and all the roles available were related to cognitive, physical, behavioural and perceptual disorders in some way. To counteract this effectively, it seemed necessary for the men to spend a good proportion of hours each week outside the rehabilitation setting, presenting themselves to people whose lives did not revolve around disability and rehabilitation. It was very clearly demonstrated in the filmed observations that these moments provided the important role-learning opportunities. It was also shown just as clearly, that in order for them to capitalise upon their opportunity, they needed to return to a place like Waimarie which could operate like the 'backstage' of the theatre and reflect upon their performances and understand what worked and what didn't work. Mark in "Negotiation" (MW Cycle Two, No.4) began to understand why he failed in his job placement, Bryce in "Work Experience at the SPCA" (BL Cycle Two, No. 5) could rehearse his role as a workmate.

'Setting the scene' for credible performances in a wider community may therefore be an important role for a rehabilitation program to perform. While outside work and socialising opportunities are the ideal arena, when the physical and behavioural disturbances are too severe, this may not be an option. Waimarie was observed to create settings within its walls which effectively imitated the world outside them, allowing people to practise 'as if' in a wider community. The transitional living flats are the most obvious example of this stage managing, but during the program hours there were many other occasions filmed where the person was able to don masks, so as to "achieve character and become a person" as Park (1950 in Goffman, 1969:31) would say. Rob demonstrated how powerful this created setting could be when he slipped into the role of the kaumatua in the group ("Discussing RHAs and CHEs" RJ Cycle One, No. 2), and the bar ("Learning to be a Kaumatua" RJ Cycle One No. 5) and of a flatmate in "Friend and Teacher" and "Getting to Know a Flatmate" (RJ Cycle Two, Nos. 1 and 2). Similarly, Max, although he was the least able to assume roles, managed some approximation of partnership and informal social chat in "Making a Toasted Sandwich" (MK Cycle One, No. 7) and "Relaxing in the Evening" (MK Cycle Two, No. 5).

This wider range of feedback opportunities was not only created by the staff at Waimarie of course. It appeared, in viewing the film, that each of the four men was also interacting with residents from a very broad social spectrum. Because one's disability was a defining characteristic rather than a stigma at Waimarie, there was evidence that a hierarchical ordering of merit, the "separate system of honour" which Goffman (1968:18) observed, was operating. Whether physical, communicative, social or cognitive, disability therefore had a direct impact upon the

friendships which were formed at Waimarie. Those who were able to interact reasonably effectively and predictably, tended to seek each other out and so unusual alliances and friendships were created across the barriers of race, education, age and sex. there came to be an a sense of self-esteem by achieving the recognition of those they saw as more able. They were all highly motivated to seek out these people and to establish friendships with them. In this way they developed the ability to relate to a much wider group than they would have been exposed to in a family group.

Mark had adopted the ideological framework of recovery and rehabilitation as a very central part of his identity and as a result, he clearly made a moral career of his disabilities. Because he was so motivated to demonstrate his success in this new career, he was in a constant state of excitement and stress, which regularly accelerated to distress. He often found it necessary to abruptly 'walk off stage' and then, bewildered and ashamed, he could not understand his own failure. Without a clear coherent inner self-directedness, his dependence upon concrete evidence of success and recovery extended to areas of emotionality and personality for which they were quite unsuited and over which his newly developing inner audience was too rigidly moral.

MARK: I am getting more honest - not lying all the time - I think more motivation.
DS: Are you? right. What things motivate you do you think?
MARK: I don't know - I just know I am turning up more for the things on my program.
DS: So, when you say that about motivation, you mean that you are going to things?
MARK: Yes.
DS: Not, a feeling of wanting to do something? It is just that you are going to it?
MARK: Yes.

The inner moral self intent upon building a moral career, diverted his energy and commitment into the structure and process of the program and the framework became an end in itself. By slavishly adhering to routines, Mark seemed to believe, external process could command inner commitment and an involvement:

JILLIAN: I have done some formal assessments and he just loves it! Thrives on being timed or measured or anything to show that actually progress has happened - he is doing good things!

A moral career led the person ultimately toward an Eriksonian (1959) 'stagnation' and 'despair' rather than 'integrity' or authenticity. This negative effect of the grouping together of people with disabilities can not be ignored. Many of the more submissive and compliant habits could be traced back to such an internalised hierarchical schematic. Any institution which fails to cut across such demeaning interpretive structures, risks encouraging the development of a soul destroying ontology. Until their clients were able to reorient their consciousness so that internal sources of reinforcement such as enjoyment, competence and seeing progress toward a personal goal overrode the need for approval and attention, they could not be regarded as having made a full recovery. The decision to admit a person with a brain injury into a residential program should not

be taken lightly. The experience of the four men suggests that there are several possible ways that such an environment can be destructive to the redevelopment of an adaptive and autonomous self. However, there were clearly also many advantages, all of which related to the dynamics which can only occur in a 'germeinschaft' style community.

Goffman's observations about disabilities and moral careers can be seen as very relevant and important consideration for recovery after brain injury. However, the filmed observation suggested that to regard moral careers as purely negative was too simplistic. The issue is one of *milieu;* of establishing a place where recovery could be a central theme at the same time as negative self-limiting roles were discouraged. This required a variety of different audiences and relationships.

LEARNING INTERACTIVE CONVENTIONS

In as much as it functioned as a setting outside normal time and relationships, so Waimarie also provided an ideal setting for the explicit or implicit coaching of another into socially appropriate interactive dynamics. Often, what began as a treatment session, became extended into something more akin to a coaching in interpersonal skills. Such a way of working acknowledged the importance of reciprocity within relationships, that outside the setting of rehabilitation others would not encourage a relationship unless they enjoyed their mutual interaction and unless they could feel that any concern or interest which they felt and expressed would be returned. There is no doubt that each of these four men desperately needed help in this field, while still wanting to 'fit in' or 'belong', all four men were clearly finding this quality elusive.

Symbolic interactionism has always regarded interaction as a socially prescribed drama which at the same time as it promotes a sense of consensus, offers the information necessary for the building of shared realities and interpretive schemes. To negotiate effective shared understandings requires that we monitor the behaviour and feelings of the people with whom we interact, adapting our own conversational offerings so as to defer to, acknowledge and shape the definitions of others. There is no doubt that each of the four men was far less capable of monitoring the feedback of others in this way and far less capable of picking up on the usual cues which allow interaction to proceed with balance and symmetry. In just about every behaviour exemplar there are constant instances where the four men have failed to pick up on cues the other interactants offered them, causing the conversation to lose a sense of an equal participation. Bryce, in a trial work situation, demonstrates how such a characteristic will affect his ability to develop new relationships and support networks for himself in the future ("Work Experience at the SPCA", BL Cycle Two, No. 5). Although he insisted later, that he enjoyed Caroline's

company and often confided in her, in this piece of film it seemed that he was only prepared to respond to her attempts at conversation when the topic gave him the opportunity to launch into talking of himself. He shared this tendency to a greater or lesser degree not only with the other three men filmed for this study, but with most of his fellow residents in the rehabilitation unit. This change in interpersonal styles, (so often labelled 'egocentricity'), made it very difficult for the people at Waimarie to strike up and develop authentic friendships with their fellow residents.

It seems extremely important therefore, to redevelop within the person's interactive style, those unconscious conventions, such as the taking of turns and showing an interest in the concerns of the other, which guide satisfactory interactions (Cicourel, 1973:33; Grice 1975). Staff were seen to engage constantly (and apparently without any conscious awareness of it) in a style of coaching which blended together modelling, explicit instruction and what I will call the harnessing and manipulating of the micro-dynamic process. Sometimes the staff attempted to shape the interaction by cuing:

> **TRUDY: Well, when he starts being really geekish like that "Grumpy dumpy do" or whatever it was on the tape, I remember sitting there (imitates herself with an incredulous, 'mock-astonished' look on her face) stunned, looking at him, sort of signalling, "What are you doing!"**
> .....

Sometimes they relied upon affirmation and encouragement,

> **LINDA: Probably , in giving him the message that, "Yes, you have made a mistake, this is where we are going to go to get back on the right track ..." Sort of valuing him as a person really, rather than treating him like a child who doesn't know what they are doing..**

While sometimes a more explicit instruction was employed.

> **TRUDY: ...And it looked really ridiculous. And I said to him. "It's really nice. Do you want to wear it inside or out?" And he said "Outside." and I said, "Well, lets go and look at this thing". And we went and looked into the mirror and I said "Is it sitting where someone would normally wear it?" and he said, "No" ,and I said, "Well, lets fix it up then"....**

Although many of the staff appeared to coach in this way, it was not always a deliberate component of their practice. It was only when pressed to analyse their own behaviour that most could see and agree that this interactive strategy coaching is a key part of their relationship with clients. In this way they carefully regulated the flow of the interaction so that their client would be able to engage equally in recovering social skills despite their lowered and less efficient level of perception and cognition. It seemed that to reinstil appropriate social interactive practices required a very special and empathic mode of fellow interactants. Conversation became a strategy by which as Bateson suggests, people without the conceptualising ability to grasp an abstract idea, were able to "discover the rules" (Bateson. 1972:19) again.

Of course the institutional setting facilitated such social skill practice partly because of its ability to insulate the four people from stigma. Because they were one of many people with a range of

disabilities, any sense of stigma was temporarily suspended while they were together, a function of institutions which Goffman (1973:46) comments upon. This appeared to alter the definition of private and public and a "separate system of honour" (Goffman, 1968:18) prevailed within which they could feel secure enough to try out more powerful roles. The following discussion which I had with Rob after we had together watched videotape of him actively participating in a group ("Discussing RHAs and CHEs", RJ Cycle One, No. 2) demonstrates how this environment created the conditions within which he could try out roles and form opinions without fear of ridicule.

DS: Does it matter who the other group people are?
ROB: I wouldn't worry about any of the other residents.
DS: Who would you worry about then?
ROB: staff.
DS: Not residents?
ROB: No it wouldn't worry me one bit if I make a fool of myself in front of them because we are in the state that everyone there can make a fool of themself
DS: It is sort of like a place where you can relax and not worry about making a fool of yourself?
JR; Yeah. In the community - in the community you have to worry. Yeah, yeah. - You know when we went in a restaurant, well I worry about that - but here you can have a go, try and see, you don't have to make a fool of yourself.

Such a setting therefore allowed the staff to set up group and individual situations which could manipulate and control the learning of interactive dynamics across a wide range of situations. Again it can be clearly seen that the germeinschaft nature of the setting was an essential element of this process.

AN INTERDISCIPLINARY APPROACH TO RECOVERING SELF AWARENESS

Any discussion of relationships and roles must take into account not only those which the four men had with staff, but also (because of the flow-on effect it created) the relationships between these staff members. In an organisation like Waimarie, people were employed in a particular capacity and each was expected to address one aspect of the person's recovery. Among the interactants in the film there were nurses (Hilda, Olwyn and Jackie), nurse aides (Winston, Ginny and Marie), a speech therapist (Lisa), occupational therapists (Jill and Esther) and their aides (Corinna, Del and Diane), education tutors (Linda, Trudy) and a tutorial assistant (Dierdre), a social worker (Philippa) and a physiotherapist (Joan). Each of these people entered the setting with knowledge of their own discipline and very little of those of the others. However, as has been very apparent throughout this discussion of the filmed observations, the various combinations of cognitive, physical and perceptual problems which the residents experienced could not easily be separated out from each other in the way such a discipline-centred approach assumes. As is demonstrated continually in the behaviour exemplars and the life histories, some

form of co-ordinated team approach is essential in a post-acute head injury rehabilitation program.

The stories of these four men reveal more clearly than more quantitative research method could, just what it is about recovering from brain damage that makes a team approach so essential. The central and dominating theme of everyone's work at Waimarie, no matter what area they worked in, was the fostering a more effective self- awareness. To achieve any quality of life after the brain injury, each of the men in this study needed to understand their own disabilities more accurately, identifying instances where disturbed cognition, perception, physical control or emotionality had an impact upon their life and independently adapting and compensating to counteract its effect. Bryce needed to understand that he had difficulty sequencing, Max that he needed to concentrate upon lifting and bending his left leg, Mark that he got angry too quickly. These and other new aspects to their lived experience would continue to cause problems until they had managed some form of mental and emotional resolution. As a result, it was usually impossible for those staff representing the various disciplines to work well in isolation of each other and impossible to work effectively unless some awareness of a wider picture of recovery was incorporated into the practice.

The physiotherapist for example, needed to understand how altered brain processes might alter body schemas and the effect this could have upon the performance of usually effortless tasks. When Joan spoke of her role with Max, this is clearly evident.

> **JOAN: ... I follow through this little formula... I don't get him to stand up and walk unless I have gone through this knee bending bit because I think that I need to reinforce that that if he is going to walk, he has got a problem with his hip and his knee and it is automatic for me to try and fix that in his mind before he starts off?**

She also needed to understand how changes in attention, memory, motivation and meta-awareness, might affect physical recovery and motor control. She became frustrated for example, when the physical programmes she designed for Mark and Rob failed not because of a lack of physical capability but because of motivational and memory problems. Untrained in these aspects of brain damage, she sought answers from her own interpersonal experience, which sometimes created problems for her relationship with her clients. She tended to define Mark, for example, as "being like a three-year-old" and so became locked into a parent-child type of conflict.

> **JOAN: Mark gets very angry very quickly and he has been learning strategies to help him cope with that and, I don't know whether it is a flare-up of anger and it just gets away on him ... it could quite easily be a personality clash as well because I am probably older and a bit like a mother figure and ....**

Similar situations occurred in the Education Unit also, where the teachers needed to provide something more complex than is usually encompassed by the word, teaching. Not only did their

clients need to learn or relearn thinking skills, but they also needed to understand their own cognitive limitations more accurately. Only then would the recreational, educational and vocational choices they made become appropriate or realistic. The more Trudy and Linda encouraged the development of this sort of insight, the more often they were confronted by emotional reactions to lost ability and skill. In "A Session on Sequencing" (BL Cycle Two, No.1), Linda was not so much teaching Bryce to 'sequence', as helping him understand the difficulty he had with this skill and helping him see how this would affect his daily life.

> **DS: So you are helping him separate out the action from the person really?**
> **LINDA: Yes. I suppose I am helping him see that. "This is a problem you have got. It is because of your brain damage." You are acknowledging it for him by saying "Ooops, you have got a problem, what can we do about it?"**

The practice issues absorbing Joan and Linda in these excerpts therefore, were not really related to their own body of knowledge and skill at all, but instead to that of social work, counselling and psychology. Throughout Waimarie, situations occurred constantly that required this sort of blending of knowledge bases.

It was not just knowledge that the staff needed to share with each other, but also goals. If the speech therapist wanted to encourage a breathing technique or help a person learn to use a communication device and if that person had severe difficulty remembering and understanding, then success would depend upon how well that speech therapist mobilised other staff, convincing them of the importance of the goal and ensuring they reinforced rehearsals. As well, she would need to become adept at monitoring the gradual removal of prompts and rewards as the person established the habit. The level of coordination could not stop there however. Not only did this speech therapist need to promote and supervise communication goals, but to stagger their introduction so that new initiatives were introduced in a careful order. While the nursing staff may have been co-operative about encouraging Max to make himself a snack, if Esther had asked them ("Making a Toasted Sandwich" MK Cycle One, No.7), they would have felt less enthusiastic if at the same time Joan asked them to get him to walk more frequently.

Alone therefore, no discipline offered this group of people the range of expertise and knowledge that they would require to support recovery. Unless each had an overview of the total rehabilitation process, they could contradict each other and confuse their client. This usually dawned upon new staff members early in their orientation to the setting and as a result, there was a tendency at Waimarie, for the boundaries between disciplines to become blurred and for the people who enjoyed working there to be those who found ways to draw upon the knowledge and skills of other professional staff and adapt their practice to fit into an atmosphere of co-ordination and co-operation rather than competition.

The behaviour exemplars reveal how important it was for the people working in this setting to manage this partnership without overestimating their own ability and skill and attempting to carry out the more specialised skills for which they had no training. Linda and Trudy might talk to Bryce and Max about their feelings, for example, ("A Perfect Day" MK Cycle Two, No. 1 and "A Session on Sequencing" BL Cycle Two No. 1) and might encourage their clients to reflect in this way about their future, but both drew back from more intense counselling in private and personal issues of relationships. Instead, they would have passed on any concerns they felt in this area to the social worker or psychologist. Because of this character of many of the interactions, the degree of teamwork at Waimarie was unique.

Having established this essentially holistic quality to recovery from head injury therefore, it follows logically that Waimarie, in as much as it functioned as a community with a shared purpose of rehabilitation and well defined roles and relationships fashioned specifically to further this goal, offered possibly the only type of setting where effective cross-disciplinary, (or inter-disciplinary) work could occur with this group of people. This is because the "germeinschaft" (Tonnies, 1955) quality allowed a blend of clinical expertise with more holistic relationships with a "whole man" (Plant, 1974:23) in a joint approach. That this occurred successfully at Waimarie was evident in a number of small subtle ways. For example, on many occasions, the pronoun 'we' prevailed in the interviews with me.

> **TRUDY: That is what we are trying to say to him ... think it through and give us some reasons. And he did manage to and so Jill said, "Fine, I will talk to her. Simple...."**

The 'we' concerned did not always relate only to the professionally qualified clinical team who were involved in the formal planning and goal setting. Many of the untrained 'aide' staff observed in the behaviour exemplars took a pro-active approach to supporting recovery and encouraging what they saw as desired behaviour from the residents. They were happy to acknowledge this. During our interviews they would objectively examine their own manner, interested in how effective they were at producing the behaviour they desired and revealing themselves as experimental hypothesis makers and testers.

> **GINNY: I can usually - I mean, he has had a lot of outbursts and sometimes something can - shut him down. But when he first came to live with us I was really nice and I pretended to be Prue - he called me Prue - That worked, but I think that if you tell him "Max that is not appropriate," "Max stop yourself and think about it" ... If you sort of shut him down. Use a harsh tone rather than a soft tone....**

Ginny's goal here did not differ in broad terms from the formally established goals of Max's placement at Waimarie, but no formal agreement underlay her actions. She was probably not even aware of the formal goal plan. She had a personal relationship with Max which convinced her it would be in his interests to acquire a more responsible and normal social manner. She did this by

energetically prompting him into interacting in ways she considered more appropriate or 'normal', sometimes verging upon the bossy and dictatorial in her determination to encourage his independence. In this excerpt, she proudly remembered her achievement in getting him to make his bed in the morning.

> **GINNY: Yes. I started him off, I said "Have you made your bed, Max?" and he goes, "No!" and I say, "Well, who sleeps in it?" and he goes "Me" and I say, "Well, you have to make it eh?", and he goes "mumble" and he decided to do it..**

The difference between qualified staff and aides therefore, was not then in their ability to see the person as a "whole man" (Plant, 1974:23) and relate to them as a fellow person, but rather in the level of abstraction at which they defined and managed their work. For Ginny there was a strong relationship between an independence in daily living tasks and an inner sense of autonomy and control. She did not explain this to Max, but merely coaxed and prompted him energetically into doing something simple for himself. She did not encourage bed making to make her own job easier, but to encourage an inner sense of self-directed and purposeful living. Trudy and Philippa, in contrast, worked more with the intellectual and emotional levels of Max's self-awareness than with any immediate practical application. Using the symbolic interactionist model therefore, it can be seen that while some staff worked more from "the outside inwards", others worked with inner feelings and helped the person adapt their self-concept to integrate feelings and experience. No matter which approach dominated however, it was clear that the actions of nearly all the staff were motivated by their desire to promote within the mind of their client, a more effective 'perspective of the other' , or in other words, a self-awareness more aligned with those that interacted with.

> **TRUDY (talking of her relationship with Mark): I am confrontative, but I don't confront him and then say "Righto, piss off." I would like to think that I convey that it is okay to be confronted and we will face it together, we will get through, we will deal with the problem ...**

Clearly, there is a dramatic difference between Trudy and Ginny's approaches to supporting self-awareness and also in the strategies they used to confront Max and prompt him into a more social awareness. The filmed observations suggest, however, that far from being contradictory and confusing, this was a healthy and positive aspect of the interdisciplinary approach. Over the course of the eight weeks of film, all four people were offered continuous opportunities to compare the attitude of a variety of different people toward their behaviour and recovery process. Interactive climates were also created within which these attitudes could be set alongside each other. Bryce for example, might tell Philippa what his father thought about his future and then sit back and listen to her response ("Alcohol, Love and Emotion" BL Cycle Two, No. 3), Mark challenged Jill by contributing what his mother had said about corn cobs ("Meal Planning with Jill", MW Cycle Two, No. 3), or noting his father's experience as an employer ("Negotiation" MW Cycle Two, No. 5). Whether in one to one or group rehabilitation sessions, or even when

chatting with friends and family during a weekend visit home, they could all draw upon such a variety of opinions, ideas and strategies and use them to develop their own ideas and ideologies.

This 'multiple interpretive frameworks scenario' might appear at first to be a disadvantage of the setting and situation, yet it offered a greater autonomy by the simple expedient of offering a range of pre-interpreted choices from which he or she could choose the most acceptable prospect. Although this sometimes caused a confusing multiplication of definitions of 'what was happening', this was more likely to cause tension between the staff and the family, than with the resident, who could sometimes be seen to play off family and staff in interactions in order to help them understand their own position.

> **Mark remembers something and looks up. "Mum says I should have that for lunch, not breakfast" he corrects her in a superior tone. What his mother says must be right, he seems to imply.**
> **"So, do you want to get some things of yoghurt?"**
> **"No." Mark shakes his head.**
>
> **("Meal Planning with Jill", MW Cycle Two, No. 3)**

Such perceived conflicts between family and clinical ideology offered important opportunities for the person to learn to mediate between the possible perspectives available to him. During the filming period, even the more serious conflicts were always eventually resolved or allowed for in some way, so demonstrating for the person, the power of the process of negotiation and compromise. In such a setting no one person was able to monopolise the recovery process, ensuring everyone involved was continually exploring 'what was happening' in order to understand their own position and response. Several remarks made by all four men demonstrated how well they were able to grasp this multidimensional perspective setting of recovery and use it to their own advantage.

> **DS: Right. But if Trudy says you did something badly and your mother says you did it well - do you get the feeling that you don't know who is correct?**
> **MARK: No. I think probably my Mum is correct. Trudy is being the teacher point of view probably.**
> **DS: Right. And what is the difference between a teacher's point of view and a Mum's point of view?**
> **MARK: A Mum's point of view is to boost you up and a teacher's point of view is to slow you up.**

Diversity of opinion therefore offered the person choice and by selecting from the range of perspectives offered, the person experienced an adapted and contained version of autonomy. What was most important about an interdisciplinary setting therefore, was not the ability to be consistent or uniform in the ideals promoted, but instead to offer a setting where people validate each other's right to different perspectives and model ways of negotiating and compromising to achieve common goals in a partnership or teamship.

SUMMARY

The experience of the four men at Waimarie suggested that rebuilding a self required specially adapted relationships from those who lived and worked with them. This is because at this stage of their recovery, they each needed to move from relatively one-way and unequal transactions with others, to reciprocal and emotionally intersubjective interactions. According to symbolic interaction principles, this process might be conceptualised as the recovery of an effective (or socially competent) inner audience. Through the use of imposed structure and role coaching, the collective 'other' surrounding each person fostered the slow transition from an external to an internal audience by providing a scaffolding which they dismantled piece by piece as the person became more capable of negotiating their own understandings and making more appropriate moral judgment based upon personal ontological schemes.

What this analysis suggests is that there is an intermediate stage during recovery after a brain injury when a person is vulnerable to alienation from an inner self and risks the loss of interpretive control over his or her life. Rehabilitation practitioners must therefore acknowledge this risk and carefully structure the interactive situations the person is encountering so that the relative power is regulated, gradually shifting the balance within the microdynamics until there is a return to more equal contributions in the negotiating of the definition of the situation.

An institutional setting which could function as a therapeutic community appeared to provide an ideal environment within which to manage this "liminal" (Turner, 1969) stage of recovery. Through forms of intersubjectivity the staff and setting of Waimarie, in coordination with friends and family, helped the four men escape from alienation and anomie by the re-instilling of an externalised objectivity. In order to be a subject, they needed first to learn to be an object to themselves again; to rediscover a realistic projected 'perspective of the other' without fear of self-shame by receiving accurate and consistent feedback paired with support and guidance in the fashioning of new, more appropriate and realistic ontological schemes. In this way they learned to accept some differences in themselves and still maintain a sense of dignity and personal worth, as well as a sense of continuity and forward momentum. This monitoring and adapting of interactive situations would have been almost impossible to control so well outside such a closed community.

My comments about institutional settings in relation to brain damage however, in no way deny the existence of destructive power relationships within such a setting. The filmed observation showed several instances where the structure created the potential for disempowerment of roles and resources and for the adopting of a "moral career" (Goffman, 1968:45) of disability. If

interpersonal relationships are to escape damaging unequal patterns, then there must be an awareness of how medical settings encourage the handing of one's body over to others and the sense of alienation from self and consequently, a determination to foster the development of new, constructive roles and identity.

Again Goffman's maxim is reinforced, that it is not the attributes, but the relationships which are the decisive factor in the nature of recovery from brain damage and the quality of future life achieved. As a result, it is clear that to create the ideal conditions for recovery means fostering and controlling in some degree, the nature of the relationships the person will encounter during this very vulnerable time in his or her life. Although at some stages of recovery, an institution is an ideal setting in which to achieve this, it is clearly important to remain sensitive to the moment when to remain in an institutional setting becomes destructive rather than constructive. Ultimately the success of any program depends upon its ability to forge new links between the person's past and present self and create the ideal conditions for a smooth transition back into the community.

Successful recovery of autonomy, purpose and adaptivity after a brain injury appears to require more than anything else, special types of relationships and settings. In the final chapter of this thesis, the key factors in a successful recovery for these four men are summarised and some comments made as to the implications for the design of rehabilitation programmes.

CHAPTER 14

DISCUSSION AND CONCLUSIONS

In this final chapter of the thesis, the objectives, framework and design are reiterated. The findings of the study are then discussed, firstly, as they relate to the creating of a new story after the pivotal event of head injury and secondly, as they relate to the intra-active and interactive experience observed during the recovery process. Some conclusions are reached concerning the practice of rehabilitation after brain injury and some guidelines for the settings and relationships of therapy are proposed. There is also a reflection upon the research process followed by recommendations for future research in this field.

THE OBJECTIVES

In introducing this thesis, I explained that my work and personal experience had convinced me that an inner 'social self' played an essential but largely unrecognised role in the course of recovery after a head injury. I proposed that models of rehabilitation needed to make this self the central focus and so acknowledge more fully the dual, dynamic and emergent nature of consciousness. I suggested that only then would it be possible to design models of therapeutic practice which encouraged people to be authentically engaged in their own recovery, to re-orient their lives, adapting them sufficiently to attain a personal sense of purpose and direction.

In the first chapter, a review of the neuropsychological and rehabilitation literature revealed a trend toward a *holistic* approach to understanding the nature of the disabilities caused by brain injury and so also the tasks of rehabilitation. It is generally accepted that damage to brain processes translates, in action, into broader disorders of personality and self-awareness. While it may be possible to predict the nature of perceptual and cognitive disorders according to the site, nature and degree of damage, researchers and practitioners have found that the integrative and interactional nature of brain function makes it much more difficult to pronounce (with any certainty) upon the likely outcomes to lived experience. The manner in which the person responds to difficulties in meaning-making and resolves the personal issues it raises, are too individual, mediated as they are by characteristic emotional and social coping mechanisms.

Instead of a fruitless attempt to clarify cause/effect relationships many researchers have thus urged an approach to rehabilitation which addresses the psychosocial aspects of recovery and which looks for creative solutions to common problems in everyday living. As a result, issues of self-awareness and identity have achieved a greater prominence and there has been a growing

acknowledgment that effective recovery cannot occur without a realistic awareness in the person injured, of the nature of the disabilities acquired and without a preparedness to make adaptations to lifestyle to accommodate for them. For the rehabilitation process to accomplish this self-awareness and adaptivity appears to require a greater sharing of control between the therapist and the client, so that people feel actively involved in defining their problems and shaping the course of their recovery.

THE THEORETICAL FRAMEWORK

In this study, a philosophy of an *intra-active self* was adopted, focusing inquiry upon the interactive strategies and relationship styles of rehabilitation practice rather than the assessment procedures and treatment regimes. Within such a philosophical framework, rehabilitation after a brain injury could be understood as the negotiating of the difficult territory between social expectations and self-sovereignty. A theoretical framework was proposed in the second chapter which, following the traditions established by Heidegger (1967), regards consciousness as developed around an ontological inner core of selfhood. Based largely upon the principles of symbolic interactionism and the work of Denzin (1984; 1987a; 1987b), this framework promoted a multi-dimensional understanding of self as inhabiting a body as *a sensate being,* as a *phenomenological being,* as a *body-for-the-person and* as a *body-for-others.* Experience was characterised as the integrating of these different modes of awareness in intra-action and interaction. The need for appropriate transitions between intentional and self-consciously controlled awareness and a more absorbed and feeling-based transparency was particularly stressed. To demonstrate these aspects of experience in everyday living situations, the metaphor of the person as an actor in social dramas was proposed. Interaction was characterised as impression management directed at oneself as much as others. Although partially reliant upon pre-formatted subsystems of habits and roles, these performances were regarded as emerging from an ongoing, interactive, interpreting process which adapts and modifies behaviour. This dramaturgical analogy allowed an understanding of how implicit social codes have come to underlie roles and it was suggested that a full recovery of adaptive and purposeful selfhood requires an induction into *reciprocal* or *interdependent* roles and so the redevelopment of team membership and belonging. It was suggested that something of this process of role induction might be traced by employing a symbolic interactionist method in the residential setting of the study.

Following logically from the assumption of consciousness as ontological, the proposed theoretical framework assumed *emotion* was a central and intrinsic part of the meaning-making process. It

was suggested that feeling engages self and consciousness either authentically or inauthentically in recovery, being both cause and effect of meaning transformation. It followed that without this emotional engagement there could be no purposeful self-direction. The therapeutic challenge, from this theoretical perspective, is to promote a balanced and integrated emotionality which would allow the self-conflict encountered during recovery to be transformed into a positive, purposeful energy. Recovery could be understood as the hierarchically ordered progression toward a sense of *authenticity* and *integrity,* the ideal balance in awareness of self and other. It was suggested that adapted forms of interaction and relationship may be necessary at earlier stages of recovery to support the return of such a sense of integrity. *Emotional intersubjectivity* within relationships was understood as a key factor guiding the interpretations and actions during the rehabilitation process.

DESIGN OF THE RESEARCH

The research project was designed to explore common patterns in the course of four lives interrupted by severe brain injury. It was argued that a better understanding of the interactive experience of brain injury emerged by tracing relationships between altered ways of perceiving and interpreting the world and altered relationality and interaction styles. By examining how these changes in relationships affected the nature of recovery, a better understanding of how other people could influence the course of recovery was possible. The question posed by this research was: *which types of relationships and interaction styles best assist the return of purposeful, adaptive and independent living*?

The nature of this research question committed me to a design which focused upon intra-active processes, linking them convincingly to observable experience and interaction during recovery. Because my concern was to describe how an inner process of meaning-making was linked with outer observable action, a method was required which would ensure that meticulous and minute inspection of a small amount of lived experience was combined with careful and well triangulated readings of its meaning. By using both the life history method and participant observation, a body of rich, descriptive, qualitative data was gathered which allowed the experience of the four men selected to be captured, cut loose and explored in depth from the perspective of all the people involved. Using symbolic interactionism and related theory of an interpreting self to inform the interpretation, several significant conclusions were reached about the experience of living with brain injury and the ideal forms of therapeutic relationship.

CREATING A NEW STORY

Examining the four life histories confirmed that traumatic brain injury has profound consequences for the nature of self and consciousness. There were clear common patterns, both ideographic and nomothetic, which emerged from these four lives.

FROM INACTIVE TO REACTIVE TO INTERACTIVE

The emergence from coma was characterised as a progressive involvement of cognitive processes in the mode of being-in-the-world. Initially *reacting* at a sensory and phenomenological level of experience, the person progressed toward increasingly *interactive* relationships as consciousness became more in touch with sensation and feelings, then more intentional and finally to more *self-aware* and self-critical. This reawakening of awareness was found to be erratic and very influenced in its course by the nature of the responses the four men received from others around them. The more the person showed evidence of interacting with and responding to others, the more assumptions of intentionality were attributed. The more the person was responded to *as if* an intentional and self-conscious awareness was present, the more they were prompted to reach for meaning rather than passively submit to treatment.

NEGOTIATING SEMANTIC NETWORKS OF RECOVERY

During the initial stages of recovery, the person (usually comatose) required medical intervention to ensure physical survival. Because of this, a medical framework generally prevailed, especially during a crisis period, defining the nature of the experience for the person and their significant others. For the recovery process to remain relevant to and effective for the person, however, philosophical principles guiding the rehabilitation period needed to move on from this orientation, toward a more sociological understanding of selfhood. Only then did the role of social interaction in recovery of inner cognitive and perceptual processes become fully acknowledged and accounted for in the practice of therapy. To support recovery clearly required that the people were offered progressively less assessment and treatment and more partnership and support in finding new meanings, roles, relationships and purpose with which to live the remainder of their lives.

The stories told of the early days after the accident, as the four men began to emerge from coma, suggest that they experienced a profound form of alienation: the inability to make sense of both self and world. By tracing the dawning sense of self and mapping the process of re-engagement with the world one central theme emerged: the 'moulding' of definitions and understandings. In order to understand what to think and feel, the four people needed to rediscover a shared reality,

something which, as Blumer (1969:5) notes, could only be derived from social interaction. In this way, they began the process of reintegrating an inner moral self which could mediate the demands of the 'I' and allow the person a dynamic inner relationship between self and 'other' in negotiating a new reality.

LINKING IMAGE AND SYMBOLS

Imagining played an important role in this early struggle for meaning. The four people combined their own ideas with the reports of others to 'create' memories which filled the gaps in their understanding. These created memories appeared to allow them to place the experience of the brain injury into the context of their lives and so imagine a realistic future for themselves. The line between what was imagined and what was remembered was frequently blurred, however, leaving the person unable to differentiate between what was real and imaginary.

Not only was it important for these people to piece together images of their life again, it was also important for them to tell these stories. *Putting words to the images and feelings* in their minds appeared to be important in developing a new and adapted sense of self. It lifted the level of awareness from phenomenological to intentional and self-conscious and so the person became able to understand themselves as a body-for-the-person and as a body-for-others. As the person told self-stories, the past appeared to be "laid to rest" (Denzin, 1987b:163) and the changes caused by the injury could be accepted. Story-telling appeared to be the ideal medium for this transformation because a positive emotional climate was created by the humour and emotional intersubjectivity which were injected into the stories. The four men seemed almost to *recreate* their past, shaping it in ways which allowed them to see coherent roles they could play in the present, as well as future pathways which gave a sense of order and direction.

An important part of this linking of sense, feeling, image and symbol appeared to be the *'identifying'* with significant others which occurred. During earlier stages of returning consciousness, before the person was capable of acting according to coherent interpretive schemes, it seemed important for the person to *adopt the attitude of the other* and act it out. In this mode they were likely to be reflecting back others' beliefs and ideals, adopting them wholesale. In this way through *identification*, "the profoundest form of play man knows", they experimented with different subject positions, "found themselves in each other" (Duncan, 1968:119), developed moral feelings and learned to regard themselves as a body-for-others.

CONTINUITY AND DISCONTINUITY

Pre-accident habits and relationships continually influenced the course of recovery. Characteristic ways of coping, whether with emotional or practical issues, could have a positive or negative influence upon the course of recovery. This dynamic was best understood by placing it in the context of developmental stages in the struggle toward selfhood. From this perspective, it could be seen that while some past strategies were still effective, others could prevent a realistic and effective self-awareness developing. Ultimately all four men needed to adapt their self-understandings to incorporate knowledge of their disability. It was only then that they were able to adapt their lifestyles appropriately and rediscover inner-centred purpose and direction.

Theoretical models which recognise stages in recovery, such as that of Ben Yishay et al. (1985) and Fugel-Meyer, A. and Fugel-Meyer, K. (1988) were also applied to the four men's experience. It was concluded that such models were useful because they organised and sequenced the different challenges encountered during the rehabilitation process. This allowed an understanding of recovery as a progression from alienation from others to re-integration of a social and moral self. In the circumstances, some monitoring and regulating of the coping and interpreting strategies being adopted by each person seemed advisable in order to foster a successful re-orientation to the world, avoiding the less effective outcomes which either minimise or overly focus upon the damage.

IMPACT OF SIGNIFICANT OTHERS

The experience of the four families involved in this study demonstrated that it was not just one person, but a whole family system which experienced dramatic transformation as a result of the accident. Other family members needed to find ways to re-orient their lives and roles if a sense of harmony and integrity was to return to family dynamics. This seemed to require the participation of all members in organising a semantic network which could create a climate of shared commitment. The attitudes toward the future of all those involved in the lives of the four men appeared to be very strongly affected by the nature of these semantic networks.

Initially, it was often necessary for family members or significant others to take over interpretive control, making decisions about meaning for the person. The stories told by family members suggested, however, that with appropriate support from medical and rehabilitation staff, family members could (and should) learn to pace their own symbolic interaction so that, as the injured person could begin to participate in meaning creation, he or she would increasingly share in the interpreting of their common present and future.

Several serious ethical issues were also revealed in studying the role of the family in recovery. The assumption by medical and rehabilitation staff that the person defined as 'next of kin' had the right to make decisions for a person in a coma failed to recognise that in many families, kinship is no longer so easily defined in terms of blood relationships and marriage bonds. Complex relationship networks caused some confusion and stress in at least two of the stories. Even when there was a clearly defined interdependent relationship, the expectations made by health and welfare agencies that family members would take the role of unpaid carers ignored the reality of New Zealand today where most households rely upon more than one income. As Opie (1991) has also observed, caregiving is still regarded as a part of women's natural domain in western society despite economic and political changes which often make it impossible to meet such expectations.

Another important issue which emerged from this study was the way in which rehabilitation was regarded as something of an optional frill in New Zealand, which could be administered at the convenience of the people supplying it. It appeared that unless behavioural, interpersonal and cognitive difficulties were addressed first, discharge home when the medical crisis was over placed an unacceptable stress upon person's support network. Because long-term personal relationships were essential to an effective recovery of selfhood, it was argued that the four men and their families required considerable emotional and practical support long after the acute period was over, from people who understood the wider implications of brain damage.

While the families needed to restructure their own lives to account for and compensate for the change in their brain-injured member, the four men needed to transform existing relationships as well as to develop new ones. This relationship building appeared to be an essential part of the process of recovery of selfhood. As Prigatano (1991a:2) puts it:

> **..to make honest and fair commitments to work, interpersonal relationships and the development of what Carl Gustav Jung called "individuality".**

The four stories were regarded as having confirmed a central theoretical principle of symbolic interactionism, that it was only through reciprocal and interdependent relationships that an authentic sense of self could be established. Interactional dynamics appeared to require careful monitoring, regulating and adapting, therefore, in order to ensure these qualities were recovered.

INTRA-ACTION, INTERACTION AND INTERVENTION

In the second phase of the research process, the interactions and relationships which developed within a residential rehabilitation setting (Waimarie) were examined from the perspective of symbolic interactionism. The findings in general supported the view that people with brain injuries require specially adapted forms of relationship during a recovery period if they are to

recover a sense of integrity, identity and (by implication) purposeful self-direction. It also appeared that the most effective relationships were those which provided a scaffold to support the interactive and intra-active interpreting process so as to allow a person to continue to make sense of the world.

In order to organise the observations, Denzin's (1984) typology of awareness levels was used to differentiate between changes in sensate and phenomenologic experience and changes in the interpreting moral person. The key goal of this section of the research, however, was not to separate out these aspects of awareness, but rather to understand how, through interaction and intra-action, they become blended together into a composite experience of being. Therefore, the guiding theme was once again the *integration* (and sometimes *dis-integration*) of these modes of experience within interactive situations. Using theoretical concepts chiefly from Denzin (1984) and Heidegger (1967), the level to which the person was capable of living an *authentic* and integrated self was understood as intimately linked with their ability to mentally manipulate *being and time.*

BEING...

Brain damage interfered with the body's ability to feel itself and be aware of itself as a sensate physical presence in the world. It was found that when the *sensible feelings* had become less available to the interpreting mind, it was much more difficult to act and interact effectively in the world. With a lessened sense of touch and a loss of spatial orientation, the four people were sometimes inclined to misinterpret social as well as practical situations and so failed to perform simple and straightforward everyday tasks effectively. It was easy for other people to misunderstand these sensory difficulties and assume a personality disorder where in fact there was only a perceptual deficit. The most effective ways of overcoming these problems involved the sensitive attunement of other interactants to the person's sensory needs. When they were able to identify sensory disorders as they occurred during interaction, other people were able to support the process of adapting to a changed sensory awareness and encourage the use of appropriate compensatory strategies.

The interactions were also affected by an altered relationship to *phenomenological feelings of the lived body.* The four people were demonstrably less able to manage their emotional state and apply socially prescribed feeling rules. As a result, there was a tendency for them to react to immediate mood states rather than controlling their self-presentation, making them appear inconsistent and impulsive to others. It was suggested that the attentional and emotional disorders often noted in the literature about brain injury were better understood as the loss of cognitive

control over the phenomenological feeling body. Less able to integrate thought and feeling, they were also less able to 'make themselves feel' what inner ontological principles dictated they *should* feel and so their body was less controlled by *'intentional value feelings'* at the level of the body-for-the person.

A common pattern of a lessened ability to make authentic connections with others was also noted. Attempts to communicate inner understandings, unmediated by *emotion work and feeling rules*, often caused progressive alienation from others and a loss of any forum for negotiating shared realities. Feedback from others became progressively less authentic and less intersubjective as social convention dictated that the person's inability to interact effectively excluded them from full group membership. This created a scenario within which the person risked being permanently consigned to sick or invalid roles, or the powerlessness of non-personhood usually reserved for children and the very elderly.

The four men managed to regain a sense of belonging and fellowship only when emotion management was *scaffolded* for them. The film exemplars demonstrated how others, aware of the person's inability to manage reciprocal interaction styles or sustain a level emotional tone, shaped interactions through the careful use of various forms of *emotional intersubjectivity*. In this way, the person was able to manage sustained activity and a controlled emotional climate for long enough to rehearse reciprocal, interdependent roles and so experience the intrinsic satisfaction which belonging and participating produces. The people were provided with a milieu within which backstage collusive intimacy, teasing and humour as well as front stage self presentation were modelled and encouraged, but with stronger indicators as to which interactive style was most appropriate moment by moment. This allowed new role relationships and ontological schemes for living to develop despite the problems with perception and cognition.

The most 'social' of the modes of self as described by Denzin (1984:126), is the experience of the *body-for-others*. Again, the filmed observation and interviews suggested that the four men not only needed to recover this inner self-regulating moral consciousness, but also needed support in integrating it authentically with an inner feeling core. Brain injury appeared to place the person at particular risk of a self-denying compliance with the interpretive frameworks of treatment and a tendency to attribute too much importance to external modes of assessing and defining themselves. Intrinsic satisfaction and other less tangible or quantifiable qualities of living were often rejected because they could not be measured and recorded as aspects of a successful recovery. The 'I' as Heidegger (1967:312) would say, was being "captured in the rule of the moral".

Language

Language, as the symbolic representation of meaning, played a key role in recovery. Particularly interesting was the way in which a "*metalanguage*" (Denzin, 1987b:42) allowed the person to disassociate self from injury and so preserve a sense of intactness and dignity. By speaking of eyesight, concentration, vocabulary, memory etc, the four people in this study demonstrated it was possible to sustain a sense of control over their bodies and minds, while acknowledging severe problems in managing independent living. By using terms such as 'physiotherapy' instead of 'a walk' and 'occupational therapy' instead of 'cooking', they felt that they were engaged positively in their own recovery and came to regard the tasks and goals of rehabilitation as new challenges or opportunities. Even aspects usually inseparable from one's own character or personality such as 'temperament', could be viewed objectively and dispassionately when redefined as 'difficulty tolerating frustration' and 'catastrophic reactions'. In this way, a metalanguage of emotionality removed the sense of personal responsibility and shame which can be attached to negative qualities identified in self-interpretations.

Denzin (1987b:42) suggests that the objectifying vocabularies found in a treatment setting had an important role in recovery. He calls it "pivotal language of treatment" and suggests it allows a person to reorient his or her life, adopting a framework of recovery and finding new directions. By regarding their perceptual and cognitive disabilities as if they were malfunctioning equipment, the people were able to adapt their lives realistically to account for the impact of the brain damage upon their future. As Lacan (1977:161) points out, "the symbolic is the primary order since it represents and structures the two (i.e. the imaginary and the real) other orders".

Roles

The trouble with metalanguage, however, was its tendency to objectify the person, divorcing measures of recovery from any inner sources of awareness and implying rehabilitation was ideally imposed by an expert 'treater'. For new directions and goals to create a sense of purpose and self-direction, the four men required a greater sense of ownership than this schematic arrangement would suggest. Because of this, the concepts of *role* and *role construct* were employed when analysing the interactions, to express the sets or subsystems of habits and ideas upon which the four people based their actions, giving their conduct its unique and personal character. A focus upon roles allowed some tracing of the interchange between the person as experiencer and the person as actor.

It was proposed that through intra-action and interaction, the four people experimented with new roles and adapted existing ones by assessing the feedback they received, both intrinsic and

extrinsic. The actions and responses of others were seen as crucial in determining the success of this recreating process. Through sensitive guidance in role playing and careful manipulation of the person's appraisal of possible roles, the others interacting with the four people, modelled, coached and generally 'directed and stage managed' this role experimentation. In this way the person learnt to recreate himself as a social actor with a number of interdependent relationships.

Goffman's (1968) observations about the impact of stigma and physical disability upon self-presentation also informed the analysis of role re-creation. A "self-consciousness" and "other-consciousness" (Goffman, 1968:30) was seen to occur frequently as a response to failed performances. Although this awkwardness in social situations was caused partly by others' reactions to their disabilities, the four people were also made uneasy and self-conscious because they were experiencing a "transformation in their ways of thinking about themselves" (Murphy, 1987:87). During this period of metamorphosis, they were particularly vulnerable to negative self-evaluations which denied them role opportunities. The normalising and universalising inner voices of the other (Munford,1995:27) caused them to restrict the roles they allowed themselves. When other interactants were sensitive to these moments of unease, they could sensitively guide the interpretive process to ensure that the four men acknowledged and explored their interactional problems and developed self-oriented solutions, at the same time as providing them with reassurance of their continued value and importance which overcame any sense of shame and doubt.

The role relationships of the four people appeared to be in a "*preparatory*"[201] (Denzin, 1987b:163) phase during the period of the research, where learning occurred through imitation and the wholesale adoption of others' perspectives and attitudes. Some early attempts at "*interaction*" and "*participation*" were also evident. The importance of shaping the environment so that it provided a variety of relationships was therefore confirmed. The four men were able to adopt multiple identities (Munford, 1995:15; Kondo, 1990:10) and consider themselves from a variety of perspectives as they reconstructed their identity. Although it was useful initially to scaffold roles by coaching and by modelling, ultimately the role understandings needed to be negotiated through interaction rather than given pre-interpreted. Unless the person was authentically engaged in the ontology building, no self-direction would result and the person would not move on to interactive and finally to participatory levels of consciousness.

...AND TIME

> **In order to perceive change in one's life - to experience one's life as progressing - and in order to perceive oneself changing one's life, a person requires mechanisms that assist her to plot the**

[201] See Chapter 2, p. 84.

> **events of her life within the context of coherent sequences across time -through the past, present and future.**
>
> **(Epston and White 1990:35)**

The loss of integrated ontological awareness in the four men was compounded by a related loss of the facility to control and manipulate their temporal relationship to the world. In varying degrees, all four men had become more fixed in the present, as well as more subject to an erratic sampling of past and future without coherence or direction. Heidegger (1967) has demonstrated convincingly that temporality structures and organises being, providing the perspective which allows people to step outside themselves and understand their life as a unit. The filmed observation suggests that therapeutic models should be adapted to acknowledge the impact of less flexible temporality more fully and compensate for it. Because of their lessened ability to anticipate and remember accurately, these four people seemed to require specially adapted forms of interaction. With appropriate structuring of their temporal interrelationships, they could be returned to a sense of their place in time

Patterns and Awareness

Without an ability to move mentally across time, the ability to *recognise patterns* was limited and this diminished the insight the four men had about their perceptual and cognitive problems. They also found it difficult to apply newly learnt skills appropriately or to learn from their experience and this also appears to relate to their difficulty seeing themes or generalising. Self-awareness came and went erratically, depending upon whether or not the immediate situation was confronting the person with evidence of a disorder or difficulty.

By using temporal relationships to organise the analysis, it became possible to understand that many of the cognitive difficulties itemised in Chapter 1 were different manifestations of this one change in consciousness: the loss of a temporal dimension to interpreting. Brook's (1990) "fluid" processing skills are in effect 'time travelling' skills, the ability to associate rather than evoke, to take an abstract rather than concrete attitude, to think in an integrated as opposed to a sequential or relational manner, to tap declarative memory as easily as procedural memory. While people without temporal control may retain considerable competence in everyday skills, they will not be able to resolve problems by adapting their actions spontaneously, creatively relating present to past and future. This will limit their ability to achieve and sustain a sense of direction and purpose.

The more effective interactions at Waimarie were those where others *scaffolded* the relationship of the four men to time. Past memories were provided to clarify the present situation, or they were encouraged to think of what they might anticipate before embarking on an activity. As they

became more self-directed, a longitudinal perspective of their own recovery developed, placing the rehabilitation experience into the context of their past and future and allowing the integration of their experiences into a coherent ontological scheme.

The Riddles of Speed, Selectivity and Attention

As well as the loss of the ability to stand back from oneself and view experience across time, the four people had less ability to sustain attention and to process information at the same speed as those around them. This 'pace' aspect of thought is intricately linked with the lessened pattern discerning skills (Van Zomoren et al., 1984). Attention could not be sustained unless the person was sufficiently aroused and engaged yet this was not possible unless situations could be interpreted in a way which allowed them to have personal meaning. A phenomenological "sounding board" (Denzin, 1984:116) requires an interpreting mind to relate a current situation to an inner feeling state.

With less ability to interpret fluidly, adapting and accommodating for the subtle feedback of interpersonal occasions, the four men were all extremely susceptible to misinterpreting and misunderstanding situations. This caused many of the confusions and problems which frustrated the rehabilitation process at Waimarie, particularly problems in the arena of sexuality and intimate friendships. Mark was confused and upset by Wayne, Rob angered Nadine and Phillip when he meant to befriend them. Bryce, Rob and Mark were all failing to develop an authentic emotional intersubjectivity with their flatmates despite their sincere and sustained efforts. Max was bewildered by his growing distance to Prue.

It was found that relationships only remained free of misinterpretation when the other interactants were willing and able to compensate for the difficulties the person was experiencing in keeping in step with interactive dynamics. It seems important, therefore, to give people with brain injury opportunities to rehearse informal interaction with fellow interactants who can monitor and regulate the encounters, where necessary slowing down or speeding up the pace of an activity or, perhaps, providing stronger cues and even open allusions to the problem behaviour while at the same time continuing to play out the interactive dramas.

This form of regulating and pacing assistance appeared to work most effectively when a positive appraisal and energy characterised the relationship. This emotional climate allowed a more sustained effort and attention than could be managed alone. By choosing joint activities or projects upon which to focus energy, some people managed to establish an emotionally intersubjective therapeutic alliance or partnership. In this way it was possible to respond to the

moment rather than following a rigid plan, strategically positioning cues and prompts to link situations to positive feeling rules and self-appraisals.

AN INSTITUTION AS A THERAPEUTIC SETTING

Throughout this discussion of the key findings, I have constantly alluded to the importance of the role of the 'other', both as an inner audience and as the other interactants with whom the four men negotiated shared meaning. What became increasingly clear in examining the filmed interactions was that the role of this 'knowing other' (whether inner or outer) was critical in determining how purposeful, adaptive and independent the person might become.

Although it seemed a paradox, an institutional setting, provided it could function as a *therapeutic community*, appeared to provide an ideal environment within which to manage recovery: it allowed people with experience and expertise to scaffold this inner audience during a "liminal" (White and Epston, 1990:7; Turner, 1969) period and then gradually withdraw their support as an inner voice began to assert itself. It appeared that as the transition occurred between an old and a new self after head injury, a person needed to inhabit a world which existed "outside their normal time" (Denzin, 1987b:50-60), so that the regeneration of a purposeful self could proceed at a manageable pace. As a 'refuge' or retreat, Waimarie effectively affirmed the person during a period when they would have felt "something other than whole" (Denzin, 1987b:50) in their usual social situation.

SCAFFOLDING AND LIMINALITY

With less ability to make sense of information, the four people were inclined to accept and adopt the interpretations of others and so by implication, to become progressively more alienated from their inner feelings and ontological core. In the circumstances, I concluded that a specially adapted and controlled setting was an ethical imperative. Through the sensitive controlling of the social and physical environment the staff allowed the four people to continue to interpret their own world. They magnified cues to overcome diminished perceptual awareness, they regulated the speed of interactive exchange to overcome pacing problems, they compensated for memory and attentional difficulties by repetition and by providing constant and consistent feedback and they overcame the problems created by impaired social judgment by providing a milieu within which what is usually tactfully ignored can be discussed.

When the four men studied were placed back into the living arrangement which prevailed at the time of their accident too early, they demonstrated how quickly any attempt to participate in meaning-making can be discarded. They were all soon regarded (and regarded themselves) as

helpless and dependent. To deny people a controlled and structured environment, therefore, may be to deny them the right to develop their own ontology.

EMOTIONAL LIMINALITY

For a balanced and integrated approach to self to emerge, one which valued inner emotional and feeling-centred experience as much as socially appropriate behaviour, a liminal period where mood was consciously manipulated by others appeared to be necessary. Identifying and responding to moments of "self and other consciousness" (Goffman, 1968:30) appeared to be a key factor in successful interrelationships at Waimarie. Sensitive staff and significant others in the person's family were seen to encourage the person to acknowledge and clarify his feelings at these times of uneasiness and to find creative solutions to feeling problems. This was only possible because the people at Waimarie were capable of creating and sustaining a climate of "persuasion and inspiration" (Ben Yishay et al., 1985:256), negotiating for emotional understandings which would support a successful transition into the community and promote purposeful self-direction and authentic re-engagement. To manage this well it was important that other interactants had some knowledge of the consequences of head injury and experience of working with people with impaired consciousness. It was also necessary for them to know the 'whole' person, rather than establishing more clinical and impersonal relationships such as might occur in a non-residential treatment centre. Only then would it be possible to respond effectively and intuitively to these people, helping them recognise and meet their emotional needs.

The pivotal "metalanguage" (Denzin, 1987b:42) of Waimarie also played an important role in this emotion mediation. Through the use of language a "dual relationship of objectification" (Wilden, 1966:161) occurred creating a sense of therapeutic alliance which allowed disabilities to be confronted without shame and self-doubt. The person could rehearse the identification of his difficulties in his day-by-day experience in a climate of co-operation and partnership, ideal for learning to apply adaptive and compensatory strategies appropriately.

OVERCOMING TEMPORAL LIMITATIONS

An institutional setting also appeared to soften the impact of changing temporality. The loss of the ability to draw upon a past and future clearly frustrated the men's need to understand the themes and patterns of their lives. Without an efficient "supervisory attentional system" (Cicerone and Tupper, 1991:281-282; Shallice, 1981), they were less able to monitor and regulate their actions according to guiding schemes. Living at a different pace they were also less able to maintain attention upon and comprehension of interactions with others.

As Crosson et al. (1989) demonstrate, effective therapeutic strategies need to allow for these temporal limitations, work within them, yet push at their edges. Environmental prompts were an important early tool of this temporal regulation, but as the men began to identify and later anticipate problems at more sophisticated levels of temporal orientation, it was necessary to keep pace by adapting the social and environmental responses they received. The use of a structured written timetable proved a particularly effective 'time-scaffolding' technique and this required both a team approach and a semi-closed spatial arrangement. Because Waimarie was small enough for everyone to know each other, the staff could also co-ordinate and manipulate the amount of interpretive support the person.

In this way a blend of top down 'supervisory awareness' coaching and 'bottom up' skill rebuilding could be seen to foster a move from regulation by others to self-regulation. This could proceed more smoothly at Waimarie because it was possible to manipulate the level of temporal control. Outside such a setting it would be difficult to manage this level of temporal manipulation.

LIMINALITY AND ROLE RE-CREATION

Denzin (1987b:42) suggests there is a need to figuratively step outside oneself to adopt a new interpretive framework. He also suggests that there are three stages to reconstituting self: *preparatory, interactional* and *participatory*. The climate of Waimarie lent itself well to the invention of new roles as it provided for non-threatening rehearsal of dramaturgical skills. The perception of what is private and what is public appeared to be altered by its institutional and vaguely 'medical' nature and most residents, regarding each other as having a similarly 'spoiled identity' (Goffman, 1968), felt less obligation to maintain the deceit of a 'front'. Because of this, they took risks in their social interactions with each other which they may not have taken in a more open and heterogenous community, experimenting with and rehearsing roles and interaction strategies, until they felt they were acceptable not only to others who shared their experience of brain injury, but also to their inner audience. They also appeared to rehearse differing power relationships with each other, learning to jockey for interpretive control with people from a wide range of social strata and experience. These attempts to organise their relationships into hierarchical schemes encouraged them to consider their obligations as well as their rights.

Goffman (1969:179) advocates forms of "milieu therapy" for people struggling to come to terms with interpersonal problems. He points out that when people are in an environment of backstage fellowship the need to perform is suspended and people can lower barriers and share front management problems with impunity. Waimarie's environment appeared to create just such a 'milieu'. The staffs' ability to slip between front- and back-stage roles, allowed the active teaching

of new thinking and feeling strategies to be combined with the rehearsal of team membership and self-presentation.

Authentic re-empowerment clearly requires intersubjective and interdependent relationships, rather than objective and independent styles of thinking and living. Recognising this, the relationships in the setting of recovery also need to be able to move progressively from relatively one-way and unequal, to reciprocal and emotionally intersubjective interactions. Other interactants need to take on the burden of extrapolating meaning (Prutting and Kirchner 1987:113) without making judgements which limit the person's social opportunities. They also need to be able to adjust their own level of interpretive support as the person demonstrates an increasing ability to share in negotiating definitions. Through the use of role coaching and modelling, the collective 'other' surrounding the four people in this research fostered this transition. In the early stages of learning how to give as well as take, the person avoided non-personhood and rejection by those who found it unrewarding to interact with them.

DISADVANTAGES OF INSTITUTIONS AND SOME SOLUTIONS

The very attributes of Waimarie which made it an ideal environment to recreate a self, however, also created the conditions for potential disempowerment and the progressive removal of belief in one's right to an interdependent place in the world. Many dangers to selfhood were noted at Waimarie and the institutional structuring of relationships and power clearly created the conditions for self-alienation just as surely as they created the conditions for re-empowering.

A MORAL CAREER

While a closed and secluded community where people all knew each other well might have been the ideal climate to relearn roles, it also encouraged the establishing of a moral career as a person with a disability. Much behaviour that was promoted as a means of recovery became destructive when it became an end in itself. Being good at rehabilitation activities was too often the only remaining source of internal gratification. Unfortunately, the intrinsic satisfaction of a perfect score in an assessment battery has no transferable value in the world outside the institution. The four men were in danger of feeling their only source of attention and approval was based within Waimarie's walls. Convinced they were interesting because of their injuries rather than in spite of them, their talk was dominated by their experience of recovery. Instead of learning independence they were learning dependence.

With lessened ability to make sense of their situation independently and with an intermittent and less effective inner conjured audience, the men were vulnerable to being controlled by others. In such circumstances, a closed community and a hierarchical arrangement of roles created the conditions for the abuse of power by staff and other residents and consequent feelings of powerlessness and helplessness in residents. Many of the staff I spoke to understood how close a line they continually walked between negative and positive use of their own personal power. Because they wished to engage the person emotionally and realistically in their recovery, they constantly suggested positive ways of interpreting the injuries and appraising the future. From this position, it was easy for them to overstep the line between defining and imposing definitions on the one hand and on the other negotiating them in interaction.

While a residential setting allows the creation of the ideal conditions of recovery, therefore, it must be carefully monitored to prevent the loss of personal power. Mead's principles which recognise the socially derived nature of any personal criteria guiding recovery, allow a clearer understanding of the fine line between re-empowering and disempowering after a head injury.

PARTICIPATION OF SIGNIFICANT OTHERS

There is no doubt that having regular contact with people and objects from the past was very significant to the recovery of all four men. The holiday at home over the Christmas period, for example, was an extremely significant event in Bryce's recovery. He had become conscious enough by then to recognise and reintegrate some of the pieces of his past. Seeing these people and objects again prompted this reintegration. Similarly, Mark's visits home gave him contact with past friends and relationships, allowing him to develop a clearer idea of how his injuries had altered him. Rob and Max were clearly disadvantaged by the distance Waimarie was from their home and in both cases past friendships were clearly disintegrating.

Regular home visits and visits to Waimarie of family and close friends could overcome this problem of residential rehabilitation while at the same time allowing the rehabilitation staff valuable feedback about problems experienced in community and family situations. In fact, some such combination of family and institutional living appeared to be the ideal rehabilitation arrangement. Families could make an effort during a weekend or holiday period, arranging orienteering activities and fishing expeditions without the stress of the ongoing daily care. Some such arrangement as Mark's 'notebook system' or else regular meetings and telephone conversations allowed Waimarie to capitalise upon the home based experiences. The person

could be helped to reflect upon what happened and develop clearer and more self-directed needs and goals at a pace they could manage.

IMPLICATIONS OF THE STUDY

Because of the focus on lived, interpreted experience rather than upon the nature of the damage itself, this thesis has revealed as much about what was "nomothetic" or universal (Allport 1942; cited in Runyan 1984:169) in the experience of the four men as it has revealed about what was distinctive. They have been presented to the reader as four human beings, responding instinctively to a crisis by redeveloping a dual inner selfhood. This method of describing their experience accentuated their sameness rather than their difference and demonstrated as much about how they managed to transcend their cognitive and perceptual limitations as it revealed how they were hampered by them. Instead of defining and labelling differences, it defined and explored the role of 'fundamental properties of mind'[202] in the recovery process. The findings of this study do not lend themselves, therefore, to the creating of models to treat cognitive deficits exclusively but, instead, suggest rehabilitation must be viewed in a holistic way, as the healing of a self or a consciousness. The role of the therapist becomes more comprehensive than it would be in other fields of rehabilitation and is best understood as the scaffolding of consciousness, temporality and emotional intersubjectivity.

SCAFFOLDING CONSCIOUSNESS

Throughout the thesis the theme of lessened awareness was uneasily juxtaposed with the theme of re-empowering an inner self. Clearly, to conduct rehabilitation effectively these people require strategies which allow the redevelopment of skills usually seen as declarative and abstract, yet these skills must be reinstituted with methods which rely upon more rigid concrete and procedural forms of learning.

Repeatedly, in describing the most effective moments in the life stories and filmed observations, I have used the metaphor of scaffolding to describe the ideal role for the therapist or significant other. Cicerone and Tupper (1991:288) have suggested that this concept, originally mooted by Greenfield (1984), offers a pivotal strategy for rehabilitation practitioners.

> **Scaffolding is not shaping through approximations, nor is it graduated task difficulty, it is the holding of the task constant, while modulating the level of structure. The therapists supports the other abilities necessary for task completion.**

Scaffolding, along with a related technique from Skinnerian psychology of shaping, allowed learning at Waimarie to precede conceptual understanding or insight. The film and interview data

clearly demonstrated the fundamental principle of symbolic interactionism that meaning arises only through interaction. By implication, interaction and production must occur before understanding, allowing cognitive processing to draw upon sensory-motor and phenomenological experiences. Rather than explain and teach, therefore, the effective therapists often co-operated with their clients in projects which would have been impossible for them alone. The level of the activity expected of the client was manipulated to maintain the work within a zone of "proximal development" (Greenfield, 1984:118), where the person appeared to be sensitive to instruction.

Dreyfus, H. and Dreyfus, S.'s (1986:129) model of the learning process[203] appears to provide a useful theoretical framework for the process of scaffolding consciousness as it was revealed in this thesis. They suggest that good teaching should promote "grokking" (Dreyfus, H. and Dreyfus, S., 1986:163), by developing intuitive awareness of patterns or rules through practice, rather than decontextualising them and teaching them separately. This model not only recognises the power of less intentional and reflective levels of consciousness but also maps the pattern of interaction between awareness and unawareness in 'whole brain' activity. A practitioner using such a model would regard his or her task as one of varying and regulating the level of the scaffolding supplied to ensure there is a progressive integrating of the symbolising, spatial, visual and imaginal powers of the mind. In effect the therapist's role is to 'position' the consciousness of the client, ensuring there is a smooth switching between analytic and holistic styles to fully tap the brain's potential.

In reviewing the neuropsychological literature, I commented that brain injury is often understood as causing some imbalance in dichotomous and interacting processing modes[204]. While these conceptualisations were useful in understanding the nature of the problems people encounter, the experience of the four men in this study suggests that any dichotomy between 'training' (using concrete and procedural) and 'educating' (using metacognitive and abstract forms of knowledge) in conceptualising rehabilitation is unwise. In fact, the key to successful rehabilitation may be to follow Dreyfus, H. and Dreyfus, S.'s lead and look for strategies which link together and reintegrate these different ways of processing. Approaches which use modelling, rehearsal and practice, for example, may provide the most powerful foundation to develop awareness and self-awareness. With adapted versions of existing cognitive learning models, it should be possible to teach a person with brain injury to monitor and regulate his or her behaviour at a procedural level of consciousness and so to accomplish functions often regarded as metacognitive. A sense of

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[202] Lacan (1968:29) suggested that phenomenology assumed the existence of "fundamental properties of mind" and sought to discover and define these properties.

[203] See Chapter 2, p. 69.

[204] See Chapter 2, p. 21.

purpose is only possible when there is a sense of self-direction. Some examples of models which could be used in this way include

- interrupted behaviour chains (Hunt and Goetz 1988);
- Wood's (1990b:18) "verbal mediation" technique, which uses specially adapted self-talk strategies to promote adaptive behaviour change.
- the regulated fading of prompts to encourage autonomous action (Mirenda et al., 1990); and
- cognitive modelling techniques, where how to think and what to say is demonstrated and learnt through supervised practice.

SCAFFOLDING EMOTION MANAGEMENT

After a brain injury, a person may be particularly at risk of becoming emotionally divided against him or herself. There appears to be a need for some monitoring and regulating of the level of emotional conflict people experience so that they are neither overwhelmed by painful emotion, nor left in a state of emotional limbo. Several forms of *emotional scaffolding* occurred in the therapeutic relationships at Waimarie, allowing the people to maintain a manageable level of arousal and a purposeful and positive approach to their situation. The research strongly suggested such techniques were powerful and effective tools in brain injury rehabilitation. In analysing the interactions, I particularly noted the importance of *putting words to feelings* drawing largely upon the work of Denzin (1987a; 1987b), Hochschild (1979) and Kelly (1955). Some other existing models which would inform the practice of emotional scaffolding include:

- *visualisation techniques*, where the person is encouraged to imagine themselves behaving appropriately and so mentally rehearse successful resolution of difficulties;
- adapted forms of *assertiveness training, stress inoculation, and self-instruction;*
- Gross et al.'s (1987:225-30) suggested strategies for overcoming the problems distinguishing between figure and ground in understanding situations, and in particular, at its most sophisticated level, "empathic dialogue coaching" (Gross et al., 1987:229-30).
- *reality testing*, or direct contact with an objective reality;
- *control theory/reality therapy* (Glasser, 1989) which encourages people to understand the influence their feelings are having upon their actions; and
- *rational emotive therapy* (Ellis, 1973; Wessler and Wessler, 1980).

Clearly all these strategies, whether directed toward social learning or toward emotional needs, require an environment to remain stable and predictable, not presenting anything not within the learnt repertoire of beliefs and responses. By a process of intense well scaffolded dialectical interaction with the environment, paradigmatic shifts were shown to occur at Waimarie even in

people with severely limited information processing powers. In a less secluded environment it is possible that unpredictable and uncontrollable stressors would overwhelm the developing emotional relationships of the person, preventing the growth of authentic emotional intersubjectivity.

SCAFFOLDING AND IDENTITY RECONSTRUCTION

When recovery is regarded as the negotiating of a shared reality, rehabilitation must be seen as a progressive responding to the challenges and interpretive conflicts encountered during the emergence of a new consciousness. Although the degree of cognitive, perceptual and motor damage varied widely, it is remarkable how closely the course of all four men's recovery mirrored the model provided by Pepping and Roueche (1991:242-5) of progressive "confrontations with reality". Unable to predict the difficulties they would have in advance, they were unable to apply adaptive strategies unless they were provided with interpretive support at the time of experiencing a problem by a knowing other. Whenever they were armed with self-knowledge in this way, they became more aware and learned to understand themselves and so to recover a sense of control and choice over their lives.

The emphasis within the acute hospital setting was upon the physical, motor and medical aspects of recovery and there was no real allowance made in planning rehabilitation programmes for the level of cognitive or interpretive recovery. After the initial physical and medical recovery process was complete, the four men experienced a period during which they were too confused and disoriented to understand or control their lives. If rehabilitation was guided by the concept of *fostering self-awareness* rather than the maximising of physical and medical recovery, then involving the client would become the primary consideration at this point. Attention would be turned to effective techniques for manipulating settings and relationships to ensure people participate at an optimal level of interactive competence. Physical and medical needs would still be addressed, but by a team of professionals cast into a secondary and supporting role, monitoring and regulating the recovery process and adapting their own responses to ensure a progressive return of power and control to their clients. Identity reconstruction could be scaffolded with the use of other modes of consciousness such as identification (Duncan, 1968) and play (Gadamer, 1975) (in particular role play) when people are still unable to organise their world in any conceptual and abstract sense. In this way some work toward maintaining a sense of integrity and personhood can be continued.

SCAFFOLDING AND THE NEW ZEALAND HEALTH SERVICES

At the time of writing this thesis, New Zealand's disability and rehabilitation services were being organised into "needs assessment" and "service co-ordination" categories. There was also a steady transition from institutionalised care of people with severe intellectual and physical disabilities to community integration. Several policy documents had been compiled to outline this process and these have attempted to identify the core support services which people with disabilities require if their communities are to provide an acceptable quality of life[205]. In the field of head injury rehabilitation, the same initiatives and paradigmatic shifts were occurring both nationally[206] and internationally and it has become widely accepted that recovery can only be regarded as successful when the person can be given access to generic services and opportunities and choose where and with whom they live.

While in theory, people with severe head injury would benefit from these structural changes and from the establishing of community based services, the findings of this study raise some concerns about such policy changes. Firstly, New Zealand's small population base makes it difficult to provide the same level of support in a community setting to which the people in this study had access at Waimarie (Bird, 1987:4). When a counselling session requires an hour's car journey each way it is not practical to schedule a daily appointment. When resources are pooled it is possible to consult a range of specialist professionals without delay. It is possible to experiment with a range of adaptive devices and make a personal choice before purchasing.

Quite apart from such practical constraints upon supporting these people adequately in the community, the person's community network may fail to provide an effective emotional climate. When people lack initiation and planning skills, purpose and motivation, it is not likely that they will use recreational and educational opportunities in their community appropriately. That same opportunity, when presented in an environment which encourages and structures the person's participation, may create a higher level of independence and self-direction. The need for residential living arrangements during a liminal period is therefore reinforced in part, by the practical and geographical limitations experienced by people in New Zealand.

The findings of this research also suggest that issues of funding arise when this model of service provision is applied to people recovering after severe brain injury. ACC, responsible for rehabilitation and compensation after accidents in New Zealand, relies upon a formalised needs assessment process in allocating its resources. There is an implicit assumption, within such policy,

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[205] e.g. "Support for Independence for People with Disabilities" (Shipley and Upton, 1992a), "Support for Independence" (Shipley and Upton, 1992b).

that there is a moment when needs are fixed and quantifiable. This study has demonstrated that people with brain injury are, in fact, emergent not fixed entities and as such, at least during a liminal period, they require fluid and empathic relationships with people who can respond to immediate needs rather than being rigidly constrained by pre-dictated treatment plans, or by long term goals which lose their relevance as the person's ontological scheme is altered. It is imperative, therefore, that the staff working within such structures and systems in this field of rehabilitation, temper any reliance upon quantitative assessment with knowledge that what they are doing is shaping relationships, not treating disorders and that this is a developmental and qualitative process. While the more concrete and practical needs may be articulated in a needs assessment document, it is not easy to define and value in money terms, the emotional and relational needs of recovery. If as this research suggests, effective interactive strategies are the key ingredients in successful recovery, even the most expensive adaptive aids will fail to improve the quality of a person's life outside an environment where other interactants support a purposeful and independent lifestyle.

Recently a Complex Personal Injury Scheme has been instituted by the ACC to apply in situations where people are experiencing complex, multiple disabilities[207]. This scheme has the potential to empower people with head injuries, allowing them to choose their living arrangements, seek out and explore opportunities and develop the highest level of adaptive, purposeful and independent lifestyle which their impairments will allow. It should also allow others to develop appropriate services and community integration schemes which would otherwise be too expensive. However, the regulations governing the payment of this allowance continue to deny the emergent nature of recovery and the life long nature of the struggle to increase independence and improve the quality of life.

What this research suggests, therefore, is that there should be a graduated structure of settings and relationships available for people as they recover from a brain injury. Because the process toward a new identity is not finite and because it is interactional in nature, ideally each degree of returning interpretive control and purposeful self-direction should be matched by a relative withdrawal of interpretive and practical support structure. This requires a hierarchical structure of living arrangements and support relationships to be made available, from a hospital ward during the medical crisis, to a secluded environment such as Waimarie "outside time" during a liminal period, to various transitional living arrangements such as the "therapeutic communities" Willer

[206] e.g. A Review of the Support Needs of People with Severe Head Injury (HISNZ 1994).

[207] People who qualify for the complex personal injury allowance are those who have become highly dependent upon assistance with personal care or who require constant supervision.

and Corrigan (1994:2) propose and finally independent living arrangements in the wider community.

Although, ultimately, the 'scaffold' may be withdrawn completely, it is particularly important to recognise in this field of rehabilitation, that there are many people (including all four of the men in this study) who will probably continue to require some level of support for the rest of their lives. Someone like Max, for example, will always require a well-structured and controlled environment if he is to experience the optimal level of purpose, autonomy and adaptivity. Others, such as Mark and Bryce, are likely to manage in many everyday living situations yet occasionally experience crises which threaten their support network and their sense of personal integrity. Such people might be better supported by a mobile support service which can intervene in such situations in a consultancy role and resolve conflict before withdrawing again. Others again may require support in only one aspect of their lifestyle such as occupational or recreational opportunities. Models of helping people within community settings such as "circles of support" (Willer et al., 1993), the "whatever it takes model" (Willer and Corrigan, 1994) and Godfrey and Smith's (1993) "Cognitive-Behavioural Approach" offer a range of creative solutions to the ongoing challenges people with brain injury are likely to experience during the course of living their lives. The findings of this study suggest that quality of life will be improved when more funding is provided to ensure such programmes are made available to people with brain damage in the community.

REFLECTION ON THE RESEARCH PROCESS

To a symbolic interactionist, all the people involved in this study, not just the residents in the rehabilitation programme, were constantly re-creating themselves by interacting with their social and physical environment. Because of the role of Waimarie, however, attention was mainly focused upon the meaning-making processes of those who had brain injury. I have frequently mentioned how this translated in interactional terms into an imbalance in the interpretive power people attributed to each other and so created the conditions for one group of people to have more influence over another and to play a role in moulding the new roles and relationships being negotiated.

I have also indicated that these adapted interpreting arrangements, while playing an important role during a liminal stage of recovery, created the conditions for ideological abuse. The four people studied (and many of the other residents of Waimarie) were extremely vulnerable to the interpretive control of others and so to an alienation from inner sources of feeling and understanding. While there were many ways of arranging the social and physical environment

which might meet the physical needs of this group of people, it was not so easy to create the conditions which ensured that, with appropriate support during a liminal stage, they could become authentically engaged in the world again.

I entered the field believing that the 'interpretive interactionist' design of this project would allow a theoretical distinction to be made between those interactive strategies at Waimarie which were effective at empowering self and allowing adaptive, purposeful and independent living, from those which were effectively disempowering. In effect, my original intention was to "track down the ideological abuse" (Denzin, 1992:74) in the setting, whether intentional or unintentional. I found instead that there was no way to make such distinctions in this field of inquiry. The impact of brain injury made the question of who controlled whose definitions much more complex than it would have been in any other rehabilitation setting. Clearly, an effective, inner audience needed to be reconstructed if the person was to participate in their world and yet because of their perceptual and cognitive difficulties, this required a high level of direction in the essentially private and personal domains of selfhood. I had to conclude reluctantly, that there was no way to offer simple instructions to rehabilitation practitioners which would ensure the sovereignty of a self.

It is also important to note that this interpretive 'anomie' or 'liminality' was not only evident in the people with brain injury at Waimarie. Many staff were also remarkably open to others' interpretations of their actions and roles. Perhaps because of this climate of ontological uncertainty, many of the staff took a very critical and reflective approach to their own practice and became troubled by the constant interpreting puzzles and ethical dilemmas which arose from it. It began to dawn upon me that, in a world where all realities were negotiated and created, the most important human skill is the ability to listen to and explore the meaning of the perspectives of others. These people looked for guidance from the research process rather than expecting only objective reflection and as a result it was difficult not to create a new layer to the interpreting dynamics, one apparently informed by expert knowledge. It was humbling to observe how eager many of the participants were to hear another's explanation of the meaning of their own actions.

For this reason, the study developed a strong "action research" (Mies, 1983) dimension. The process of inquiry engaged with and changed the experience and interpretations of a large number of the people who lived and worked at Waimarie. An important principle of naturalistic inquiry is that the research act itself is an instance of symbolic interaction, a two-way interaction between theory and people. This study taught me how true this was.

In light of this discovery of the active role I was taking in the meaning-making process in the setting, I re-examined the use of film. It became clear that a videocamera is a remarkably

powerful tool in meaning negotiation but not necessarily always a positive one. Over the fourteen months of the data collection, I showed many people film of themselves and discussed their actions as we watched. The effect upon these people was fascinating. Most were startled, even horrified to see themselves in interactions[208]. While many felt it was helpful to examine themselves in this way, I came to believe some caution was necessary over what was shown to whom. As Goffman understands so well, it is important for a person to preserve a sense of a coherent front and to act 'as if'. When imagining oneself from the perspective of the other, a person is able to deny or ignore the small front slippages that betray the deceit and social convention dictates that we all behave as audiences willing to be deceived.

Another important issue which arose later in the research process was the difficulty recording what was essentially complex, integrated and multi-dimensional material in a sequential and linear form. The limitations of words to express in full the qualities of the experience of head injury sometimes overwhelmed and disheartened me. It is important, therefore, to acknowledge that this discussion of the experience of brain injury only manages an approximation of what these four men lived, and many important elements of their inner feelings and interactional dynamics may have escaped attention and expression. Max, Rob, Mark and Bryce will always remain the only experts in their own lived experience and it has only been possible to explore and articulate some part of this experience.

RECOMMENDATIONS FOR FUTURE RESEARCH

Successful recovery of autonomy, purpose and adaptivity after a brain injury appears to require the development of very special types of relationships with those who surround them as well as special types of settings. Recalling Sacks's (1985:141-2) comment quoted at the beginning of this thesis, if there is a basis for a "new and beautiful existential science and therapy" then, it will only be found by studying how meaning is negotiated in interaction despite impairments of cognition and perception.

This study traced the experience of four men and concentrated attention upon one small portion of their life, in one residential institution, in the period of time shortly after the head injury. Under the circumstances, any findings have only a possible relevance outside these parameters. Research

[208] This raised an important ethical concern for me. Whenever people expressed feelings of distress or horror about their self-presentation, I attempted to explore their feelings further with them and help them resolve any negative self-feelings. The conversations which resulted from such moments were usually positive and several of those who were most critical of themselves later remarked that they had found the experience very useful and would like to repeat it. Because of this, I felt confident about continuing with the research despite discovering this higher level of reactive effect than I had expected. See Chapter 3 p.122 for further discussion on this issue.

focused upon interaction and relationships outside a residential institution would allow clarification of the degree to which the nature of the setting influenced the recovery process. Research 10 or 12 years after the accident would offer a longer-term view of how people and their significant others resolve the crisis of head injury and continue to live their everyday life despite difficulties with awareness. It would be useful to compare the lifestyle and the degree of self-directed autonomy in people living in therapeutic communities, or living with a 'circle of support' with those who had returned to the living arrangement which existed before their accident.

As a woman researcher, I was saddened that it was not possible to include a woman as a subject within the study. At the time of the research, no women were admitted to the programme who met the requirements I had laid down.[209] Under the circumstances, it was debateable how much any findings could be applied to the experience of women with head injuries. Further research which explored the experience of women, particularly research which focused (as this study did) upon roles and role relationships, could find some interesting contrasts. It is very likely that such differences would raise important considerations in the planning of rehabilitation programmes and the designing of interactive strategies. Any findings may not apply to men in different cultures and settings.

Because the initial aim of this study was to discover what interactive strategies were most effective in supporting recovery of adaptivity, purpose and independence, the most obvious direction for further research suggested by this study, was the training and induction of new staff into the roles of a rehabilitation team in a residential setting. This study revealed just how important it was that the people the four men interacted with were sensitive, self-aware and capable of developing an emotional intersubjectivity. Just what staff training methods produce such people is a question which deserves further attention.

In this study, the framework of symbolic interactionism offered a new perspective upon recovery after brain injury because it allowed a linking together of psychological, philosophical and sociological theory. In this way an understanding could develop of how fundamental properties of humanness determine the course of recovery. My experience at Waimarie and in the process of conducting this research has convinced me that there is an urgent need for such a blending of traditionally separate fields of inquiry to continue. People with brain injury require the resources of a vast range of different knowledge bases, but even more, they require the creative blending of

[209] See Chapter 3, p. 99.

such resources by people who understand the self as the central guiding ideal of recovery. As Benner (1985:13) points out:

> **Extreme objectification and subjectification can not capture the experience of health and illness because human beings are never fully object or fully subject; they exist in the network of concerns and relations...Heideggerian phenomenology generates forms of explanation and prediction that offers understanding and choice rather than manipulation and control.**

For example, the field of electronic devices offers exciting and apparently boundless opportunities to people with disabilities to overcome a wide range of sensate, motor, visual and communicative disabilities. However, there is a need for people in such fields to understand that it is not the deficits which should guide the course of adapting to disabilities, but meanings and relationships.

CONCLUSION

From the perspective of symbolic interactionism, recovery from head injury was regarded as the rebuilding of an ontological self, capable of engaging in and interacting with its world again upon the basis of shared meaning. It was shown that people with impairments of memory, perception, attention and judgment were considerably more reliant upon their social and physical environment in managing this process during a liminal period. This reliance put them at risk of becoming divided against themselves during the recovery process. As a result, the relationships and interactive strategies which best supported recovery were those which scaffolded awareness during the recreation of self-understandings.

It was shown that recovery from brain injury can be usefully understood as the restoring and re-integration of the dynamic of a dual inner self. This process does not follow a linear path, nor does it fit neatly into a theoretical continuum but is the outcome of a complex and erratically proceeding blending of different levels of awareness. This appears to involve both interaction and intra-action and requires the emotional engagement of the person as a meaning-making entity. The concept of consciousness can not be understood as a number of discrete functions, therefore, but only as the negotiating of a new ontology or selfhood. As Sacks (1985:110) explains it:

> **To be ourselves we must have ourselves - possess, or if need be, re-possess, our life stories. We must "recollect" ourselves to ... maintain identity. The therapeutic challenge can be summed up as "only connect".**

Although the crisis is produced by damage to brain and nerve tissue, the only solutions for disorders of consciousness are those which encourage this process of recollection and connection. Because of this the only solutions are interactive and relational. Symbolic interactionism provides an alternative way of looking at the problems caused by brain injury; a way which points to interactive strategies which encourage purposeful, adaptive and independent living.

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APPENDIX A: INFORMATION SHEETS

MASSEY UNIVERSITY

DEPARTMENT OF SOCIAL POLICY AND SOCIAL WORK

Cognitive rehabilitation from a Symbolic Interaction

Perspective

Information Sheet for participants (apart from the four subjects)

1. THE RESEARCHER:

The researcher is Deb Sutherland, a part time polytech tutor at Waimarie Centre, and PhD student with the Department of Social Policy and Social Work, at Massey University.

She can be contacted at Waimarie, or at 19 Panui Rd, Waitanui, ph. 8587370

2. THE AIMS OF THE STUDY:

The researcher's goal is to understand how severe head injury affects the way people "interact." This will involve observing, filming and describing some of the different relationships, conversations and activities which four residents of Waimarie have over a period of two months. By analysing these, and by discovering the thoughts and feelings of all those involved in the interactions, some knowledge or ideas about working effectively with this group of people should emerge.

3. YOUR INVOLVEMENT IN THE STUDY:

If you agree to participate in the study, you may find that you have some of your conversations or treatment sessions observed and/or videotaped by the researcher. This would only happen when and if you spoke with or worked with one of the four subjects, and even then, only if you happened to be with them during the ten hours planned for videotaping each month.

Also, if that piece of the videotape is selected for a more "in depth" analysis, you might be asked to take part in an interview with the researcher, during which you would look at the videotaped session and discuss what was happening, describing your thoughts and feelings. The time commitment would never exceed one hour per month. These discussions would be recorded and the researcher may include your interpretations and attitudes in the final report.

4. HOW WILL THIS STUDY AFFECT YOU?:

The aim of this study is to capture on film, the normal everyday life of the four "subjects." You would not be expected to change what you would normally do, or to do anything extra. If you are asked to look at film of your interactions and discuss them, you will usually find this a rewarding and productive learning opportunity. However, you may sometimes have bad feelings about the way you dealt with a particular situation and feel it would be upsetting to "relive" such an experience. It is important therefore that you understand you have total control over the use of any such material. Your involvement in the study is based upon your willingness to participate, and the following protections will always apply:

(i) You are free to ask for further information about the study at any time.

(ii) All information obtained by the researcher will be treated in strictest confidence and your identity will not be revealed and nor will Waimarie be mentioned by name in any written document. The only exception to this would occur if you were involved in an activity which could seriously harm another

person. In this situation, the researcher would be ethically obliged to intervene, and/or breach confidentiality.

(iii) You are free to withdraw from the study at any time, and you are also free to ask that the videocamera be switched off or that the researcher remove herself at any time.

(iv) You have the right, either as a member of the staff or as a fellow resident, to ask for the filming to be stopped if you feel that it is distressing or destructive in any way. Even if you are not at that moment involved in being videotaped yourself, you have the right to have your concerns for someone else dealt with before the research can continue.

Similarly, the researcher has an obligation to switch off the camera and remove herself voluntarily when the situation seems too sensitive, or the participants especially vulnerable and at risk of psychological harm from the filming process.

(v) No one else, apart from the researcher and others being filmed alongside you, will view any videotape. Once the thesis has been completed, most of the tapes will be erased. If anything is kept, it will be for demonstration and/or teaching purposes. and your permission will be requested separately for each such "behaviour specimen."

MASSEY UNIVERSITY

DEPARTMENT OF SOCIAL POLICY AND SOCIAL WORK

Cognitive rehabilitation from a Symbolic Interaction

Perspective

Information Sheet for the four subjects of the Study

1. THE RESEARCHER:

The researcher is Deb Sutherland, a part time polytech tutor at Waimarie Centre, and PhD student with the Department of Social Policy and Social Work, at Massey University.

She can be contacted either at Waimarie, or at 19 Panui Rd, Waitanui, ph. 8587370

2. THE AIMS OF THE STUDY:

The main aim of this study is to understand how having a head injury changes the way people "interact" with others. It will do this by observing and then analysing some of the conversations and activities you have during a normal daily routine. By focusing upon your experiences and how they are felt and understood by you, this study should help us learn how to work more effectively with people who have had a serious head injury.

3. YOUR INVOLVEMENT IN THE STUDY

If you agree to participate in the study, you will firstly be asked to assist me in recording your life story. This will involve up to four audio-taped interviews of no more than two hours each. Your family or other people very close to you would also be asked to discuss your life with me. Both you and your family would have the opportunity to read or hear everything I planned to say about your life as a result of these interviews, and you may change anything you do not agree with.

Once the life history is completed, I would expect to follow you about and "observe" your daily life and, using a video-camera, film some of your activities. This observation would be for a period of ten hours a week for one week in a month. When the ten hours of tape has been analysed, smaller pieces of tape which are especially interesting will be edited out. You will then be asked to look at this tape and discuss it, describing your thoughts and feelings about the experiences you see yourself going through on this film.

For two months, this routine will continue: one week of being observed and filmed, and then two or three interviews over the next three weeks to discuss the film. At the end of the two months, there will be a final interview to present you with everything from these discussions that will be used in the written report. You would have the right to confirm or challenge any of this material.

4. HOW WILL THIS STUDY AFFECT YOU?:

The first step, collecting the life history:

Collecting all the information for your life history will demand some of your time. However, to reflect upon your life and its meaning both before and after your accident should be a positive and rewarding experience. A copy of the written life history will be made available to you.

The second part of the research, the observation and recording of your daily life:

Because the aim of the study is to capture on film your normal everyday life, you would not be expected to change what you normally do or do anything extra, just to accept my presence as I observe you. This would not exceed four hours on any one day.

Looking at film of your actions and discussing them will usually be a rewarding amd productive learning opportunity. However, you may sometimes have bad feelings about the way you dealt with a particular situation and feel it would be upsetting to "relive" such an experience. It is important therefore that you understand you have total control over the use of any such material. Your involvement in the study is based upon your willingness to participate, and the following protections will always apply:

(i) You are free to ask for further information about the study at any time.

(ii) All information obtained for the research will be treated in strictest confidence and your identity will not be revealed and nor will Waimarie be mentioned by name in any written document.

(iii) You are free to withdraw from the study at any time, and you may ask that the videocamera be switched off or that I leave at any time when you feel uncomfortable.

(iv) I will switch off the camera and remove myself voluntarily when the situation seems too sensitive to film comfortably.

(v) No one else, apart from the researcher and others being filmed alongside you, will view any videotape. Once the thesis has been completed, most of the tapes will be erased. If anything is kept, it will be for demonstration and/or teaching purposes. and your permission will be requested separately for each such item.

APPENDIX B: CONSENT FORMS

MASSEY UNIVERSITY

DEPARTMENT OF SOCIAL POLICY AND SOCIAL WORK

Cognitive rehabilitation from a Symbolic

Interaction Perspective

STATEMENT BY NEXT OF KIN, AND/OR LEGAL GUARDIAN OF THE

SUBJECTS

I have been given a copy of the information sheet for subjects of this study, and also that for other participants. I have read these and I have had my questions answered satisfactorily.

1. I agree with and support _____'s decision to take part.
2. I agree to be interviewed in the collection of material for the life history.
3. I agree to have my own interactions videotaped under the conditions explained in the information sheet for participants (if I should happen to be at Waimarie during a filming period).
4. I agree to have this material used in the researcher's thesis and subsequent professional publications.

I understand that the study has been approved by two ethical committees, one appointed by Massey University, and the other by Health Care, Haverley, (Ref. No. 1993/31) and also that I may withdraw my agreement to participate at any time. I understand that all material will be confidential, that Waimarie's name and _____'s name will be changed in any written report. I understand that taking part in this study will not effect the position of _____ at Waimarie in any way.

SIGNATURE OF FAMILY
MEMBER/GUARDIAN_____

SIGNATURE OF
RESEARCHER_____

DATE_____

MASSEY UNIVERSITY

DEPARTMENT OF SOCIAL POLICY AND SOCIAL WORK

Cognitive rehabilitation from a Symbolic

Interaction Perspective

STATEMENT BY NEXT OF KIN, AND/OR LEGAL GUARDIAN OF PARTICIPANTS

I have been given a copy of the information sheet for participants in this study. I have read it and I have had my questions answered satisfactorily.

1. I agree with and support _____'s decision to take part.
2. I agree to have this material used in the researcher's thesis and subsequent professional publications.

I understand that the study has been approved by two ethical committees, one appointed by Massey University, and the other by Health Care, Haverley, (ref. No. 1993/31) and also that I may withdraw my agreement for _____to participate at any time. I understand that all material will be confidential, that Waimarie's name and _____'s name will be changed in any written report. I understand that taking part in this study will not effect the position of _____ at Waimarie in any way.

SIGNATURE OF FAMILY
MEMBER/GUARDIAN:_____

SIGNATURE OF
RESEARCHER: _____

DATE: _____

MASSEY UNIVERSITY

Department of Social Policy and Social Work

Cognitive Rehabilitation from the Perspective of Symbolic Interactionism

Consent Form For Participants

I have read the information sheet and/or been given information about the details of this study. My questions have been answered to my satisfaction, and I understand that I may ask further questions whenever I wish to, and also that I may withdraw from the study at any time.

I understand that the study has been approved by two ethical committees, one appointed by Massey, and the other by Health Care, Haverley, (Application No. 1993/31).

I understand that all material will be confidential, that Waimarie's name and my name will be changed in any written report and that taking part in this study will not effect my position at Waimarie in any way.

I wish to participate in this study under the conditions set out in the Information Sheet.

SIGNATURE OF
PARTICIPANT: _____

SIGNATURE OF

RESEARCHER: _____

DATE: _____

WITNESS: _____

MASSEY UNIVERSITY

Department of Social Policy and Social Work

Cognitive Rehabilitation from the Perspective of

Symbolic Interactionism

Consent Form For Subjects

I have read the information sheet and/or been given information about the details of this study. My questions have been answered to my satisfaction, and I understand that I may ask further questions whenever I wish to, and also that I may withdraw from the study at any time.

I understand that the study has been approved by two ethical committees, one appointed by Massey, and the other by Health Care, Haverley, (Application No. 1993/31). I understand that all material will be confidential, that Waimarie's name and my name will be changed in any written report and that taking part in this study will not effect my position at Waimarie in any way.

I wish to participate in this study under the conditions set out in the Information Sheet.

SIGNATURE OF PARTICIPANT:_____

SIGNATURE OF NEXT OF KIN:_____

SIGNATURE OF RESEARCHER:_____

DATE: _____

WITNESS: _____

APPENDIX C: LETTER TO RESIDENTS' FAMILIES

WAIMARIE CENTRE
Haverley Health Care
WAITANUI

Dear

We would like you to be aware that _____ has agreed to participate in a research project here at Waimarie which may involve being filmed.

S/he would not be the main subject of the film, which is about the daily life and experience of people with head injury, but may be filmed interacting with, or doing some group activity with one of the four subjects.

The research project is being carried out by Deb Sutherland, a part time polytech tutor employed here. She is also an extramural PhD student with the Dept of Social Policy and Social Work at Massey University and is interested in studying severe head injury and its effect upon social interaction and relationships.

The research has been approved by the Massey University Ethics Committee and the Haverley Health Care Ethics Committee (Ref. No. 1993/31) and there are safeguards built into its design to ensure any information is confidential and nobody is ever put in a stressful situation. Of course, all the staff here would also put the interests of residents ahead of any such project.

While the project was explained to _____ before s/he gave his/her consent, you may wish to have any concerns discussed with you as well. Deb Sutherland will be happy to send you any further information you wish, or to talk over any concerns you have with you.

Yours sincerely

PP Waimarie Clinical Team

APPENDIX D: RANCHO LOS AMIGOS COGNITIVE SCALE

LEVEL I	No response to pain, touch, sound or sight.
LEVEL II	Generalised reflex response to pain.
LEVEL III	Localised response. Blinks to strong light, turns toward/away from sound, responds to physical discomfort, inconsistent response to commands.
LEVEL IV	Confused-Agitated. Alert, very active, aggressive or bizarre behaviours, performs motor acitivities but behaviour is non-purposeful, extremely short attention span.
LEVEL V	Confused-non-agitated. Gross attention to environment, highly distractible, requires continual redirection, difficulty learning new tasks, agitated by too much stimulation. May engage in social conversation but with inappropriate verbalisations.
LEVEL VI	Confused-appropriate. Inconsistent orientation to time and place, retention span/recent memory impaired, begin to recall past, consistently follows simple directions, goal-directed behaviour with assistance.
LEVEL VII	Automatic-appropriate. Performs daily routine in highly familiar environment in a non-confused but automatic robot-like manner. Skills noticeably deteriorate in unfamiliar environment. Lacks realistic planning for own future.
LEVEL VIII	Purposeful-appropriate.

FROM: *Intervention strategies for Language Disorders Secondary to Head Trauma.*
HAGEN, C. and MALKMUS, D. 1979. a Paper presented at American Speech-Language-Hearing Association Convention. Short Course, Atlanta.

APPENDIX E: LIFE HISTORY INTERVIEW CHECKLIST

SUBJECT INTERVIEW QUESTIONS:

1. The 'Chapter headings' of your life before the accident?
2. In what way has the head injury changed your abilities?
3. In what ways have your social relationships changed?
4. What treatment do you think you need at the moment?
5. How would you describe yourself emotionally?
6. Do you have any strategies to help you cope??
7. What are your goals?
8. How do you see yourself 10 years from now?

FAMILY/SIGNIFICANT OTHER QUESTIONS:

1. The 'chapter headings' of the person's life.
2. Perceptions of changes to the person as a result of accident.
3. Experiences crucial to life career both before and after accident and why.
4. Influential people - before and after - why.
5. Initial reactions to head injury - yours and others.
6. Your perception of the change.
7. Your perception of the subject's perception of the change.
8. Personal Goals.
9. Your Perception of goals and or the future.
10. Relationship patterns then versus now.
11. Ideal rehabilitation model.
12. Perception of subjects social role performance, emotional status, coping strategies, social support.

BACKGROUND HISTORY CHECKLIST

- Coma/PTA duration.
- Retrograde amnesia.
- cognitive changes
- physical/motor changes
- perceptual changes

1. Identification: education level, professional qualification, and position.
2. Circumstances of accident: recent alcohol consumption, life events during the year preceding the accident.
3. Pretraumatic: medical problems, previous injury, psychiatric problems, social and family problems.Behaviour problems

APPENDIX F

CHECKLIST FOR INTERVIEWS ABOUT FILMED INTERACTIONS

1. What happened in this interaction (or at this moment)? How do you feel about this?
2. Functions and/or consequences of your and others' behaviour.
3. Typical of your interactions with this person? If not how would it differ and why do you think this interaction was different?
4. How would you describe your goals if any, in this interaction and do you think anything was accomplished? Was there any unintended outcome.
5. Would you describe this interaction as being a positive, negative or neutral experience, a) for you and b) for the other interactants.
6. Differences/similarities found in this interpretation and that of others interviewed.
7. Reaction to the researcher's analysis of the theme depicted in this exemplar.

CHECKLIST FOR ANALYSING THE INTERVIEW ABOUT THE INTERACTIONS

1. Internal or external attributions. Characterological or behavioural.
2. Epistemological conflict and emotion - justifications and rationalisations.
3. The relative status (insider/outsider).
4. The interview technique (jogging memory vs open ended strategies etc).
5. Preconceived categories which might affect understandings.
6. The alertness of the participants.
7. The obtrusiveness of the video recorder and/or taperecorder and its apparent effect if any, upon those involved.
8. The rhetorical scheme or performance being played out - complementarity.