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**Beyond the text:  
Voices of self in aphasia**

A thesis presented in partial fulfillment of the requirements for the degree of

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New Zealand

Maxine E. Bevin

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## ABSTRACT

This thesis is about the stories people with aphasia tell about self and identity. It is also a story about the process of research with people with aphasia. It is about narrative and self-construction and it is in itself a narrative. While there has been much discussion about the need for interventions which take into account self and identity in aphasia and innovative pioneering work on therapies addressing identity, there is, however, still little specific reported research in aphasiology that addresses these issues. This applied project sought to further understand the impact of aphasia on the construction of self by exploring self and identity using a narrative approach and using a more participatory approach to research. It was grounded in narrative and relational theory and this led to exploring self and identity through life stories. Eight people with aphasia took part in a life story interview. These were analysed using the voice centred relational method which culminated in eight interpretive narratives. The main findings of this qualitative inquiry were support for the notion that biographical disruption is not the only response to aphasia, support for a relational approach to self and identity and support for inclusive research practices in aphasia research. The strengths and limitations of the project were examined and implications for research and practice were developed.

Dedicated to Marcus Bevin

02.06.1970 – 04.05.2000



With permission of the artist, Terry McKenna, Hawke's Bay

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## EPIGRAPH

The outcome is a demonstration of knowledge as a subjective relational enterprise, always created and recreated between individuals rather than in isolation.

Ruthellen Josselson and Amia Lieblich, 2001, p.285.

## READERS' GUIDE

I entered this process with a background in speech-language therapy and a particular interest in aphasia. I had already completed an Honours project in psychology with people with aphasia using a narrative approach and I felt that this project could be broadened to consider self and identity in aphasia. I assumed that this would be a very straightforward process. However, the time of doctoral exploration has exposed me to many approaches to self and identity and to research philosophies in the human sciences. What appears in print, here and now, will never represent the process as it occurred. It is laid out in a linear way, chapter by chapter, but it will not capture the circular and sometimes serendipitous nature of the research process and of the discoveries. I have formed this text to achieve a piece of work that is intelligible. In developing a methodology to support people with aphasia to tell about self and identity, I am greatly influenced by the subjective and relational nature of knowledge creation (Josselson & Lieblich, 2001). I consider the reading of this document to also be a relational activity. However the conversations are constrained by time, by the distance between text and meaning, and by the silence of the conversations that may be had with the participants as the stories of this research project are read.



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SECTION A

SETTING THE SCENE

Chapter 1: Understanding aphasia

Chapter 2: Understanding the project

## Chapter 1

### Understanding aphasia

**An orientation**

**Overview**

**What is aphasia?**

Classifying aphasia

**The purpose of a definition**

An aphasia-friendly definition

A social definition of aphasia

**“My asphasia word”**

**Summary**

## An orientation

- 1953<sup>1</sup>. Mary: *It's very pleasing for me, that I,*
1954. Maxine: *[I bet.*
1955. Mary: *I'm able to talk about things, and talk with others.*
1956. Maxine: *Yes.*
1957. Mary: *'Cos, for a lot of what I was, I couldn't even talk myself,*
1958. Maxine: *And how did that feel,*
1959. Mary: *[of myself.*
1960. Maxine: *[at that time? You couldn't talk to yourself?*
1961. Mary: *Yeh. But it was also going on here (and she gestures a circular motion beside her head). So it's okay. It was all there.*
1962. Maxine: *Yeh.*
1963. Mary: *So I'm quite pleased that it's happening now.*
1964. Maxine: *Yes. And, I think too, that the reading becomes part of your life. And then, when it's not as easy, it must be frustrating.*
1965. Mary: *Well, I think it's important, that I write things every day,*
1966. Maxine: *Mmm, mmm.*
1967. Mary: *do something.*

Mary and I completed a life story interview in 2004. Mary had aphasia as the result of a stroke which had occurred four years earlier. Our interview was the last one of the project. While Mary's story is presented in a later chapter, her description of her experiences of communication disability serves here as a starting point for our understanding of aphasia. Rather than providing a breakdown of the types of linguistic impairment in aphasia, Mary's personal explanations tell of the meaning that the talking difficulty has had for her.

Significant to Mary is her ability to talk about things to others, her continued commitment to improving her reading and writing abilities and the subsequent satisfaction with this. Although Mary was not asked to define what aphasia was, she introduces us to aphasia as it is in her world. However, there are other definitions and this chapter provides some of those available through the

<sup>1</sup> The line number in the transcript (see Appendix A).



literature. While these are a necessary backdrop to the project, it is important to the project that we listen to Mary and to other people with aphasia as their experiences have the ability to move us beyond the content and structure of aphasic language and tell us about what it means to live with aphasia. A project about how aphasia impacts on self and identity and how self and identity are reconstructed following aphasia relies on what people with aphasia share with us and how that sharing is negotiated.

### Overview

This chapter is the first of two in Section A, "Setting the Scene", which is a beginning point for understanding aphasia, identifies why the research is needed and lays out the structure of the thesis. Chapter One provides an introduction to aphasia so that subsequent discussions about the project make sense. It is primarily a technical narrative, however it also advocates for an understanding of aphasia from the perspective of the person with aphasia; a theme which permeates the research and the writing.

### What is aphasia?

*Impairment, as a result of brain damage, of the capacity for interpretation and formulation of language symbols; multimodality loss or reduction in the efficiency of the ability to decode and encode conventional meaningful linguistic elements (morphemes and larger syntactic units); disproportionate to impairment of other intellectual functions; not attributable to dementia, confusion, sensory loss, or motor dysfunction; and manifested in reduced availability of vocabulary, reduced efficiency in application of syntactic rules, reduced auditory retention span, and impaired efficiency in input and output channel selection.*

Frederic Darley, 1982, p.42.

What is aphasia?<sup>2</sup> What follows is in contrast to but always grounded by Mary's introduction. The following definitions, similar to the Darley (1982) quotation, are the traditional descriptions that you would find if you were to consult a textbook on aphasia. Aphasia is an acquired impairment in language and the cognitive processes underlying language caused by organic damage to the brain

---

<sup>2</sup> Some authors, researchers and clinicians may use "dysphasia" to indicate a lesser severity of the same problem. For continuity in this project, the term "aphasia" will be used.

(Chapey, 1981). Aphasia may affect any or all language modalities including understanding of spoken language, speaking, reading, writing and gesture on a continuum of severity (Darley, 1982). Aphasia is not a speech or mechanical disorder and, as such, it is not due to weakness, slowness or inco-ordination of the muscles of speech or writing. It is not due to poor sight or hearing or intellectual impairment primarily, although these may co-exist with aphasia (Goodglass & Kaplan, 1983). Aphasia results from focal damage to those regions of the brain that form an anatomical basis for language. There exists an almost exclusive relationship between aphasia and damage to the left hemisphere (Bayles, 1986; Goodglass, 1993). It is a disorder most commonly associated with cerebrovascular accident (stroke) but it may also be caused by traumatic brain injury, neoplasm, inflammation, infection or surgery. These can also cause other communication disorders including dysarthria (a motor speech disorder resulting in slurred speech), apraxia of speech (a motor speech disorder resulting in difficulty recalling the motor patterns and sequences for speech), language of generalized intellectual impairment, cognitive-communicative disorders, and right hemisphere communication impairment. It is possible for people to present with more than one communication disorder.

### Classifying aphasia

Analysis of patterns in aphasia has a long history and it has led to the identification of different types, or syndromes, of aphasia. This is but one way of classifying aphasia but it tends to be the system most shared between professionals involved in assessment, treatment and research in aphasia. The syndromes represent regularly occurring patterns of language behaviour and lesion sites (Goodglass & Kaplan, 1983) and are summarized in Table 1.1 (adapted from Bates, 2002). The most common syndromes are: Broca's aphasia (non-fluent conversational speech with relatively good comprehension), Wernicke's aphasia (fluent speech with paraphasic errors where an incorrect or unintended word is produced for a correct one and poor comprehension), anomic aphasia (paraphasic errors, circumlocution and difficulty with word recall) and conduction aphasia (non-fluent conversational speech and difficulty with repetition skills) (Chapey, 1994). Most people within these aphasic syndromes will experience some difficulties with reading and writing and word recall as part of their syndrome. Within each syndrome severity ratings range from very mild to severe. It is important to note, however, that less than sixty percent of people diagnosed with aphasia will be able to be classified as one of the aphasic syndromes.

Table 1.1: Classification of syndromes of aphasia

<b>Classic Aphasia Taxonomy</b>				
- = relatively impaired      + = relatively spared				
APHASIA TYPE	NAMING	FLUENCY	COMPREHENSION	REPITITION
Broca's	-	-	+	-
Transcortical Motor	-	-	+	+
Wernicke's	-	+	-	-
Transcortical Sensory	-	+	-	+
Conduction	-	+	+	-
Anomia	-	+	+	+
Global	-	-	-	-

### The purpose of a definition

Traditionally, aphasia has been defined in neurogenic and linguistic or cognitive terms (Kagan, 1998). However, the way we define or describe aphasia is also directly related to who we are, for what purpose and for whom we are providing the definition, and the time and paradigm within which we are formulating that definition. Aphasia texts and aphasiologists may differ in their definitions on the basis of their theoretical understanding of aphasia.

McNeil and Pratt (2001) argue that researchers and clinicians need to specify the definition of aphasia under which they operate "as a way of increasing the validity and replicability of both research and clinical procedure" (p. 901). A formal definition can support the development of therapy and clinical practice. Insight into the clinical and theoretical assumptions of the researcher or clinician allows a reader to place findings into a meaningful context.

Darley (1982) made three distinctions based on what can be included and what can be excluded in order to arrive at necessary concepts and nomenclature. Firstly, aphasia is not a speech disorder. It is a language problem and has to do with the ability to decode and encode “meaningful linguistic units” (p. 8). Secondly, it is language-specific. Language difficulties are disproportionate to dysfunction in other cognitive areas. Thirdly, aphasia is not multimodality-bound, that is, it does not result from impairment of a specific input or output transmission channel (for example hearing impairment). Chapey and Hallowell (2001) acknowledge the complexity of aphasia and therefore the many ways of conceptualizing it but attempt to manage this complexity by identifying and expanding on four primary facts critical to an adequate definition of aphasia: “. . .it is neurogenic; it is acquired; it affects language; and it excludes general sensory and mental deficits” (p. 3). Wertz (2000) has an alternative way of describing the difficulty that exists in trying to define aphasia:

*A solution to the problem of stating the nature of aphasia is to say that aphasia is what aphasiologists say it is. Or we could adopt the United States Supreme Court’s position on pornography – ‘We don’t know how to define it, but we know it when we see it’.*

p. 4.

### An aphasia-friendly definition

The preceding discussion has been concerned with aphasia as aphasiologists perceive it. Are these then the definitions we communicate to the person with aphasia and their family? How do we, as professionals, define aphasia for the benefit of people with aphasia? Parr, Pound, Byng and Long (1999) developed a handbook on aphasia for people who have aphasia. Aphasia, in this handbook, is defined so that people with aphasia and their families may better understand what has happened to their communication and it is based on a prior exploration of aphasia from the point of view of the person with aphasia, as shown in Figure 1.1.


Finally, people with aphasia, as experts, are able to define what aphasia is as they experience it. Parr, Byng, Gilpin and Ireland (1997) completed in-depth interviews with fifty people with aphasia. This was an extensive account of aphasia by people with aphasia and it rightfully made claim to breaking new ground. These interviews give a wealth of material about what aphasia is for people who have aphasia. Parr et al. (1997) point out that people with aphasia do not actually talk about “aphasia” nor do they talk about “language”. People do not usually think about their difficulties as a disruption of a general language system but rather they identify the very things they are having difficulty with. They talk about not remembering, an inability to read or write, or not being able to


talk properly. For the purposes of this writing, I would like to think that a definition of aphasia would assist the reader to understand what aphasia is in order to make sense of the subsequent text and the story. It should also serve as a starting point for the "outsider" to begin to gain some understanding of the experience of aphasia. Darley's (1982) definition, based on inclusion and exclusion, is a workable definition. However, it excludes reference to the context and the consequences of aphasia. Although aphasia is certainly a disruption at a physiological level, this definition tells nothing of the disruption that occurs at a personal and interpersonal level.

## What is aphasia?

You may have been told that you have **aphasia**.

What is **aphasia**?





If you have aphasia, you may find it hard to:


- talk
- understand others when they speak
- read
- write
- use numbers and do calculations.

People who have aphasia can think clearly.  
But they have difficulty getting **messages in and out**.  
They know what they think and feel, but can't get to the words.

If you have aphasia:

- you are still a **competent adult**
- you **know** what you want to say
- you can make your own decisions
- you are not deaf.

I have **aphasia**.  
I can think clearly.  
But I can't get the  
messages in and out.



But aphasia means you have a problem with **communication**.

Figure 1.1: Definition of aphasia for people with aphasia

(Parr et al., 1999, p. 2).

## A social definition of aphasia

If we consider aphasia to be more than the disruption to language and communication and consider it instead to be a disruption to the social use of communication and psychosocial wellbeing, then aphasia rehabilitation takes on a new form (Lyon, 1998). Kagan (1998) calls for an expansion of more traditional definitions of aphasia to include aphasia as an acquired neurogenic language disorder “that may mask competence normally revealed in conversation” (p. 818). It may be hard for people with aphasia to take part in conversation and this may result in them being perceived to be less competent in knowledge and in social interaction. Simmons-Mackie (2001a) also expands the definition of aphasia to include “diminished participation in life events and reduced fulfillment of desired social role” (p. 248). While the disruption to processes of language is embedded within Darley’s definition (1982), Lyon (1998), Kagan (1998) and Simmons-Mackie (2001b) enable us to consider the disruption to psychosocial well being and the social use of communication. The key is that these processes are disrupted or altered, not lost. Such a definition has an impact on how we approach our research and our practice with people with aphasia.

### “My asphasia word”

The final word, however, most aptly sits again with the person with aphasia. An insider’s perspective can be a powerful tool for both educating others but also for strengthening identity. Chris Ireland, whose poem is reproduced in Figure 1.2, is a poet who has aphasia and who uses her language to entertain and to empower. Her poem “My asphasia word” captures the world of aphasia but also challenges the reader to consider the language of aphasia in its totality (Pound, 2004).

### Summary

This chapter was a brief orientation to aphasia so that further discussions would have a location. It considered formal definitions and then introduced the understanding of aphasia as a disruption to social communication. Finally, an insider’s perspective was included linking back to the opening excerpt from Mary’s life story.

The next chapter is the final chapter in this section on setting the scene. It reviews my background in aphasia and an earlier project about aphasia. It develops the reasons for the research interest in self and identity in aphasia and summarises the research aims, outcomes and questions. It closes by outlining the organisation of the thesis.

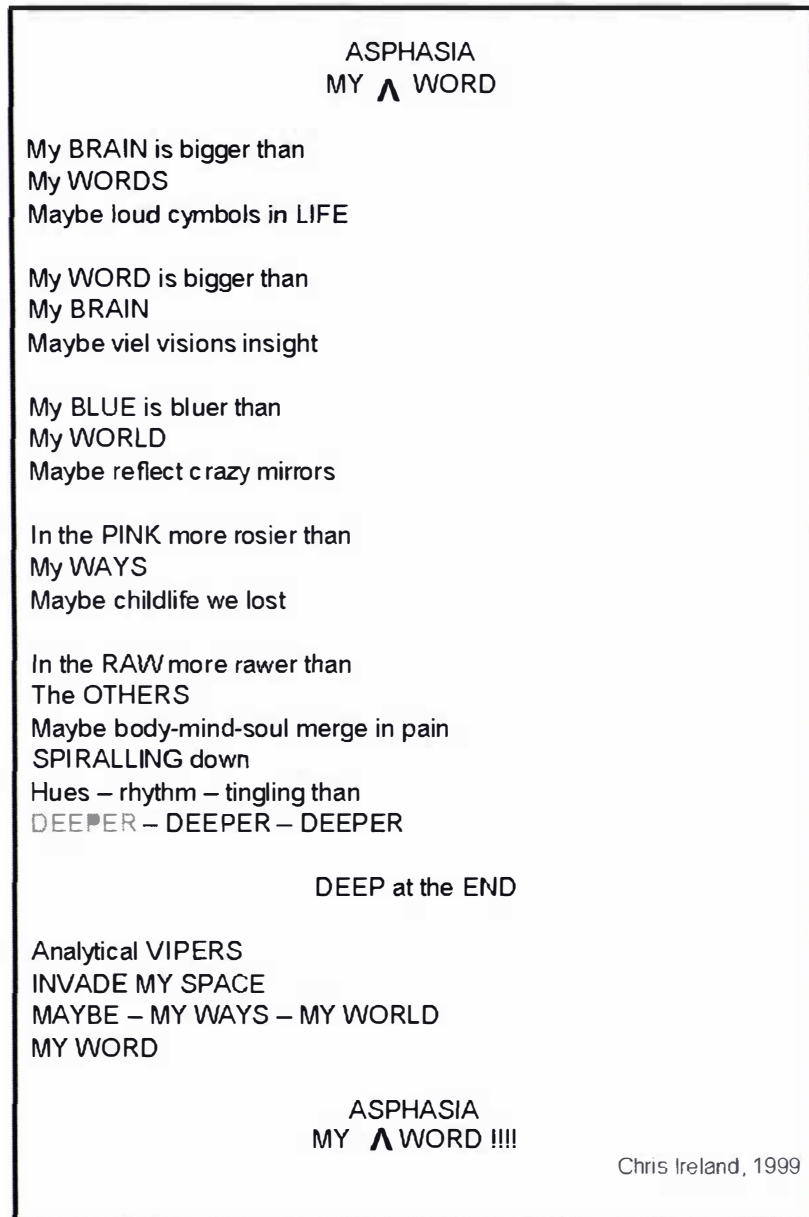
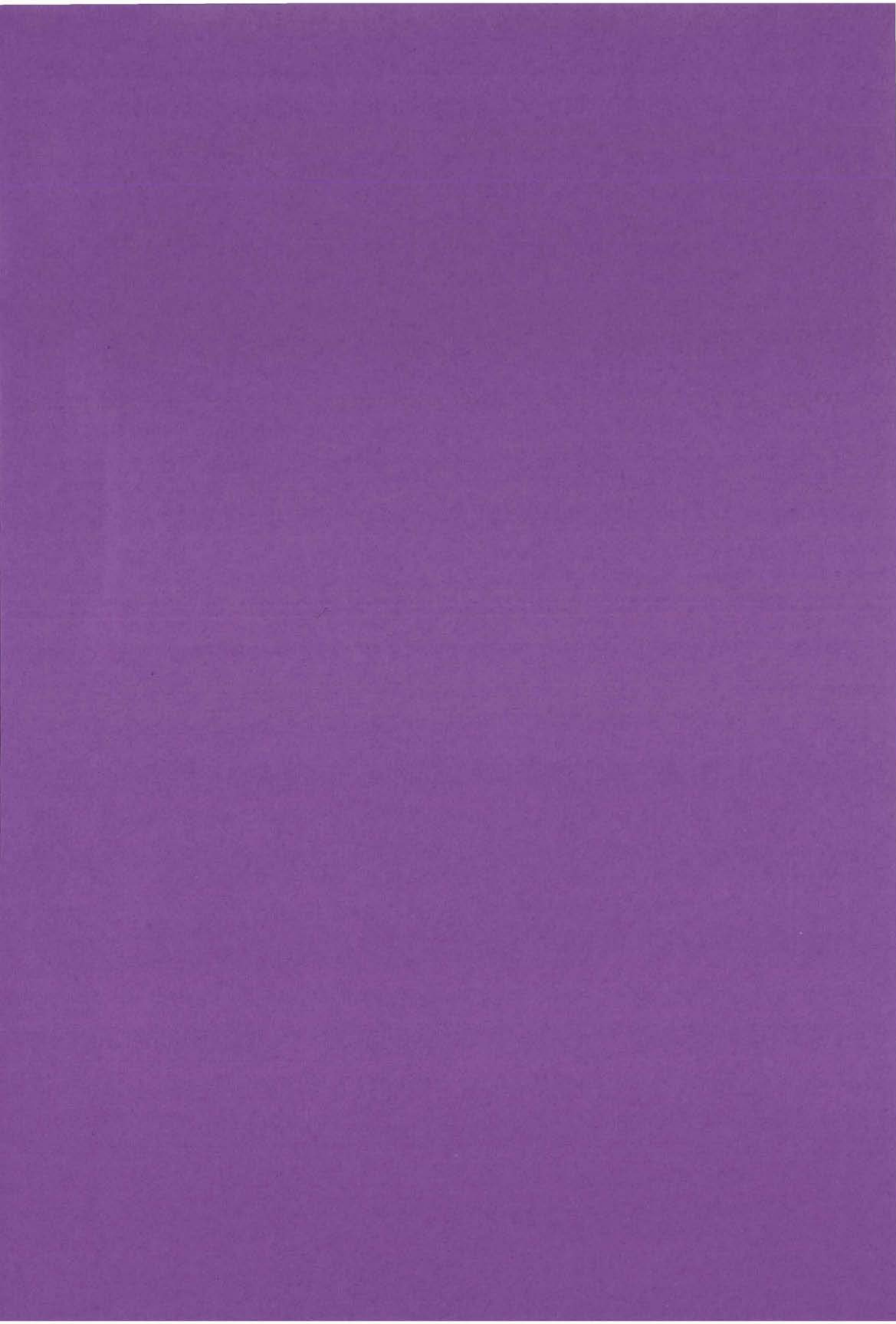


Figure 1.2: My asphasia word

(Pound, 2004, p. 48-49)





## Chapter 2

### Understanding the project

#### Overview

#### Aphasia: a part of my biography

#### An exploratory project

Looking outside the square

Psychosocial consequences of aphasia

The project

#### Why self and aphasia?

A brief history

Social approaches to aphasia

By social model alone?

Psychosocial issues

The self in aphasia

*Beyond traditional boundaries*

*Philosophies, assumptions and values*

*Stories of aphasia*

Researching the self

#### Conceptualizing the project: aims, outcomes and questions

#### Organizing the thesis

#### Summary

## Overview

The previous chapter was an orientation to aphasia, not just from a technical point of view, but more importantly from the perspective of the person with aphasia. Chapter Two completes the setting of the scene by summarizing my background in aphasia and reviewing an introductory project that was a catalyst for this research. The reasons for the current research interest in self and identity in aphasia are then discussed and the research aims, outcomes and questions are considered. The chapter concludes with an outline of the subsequent chapters to provide some direction for a reader.

### **Aphasia: a part of my biography**

What follows is an attempt to provide a context and start the process of identifying my working assumptions based primarily on my own history with aphasia. It may then be clearer to the reader the location for the project but also to how my work may be interpreted. As a speech-language therapist, my clinical experience over the last twenty-five years has involved working together with people with aphasia and their families. I think back to the influencing presence in my history of several aphasia therapists and I recall their “values” being the gift that I took away from my clinical practice with them. What were those values? They were the centrality of the person with aphasia to the therapy process and the respect which was evident in their actions and their words. I also took away a significant message that the person was more than the aphasia.

As a student, I encountered the academic complexity of aphasiology. Through my associated clinical placements I had the opportunity to be involved in people’s lives in a productive way. The therapy I observed, and was supervised in, was based on mutual respect and rapport and I was greatly influenced by these experiences. Later, in the late nineteen seventies as a new graduate speech-language therapist, I worked in a hospital setting where my main work priority was people with communication disability following stroke. At this time, the effectiveness and efficacy of speech-language therapy in aphasia was a question for debate. Working within a medical environment brought challenges from medical staff about whether speech-language therapy really made a difference for people with aphasia. Therefore, some of my intuitions about the therapeutic relationship, the importance of psychosocial aspects and quality of life were dominated by the need

to demonstrate clinical effectiveness. The importance of those intuitions, however, was still very much present in my interactions with the person and their family but they were less visible in my oral and written reports. I instead emphasized the results of assessments and testing that identified the status of the impairment of aphasia. While my clinical work has been a priority, I have continued to feel the need to support my practice by extending my knowledge and by reference to research. This saw me embark on further study and I have complemented my role of clinician with exploring the role of researcher as a post-graduate student.

### **An exploratory project**

My post-graduate study has not specifically been in aphasiology or, in fact, in speech-language therapy but in psychology. After graduating, unable to access further study specific to speech-language therapy, I started an arts degree majoring in psychology. I chose psychology because there were many common threads linking psychology and communication disorders. A lack of choice has, in fact, been serendipitous. My introduction to health psychology further broadened my outlook and this led me to completing a small exploratory project in aphasia (Bevin, 1999). While the project was specifically about aphasia, it was also influenced by several other developments occurring in the context of research and practice at that time. These included the relationship between aphasiology and health psychology, an increased interest in the psychosocial consequences of aphasia, disability research, qualitative research and illness narratives.

### ***Looking outside the square***

Health psychology is a richly interdisciplinary field with new applications waiting to be discovered. While it has been suggested that most of the exciting research topics lie between disciplines, communication disability is rarely something health psychology addresses (Brumfitt, 1999; Marks, Murray, Evans & Willig, 2000). I was interested in the potential for a relationship between speech-language therapy, specifically the study of aphasia and health psychology. They are both developing disciplines with recent histories and coming from a strong biomedical background, they have found themselves as part of the medical agenda. A medical discourse dominates where illness is a pathology located within the physical boundaries of the individual (Marks, 1996; Spicer & Chamberlain, 1996). This individualism has gone hand in hand with a medical model where disease is constructed as a failure in or of the individual (Marks, 1996). And it also exerts an influence on

aphasia research and practice. Many of the issues faced by aphasiology stem from its adherence to a model which focuses attention on pathology rather than disability. Health psychology has connections with a range of social, biological and health sciences and aphasiologists concur that aphasia cannot be fully understood by one discipline only (Marks et al., 2000; Byng, Parr & Cairns, 2003).

Therefore placing this project within health psychology establishes a beneficial relationship and also allows aphasiology to consider alternative approaches. While social constructionism has emphasized the role of language in shaping and even creating reality, speech-language therapy has traditionally focused on linguistic analysis and is only now beginning to explore the sociocultural aspects of communication (Murray & Chamberlain, 1999).

### *Psychosocial consequences of aphasia*

At the time of developing the questions for this project, the influence of a biomedical approach to aphasia appeared to be to the neglect of psychological and social considerations. Although many of the psychosocial consequences of aphasia had been identified in the literature, very few published research studies had particularly addressed the psychosocial issues related to aphasia:

*The general lack of sensitivity in some studies to the 'person' dimension of aphasia, and the relationship of linguistic impairment to non-linguistic variables, have made some research results irrelevant to the issues which surround aphasia treatment and recovery.*

Martha Sarno Taylor, 1993, p. 322.

Reported studies have demonstrated the importance of addressing the psychosocial consequences of aphasia. Le Dorze and Brassard (1995) detailed the complex relationship between language impairment, personal interpretation and disability. They aimed to describe the handicap associated with aphasia based on the personal accounts of people affected by aphasia. The focus on psychosocial consequences enabled attention to the impairment but also to the restriction that impairment places on the person with aphasia's ability to participate in society.

### *The project*

I was interested in exploring the meanings that a person with aphasia brought to her/his experience of aphasia. The aims of the project were to explore the notion of change resulting from the disruption caused by aphasia for people with aphasia and to explore the meanings that people with aphasia brought to their experience. I investigated narrative research as an approach suited to the research questions and I was interested in people's storied accounts. Interviews were completed with three people with longstanding aphasia as the result of a stroke. These were analyzed identifying the core narratives that emerged from the interviews. The three participants were able to use their language to tell of their individual experiences of aphasia and their life after aphasia in their own words. They narrated their stories through the medium of their aphasic impairments. Although some of the structure of each narrative was determined by the interactions with me and the questions that I asked, it was possible to identify a core narrative around which the story units developed coherence. Regardless of the specific linguistic differences for the participants, each one told a story. The outcome of this project suggested that narrative analysis may be used to explore meaning and change in other people with aphasia. A secondary story from this project was my own account of sense making. What began as a search in others for meaning, became a search for meaning for myself as a professional, as a researcher and as a person. What began as a project to apply a particular method to research in aphasia became a journey of locating myself within the unfamiliar field of qualitative practices.

In researching the literature for this project, I found reference to concerns about self, identity and aphasia:

*Whatever the approach taken to communicative rehabilitation, the person's need to be understood – to regain a sense of what he or she used to be and to evolve a new identity – needs as much attention as detailed therapeutic exercises directed at language and speech.*

Shelagh Brumfitt, 1993, p. 574.

I concluded that this appeal for speech-language therapists to address the concept of self in aphasia (and in other communication disorders) was timely and, based on the findings of this exploratory study, narrative analysis would be an appropriate method to be used. This led to considering self and identity in aphasia for this doctoral project.

## Why self and aphasia?

The current research project is about self and identity in aphasia. My initial research interest had been in the psychosocial aspects of living with aphasia and this led to the consideration self and identity. What follows is an exploration of why there is now an interest in identity issues in aphasiology and why this research has been proposed. The conclusion is the development of the research questions.

### A brief history

From an historical perspective, the emergent interest in self and identity in aphasia seemed destined to become significant. Duchan (2001) chronicles the history of speech-language therapy and identifies the importance of external influences through defining four historical periods. In the formative years (1900 – 1945) speech-language therapy began to establish itself as a separate profession from medicine and the focus of therapy was on the remediation of speech disorders. The second stage, the processing period (1945 to 1965), saw a move from speech disorders to how language was processed in both children and adults. During the linguistic period (1965 – 1975) there was a shift from language processing to language as a structured system. The early emphasis of psycholinguistic theory was on syntax but by the early 1970s it was on semantics.

The late 1970s saw developments in defining language in terms of form and content while the next period, the pragmatics period (1975 – 2000), saw a shift in emphasis to defining language in terms of the social context. While communication had been considered to be primarily transactional where information is exchanged, it was increasingly being recognized that it was also interactional, a tool for social affiliation (Simmons-Mackie & Damico, 1995). In the early stages of this period, attention was still on remediation of a client's knowledge or processing problems with the assumption that the problems lay with the person with communication disability. Subsequently, a conversational turn saw an important role for communication partners and social approaches to assessment and intervention (Duchan, 2001). Aphasiology was also beginning to feel the influence of changing approaches in other social sciences such as psychology and sociology (Lesser, 2000).

What now are the issues for aphasiology that background this project? While the research agenda in aphasiology is still dominated by experimental research, there has also been an increase in research concerned with functional approaches to communication, quality of life, research based on the ICF<sup>3</sup> model, and research adopting qualitative methodologies (Parr et al., 1997; Damico, Oelschlaeger & Simmons-Mackie, 1999; Pound, Parr & Duchan, 2001; Parr, 2001; Davidson, Worrall & Hickson, 2003; Sorin-Peters, 2004; Cruice, Worrall, Hickson & Murison, 2005). In the practice realm, there has been increased attention to a social model of aphasia.

### **Social approaches to aphasia**

Although aphasia therapy has been founded on an individual pathology model of disability, the last decade has seen major steps being made in the growth of a philosophy embracing social approaches to aphasia (Jordan & Kaiser, 1996). This has been influenced by the work of key aphasiologists and also by the impact of changes within the humanities and social sciences. Other influences include the attention to the chronic nature of aphasia, funding restraints calling for balancing outcomes of treatment with cost, and demands from consumers to improve outcomes (Simmons-Mackie (2001a).

Two main approaches to a social model in aphasia have been identified; one focusing mainly on the dynamics of social interaction and the other focusing largely on reducing barriers and issues of accessibility at a societal level (Parr & Byng, 1998; Kagan, 1998; Simmons-Mackie, 1998). These differences appear to have a geographical orientation (United States and United Kingdom respectively) which implies an influence of cultural and historical variables in how the different "approaches" of the social model have developed.

It is suggested that we, as therapists, should redefine our role from one of expert to considering the person with aphasia as the real expert on the consequences of aphasia (Simmons-Mackie, 2000a). Byng, Parr and Pound and their colleagues at Connect<sup>4</sup> (Byng, Pound & Parr, 2000; Pound, Parr, Lindsay & Woolf, 2000; Pound et al., 2001) have based their service on this and have a vision of a

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<sup>3</sup> The International Classification of Functioning, Disability and Health (ICF) is a "recognized framework for conceptualizing the functional states associated with a health condition" as provided by the World Health Organization (Davidson et al., 2003, p. 244).

<sup>4</sup> The Communication Disability Network is a charitable organization in London working with people with communication disability to find new ways of 'talking' and new ways of living (Connect, 2001).

world where aphasia is no longer a barrier to opportunity and fulfillment. This work has been influenced by the developments in the disability movement in the United Kingdom and collaborative research with disability researchers has grown from this orientation. Key issues within a social model philosophy are those of empowerment and emancipation; involving people with disability in determining their own agenda and setting out to change those policies, practices and structures that disable them (Pound et al., 2000).

### **By social model alone?**

Current literature reveals an ongoing tension between personal, or individual, and social approaches. With a move away from a medical model in aphasiology towards identifying the social context of communication, the value of an impairment-based approach has been questioned. There are some conflicts to be opened up particularly if a social model of disability is used as a basis for building a social model of aphasia. The debate centres on the acknowledgment of impairment and of personal experience within a social model. While it is not restricted to aphasiology, the common theme appears to be the divide between the individual and the social. The debate in speech-language therapy is between the impairment and social views in clinical practice. It has been argued that the two approaches are fundamentally incompatible and the impairment approach is criticized as "operating out of context" (Duchan, 2001, p. 41). Rightfully, the debate needs to be considered as philosophically driven and the task is to identify the philosophical foundation on which models are based (Simmons-Mackie, 2001b). Byng (2001) however focuses on the integration, rather than opposition, of approaches. She highlights the value of such debate in encouraging us to examine the assumptions on which our therapies are based and makes a strong point that such polarity can encourage clinicians to "adopt positions and focus on approaches" (p. 71). What is of concern is that people with communication disability do not appear to have an interest in positions or approaches. They want to be listened to and for clinicians to then use their resources and skills in considering a range of intervention in partnership with them. She provides a grounded summary:

*I know if I became aphasic I would like speech and language therapists to help me understand my communication, change and maximize my residual communication skills through working directly on my impairment and through helping me to use a range of strategies, as well as working on changing my environment, supporting and my family/friends in understanding and coping with what has happened, and challenging society's attitude and practices towards me.*

Sally Byng, 2001, p. 71.



The growth of functional and social approaches can be seen to signal an overall movement from concern with not just language and communication repair but with “facilitating purpose and meaning in life and strengthening ties with others in those natural life contexts that matters the most” (Lyon, 1999, p.689). A message, arising particularly from the discussions around social approaches in aphasia, has been that psychosocial issues are not separable from communication rather they are woven together (Byng et al., 2000; Simmons-Mackie, 2001a).

### **Psychosocial issues**

From a psychosocial perspective, the inability to communicate in a social context affects how a person defines herself and this has an impact on self-esteem and the ability to develop and maintain relationships (Kagan & Gailey, 1993). While recognizing the impact of aphasia on psychosocial functioning, there has been an ongoing debate within the aphasia literature about the role of the speech-language therapist in attending to this domain. There is still a large collection of issues under the umbrella of “psychosocial” which makes assessment, intervention and research in this area difficult. These include vocational, social, psychological and familial domains (Hermann, Johannse-Horbach & Wallesch, 1993; Hermann, 1997). Parr (2001) explored the complexity of psychosocial issues through the experiences of people with aphasia. Byng et al. (2000) provide some clarity by considering psychosocial effects within three categories: issues affecting lifestyle, issues affecting the person, and issues affecting others in the person’s social context. Loss occurs frequently in communication disorders and therefore a person’s psychological status, their personal reaction to loss, is not able to be disassociated from the neuropathology of speech and language disorders (Tanner & Gerstenberger, 1988; Hermann et al., 1993). Lyon (1992) identifies past treatment biases as reasons why there has been minimal interest in treating the psychosocial handicap of aphasia. Firstly, the handicap may not be seen as the main reason for the restriction on communication in natural settings. It could be that even if the handicap does influence the use of communication, it is a secondary one and there is also the belief that professionals with expertise would best manage psychosocial issues. He challenges these by saying that the disorder of language and communication and the disorder of psychosocial well-being are not just linked, they are interdependent because “disorders breeds disordered psychosocial wellbeing, and disordered psychosocial well-being breeds disordered language and communication” (p. 11). Attention to the psychosocial handicap of aphasia may be this missing aspect of our treatment.

Within this context, a “Life participation approach to aphasia” (LPAA) has been developed by North American aphasiologists as a consumer-driven service philosophy (Chapey, Duchan, Elman, Garcia, Kagan, Lyon & Simmons-Mackie, 2001). It recommends a range of social approaches which are designed to increase participation in authentic communication events, to focus on conversation, to provide communication support and to increase communicative confidence and empowerment. LPAA has developed from the background of functional and pragmatic approaches to aphasia but the project group believes that the term “functional” does not encompass the breadth of this work. While it is often used to narrowly mean just getting a message across in a functional manner, LPAA is part of a bigger picture where the goal for aphasia therapy is “re-engagement” with everyday society (Chapey et al., 2001, p. 237). Although functional communication has expanded aphasia treatment, there is currently still little account of the isolation and loss of identity that occurs with aphasia (Simmons-Mackie, 1998). The focus on linguistic impairment and basic functional skills is a philosophical bias that means that psychological and social issues have not been considered primary even though social affiliation and maintaining one’s identity are “goals” of communication (Simmons-Mackie, 1998, p. 233). Consequently one of the goals of intervention within a social model must be to increase communicative consequence and positive sense of self. Social approaches must address the development of a strong social identity as well as being successful as a communicator in people with aphasia (Simmons-Mackie, 1998). Sarno and Gainotti (1998) suggest that the loss of normal communication “strikes at the very roots of a person’s sense of self inasmuch as identity is based primarily on relationships, which in turn, depend largely on communication” (p.569).

### The self in aphasia

*I was a composer and a conductor for Heaven’s sake. I’ve conducted in most of the great music venues of the world. They don’t know that. They treat me like an eccentric old man. They sure don’t know who I am. Maybe that’s because I’m not anymore.*

Leonard Lapointe, 2001, p. 249.

A key moment in thinking about self and identity in aphasiology was a clinical forum in *Aphasiology* entitled “Losing your sense of self: what aphasia can do”. Brumfitt (1993) provided the introductory paper aimed at restoring the balance between the predominant interest in technical aspects of aphasia and the limited attention given to the personal impact of aphasia. She asks what happens

to a person's self-knowledge when she is changed from a normal speaker to a disabled speaker and how is identity affected. This loss of self is described by Tanner and Gerstenberger (1988) as occurring when a person "perceives that he/she no longer possess some aspect of his/her physical or psychological integrity" (p. 80). I would add that we also need to acknowledge that social integrity is also threatened in aphasia. If the person with aphasia is to adapt to the change thrust upon them by aphasia, then it has been suggested that it is essential for the person to develop a new and alternative sense of self (Brumfitt, 1993, p. 591). Renegotiating identity after trauma or loss often takes place through the medium of talk (or of writing) and so the presence of communication disability for the person with aphasia has the potential to create barriers to this coping work. The person with aphasia may need language in adapting to loss and developing a new sense of self but aphasia in itself interferes with the ability to do this. Aphasia is particularly cruel in that it interferes with language; a "major vehicle of its own treatment" (Jaffe, 1981, p. 253).

Parr et al. (1997) conclude that although language may not be essential to coping, it enriches the process and offers more scope in living with aphasia. They suggest that people with aphasia are able to build their own accounts and identities and this was also identified in my original exploratory study. However, difficulties with communication have the potential to make it hard for people with aphasia "to share their interpretations, to understand other people's account, to be listened to by those closest to them and those whose job it is to support them" (p. 116) and to have the "healing conversation" (Jaffe, 1981, p. 253).

Parr et al. (1997) propose a model of coping with aphasia which is continuous and sometimes untidy. It involves ongoing interaction of different stages and components. They highlight an important component of coping with aphasia is personal identity which includes the "pre-aphasic identity" and the "aphasic identity" (p. 111). The experience of aphasia disrupts the biography of the person with aphasia and their sense of identity. They propose that people construct an account of aphasia and in doing so, some people construct new identities for themselves. The identities that emerged from their interviews included those that were metaphorically labelled as "dogged fighter", "recovered against the odds", "helper and adviser", "campaigner", "tragic figure" and "machine which needs fixing" (p. 113). The process is complex and people may not just draw on one account or one identity.

We are now recognizing that addressing the wider issue of learning to live with communication disability involves attention to social and interpersonal dynamics. Considering self and identity is a crucial part of this but many of the long-term consequences of aphasia including social isolation, role changes and stigmatization are not addressed by traditional aphasia treatment (Simmons-Mackie, 2001a). Although there has been increased attention to social participation, Shadden and Agan (2004) identify that “there is still a need for approaches that facilitate the social construction and reconstruction of identity without targeting explicitly some aspect of communication” (p. 174). Although we recognize its importance, we are still only talking about how we might address this in clinical practice.

Brumfitt (2003) surveyed speech-language therapists about their experiences of the psychosocial impact on people of aphasia. 173 therapists responded: 97% thought that the psychosocial aspects of the clients’ condition were important or very important to the overall management of the client, 95% indicated that they believed the psychosocial status of the client was important or very important to outcome, and between 30% and 70 % of their time working with people with aphasia was spent on psychosocial issues. Of interest were some of the narrative comments: “Direct work on psychosocial aspects is essential but where I work almost nil is available”; “This aspect of work in my opinion is the driving force for therapy”; and “I’m concerned at the overemphasis of the psychosocial aspects if this steers speech-language therapists away from their aim of improving communication”.

While there has been much discussion about the need for interventions which take account of self and identity in aphasia, there has been little if any impact on our wider practices. It has started to be recognized that the conversation between practitioners and clients is central to identity construction and that identity needs to be incorporated into practice; not as a particular therapy but as part of the way in which we interact (Hagstrom, 2004; Shadden & Agan, 2004). There has also been some innovative pioneering work on therapies addressing identity in recovery (Parr et al., 1997; Byng et al., 2000; Pound et al., 2000) but there has been little reported research on the nature of self and aphasia. The research that is now starting to emerge is original and a dominant theme has been inclusion of people with aphasia (Mackay, 2003; Hagstrom, 2004; Moss, Parr, Byng & Petheram, 2004; Parr, 2004). In particular, Parr’s (2004) study of people living with severe aphasia could be considered one of the first works of a critical nature to appear in the literature on aphasia and has wider implications for considering exclusion to be a question of social justice.

One difficulty with research in self and identity has traditionally been methodological; issues of measurement arise when language is impaired. Because of this, while we have a lot of research information about classification, localization and intervention techniques, we have very little about the effects of aphasia on the person (Taylor, 1993). Conducting research is problematic because of the difficulties with measurement. There are three inter-related issues that I think enable us to move beyond this obstacle: looking beyond our traditional boundaries, exploring our philosophies and narrative practice in aphasia.

### ***Beyond traditional boundaries***

Understanding aphasia requires us to consider the perspectives of a range of disciplines (Byng et al., 2003). Taylor (2004) wisely recommends our profession needs to place a greater emphasis on the social sciences if we are to work within a social model. Surveying the literature that is developing around self and identity has identified a growing awareness of the role of sociocultural practices in therapy (MacKay, 2003; Diviney, 2004; Hagstrom, 2004; Shadden & Agan, 2004). While disability studies have had a vital influence on a social model in aphasia, there is also now a contribution from sociocultural studies which crosses several disciplines including sociology, psychology and anthropology. A key contribution has been an understanding of the importance of language in maintaining and negotiating a sense of self; an understanding that a focus on traditional individual language interventions and clinical environments has perhaps been reinforced by the biomedical dominance in aphasiology. With clinicians and researchers gaining new insights into the practice of speech-language therapy, attention to self and identity is a positive outcome. Our dialogue outside our profession also changes by actively listening to other voices; sociology and critical psychology introduce us to notions of hegemony, power, the expert role, authority and politics (MacKay, 2003).

### ***Philosophies, assumptions and values***

Looking outside traditional boundaries is also about understanding the philosophies or ideologies that operate in our lives; professionally and personally. It is about challenging our values and assumptions because these shape how we conceptualize aphasia research and practice. The ethical and moral issues involved in working with people with aphasia are enormous, yet these have scarcely been acknowledged or investigated (Taylor, 2004). Only recently have discussions about the need for aphasia therapists to examine their values and philosophical perspectives been evident

in the literature (Worrall, 2000; Byng, Cairns & Duchan, 2002). Being more transparent about our philosophical perspectives could be seen to be either coincidental to, or associated with, considering different ways of addressing research questions and methodologies in aphasiology (and speech-language therapy) which comes from outside influences. With a strong allegiance to experimental research, the questions about philosophy rarely arose; it was an assumption that we all (including clients) held the same world view. The recent debates about the social model (Byng, 2001; Duchan, 2001; McNeil, 2001; Simmons-Mackie, 2001b; Worrall, 2001), the ICF (Duchan, 2004; Threats & Worrall, 2004) and evidence-based practice (Beecham, 2004; Reilly, 2004) are, at their core, philosophical debates although I am not sure that these are always articulated as such. Byng et al. (2003) locate the discussion about medical and social ideologies within a discussion about their underlying assumptions. They identify an empiricist perspective operating in biomedical practice.

This discussion is welcomed as it has been for the most part absent from aphasiology and has come from researchers and practitioners looking to other fields such as the social sciences and disability studies. In echoing Worrall (2000) calls for speech-language therapists to become more explicit about their underlying values "to help elucidate the perspective and approach of the clinician" (p. 193), there is also a need to be explicit about the ontological and epistemological base of our research and practice. Penn (2004) calls for a critical speech-language therapy where we begin to adopt methodologies that are contextually relevant.

### *Stories of aphasia*

Narrative in aphasia has most often been considered as a discourse genre and analysis has been linguistically based. Ulatowska and Olness (1997) found that the narratives produced by people with aphasia demonstrated poor sentence grammar but they were conceptually organized suggesting that people with aphasia were able to express events in a coherent way. While there is interest in the role of personal narratives to be able to draw an audience into the experience being described, the attention is to stories for their content and devices rather than the role of narrative in meaning making and self construction (Ulatowska, Olness, Samson, Keebler, & Goins, 2004; Ulatowska, Olness & Williams, 2004).

There have, however, been several key pieces of literature which consider the role of narrative in meaning making including personal narratives specific to aphasia therapeutics and to research (Pound, 1999; Barrow, 2000; Pound et al., 2001; Khosa, 2004; Pound, 2004).

### **Researching the self**

I have attempted to build a context for the development of the significance of identity issues in aphasia leading to my research questions. I have been strongly influenced by Connect in their ground breaking work in self and identity in aphasia and by their authentic commitment to involving people with aphasia in research and in evaluation (Byng et al., 2000; Parr, Duchan & Pound, 2003; Duchan & Byng, 2004; Parr, 2004). Therapies to address identity in aphasia have been developed and are a key part of Connect's programmes (Pound et al., 2000). From this group of people and their international associates there continues to be exciting dialogue about research and therapy that challenge our practices with people with aphasia (Duchan & Byng, 2004).

### **Conceptualizing the project: aims, outcomes and questions**

As I have outlined, there is support for addressing self and identity as a psychosocial concern in clinical practice but there is little specific reported research in this area although there is an acknowledgement of the importance of this psychosocial concern in clinical practice. I believe Brumfitt's (1993) early work was far-sighted but that this was not easily taken further because the accepted methodologies within aphasiology at the time were restricted to an objectivist epistemology. The timing is right to pose questions and to identify how to do research in self and identity with aphasia. Research outside aphasiology has much to offer the exploration of self and identity and so my study in psychology provides an entrance to firstly, a theoretical understanding of self and identity and secondly to methodologies with which to engage in research in self and identity.

The current project aims to explore the impact of aphasia on self and identity in people with aphasia, again through narrative research. The beginning conceptualization of the project is best explained in Figure 2.1. The three critical areas for the project are narrative, self and aphasia. While there are research connections between narrative and self, self and aphasia, and aphasia and narrative, this project sought to explore self in aphasia using a narrative approach (the dotted line).

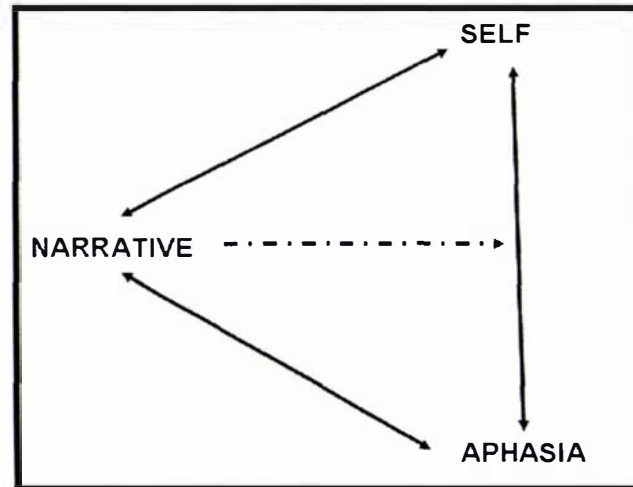


Figure 2.1: A diagrammatic view of the project

The aims of this research project include to further understand the impact of aphasia on people's sense of self and identity using a narrative approach. This would contribute to the clinical realm and to the emerging body of literature on self and identity as a psychosocial consequence of aphasia. A further aim would be to explore a research process that encouraged a more participative approach and therefore contributed to how research is carried out with people with aphasia.

The outcomes sought for the project are, firstly, an increased understanding both of the impact of aphasia on self and identity and of the construction of self and identity in aphasia. Secondly, the project seeks a process which gives voice to the participants through an appropriate research methodology while also acknowledging the role of the researcher in co-constructing stories.

Finally, to address these research aims and planned outcomes, I want to answer the following questions: how does aphasia impact on self and identity, how do people with aphasia tell about self and identity and what research methodology enables people with aphasia to tell their stories?

### Organizing the thesis

The remaining text is divided into a further four sections following the setting of the scene in Section A. Section B is titled "Finding a location" and it is predominately focused on placing the research questions within a theoretical framework. Chapter Three, "Locating the self", looks at the ontological, epistemological and theoretical understandings of self and identity and enables me to



locate the project and myself. Chapter Four and the final chapter in Section B, "Locating the process", acts as a link to the next section. It looks at other theoretical perspectives and personal experiences that contribute to how the research was further refined. Section C is called "Finding a way" and it finalizes the methodology section of the thesis. Narrative inquiry, as an important framework, in the research is discussed in Chapter Five and the project methodology is completed. Chapter Six then looks at how the research was carried out in detail. Chapter Seven is the only chapter in Section D and presents the participants' stories which include the outcome of the analyses and the issues arising from the research process. The final section, Section E is called "The act (or art) of splicing". It brings the thesis together and to a conclusion. Chapter Eight summarizes the project by developing the conclusions and identifying the research limitations and implications. Chapter Nine is an epilogue to the project. The back cover houses a CD ROM which is optional reading. It is included because I wanted to document, in some way, another story. The CD ROM is a way of representing the less intelligible parts that are additional to my formal presentation.

### Summary

This chapter has provided a background to the project by describing my history with aphasia and by summarizing an exploratory research project. This led to a discussion of the need for research in self and identity in aphasia. As the final chapter in this initial section about setting the scene, it has identified the research aims, outcomes and questions and closed with an overall view of the thesis. The next stage of the project is Section B, "Finding a Location" which concerns the theoretical framework for the project. Chapter Three begins this process by examining self and identity.



SECTION B

FINDING A LOCATION

Chapter 3: Locating the self

Chapter 4: Locating the process

## Chapter 3

### Locating the self

#### Overview

#### Considering the self

#### An elusive phenomenon

What it means to be a person

Different approaches

#### “Sorting things out”

Ontology

Epistemology

Constructionism: “A disparate family”

*Constructionism or constructivism?*

#### Notions of the self

The modern self

An emerging social self

*William James*

*George Mead*

*Erving Goffman*

The decentred self

*Postmodernism*

*Social constructionism*

**The self of the project**

*Insights from pathology*

*Finding a middle ground*

*Weaving the strands together*

**Locating the project**

Theoretical foundations of the project

*Ontology*

*Epistemology*

*Theoretical perspectives*

**Summary**

## Overview

This chapter is an introduction to self and identity. It is a review of the literature about self and identity in, primarily, psychology. It leads to the ontological, epistemological and theoretical background to this project through the process of locating the self. It traces notions of the self from classical origins through to the contemporary and it synthesizes several interdependent perspectives in theorizing the self. It is also a chapter about locating myself.

## Considering the self

In 1975, Shotter commented that psychology was in one of the most exciting times with the ability to perhaps solve the problem of “Why is I, I?” (p. 11). Thirty years later and the problem has not been solved. However, there is increased understanding amidst blurred boundaries and genres, paradigm shifts and dialogue (Denzin & Lincoln, 2000). What has happened to the study of the self over time and where have we arrived? A starting place is to identify my own beginning assumptions. Although I had not articulated them as such, my assumptions could have been determined to be based on an individualistic<sup>5</sup> perspective. My university study began during the early seventies and my first exposure to counselling in a helping profession was Roger’s client-centred approach within a humanistic psychological framework. Humanism focuses on the individual, the subjective nature of the self. It emphasizes the unified, coherent and rational nature of the individual who is regarded as an agent of her own experience or meaning, rather than emphasizing other sociocultural resources (Burr, 1995; Crossley, 2000a; Parker, 1999a). My clinical education and subsequent practice in speech-language therapy were grounded in a humanistic perspective. This provided a way of being, both as a therapist and as a person, working with people in life changing situations.

Much later, in the mid-nineteen nineties, approaches to aphasia were beginning to be influenced by a social model of disability which increased the awareness of the social construction of communication disability. This was in contrast to the traditional impairment-based approaches

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<sup>5</sup> Individualism describes a theoretical emphasis on the individual with the assumption of a pre-existing self independent of society (Burr, 2002).

fostered by a medical model. I was already conscious of the tension between “self” and “social” and the challenges to humanism’s view of the self as autonomous and individual. It was from this background that the project began. What follows is an exploration of concepts of self and identity from a growing body of literature in order to find a sense of fit for myself and for the research methodology.

### **An elusive phenomenon**

The terms “self” and “identity” are often used interchangeably. Despite an enormous volume of literature on self in the last quarter century, the answers to questions about what self and identity are have not been clearly articulated. No coherent theoretical foundation has emerged and definitional consensus remains difficult (Breakwell, 1992; Côté & Levine, 2002). This conceptual elusiveness is one reason why Baumeister (1999) suggests the study of self has so many sides and subtopics: self-awareness, self-monitoring, self-presentation, self-concept, self-esteem, self-actualization, self-verification, self-schema, self-enhancement and self-regulation. Despite this difficulty in theoretically conceptualizing selfhood, if psychology is all about trying to understand people’s behaviours and experiences then the issue of what it is to be a person would seem to be a key question we need to be asking (Burr, 2002). While self has become one of the most actively researched subject matters in psychology, as lay people, within a Western culture at least, the notion of self seems to be quite obvious and relatively simple as we all have direct experience of our own “self”. Most of us still retain a strong sense of an individual self. We have an overall sense of a unique biography and a consciousness with a sense of continuity over time, even with change. We experience ourselves existing as separate individuals with a mind or self within us and apart from a material world (Kitzinger, 1992; Stevens, 1996; Baumeister, 1999). What is apparent is that any definitions of self and identity will be linked to a particular theoretical tradition. A very broad review of what it means to be a person now follows and this precedes a more detailed consideration of how self and identity are characterized for this project and directly related to its theoretical framework.

### **What it means to be a person**

Stevens (1996) considers five broad and interwoven aspects which appear to be fundamental features of what it means to be a person: embodiment (which recognizes the body’s central importance to being a person), subjective experience (which includes and is influenced by

consciousness), some sense of self or identity and of agency (and also the cognitive skills for processing and making sense of that experience), social setting and social practices as a medium for the existence of self, unconscious feelings (the sense that some of our experiences and our reactions emanate from feelings deep within ourselves of which we may be hardly aware) and some sense of these threads being interrelated. Baumeister (1999) identifies three universal human experiences that form the basis of selfhood. Firstly, the self has a reflexive consciousness or self-awareness which enables the human mind to turn attention towards itself and construct knowledge by itself. Secondly, one of the essential functions of the self is the ability to relate to others. This interpersonal facet acknowledges that the self is not “discovered or created in isolation” (Baumeister, p.2). Thirdly, the self has an executive function enabling it to make choices and to be able to do things. Without this sense of agency the self “might still be something that could be known and could relate to other people – but it could not do anything” (p. 2).

One way of thinking about identity is to consider it as a “fusion” of personal and social identity. Personal identity is that part of the self-concept unique to an individual, a product of experiences specific to the individual and their private reflections on these. Social identity refers to the characteristics and roles consequent to group membership (Stevens, 1996). Highlighting the continuity of and changes in identity construction across the adult life span, McAdams (2001) defines identity as “an internalized and evolving story of self that integrates the self synchronically and diachronically” (p. 102).

### Different approaches

This general consideration of self and identity may appear to have prematurely simplified answers to questions about them. Philosophically and theoretically, however, the answers are anything but straightforward. Shotter (1975) uses “images of man” to characterize the philosophical assumptions or root metaphors that highlight the different ways of understanding what it means to be a person. Different approaches provide different images; behaviourism uses an image of the person as a mechanism, while the image of the person as an organism is employed by neuropsychology, developmental psychology and humanistic psychology. For early cognitive psychology the image of a person was as a computer. The significance of these “images” is that they expose underlying philosophical assumptions about what it means to be a person as well as translating them into images of how we conduct our practices (McLeod, 1997).

Stevens (1996) calls for a “multiple perspective approach” to self where we need to consider a co-existence of perspectives rather than those that are mutually exclusive as found in the natural sciences (p. 32). It may be possible to gain a richer understanding while acknowledging “we are complex creatures; at the same time being biological organisms, using a language and a symbolic world assimilated from our society, and perhaps also ourselves capable of generating novelty and change” (p. 33). As well as a multiperspective approach, there is multidisciplinary interest in and engagement with the self. Something as complex as the self cannot be fully understood from one perspective only and better understandings will develop if we consider what other disciplines are saying (Côté & Levine, 2002). The range of interested parties in self and identity include psychology, sociology, philosophy, neurology, cognitive science, anthropology, sociolinguistics and medical ethics.

Exploring self and identity in psychology is about exploring the history of psychology. Up to this point we have considered what we broadly understand self to be today. However, theories of self and identity parallel the different paradigms which have emerged in psychology. Any discussion has at its heart the social, cultural and historical context in which it develops. Psychological theory and research are embedded in historical and sociocultural contexts and theoretical perspectives are a sign of the very context in which the theorizing takes place. The same is true of the psychology of the self. What follows is a history of the self through examining different notions of the self. Because our discussion is developing a theoretical grounding for the project and the terminology surrounding this is philosophical, some initial “sorting out” is required. While this may seem pedestrian, it is also a narrative of my assimilating new understandings which underpin the theoretical arguments and have ultimately fashioned the project.

### “Sorting things out”<sup>6</sup>

Understanding the location of the self within psychology requires an understanding of the philosophical setting and history. Focusing on methodology in psychology, particularly within qualitative inquiry, has been suggested to be to the detriment of other considerations including the philosophical positioning of research (Chamberlain, 2000). If we are to understand the current theoretical arguments around self and identity and what these mean to psychological research and practice, then we must understand its philosophical roots. That means understanding the

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<sup>6</sup>Crotty, 1998, p. 183.



assumptions underpinning different ontologies and epistemologies. Guba and Lincoln (1994) consider that inquiry paradigms, or theoretical perspectives, can be defined by three key questions; ontological, epistemological and methodological questions. These questions are interconnected and their order constrains how subsequent questions can be answered. However these paradigms remain human constructions and most of them are still in a stage of development. Some ambiguity is present when it comes to the distinction between positions, particularly between what people define as either an epistemological stance and a theoretical stance (Crotty, 1998; Schwandt, 2000; Snape & Spencer, 2003). In an attempt to offset some of the confusion around terminology in social research, Crotty (1998) introduced the notion of scaffolding. While the levels in the scaffolding overlap and weave together, the decisions made at each level constrain the next: epistemology, theoretical perspective, methodology and methods. It is suggested that ontological and epistemological issues combine together and therefore can be discussed together (Guba & Lincoln, 1994; Rosen, 1996; Crotty, 1998). However, it is helpful in considering the development of the project's location to define them separately. Figure 3.1 has been adapted from Crotty (1998) to include ontology (p. 4).

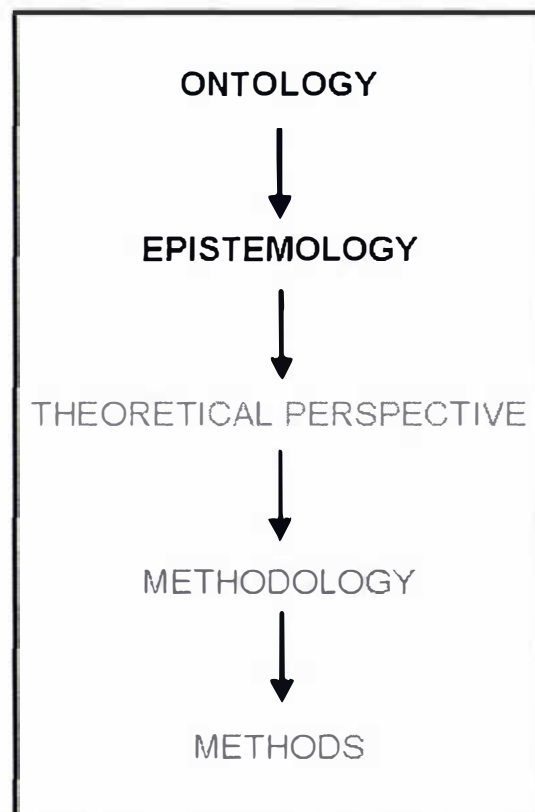


Figure 3.1: Theoretical scaffold

*(Adapted from Crotty, 1998, p. 4).*

## Ontology

Ontology is concerned with the study of being (Crotty, 1998). A key ontological question is whether or not a social reality exists independent of people's beliefs and interpretations (Guba & Lincoln, 1994; Snape & Spencer, 2003). The major ontological positions<sup>7</sup> (or answers) are: realism (an apprehensible social reality exists independent of the human mind and beyond observation and interpretation), materialism, a variant of realism (a real world exists beyond the human mind but only the material or physical features hold reality), idealism (reality does not exist independent of but only as constructions in the human mind) and relativism, a variant of idealism (there are multiple realities) (Guba & Lincoln, 1994; Crotty, 1998; Priestley, 1998; Snape & Spencer, 2003).

## Epistemology

Epistemology concerns itself with how we can know about reality and the philosophical basis of that knowledge. It is "a way of understanding and explaining how we know what we know" (Crotty, 1998, p. 3). Our epistemological perspectives develop into the criteria we use to make decisions about theoretical explanations (Botella, 1998). Crotty (1998) identifies three main epistemological positions, one of which is constructionism. The other two are objectivism (a meaningful and rationally structured reality exists independently of conscious experience with truth and meaning inherent in the object no matter what a person happens to believe about it<sup>8</sup>) and subjectivism (meaning is imposed on the object by the subject, and the object is not involved in the generation of meaning) (Hermans, Kempen & van Loon, 1992; Crotty, 1998). Constructionism is a key epistemological stance for qualitative research and a deeper exploration is essential to our later discussions.

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<sup>7</sup> Concerned about oversimplification, I concur with Guba and Lincoln (1994) that "these descriptions are apt as broad brush strokes" (p. 117).

<sup>8</sup> "Subject" and "object" are used here in a philosophical sense (Hollway & Jefferson, 2000). Although suggestive of dualism with its separation of mind and body, Crotty (1998) believes we all "invoke" the concepts of subject and object and while we cannot avoid talking about them as conceptually distinct, it does not mean making it a "real" distinction as Cartesian dualism does (p. 217).

*Constructionism: "A disparate family"*<sup>9</sup>

If I have drawn heavily on Crotty's (1998) construction of the underpinnings of social research, it is because I have found it has provided a structure that enabled me to make sense of the landscape. This has been particularly so in his explanation of the epistemological perspective of constructionism which is important to the understanding of self. He identifies three key points in his treatise on constructionism. Firstly, constructionism is the rejection of the existence of an objective truth or meaning. Meaning, instead, is constructed through engagement with the world. Secondly, meaning is not discovered, it is constructed. That is, the world holds no meaning until human beings engage with it. Thirdly, constructionism involves a relationship between subject and object. Crotty (1998) believes that constructionism brings and holds objectivity and subjectivity together:

*Because of the essential relationship that experience bears to its object, no object can be adequately described in isolation from the conscious being experiencing it, nor can any experience be adequately described in isolation from its object.*

p. 45.

Constructionism or constructivism?<sup>10</sup>

There are multiple schools of constructionist thought highlighting the differences of opinion about the nature of the relationship between the knower and the known. Constructionism and constructivism and associated labels of social constructionism and social constructivism, may be used almost interchangeably. Differences in concepts and priorities exist but all constructionisms have several features in common: the way human beings and societies create meaningful understandings of the world, their opposition to dualism and positivism<sup>11</sup>, their rejection of a belief in mental representations mirroring an objective reality and their attempts to overcome a realism - idealism dichotomy (Pearce, 1992; Rosen, 1996; Chiari & Nuzzo, 2001; Raskin, 2002).

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<sup>9</sup> Raskin, 2001, p. 286.

<sup>10</sup> I am very aware that attempts to reach some precision in definitions or to create categories have the potential to minimize the complexity of the concepts and the associated debates.

<sup>11</sup> Positivism is a response to the question about how it is possible to know about the world. It is based on dualist and objectivist assumptions and claims that reality can be investigated through the methods of the natural sciences including objective and value-free inquiry (Guba & Lincoln, 1994; Lincoln & Guba, 2000; Snape & Spencer, 2003).

Crotty (1998) distinguishes between *constructivism* when there is a focus on the meaning making of the individual mind and *constructionism* when the social generation of knowledge is dominant. Crotty (1998) also suggests that there is more of a critical<sup>12</sup> nature in constructionism whereas constructivism has a conformist character.

### *Constructivism*

While there are several ways of conceptualizing constructivisms (Pearce, 1992; Chiari & Nuzzo, 1993; Hruby, 2001), most are inclusive of social constructionism in some way. Mahoney (2003) proposes that there are five central themes which articulate a view of human experience as being constructive. The first theme, in distinguishing constructivism from determinism<sup>13</sup>, is that the act of experiencing involves human agency<sup>14</sup>. The second contention is that much of human activity involves ordering processes. A third theme argues that, although relationships are acknowledged to be important, selfhood and identity are self-reflexive and phenomenological. Fourthly, individuals can only be understood if they are recognized to be embedded in social and symbolic systems. The fifth theme concerns an ongoing developmental process in which there is a tension between order and disorder over the life span. Raskin (2002) identifies three distinct forms of constructivist thinking; personal constructivism, radical constructivism, which are discussed in the following sections, and social constructionism which I discuss separately. I have maintained a distinction between constructivism and social constructionism as it is important to the personal-social debate.

Personal constructivism is considered to be the most developed of the constructivisms and is brought together in Kelly's personal constructs theory, a theory about how people make sense of the world by interpreting experiences (Raskin, 2001). Because there are alternative interpretations available, a construct is a discrimination that people make as they accept successive approximations to reality (Beail, 1985; Hermans, Kempen & van Loon, 1992). Kelly used the metaphor of all people as "scientists": "We develop hypotheses, test them out, revise them and develop our theories to make sense of our experiences" (Beail, 1985, p.1).

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<sup>12</sup> Critical approaches are those that challenge our inherited understandings and issues of power and oppression that exist socially and culturally (Crotty, 1998).

<sup>13</sup> Determinism is a belief that all human action is caused by something and that there is no real free will.

<sup>14</sup> Agency includes an individual's ability to consider alternative actions and is associated with the notion of free will. Choice and action are judged to be voluntary and to originate in the individual mind (Burr, 2002).

The self in personal constructivism is viewed as a construct. Although social and relational aspects are important to an understanding of self, the constructive process is still centred primarily on the individual (Raskin, 2002). Personal construct theory has developed as an individual psychology primarily because of its roots in humanism, and therefore an emphasis on agency, and its location within psychotherapeutic practice with its clinical focus on the individual (Butt, 2001)

Kelly's work was ground breaking because it proposed that alternative constructions of the world were possible and challenged the accepted view of an objective reality (Hermans et al., 1992). Shotter (2003) acknowledged that there were several themes in Kelly's work that, if they had been developed, would have led to social constructionism and perhaps even helped us to understand some of the current issues for constructionism today: a concern with practice, a more collaborative role for psychologists, and an emphasis on behaviour as being inquiring and anticipatory. This potentially positive relationship between Kelly's personal constructionism and social constructionism has also been highlighted by other theorists (Butt, 2001; McNamee, 2004).

Radical constructivism, with its key theorists being von Glasersfeld and Maturana, views people as a closed system with no direct access to an external reality because there is no reality beyond individual experience (Rosen, 1996; Raskin, 2002). Knowledge is regarded as being built up by the cognitive actions of an individual while the function of cognition is not to discover truth or an objective reality but to be an adaptive tool that allows an individual to organize her/his experiential world (Pearce, 1992). Although social interaction is sustained by language, an individual is still seen as operating within a private and isolated self-constructed world (Raskin, 2002).

### *Social constructionism*

The term social constructionism was first used by Berger and Luckman (1966) who made the claim that reality is created in social interaction. Gergen (1985) retained this label to avoid confusion with the cognitive constructivism of Piagetian theory and its individualism. He challenged what constituted knowledge and how it was acquired. Rather than locating knowledge within the world or within the individual, explanations were considered to be located within social interchange and relationships. This challenged not just an empirical psychology but also a scientific knowledge that is "objective, individualistic, ahistoric" (Gergen, 1985, p. 272). Social constructionism, in rejecting the notion that meaning resides in the mind of an ahistorical and decontextualized individual,

considers meaning making as a relational activity (Rosen, 1996; McNamee, 2004). Edley (2001) asserts that there is confusion between two different senses of social constructionism: ontological and epistemological. He maintains that the often cited statement of social constructionists that there is nothing outside the text is most often challenged from an ontological position. He believes, however, it is about epistemology. Language, or discourse, is the medium through which we come to know the world and therefore the claim is not about what the world is, as an ontological claim, but rather an epistemological claim. It is about the constructive nature of language and how we know the world. This resonates with Crotty's (1998) claim that realism and constructionism are compatible: "To say that meaningful reality is socially constructed is not to say that it is not real" (Crotty, 1998, p. 63).

This introductory account of some important philosophical constructions is offered to aid an understanding of the self and the locating the self of the project. What follows is a history of the self but it is a selective history. Although the self is central to all of psychology, the history I present here is not all encompassing. It does not specifically discuss the self in other psychologies such as behavioural, psychodynamic, developmental, personality or cognitive, although boundaries are blurred. It is, instead, a history of the development of the social self by drawing predominately on theories in social psychology and sociology. This selectivity is influenced by the current challenges in aphasiology, the nature of the project, by my own questioning and by my changing assumptions as I work towards a theoretical location for this project. It also highlights the increasing importance of language in self and identity.

## Notions of the self

### The modern self: *Cogito ergo sum*<sup>15</sup>

The story of the self dates from ancient Greek philosophy with Aristotle's attention to the distinction between the physical and non-physical aspects of human beings. Plato perpetuated this conceptualization by drawing a distinction between the body and the soul and considering them to be separate entities. The self was described in terms of the spirit or psyche and was regarded as separate from the physical body in which it dwelled. The related ontology of the self which has

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<sup>15</sup> Descartes' famous aphorism, "I think, therefore I am".

dominated Western thought for the last four centuries and which we take for granted emerged in the intellectual context of the Renaissance and Enlightenment periods and the work of an important figure, René Descartes (Yardley, 1999; Tesser, Felson & Suls, 2000; Pajares & Schunk, 2002). Cartesian dualism, as Descartes' theoretical framework is known, depicted mind and body to be separate and fundamentally different; the objective world was considered independent of subjective experience. In the search for truth, he considered objectivity and evidence to be important (Tolman, 1998; Yardley, 1999; Lincoln & Guba, 2000; Snape & Spencer, 2003). The self was not the body; it was a substance different from that of the body but located inside the body (Tolman, 1998). This method of thinking has continued to influence how we have thought about ourselves since that time (Shotter, 2004). The legacy of Descartes' dual substance theory is a number of related dualist dichotomies: subject-object, perception-action, subjective-objective, internal-external, rational-irrational, human-inhuman, mind-body, cognition-behaviour, self-other, individual-society (Yardley, 1999; Butt, 2001).

Sampson (2000) proposes that Christianity with its dualism of the person-other relationships has contributed to individualism while Kitzinger (1992) suggests that it is derivative of liberal political theory. Cushman (1990) identifies parallel historical, economical and political developments including industrialization and the rise of the modern state as having some responsibility for the development of the "decontextualized individual" (p. 601). He regards the self in the post-World War Two era in America as being one of the "empty self", a self shaped by "a significant absence of community, tradition and shared meaning" (p. 600). Although we may now consider ourselves to be more aware, Cartesian concepts, particularly the mind-body relationship, are still pervasive within our everyday lives and our academic inquiries in mainstream psychology. It is the basis of the assumption that psychologists should be concerned with what is "inside" a person, leaving what is "outside" to sociologists (Shotter, 1993a; Tolman, 1998; Butt, 2001). Tolman (1998) challenges what he considers to be psychology's hegemonic commitment to Cartesianism and he suggests an altered slogan "Sumus ergo sum" ("We are, therefore I am", p. 3). This challenge is for explanations that are characteristic not of "the intracranial, Cartesian space, but of interpersonal, historical, societal, moral space" (p. 22). Regardless, it remains an influential framework in psychology and Western philosophical thought.

## An emerging social self

The powerful influence of the belief in an autonomous individual is deeply rooted in Western traditions and is not necessarily shared by other cultures (Fishbane, 2001). While individualism and associated thinking still permeate our practice and research, the beginning of the twentieth century saw the emergence of a sociological social psychology with several theorists within psychology and sociology contributing to an awareness of the social nature of self (Burr, 2002).

### *William James: The knower and the known*

James (1842 – 1910) made a significant contribution to the study of the self. As a pragmatist<sup>16</sup>, he was not interested in the self merely as a philosophical problem; he was interested in how selves were in the world and how ordinary people managed their social interactions (Holstein & Gubrium 2000). James introduced a distinction between two aspects of the self; the self as subject (“I”) and the self as object (“Me”) (Baressi, 2002). The “I” is equated with the self as knower and the “Me” with the self as known while the constituents of “Me” were divided into the material me, the social me and the spiritual me. The empirical self, or me, is depicted as the sum total of all a person feels as belonging to oneself that includes not only the body and “psychic powers” but people and things in the environment as far as they are experienced as “simply mine” (James, 1999, p. 69). This contrasts with a Cartesian self and became the inspiration for later conceptual work (Hermans, 2003). James considered that a person had as many social selves as there were others who knew her and carried their own image of her. According to James, personal identity develops over time and, although it will be revised, a unity remains as past events are remembered and connected with the “Me”. This allows a person to consider life as a coherent narrative. Although this was not James’ focus, Baressi and Jukes (1997) believe this conceptualization of “Me” as the object of self awareness could be considered to be the basis for narrative self-construction. While not a mentalist, James’ desire to develop a psychological science saw him focusing on the inner aspects of communication. Denzin (1995) describes James as a phenomenologist. Mead, critical of this, extends this work by taking the self “outside of itself” and locating it within social behaviour (Holstein & Gubrium, 2000, p. 23).

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<sup>16</sup> Pragmatism, an American philosophical movement, considers philosophy not as a “contemplative exercise” but as a practical activity; the meaning of an idea is dependent on its practical outcome (Butt, 2001, p. 77).



***George Mead: The interactional self***

Mead (1863 – 1931) is associated with a sociological approach to psychology and his work is credited with transcending the dualism of self and other (Burr, 2002). His social psychological theorizing is considered to have had a major influence on introducing psychology to constructionism (Sarbin & Kitsuse, 1994). Mead refuted the self as mentalistic and regarded it as a product of social interaction. He argued that self and mind were social and cognitive processes that were socially located and therefore the self was the result of social forces shaping us and our behaviour (Denzin, 1995; Crotty, 1998; Elliott, 2001).

Mead placed great emphasis on language as the primary tool in sense making and in construction of the self. Language gives us the means to internalize, represent and reflect on social interaction (Burr 2002; Elliott, 2001). He referred to inner conversation as the mind and Mead used James' "I" and "Me" to explain how the conversations we have with ourselves are like the conversations we have with others. In effect, Mead was saying the relations we have with ourselves and with others are communicatively identical and how we learn about others is also how we learn about ourselves (Pajares & Schunk, 2002; Holstein & Gubrium, 2000). Language, society and culture were an important part of understanding people's behaviour and, in opposition to the individualistic philosophy of a psychological social psychology, Mead believed that "the self does not pre-exist society, it emerges from it" (Burr, 2002, p. 17). He argued that the study of individual behaviour cannot happen without consideration of social and historical context. Mead was also a pragmatist and is credited with being the founder of symbolic interactionism which is based on three core premises: it is not what things are rather what they mean for people that mediate people's actions, the meaning of things is derived from social interaction, and meanings are modified in an ongoing interpretive process (Denzin, 1995; Crotty, 1998; Holstein & Gubrium, 2000).

Criticisms of Mead's model of the self centre on it being too cognitive, lacking attention to the emotional realm and disembodied. However, there are several themes from Mead's theorizing that can be found in current discussions about the self: identity is developed by engagement with others, communication is essential to the development of self and identity, and being able to take on the role of others is closely linked to the development of self-consciousness (Elliott, 2001).

*Erving Goffman: The socially situated self*

While Mead and the symbolic interactionists brought the self in social interaction into view, Goffman (1922 – 1982), a sociologist, located the self in everyday life. He was concerned not only with the interactional nature of the self but also with the circumstances of the interaction. He considered that there was more to self formation than just interaction and his dramaturgical approach utilized the metaphor of the theatre: scenes, scripts, front stage, back stage and performance (Holstein & Gubrium, 2000; Elliott, 2001). The self has the ability to play many roles in different contexts and actors or players involved in social interaction engage in impression management. This presentation of self is not considered to be the self but rather it is an identity performed for a particular audience in a particular social circumstance (Elliott, 2001). How we present ourselves to others is a major part of our social life but Goffman is not suggesting that we are presenting a pre-existing or inner self to the world; rather that the self is the presentation. Neither is this self without agency. A person is cast as a creative and reflexive agent who has the ability to reflect on their own and the performance of others with room for improvisation (Burr, 2002; Holstein & Gubrium, 2000; Elliott, 2001). Elliot (2001) believes that this account of the performative and situationally defined self is a precursor to postmodern theory where “personal identity and social life are filtered through surfaces, images, performances, fragments and constructions” (p. 36).

These theorists have been key contributors to the story of an emerging social self. Although self was an important issue for psychology during the early part of the century, the rise of behaviourism meant that concern with the self was left to sociologists such as Mead and Goffman. It was in this context in the fifties that humanistic psychologists including Rogers, May and Maslow called for a return to work on the self. Their perspective on the self was that it was not the mind or a thing but a tendency for self-actualization (Polkinghorne, 2001). A humanistic approach highlighted the uniqueness of the individual and the belief in human agency (Crossley, 2000a). Behaviourism, however, remained influential and a cognitive psychological perspective was becoming prominent. A social psychology influenced by cognitivism explained social behaviour in terms of an individual’s mental processes. Subsequently, during the 1960s and 1970s, there was increasing dissatisfaction with a social psychology that some researchers felt placed too much emphasis on cognitive components.

Further criticisms were that it was restricted to experimental work and concerned with issues of scientific adequacy with a commitment to positivism. There was also concern that explanations were heavily weighted towards individualism resulting in less focus on the social (Burr, 2002; Hepburn, 2003). This dissatisfaction was seen as a crisis in confidence and the dialogue that ensued was also evident in other social sciences with the emergence of postmodernist themes (Crotty, 1998; Richardson, Rogers & Carroll, 1998; Holstein & Gubrium, 2000). So what notions of self became prevalent and what happened to the social self?

### **The decentred self**

The notions of self used to describe the contemporary self are numerous: the "empty self", "minimal self", "death of the self", "saturated self" and "decentred self". They all challenge psychology's discourses of a core, rational and unitary self (Cushman, 1990; Smith, 1994; Richardson et al., 1998; Gergen, 2001, Callero, 2003). This draws us into discussion about contemporary thinking including reference to postmodernism and social constructionism and their influence on self.

### ***Postmodernism***

While it lacks a clear and coherent definition, postmodernism is most often used to describe what comes after modernism. Modernism, as a movement, was well established by the nineteenth and twentieth centuries which were critical periods for the development of psychology with the advance of science and knowledge, and the conception of a self-reliant and autonomous individual (Lemke, 1994; Crotty, 1998). The study of self and identity has essentially remained a modernist project with an adherence to individualism, objectivity and reason. However, disenchantment with this reliance on the individual as the key to the organization of society influenced the development of the postmodern movement (McNamee, 1992; 1996).

As an intellectual movement postmodernism is not restricted to philosophy or psychology and it has a presence in architecture, the visual and literary arts and in performance (Kvale, 1992; Polkinghorne, 1992, Burr, 1995). It is not a specific philosophy, rather it is a collection of perspectives and this plurality of approaches and thinkers is a defining characteristic of the postmodern movement (Lemke, 1994; Rosen, 1996). The uniting theme remains the challenge to modernism with a reconsideration of the concepts of individual knowledge, objectivity, scientific

progress and truth. By challenging these modernist notions of a rational, knowing self with the ability to pursue truth and human progress, postmodernism is said to decentre the self (Kvale, 1992; Richardson et al., 1998; Gergen, 2001; Hepburn, 2003).

While some theorists regard postmodernism as having roots in the intellectual movements of structuralism and post-structuralism, others make a distinction between them (Lemke, 1994). Structuralism gained inspiration from modern linguistics and Saussure's theory of the sign. Language was regarded as a system of signs and the relationship between a word as the linguistic sign and a concept was considered to be an arbitrary one. Language is, therefore, a system of social meanings rather than an account of reality (Crotty, 1998). Developed as a consequence of structuralism, post-structuralism is a set of theoretical positions which contests the self as presented in positivist and humanist theories and instead conceives of the self as created through socially and culturally produced discourses. Language creates social reality and it is where subjectivity, our sense of self, is constructed (Francis, 2000; Richardson, 2000; Lye, 1997). Associated with post-structuralism is deconstruction which is a fusion of "destruction" and "construction", implying the taking down of old ideas for new ones to be erected (Løvlie, 1992). Deconstruction is a tool used by postmodernists to reveal the contradictions of modernism's apparently stable meanings and bring into view the infinite possibilities for interpretation (Polkinghorne, 1992; Rosen, 1996). It attempts to take texts apart and demonstrate the contradictions and assumptions (Burr, 1995). In teasing out the differences and the similarities between postmodernism and post-structuralism, Crotty (1998) suggests that they both inform and promote the development of one another: "There are post-structuralisms that are not at all postmodernist. And there are forms of postmodernism that are neither structuralist nor post-structuralist" (p. 196).

### The self and postmodernism

The project of the self in postmodernism is not concerned with discovery; it is concerned with deconstructing the self. Essentialism<sup>17</sup> is challenged and the self is considered to be reliant on discourse (Callero, 2003). Postmodernists' conceptualization of the self as "fragmented, multiple and dispersed" has been influenced by the changing social, political and cultural conditions including globalization and new technologies (Elliott, 2001, p. 136). There are changes, too, in the

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<sup>17</sup> The philosophy that things have an essence or ideal nature independent of and prior to their existence.

way the topic of the self is discussed. While I have used the term "self" throughout this discussion<sup>18</sup>, subjectivity is a term used within postmodern writing to indicate an anti-individualistic stance and to contrast with the traditional way in which self is talked about as an inner essence as in humanism. It is drawn from the writings of Foucault whose work on power has also had an influence on understandings of the self (Hepburn, 2003). In Foucauldian practice the self is conceptualized as the outcome of power and historic discourses. What might be considered humanitarian interventions such as schools and hospitals are in effect sites for mechanisms of domination (Callero, 2003). Gergen (2001) proposes a saturated self which comes from the sheer number, frequency and varieties of relationships that our postmodern lives makes possible with its emerging technologies of travel and transmission.

### Challenges to postmodernism

Postmodernism is certainly not without its critics and dialogue about psychology and postmodernism has at times been heated. Gergen (2002) would suggest that there has been exaggeration and misunderstanding. Locke (2002), however, describes postmodernism as being intellectually bankrupt and concludes that "it is best to ignore postmodernism and let it destroy itself, as it must in the end" (p. 458). Gergen and Gergen (2000) argue that the idea of a singular or unified self is problematic intellectually and politically and is conceptually and ideologically limiting. The presumption of the coherence of self and the value placed on integration and clarity of purpose, they believe, has its roots in the rational and morally informed self of the Enlightenment period. They favour polyvocality which acknowledges the diversity of voices and identities and the competing contradictions within research. Freeman (2000) suggests that we are in the middle of a "cultural upheaval" and it is leading to different ways of conceptualizing our selves and the world we live in (p. 118). While he does not set out to denounce postmodern thought, in considering the discourse of postmodern interpretations of identity, specifically Gergen's saturated self, Freeman (2000) asks whether we are, at heart, modernists. He suggests that it has actually been much easier "to think postmodern than it has been to live it" and there is the danger that a world stripped of its presence and replaced only with our constructions may become a world difficult to endure (p. 124).

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<sup>18</sup> I have continued to use "self". Cromby and Standen (1999) suggest that this terminology has been retained by some "who are attempting to learn from postmodern critiques of the subject while nevertheless retaining some notion of the embodied person" (p. 142).

The rise of the postmodern movement over the last twenty years represents the division between attention to the human subject and the importance of society and highlights the classical individual-social division. A key theoretical perspective that is important to discussions of the contemporary self is social constructionism. While social constructionism is not postmodernism as such, postmodernism has reinforced an antirealist stance and this has given weight to social constructionism (Crotty, 1998; Archer, 2002). Slife and Williams (1995) consider social constructionism to be a postmodern “way of knowing” (p. 77) while Gergen (2001) describes social constructionism as “a page from the postmodern text” (p. 2).

### *Social constructionism*

Earlier we considered social constructionism in our discussion of epistemologies. The present discussion aims to further explore theories of self in social constructionism. To reiterate, social constructionism, like postmodernism, is not a single movement or a single position. Although there is no one specific definition of social constructionism, it can best be described as a theoretical orientation or a set of theories which offer radical and critical alternatives in the social sciences and humanities and are strongly critical of an individual approach to self and identity. It is not a static body of thinking; it is changing and dynamic (Burkitt, 1994; Burr, 1995; Stam, 2001).

The different versions of social constructionism draw on a wide range of theorists from a wide range of intellectual traditions: Vico, Vygotsky, Bakhtin, Derrida, Foucault, Heidegger, Wittgenstein, James, Mead and Bateson (Pearce, 1992). We have already identified that social constructionists consider themselves as such to make a distinction with constructivists who favour the notion of self as an individual knower (Raskin, 2002). Although it is not possible to define a single social constructionist position, some common features can be identified. Social constructionist assumptions include: a critical and challenging stance towards how the world is understood, an understanding of the world that is not only historically and culturally specific but is also a product of history and culture, recognition that knowledge is sustained by social interaction and that social processes are dominant and a belief that knowledge and activity are intertwined (Burr, 1995; Cromby & Nightingale, 1999).

## The self, language and social constructionism

Social constructionists are critical of traditional approaches to self and identity which are based on realist assertions that assume an internal self pre-exists language. Language is critical to social constructionism. It focuses on the constructive power of language which informs how we understand the world and how our world is constructed in interaction with others. Language is not just a way of expressing ourselves. It is performative in that it actually does things. The self, therefore, in social constructionism is considered to be a product of language and social interaction. Interactional and relational approaches consider that people are both constructed through and constructing in their relationships with others and the self gains identity through relationships (Gergen & Gergen, 2000; Burr, 2002). Rather than the unified and coherent self of humanism, the self of social constructionism is a constantly changing notion dependent on context (Burr, 1995; Crossley, 2000a). In rejecting the notion of an innate self, social constructionism talks instead of identity. How people are talked about and treated contributes to identity and a person may live out different identities in different contexts (Raskin, 2002). This means that our explorations into self need to reach beyond an isolated individual and consider social, political and economic influences (Burr, 1995). Botella (1998) suggests that the question that psychology asks is not about what is a human being but rather should be "what kind of human being is constructed by our theoretical discourse?" (p. 2).

### Challenges to social constructionism: "What's wrong with social constructionism?"<sup>19</sup>

Social constructionism has provided a much needed voice in psychology and has greatly influenced the concept of the self with an emphasis on the role of language, society and culture. Its strong critique of individualism and the limitations of mainstream psychology, its challenging of our understandings of language, power and identity, and the recognition of social, cultural and historical processes in shaping the individual are extremely important contributions to our understanding of the individual in psychology. However, a social constructionist approach to self and identity is not without its problems (Burr, 1995; Nightingale & Cromby, 1999; Martin & Sugarman, 2000)<sup>20</sup>.

<sup>19</sup> Cromby & Nightingale, 1999, p. 1.

<sup>20</sup> Shotter and Lannamann (2002) write that the debates about social constructionism attest to the "widely divergent social realities we, as individual theorists, inhabit" (p. 578).

The focus on discourse has been suggested to the detriment of understanding the self as an embodied social being with personal and social histories (Burkitt, 1994). Social constructionism has also been widely criticized for its relativism and for its focus on language which has sometimes been promotional of the stance that there is nothing outside the text (Gergen, 1997). Two key areas that are problematic are those of personal agency and embodiment (Burr, 1995; Nightingale & Cromby, 1999).

Social constructionism's stance on agency is that we are what society makes us and that notions of selfhood and reflexivity are all the result of society's discourse (Archer, 2002). However, the degree to which social constructionism attributes the individual with personal agency differs and there are social constructionists who attribute the individual with "the ability to reflect upon and accept or resist subject positions in discourse" (Burr, 2002, p. 132). The problem of agency is about how we conceptualize a person as someone who is both formed by her social world and who also has the ability to transform that world (Archer, 2002). If the person remains a product of discourse then there is the problem of personal agency but promoting personal agency may appear to support the privileging of an independent individual and of autonomous thought and action. However, notions of personal agency and intentionality open up opportunities for people to a range of identities.

Nightingale and Cromby (1999) question a social constructionist psychology which focuses intensely on the role of language in constructing both the world and the person. While they identify themselves as social constructionists, they argue that there has been a lack of attention to embodiment, materiality and power and that it is not possible to reduce these elements to discourse alone. Different forms of social constructionism treat the body in different ways. The weak form of social constructionism acknowledges the experience of the body but qualifies that it is only meaningful as a cultural not a biological construction while the strong version rejects physiology (Baerveldt & Voestermans, 1998). Burkitt (1994; 1998), in rejecting a textual metaphor for how we can understand the body, considers an embodied self; a body made active by social relations. Citing the work of Bourdieu and Elias in attending to how social relations and practices actually shape bodily experience, he argues against a Cartesian view where self is identified with the process of thinking and not with the body: "The body is the locus of social relations, its sensual and perceptual experience moulded by cultural and historical circumstances" (1998, p. 69).



Where does this leave the self?

Kitzinger (1992) credits social constructionism with identifying the historical, social and cultural specificity of the individuated self-concept in psychology. However, if we accept the challenges to an individualistic, pre-social self and engage with a self that is socially derived then where do we find ourselves? What kinds of self (or selves) can we talk about if we wish to move beyond the tension of the psychological and social? What kind of self (or selves) can we construct if we wish to find an alternative perspective from a modern, saturated, empty, minimal or decentred self without losing the gains made in the understanding of and the insights to the self? This discussion about notions of self has led to a questioning of individualism and the traditional view of a psychological self to a focus on a social self. But does that mean the social becomes the forefront of conceptions of self and identity? Wortham (1999) warns that if we foreground the social we risk trading psychological essentialism for social essentialism.

In summary, an essentially psychological approach in which self is considered to develop predominately through the internal cognitive process of the individual does not account for the key contributions of social, relational and discursive practices to the construction of self. However, if we privilege the social, we fail to appreciate the role of personal agency, responsibility and embodiment (Tappan, 1999). So where to from here? Is it about trying to transcend the self-other binary or is it more about accepting that these debates still remain incomplete and unfinished (Gergen, 1999; Stam, 2001)? Alternatively is it, as Stam (1996) suggests, that such issues “invite further elaboration, contribution and dialogue” (p. 557)? The next section develops a perspective of self based on engagement with the literature and drawing on experiences from the practical realm of people living with chronic illness and disability.

### **The self of the project: getting on with it<sup>21</sup>**

With an exploration of notions of self and a focus on the emergence of a social self through to the postmodern decentred self, and the identification of some of the problems with the self of postmodernism and social constructionism, we need to consider now an account of the self that reflects my understandings and my assumptions. My difficulty in negotiating the personal and the social are echoed through the current literature.

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<sup>21</sup>Lincoln & Denzin, 2000, p. 1059.

Martin and Sugarman (2000) are not alone in their resistance to a forced choice between modernism and postmodernism drawing on sociocultural, phenomenological and hermeneutic thought. While they are in agreement with much in postmodern thought as a counterbalance to realism and individualism, they argue for a "kind of sceptical, middle-ground position" for human beings and understanding (p. 399).

Before locating a version of "middle ground", there is one further body of knowledge that greatly contributes to an understanding of self for this project and draws together thinking about self, agency and embodiment. As I have read and thought about the self and as I have explored it through the literature, I have also been very aware of the practical realm of working with people who have sustained brain injury. The participants in this project are people with aphasia. The research questions concern self and identity in aphasia. These are people who were at one point communicating satisfactorily. They had no pre-existing problems that interfered with their ability to take up their social roles in an essentially verbal world. Stroke challenged these "taken for granted" abilities and damage to the areas of the brain imperative for speech and language production and comprehension resulted from aphasia. Stroke also, for some people, resulted in physical changes including weakness in an arm or leg, or both. It may have also resulted in damage to those areas that control the muscular movements necessary for producing voice, for swallowing and for the clear production of speech sounds. What insights does aphasia and other outcomes of brain pathology give to our understanding of self?

### *Insights from pathology*

Phineas Gage's story is well known within the study of brain and behaviour. He was a foreman of a railway construction gang working in Vermont in the mid-1800s when an explosion blew a three and a half foot long tamping iron through his head. He survived the accident but reports from that time indicate that, despite intact motor and intellectual functioning, Gage underwent major changes in his personality and his behaviour and his friends said that he was no longer Gage. There are different views about the areas of brain that were damaged but it is most likely that these changes were the result of damage to his frontal lobes (Guyer, 1994; Macmillan, 1999).

Despite the significant time lapse since Gage's accident, it remains most likely that if any of us were to acquire the same injury in the same region of the brain, we would also experience changes in who we were (Solms & Turnbull, 2002). So what possible insights about self can we gain for the study of brain pathology? What does neuroscience contribute to our understanding of self?

Even with the advances in science and technology since the time of Gage, there remains conflicting views about the efforts to find a neuroanatomical location for the self (Morin, 2003). Early studies focused on the study of lesions and identifying localization of functional specialties in the brain (O'Brien & Opie, 2003). This included identifying the role of the cerebral hemisphere in commissurotomy patients where the connection between the two cerebral hemispheres has been surgically split. While this provided information about the lateralization of language and the role of the right hemisphere, the evidence was open to interpretation. More recently, the development of new brain imaging technology in both normal and abnormal function has allowed the identification of specific areas of the brain that are activated when people engage in tasks involving speech, perception, thought and sensation.

A consequence of these developments is the application of this technology to the questions about the location of self in the brain. Of particular significance is self-awareness, the ability of the self to reflect upon itself and a research focus on what regions show increased brain activity when a person engages in self-reflection. What emerges from these studies into the processing of self-relevant information is that there is, in fact, bilateral hemispheric activity and, in the case of autobiographical memory, areas in the left frontal lobe hemisphere are particularly active (Morin, 2003).

Drawing on symptoms of schizophrenia and particularly the splitting of a sense of agency from the sense of subjectivity in delusional schizophrenia, O'Brien and Opie (2003) suggest that the self is a complex entity constructed out of independently conscious parts. They favour a more parsimonious account based on phenomenological and neuroscientific understanding. This multitrack, or polyphonic, model considers self and self-consciousness not to be the product of a single neural system but rather made up of a number of parallel tracks, each produced by a distinct mechanism in the brain.

## Beyond the brain

So how do we bring together the insights from neuroscience with the current discussion of the self, particularly considering the social construction of the self? A focus on lesions and location and brain behaviour seems bound to reinforce a mind-body split and seems far removed from psychology's exploration of the social construction of reality and self. However, it is possible to identify the emergence of a broader understanding of the impact of the social in neuroscience which Cromby (2004) calls "socio-neural" (p. 800). Damasio (1998) considers that decision making is related to emotions and feelings and when we engage in decision-making, the brain creates associated patterns of feelings (somatic markers). These brain states simplify and speed up the process by ruling out unfavourable options. Of interest is Damasio's hypothesis that while these somatic markers are neurally based, they are the result of an individual's socialization. Social interaction influences the brain which generates these somatic markers that feed back into social interaction (Cromby, 2004).

The impact of brain injury on the body and on communication contributes to the debate about embodiment and the dominance of the text. This is current also to research and practice in chronic illness and disability which challenges social constructionist and postmodern tenets. Williams (1999) maintains that disability theorists who regard disability as the result of social oppression have attempted to "write the body out" in their lack of inclusion of impairment (p. 803). In the extreme, it is suggested that this has created a notion of a disability as disembodied. He suggests that postmodernism also suffers from this "somatophobia" (p. 804). He makes a case for a critical realist position which defends the body as a real entity and challenges the discursive body of postmodernism and social constructionism and the disembodiment of disability theory. He refers to the case histories of the neurologist Sacks which show that "identities are indeed organically moored, and individuals, sometimes against all odds, struggle hard and heroically to maintain a sense of personal coherence and continuity in the face of their adversity" (p. 811). A study by Ellis-Hill, Payne and Ward (2000) into perceived life and identity changes following stroke suggest that people experiencing physical impairment as a result of their stroke experienced changed relationships with their bodies, changes that are dynamic over time but that are influenced by the social setting. While people may have become accustomed to changes at home where the body did not have a social focus, a return to the community or to work brought new issues and "the uncomfortable experience of a heightened disparity between body and self" (p. 731). They concluded that the meaning of the changed body is socially defined.

### *Finding a middle ground*

While critiques of postmodernism and social construction have been cited to highlight problems with their constructions of the self, they still greatly influence the development of the self for this project and also influence my developing approach to social inquiry through the research process. I have also used the insights from pathology to contribute to the notion of a self that is also an embodied self with the ability to contribute to change through action. Through this process, I have identified three strands that currently shape my understanding of the self: dialogical, relational and narrative practices. These, however, overlap and often draw on the same theoretical traditions and theorists. They also acknowledge, question and build on some of the challenges presented by postmodernism and social constructionism in their contributions to an understanding of self and identity.

#### Dialogical practices

Richardson et al. (1998) propose a balance between a partly decentred self with multiple voices and meanings and an embodied individual still possessing a degree of agency and responsibility. They describe this as a dialogical self. Bakhtin introduced the term dialogic to describe how “all forms of human intention are mediated by our dialogic relation to others” (Josselson & Lieblich, 2001, p. 277). From this point of view the self is also considered to be in dialogic relation. Hermans et al. (1992), critical of contemporary psychological theories of the self based on individualism and rationalism, also argue for a dialogical self. This dialogical self is an interface between the work of Bakhtin and James (Hermans, 2003).

Hermans et al. (1992) take inspiration for the notion of dialogical narrator from Bakhtin’s metaphor of the polyphonic novel emphasizing the plurality of perspectives and worlds and from James’s view of the “I” as self-knower. The “I” can move from one position to another and may even take an opposing position. Dialogical relations are established between positions and the result is a “complex, narratively structured self” (Hermans, 2000, p. 27). Hermans (2003) contrasts the dialogical self with its dynamic array of voiced positions in this imaginal landscape of the mind with the Cartesian self. The dialogical self is considered to be embodied, it is inclusive of the other, it is contextualized by history and culture and it has open boundaries.

What is found in current theorizing about self is that self is a process rather than a fully formed entity. Giddens (1991) proposes a dynamic and reflexive self. He considers that selfhood is an ongoing process or project, a dialogue that we carry on with ourselves in response and relation to changing circumstances. This parallels Mead's assumption that the self becomes known in interaction with others (Coupland, Nussbaum & Grossman, 1993). A dialogical conception of self is that we create a sense of self in dialogue with others who may confirm or challenge accounts of who we are (Neimeyer, 2001).

### Relational practices

Shotter (1993) believes that social constructionism is fundamental to the development of self. He takes a relational view of the complex negotiations between self and other where becoming and being is only possible in relationship with others. He positions social constructionism between the polarities of objectivism and subjectivism, in a location where the flux of social life and relational practices take place. I find Shotter's extensive writings relevant not only to the theoretical background to the self but also very relevant to, not just language, but communication; a key component of the project. Shotter and Lannamann (2002) write that what has been neglected in psychology "... is the nature of the living, embodied, reciprocal spontaneity that constitutes social interaction" (p. 579).

I have included Shotter's work within relational practices but he called his early definition of his thinking dialogical psychology. He draws, among others, on the works of Vygotsky, Mead, Bakhtin, Volosinov and Wittgenstein. His writing sets out to shift the focus from how we understand objects (epistemology) to how we understand each other (hermeneutics). With an interest in the relational aspects of communication, he explores a more dialogical social constructionism where the space between people becomes a location for the construction of living and being. He refers to this as a rhetoric-responsive version of social constructionism that considers what speech actually does for us in contrast to what we use speech to stand for as a referential-representational function. He asks what we do with our talk. Rather than an individualistic perspective where we are merely using words to express our inner ideas, his stance is that language is sociorelational and that we are engaged in constructing our social relationships. It is not just about the shared ideas and understandings developed in conversation. What is more important is the nature of the events that take place within the emergent relationships. This changes the focus from how we come to know

the world and its objects to “how people first develop and sustain certain ways of relating themselves to each other in their talk, and then, from within these ways of talking, make sense of their surroundings” (1993, p. 2). This “joint action” (Shotter, 1993, p. 7) refers to how the meaning of an utterance is dependent on subsequent utterances within a relationship and the ongoing dialogue: not only do our words and actions take their meaning from the context but they actually create the context (Pearce, 1992; Gergen, 1997).

### Narrative practices

Storytelling is an intrinsic aspect of humanity and narratives produce the form and meaning that is human activity. It is considered to be the primary means by which people make sense of experience and it is through the act of storytelling that we make sense of our world to ourselves and to others. It is also how we make sense of who we are (Polkinghorne, 1988; Linde, 1993; Murray, 2004). While we cannot directly observe experience or narrative meaning as these are only directly knowable to the experiencer, we can observe stories (Polkinghorne, 1988; 1996). Despite a lack of agreement about the extent to which the self is created through narrative, most theorists consider narrative as a resource for the construction of self taking into account the social and cultural context (Schiffman, 2000). Crossley (2000b) highlights the essential link between “experiences of self, temporality, relationships with others and morality” (p. 533). She focuses on the study of language, stories and narratives that represent the self, particularly in regard to living with serious illness.

Narrative becomes particularly important in the restoration of a sense of order when life has been affected by dramatic changes such as in chronic illness and trauma (Crossley, 2000a). A narrative approach edges towards the middle ground. It takes account of the social, cultural and historical milieu and provides the ingredients for a discussion about the dialogical nature of language and the relational aspects of discourse while ascribing the individual with a “reflexive, self-determining capacity” (Martin & Sugarman, 2000, p. 399). It also goes some way to finding a “centre” where there is a “humanistic commitment of the qualitative researcher to study the world from the perspective of the gendered, historically situated, interacting individual” (Denzin & Lincoln, 2000, p. 1047).

### *Weaving the strands together*

These three strands as they weave together develop an understanding of self for this project. Although I had been more recently exposed to social models within aphasiology, my initial assessment of self was from a humanistic perspective. So how does this influence my perspective when I have already talked about the challenges to individualism and humanism? The review of the literature has been a process which has allowed a deeper exploration of the social and relational nature of the self. However, humanism still influences my writing and how I speak about the self. It is also present in psychology's writing as well and this warrants discussion. Several theorists have attempted to deal with how some of the features of a humanistic perspective can be sustained within a climate where linguistic, historical, social and cultural influences have a dominant role in the construction of the self.

Narrative approaches share some common ground with humanistic approaches to self and identity. Josselson and Lieblich (2001) suggest that narrative could be regarded as a "present day heir" to a humanistic psychology (p. 275). They cite the areas of commonality as being an attempt to place the experiencing human being back at the centre of psychology, the regard for people as complex, unified and context-bound and a goal of understanding and description as opposed to prediction, causation and control. However, unlike humanism, narrative avoids a pure subjectivity and considers subjectivity to be instead a site where identity is continuously reshaped by sociocultural influences. Rather than a self-actualizing person, the self of personal narrative is considered to be "multilayered, multivocal, and multidetermined" (p. 277).

Plummer (2001) acknowledges that the elimination of the subject in the critique of humanism is supported by complex arguments but he suggests that it denies the role of active human beings and lived experience (p. 5). He calls for a new pragmatic critical humanism that rejects the notion of a "unitary" self-actualizing individual but takes the human being as an "embodied, emotional, interactive self, striving for meaning in wider historically specific social worlds" (p. 257). Wedekind (2001), however, argues that Plummer would have difficulty escaping from the criticism that humanism over emphasizes the role of the individual. This continues to be a tension and a site of ongoing debate. Parker (1999a) believes we still need to maintain some form of humanism within psychology but that it needs to be more theoretically sophisticated, reflexive in its theory and practice, and acknowledging of the role of power in psychological research and practice. He describes this as a "critical reflexive humanist approach" (p. 24). Gergen (1997) suggests recasting



humanism as a relational process. He is critical of the ability of the assumptions of humanism (individual subjectivity, human agency and individual liberty) to deliver a more humane society and in doing so, looks to the positive potential of social constructionism. By addressing how each assumption could be re-visited in a relational manner, he articulates a relational alternative for individual humanism.

Throughout the larger discussion the assumptions of humanism and individualism have been challenged. I acknowledge in my writing and my arguing for and against positions I demonstrate that the project is still steeped in humanistic values; empathy, respect, honesty, a desire for openness and reflexivity. I am mindful of Parker's (1999a) concern that while humanist values are important for social change, they do become problematic when they are reduced to the level of the individual and when they remain uncritical of social processes. Stated simply, the account of the self laid out here has been about finding a balance between the modernistic isolated, individual self and a postmodern, decentred self while maintaining values that enable people to be in relationship. The balance rests, for me, in the weaving together of the three interdependent practices. The working self of the project is a relational and storied self in dialogue with the world with all its historical and cultural influences. Thus the self that inhabits the project is "a subjective relational enterprise always created and re-created between individuals rather than in isolation (Josselson & Lieblich, 2001, p. 285).

### Locating the project

So where does this project sit? The point of the preceding history and discussions has been to get to this position where the foundations of the project can be made clear. While I have tried to create a picture of the journey of the self and the associated theoretical locations, I have also tried to be transparent in my selectivity. Early decisions about the direction of the project were influenced by my wanting to explore further the social self. I chose not to consider other psychological perspectives in depth because they did not strongly motivate this work even though they have never been absent from the discussions. I have taken a long time to work through the complexity of issues and ideas to arrive at this point. In developing a location for the project, I have not set out to only critique or defend a specific perspective in an abstract manner. While I could have assumed a particular standpoint early on, I wanted to understand what I was doing and I wanted to understand what assumptions I was bringing to the process.

There were several reasons for this. Firstly I wanted the research to be rigorous and the product to be sound and secondly, I have an ongoing responsibility to the participants to ensure that what we were doing together and how I used their stories were ethically sound. I wanted to find a respectful and credible way of engaging in research with people with aphasia that addressed the research questions<sup>22</sup>. To do that I needed to clarify the assumptions which underlie my work for the participants in the project, for the readers of this work and for myself.

I have spent time exploring constructionism because it represents the challenges that have been alive for me in this project and it has influenced the theorists whose work currently influences my own. While the research process has opened me to listening to additional voices to humanism and individualism and to question some long held assumptions, the tension between personal and social has remained a dominant theme for me. This reveals the power of my own personal and professional biography, particularly my clinical relationships with people with disability. It has also influenced the choices I have made in my reading of particular theorists and how that has contributed to the shape and structure of the project. I have identified with some of the main tenets of social constructionism particularly its challenges to psychology's dominant practices of individualism and positivism, the relationship between the knower and the known, and the key role of language and interaction in the construction of self. However, I have not felt a resonance with what I consider to be the loss of self to discourse alone. Through engaging with constructionism, I identified the constructivist perspective as introducing social processes to the action of personal meaning making. What I have tried to do is find a place that recognizes agency and responsibility but also that values the relational nature of self construction. I acknowledge my therapeutic background and my initial experience with narrative research which privileges the personal but I also want to distance this work from an individualistic paradigm. Finally, I have often wondered what is at stake that I feel so compelled to tease away at, rather than be accepting of, the tensions that exist (and will continue to exist). If I shake it up, and watch it all settle, it is about being ethical in the research process but it extends beyond research to my relationship with people with communication disability in my clinical world. It is about power and responsibility and it is about how shared understandings of being in this world are achieved. Through this narrative, I hope to have described my thinking and I hope that the next step of laying out the foundations of the project will seem to be a natural progression.

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<sup>22</sup> The project is also motivated by how the research might contribute to the real lives of therapists and people with aphasia and their families.

## Theoretical foundations of the project

Mindful of Stam's (2000) caution that theory is not a luxury but a responsibility when we intervene in other's lives, what follows is a way of representing the project. Returning to Crotty's (1998) metaphor of scaffolding with the inclusion of ontology (Figure 3.1) provides a way to present the theoretical foundations of the project. I am also mindful, as I set about a process of demarcation, of Crotty's caution that this is to be a scaffold and not an edifice. It is but one way of making sense of the research process with the aim of inducing a sense of stability and direction. I hope that the spirit of the research is not somehow obscured by what sometimes feels like oversimplification.

### *Ontology*

If I consider the ontological question of whether an external reality exists or not, the answer is either "no" and I adopt an ontological stance of idealism, or "yes" and I adopt realism as my ontological perspective. But how do I begin to account for the belief that there is some underlying reality and yet still maintain a more critical approach towards psychological theories (Burr, 2002)? This has been an important consideration for me as the proposal for this research includes life story interviews with people with aphasia. Am I assuming from a realist perspective that these interviews are a way to gather information about a person's account of her life? Or am I assuming that there is no social reality beyond the interview or even that there are multiple realities. Identifying an ontological position is significant to how the research is planned with each decision from ontological to epistemological and methodological informing the next. It is also significant to how the research proceeds; how interviews are carried out, how they are transcribed and analyzed, and how they are interpreted and reported. Ultimately it tells about my own role in the research and the influence that has on the outcomes.

When I consider my own position, I am looking for a "middle ground" (Crossley, 2000a, p. 88). That is, I have an assumption that people are not just producing a story but that they are expressing something about their lives. This does not exclude attention to the social and, as my methodology is explored, the social is significant to the project. While I do not believe that reality is out there to be represented or that it is purely in the mind, I consider that what people say does have some significance to them and does have some relationship to their psychological and social realities and they are communicating something about their lives (Mauthner, 1999; Crossley, 2000a; Hollway &

Jefferson, 2000a). Is there an alternative ontological position that supports a belief in the existence of an external reality without the assumption that we have direct access to it? Crossley (2000b) pursues a narrative psychological approach in her work and makes use of social constructionist approaches. However, she suggests that, particularly in the applied fields such as health, realist assumptions about the relationship between people's narratives, for example, about illness or trauma and how they experience it, are important, for researchers who wish to make a difference in practice.

In working with people who are working to reconstruct or to re-establish their lives after stroke, I may see distress and despair for families as they address the physical, communicative and social changes with the resources they have available. But I also listen to their hopes and wish for things to return to how they were or for things to get better and I witness their active attempts to make sense of what has happened and in doing so transform their situations. The changes in the ability to communicate and often the accompanying physical changes to people's bodies following a stroke represent a sudden neurological change affecting physicality and this is salient to the discussion of self, identity and embodiment.

From my perspective in being alongside people in this process, this is better understood through a critical realist ontology. I consider it also bridges the issues that arise with constructionism, specifically agency and embodiment. Critical realism originates in the work of Bhaskar which offers an alternative to the relativism of postmodernism and constructionism. Critical realism acknowledges that there is a reality, a domain which exists independent of our knowledge but how we know it is shaped by language and culture (Williams, 1999). Crotty (1998) qualifies this further by pointing out that accepting that there is a reality independent of our consciousness does not suggest that meanings exist independently of consciousness. While no knowledge claim can be privileged, a radical relativism would leave the people unable to make a choice or unable to take a stand (Botella, 1998). Not to muddy the waters, Crotty (1998) acknowledges that people may well inhabit different worlds and that there may be different interpretations and different ways of knowing.

*Epistemology: modernity's man or society's being?*<sup>23</sup>

I started with a desire to explore the social self further for this project and in doing so I have highlighted the social influences in the construction of the self. I have also highlighted my support for agency in self construction and the reflexive nature of self. However, I acknowledge the role of power and of the historical, cultural and political influences on self and identity. My background and particularly my clinical role in working with individuals and their families would see my epistemological standpoint as constructivism. If we recall, Crotty (1998) identified constructivism as a focus on the meaning making of the individual mind while constructionism is when the social generation of knowledge is dominant. However, within the literature, the distinction is not always clear.

Several theorists have attempted to link more closely personal constructivism and social constructionism and this body of knowledge has resonance within my locating an epistemological stance for this work. Botella, Herrero, Pacheco and Corbella (2004), in an effort to establish dialogue between constructivism and social constructionism, propose a relational constructivism. Their work has been developed over the last ten years from both research and from clinical practice and is heavily influenced by the works of Wittgenstein and Bakhtin who are most often associated with social constructionism (Botella & Herrero, 2000). Botella's earlier work centred on Kelly's personal construct theory and its potential contribution to a postmodern psychology (Botella, 1998). The key assumptions of relational constructivism include: being human entails construing meaning, meaning is an interpretive and linguistic achievement, language and interpretations are relational achievements, relationships are conversational, conversations are constitutive of subject positions, subject positions are expressed as voices, voices expressed along a time dimension constitute narratives and identity is both the product and the process of self-narrative construction (Botella et al., 2004; p. 120 - 123). If I consider these assumptions, they are echoed throughout the previous discussions on self as dialogical, relational and narrating. Their work has a pragmatic origin within a clinical sphere as they are psychotherapeutically based, they attend to the ontological and epistemological foundations of their approach and they address the tension between subjectivism and objectivism. Their work has strong links to the theoretical perspectives that inform the project. A relational constructivism enables me to integrate the theoretical practices that influence my understanding of the construction of knowledge and my understanding of the construction of self.

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<sup>23</sup> Archer, 2002, p. 11.

### *Theoretical perspectives*

There are several key theoretical approaches that underpin this work and support the proposed methodology. These have emerged from an involvement with selected literature and with the research questions and the locating of a self for this project: narrative theory, relational theory, and hermeneutics. They are best described as interpretivist. Crotty (1998) believes that interpretivism, in contrast to feminist, postmodernist and critical research, offers a less critical exploration of social, cultural and political influences. He also suggests that this is the basis of the difference between constructivism and constructionism with constructivism having a less critical stance and a more conformist approach to social research. While I would like to think that the project has some criticality in its contribution to research and practice with people with aphasia (and this will be taken up in the next chapter in considering the nature of carrying out research), the project is concerned with the subjective experiences of the researcher and the participants and it is essentially an applied project. Identifying practices that support or hinder people with aphasia in renegotiating self and identity following stroke has personal, interpersonal and social ramifications. However, it is fair to say that it is therefore "local" in its scope and while it is influenced by my exposure to a critical psychology, it is less "critical" than other theoretical perspectives.

The inclusion of the following theories is influenced by my understanding of what I have read and by my context and therefore influences how I have structured this account. There are some areas of overlap, for example, narrative has its roots in hermeneutics and phenomenology (Josselson & Lieblich, 2001). A major connection between these theoretical perspectives is the significance of language which is essential to research with people with aphasia. They are also linked by ethical concerns and thus reveal the humanistic values that influence research and practice. Narrative, relational and hermeneutic theories are linked too by their historical and philosophical backgrounds as well as through the theorists cited in their development and, of course, particularly in their collocation for this project. As already discussed, the subsequent theoretical perspectives are informed by my ontological and epistemological standpoints (Crotty, 1998; Lincoln & Guba 2000).

## Interpretivism

Interpretive research approaches have received increased interest associated with the awareness that research arising from positivist assumptions fail to capture what social activity means for individuals and social structures. The claim is that the methods of natural science are not appropriate for the study of the social world because human and social action is intrinsically meaningful. In an interpretive perspective, the social world is understood as a developing process in which people create shared understandings and experiences (Addison, 1989; Schwandt, 2000; Snape & Spencer, 2003; Goodley & Lawthom, 2005). In relation to research, interpretivism is concerned with both the researcher's and the participants' understandings and, compared with conventional social science where ethical concerns exist outside the process, ethical concerns are embedded within the practice of interpretivist social science research (Lincoln & Denzin, 2002; Snape & Spencer, 2003). I want to better understand what changes in self and identity occur as the result of aphasia and how self-understanding is achieved in the presence of aphasia by listening to people with aphasia. These types of questions are best addressed by interpretive approaches and I consider three streams as being influential to this project: narrative theory, relational theory and hermeneutics.

### *Narrative theory*

While it is acknowledged that there is no one theory of narrative and there is, instead, in its place "great conceptual diversity", I consider narrative to be a theoretical standpoint that greatly influences this project (Riessman, 1993, p. 17). It is through narrative that "we define who we are, who we were and who we may become in the future" (Crossley, 2000a, p. 67). When we reflect on and tell about events, we provide meaning and coherence to experience and we create a shared history with our listeners (Smith, 2000). Sarbin's (1986) seminal work on narrative psychology advocated that people think, perceive and make moral choices using narrative as an organizing principle. He proposed that narrative could provide a root metaphor for psychology as a whole, replacing the dominant metaphors in Western culture and traditional psychology of mechanism and organism. Ezzy (2000) regards narrative theory as a response to the philosophical and methodological issues raised by postmodernism. He considers that narrative theory provides a way of addressing the relationship between experience and interpretation and that neither is ignored

(Ezzy, 2002). Squire (2004) suggests that narrative may allow us a synthesis between “modern” interests and “postmodern” concerns, between the interest in individual experience and the concern with representation and agency (Introduction section, paragraph 4).

While I cite narrative as a theoretical position informing the project, constructionism as a theory of knowledge is embedded in narrative. Narrative is not, however, only understood as a theoretical perspective; Sarbin (1986) considers stories as having ontological status: “The narrative for human beings is analogous to the ocean for fishes” (Hevern, 1999, p. 301). For some theorists, narrative is of epistemological significance. I have not identified narrative as epistemological and this needs further explanation. Botella et al. (2004) identify that earlier approaches to narrative such as traditional sociological and anthropological work were based on objectivist assumptions in that both individual and collective narratives were considered to provide a study of the reality. More recent approaches such as symbolic interactionism and cognitive psychology, they claim, have been based on subjectivist assumptions within which narrative is considered to give access to inner realities. So it is possible for narrative to be informed by different epistemological positions. This, coupled with my reading of Bruner’s (1990; 1991) work may help clarify why I have identified narrative as a theoretical framework. He suggests that culture with its symbolic organization, including narrative, shapes our lives and our minds. Narrative not only represents reality, it is also a way of constituting it. Narrative is concerned with interpretation and, as such, not with the cause for things but rather the reasons. He identified two modes of thinking which both produce useful knowledge: paradigmatic cognition and narrative cognition. Paradigmatic cognition or reasoning is based on the traditional logico-scientific mode of knowing. This has a classificatory function and seeks commonality. It enables us to represent our experience in a consistent and ordered manner. In contrast, narrative thought is based on storied knowing and a subjective perspective. It enables us to understand human action through focusing on what is different and diverse (Murray, 1995; Polkinghorne, 1995). From my reading of this and my understanding, narrative is one way of knowing our world and can be embedded in other epistemological perspectives other than constructivism thus I interpret narrative theory as a theoretical approach to our construction of the world. Narrative can also be regarded as a method of analysis, as a method for gathering data or as research data that is textual as opposed to numerical (Polkinghorne, 1995). How narrative is understood and how it is applied in research is related to the purpose of the research and is grounded in the researcher’s overall theoretical orientation. Given the research questions and the methodology, narrative theory is a key theoretical influence for this project. Further discussion about narrative forms a substantial part of Chapter Six in developing the project’s methodology.



### *Relational theory*

Relational theories originate from feminism and include the work of Gilligan (1982) which centred on women's moral and psychosocial development. Her findings indicate that women develop a sense of identity through relationships; she argues that women's sense of self and identity is closely linked to their relations with others. This has influenced the reframing of psychological development as a relational process (Burr, 1995).

A major principle, therefore, in relational theory is the importance of relationships not only for growth but for ongoing development. We cannot disengage our sense of self from our relationships with others and from our culture (Gilligan, Spencer, Weinberg & Bertsch, 2003). Relational theory focuses on intersubjectivity. The concept of self becomes not one of a separate individual but one that develops from within relationships. Rather than championing the rational self pursuing individual goals and self-interest, a relational view attends to the interdependence of and interconnection between people. This challenges individualism and instead hypothesizing human beings as interdependent and part of a complex social world (Tronto, 1995; Mauthner & Doucet, 1998; Nolan, Davies, Brown, Keady & Nolan, 2004).

A relational perspective provides an important framework for this research by not just acknowledging the self as a relational process but also the relational nature of the research context: the interdependence of the researcher and the researched, the knower and the known, and the subject and the object: "Knowledge is constructed in the intersubjective space; what is known is a product of what the teller can and will tell and what the listener can hear" (Josselson & Lieblich, 2001, p. 285).

### *Hermeneutics*

Hermeneutics is the study and art of interpretation which was originally applied to sacred written texts. Contemporary hermeneutics is an interpretive activity focused on what it is to be human (Packer & Addison, 1989; Martin & Thompson, 2003). What we do and say are all considered expressions of meaning and gaining understanding requires interpretation. Hermeneutics claims that people are self-interpreting beings and that self understanding is achieved through a process of

interpretation, experience and reinterpretation: the hermeneutic circle. However, culture and history are central to this process (Crotty, 1998; Richardson et al., 1998; Wolszon, 1998).

Hermeneutic inquiry is proposed as an alternative to the simple realism of scientism and to the relativism of postmodernism (Martin & Sugarman, 2001). From a hermeneutic viewpoint, human lives are temporal and narrative in structure: "We know and understand ourselves only through conversations with our past, present, and future projects" (Wolszon, 1998, p. 552).

Thinking about my theoretical perspective

To summarise the discussions leading to the development of the theoretical framework as outlined in this chapter, Figure 3.2 develops further the notion of scaffolding for this project.

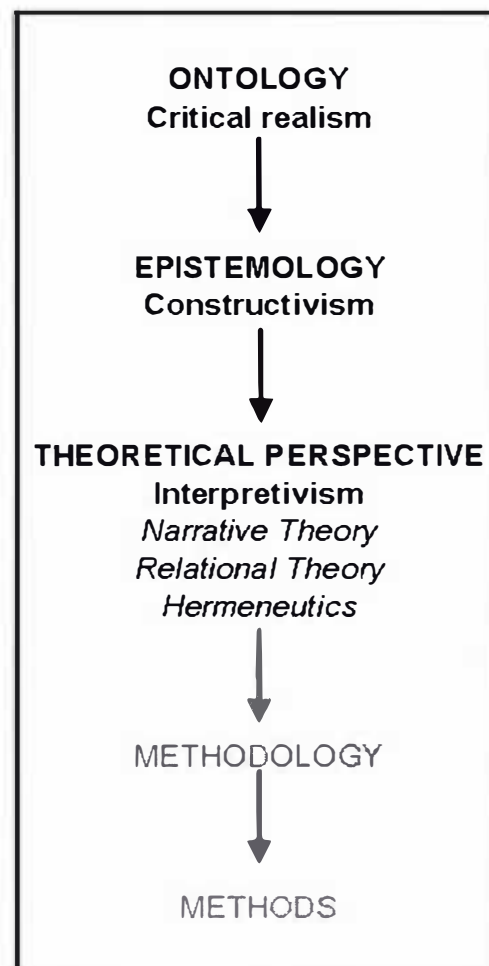


Figure 3.2: Developing the theoretical scaffold

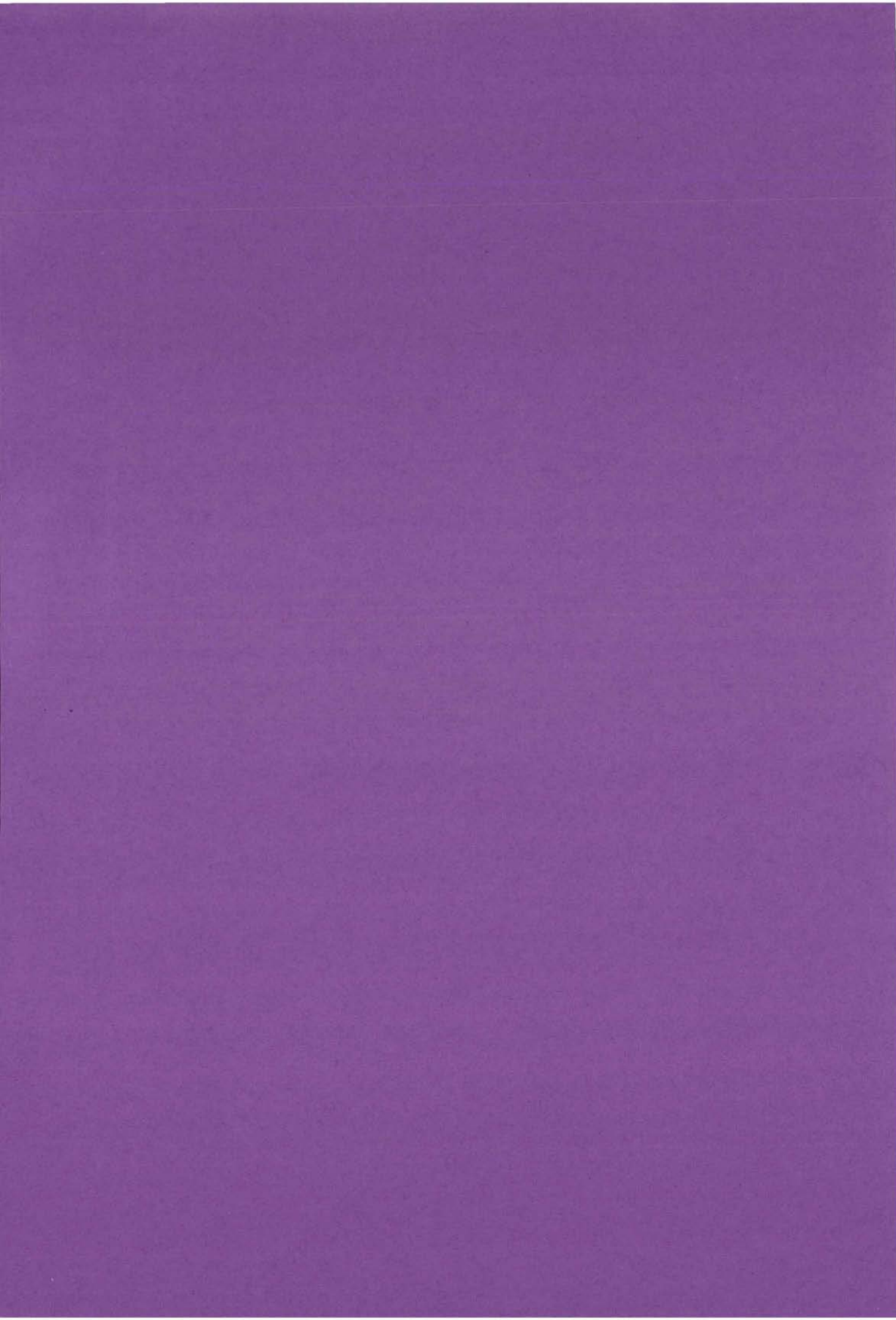
(Adapted from Crotty, 1998, p4).

While writing this chapter, I have often revisited the initial motivation for the project and its applied nature. The chapter is formal and theoretical although I have tried to be reflexive in my writing. However, my identity as a researcher is much more recent than my established identity as a clinician and it is expected that I would be drawn back to questions of relevance and practice; how will this knowledge influence my practice? The desired outcome of this process has always been to gain a better understanding of how people experience self in living with aphasia and therefore, how best to be able to work together with people with aphasia.

However, as I think about the theoretical material I have read and as I take part in my own debates, I have sometimes felt that I may be losing a balance between theory and the practice of living and therefore risk making the process depersonalized and distant. Shotter (2003) talks about the debates over ontologies and epistemologies and considers that the concern should be with helping people to change their everyday practices: "It is not a matter of putting theories into practice, but of inserting or intertwining new reflective and critical practices into our already existing daily practice" (Paragraph 4).

### Summary

This chapter introduced ideas about self and identity and then reviewed selected notions of self after considering philosophical issues. In its selectivity, the chapter focused on the development of the social nature of the self leading to dialogue concerning the post-modern self and social constructionism. The chapter concluded with a discussion of a relational and storied self. Significant to all this, and to the project, is the role of language in not just how the self is talked about but its importance in how the self is constructed. Finally, I set about laying out a location for myself and for the project. The next chapter extends on this and considers other strands of influence that also contribute to locating a process that enables the impact of aphasia on self and identity to be explored.



## Chapter 4

### Locating the process

#### Overview

#### Research story

#### Blurred boundaries

Feminism

Critical psychology

Disability studies

Qualitative inquiry

*Autoethnography*

*Participatory inquiry*

*Reflexivity*

*The crisis of legitimation*

#### Locating the strands

#### Summary

## Overview

The previous chapter began the process of locating the project by locating its theoretical background. My epistemological stance was developed as relational constructivism with narrative theory, relational theory and hermeneutics as the foundational theories. This chapter explores other perspectives that have also influenced the shape and form of the project as another step towards completing the scaffolding of the project.

## Research story

I bring to this project other experiences that influence how the project has developed. From my own biography, I recount an experience as a first year psychology student in the early seventies. There was an expectation in the department within which I was studying that students would be available to be subjects for experiments. As a result I became a subject for several experiments and one, in particular, I still recall.

I remember a small windowless room with one wall dominated by a large mirror. The primary experimenter was a post-graduate student in the department whom I knew by sight and by status. When I was seated, he methodically attached electrodes at various points on my body, while describing what he was doing. He asked if I knew what the electrodes were for and followed my awkward reply with an explanation about recording information regarding galvanic skin responses.

I knew that there were faces beyond the mirror and I was told that they would be recording information about other relevant behaviours. I was aware that they would most likely be senior students and, although I would not be able to recognize them around the department or on campus, they would know me. There I sat, embroidered with electrodes, positioned in a chair facing a one-way mirror. I don't think I had eye contact with the experimenter and there was no recognized protocol for me to establish any form of contact either before, during or after the experiment with the observers, screened from me by the mirror.

What followed is not clearly recollected. I remember being nervous on top of my shyness. I also remember fearing what my baseline measurements would be as I was experiencing a reasonable degree of anxiety. I knew that, while I may have appeared composed, somewhere there were recordings going wild. The experiment began with the experimenter chatting with me and then he

asked me if he could ask me something personal. At that moment, I must have provided a great research response. I was self-conscious, nervous and now I was feeling uncomfortable. He asked me to tell him about an embarrassing moment and, looking back, that specific moment would have filled the criteria. I never thought of withdrawing and I went on to provide a story about an incident for the experiment. I do not recall how it ended and I have no recollection of any feedback about the completed experimental process.

While this episode is more revealing of me as an eighteen year old, it is now over thirty years later so why revisit this particular memory? It has to do with the present and defining what research is for me now and what I feel it should offer participants who share the process with me. It has to do with addressing the concerns that arise from my experience and the journey in between: informed consent, confidentiality, power and position, participation and collaboration, and the worth of research to participants' lives. It is about the way in which any research (and practice) with people is carried out.

### Blurred boundaries

Revisiting this experience encouraged me to consider other research approaches that would provide more resonance and contribute to defining a research strategy for exploring self in people with aphasia. These perspectives share commonalities and include feminism, critical psychology, disability studies and qualitative inquiry.

### Feminism

Feminism<sup>24</sup> is difficult to define but it is considered as a diverse, dynamic and challenging field of research and practice which has had important political and intellectual influence in the social sciences (Olesen, 2000; Travers, 2001). A feminist perspective recognizes the oppression of women and the main goal is to dismantle that oppression. It also acknowledges that there are other forms of oppression and that a core aim is to actually improve all our lives (Wilkinson, 2004). Olesen (2000) describes feminist qualitative research as "a complex, diverse and highly energized enterprise of

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<sup>24</sup> Jane Ussher (1999) suggests that there are in fact many different 'feminisms' arising from different epistemological and methodological perspectives.

which it can be said there is no single voice" (p. 235). However, there are some key assumptions underlying a feminist approach to research as summarised in Figure 4.1 (Mauthner & Doucet, 1998; Mauthner, 1999; Olesen, 2000; Morawski, 2001; Murray, 2001; Travers, 2001; Wadsworth, 2001; Way, 2001; Legard, Keegan & Ward, 2003).

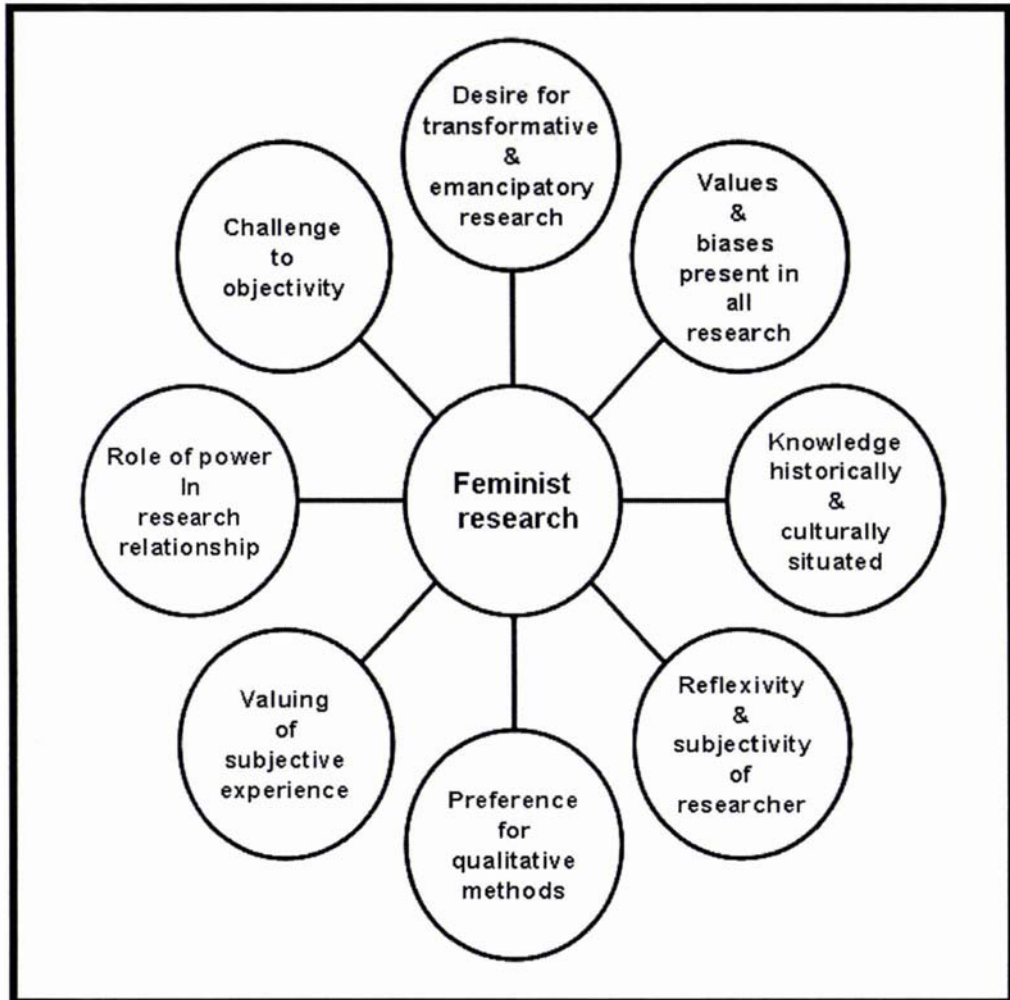


Figure 4.1: Some key characteristics of feminist research

This project is predominantly influenced by feminist experiential approaches which focus on individual experience, traditionally ignored or silenced in research (Wilkinson, 1996). Focusing on personal accounts and giving authority to the voice of the individual is also applicable to other groups who experience exclusion. While this project is not specifically about the experience of women, it is about social inequalities that can arise from the difference between people "without" aphasia and those "within".



## Critical psychology

My initial location in health psychology introduced me to discussions about underlying epistemological concerns and qualitative methodologies in psychology and I became increasingly aware of a critical perspective. The emergence of critical approaches is a reflection of a number of theoretical and methodological developments that have taken place both within psychology and the human sciences over the last twenty years (Parker, 1999b; Tuffin, 2005). Although critical psychologists come from a variety of theoretical and methodological backgrounds, there is a shared dissatisfaction with mainstream psychology's assumptions and its neglect of social and political issues.

In common with critical approaches in other disciplines, critical psychology identifies the pivotal role that power has in the activities of the discipline and considers how psychologists might do psychology critically (Prilleltensky & Nelson, 2002; International Society of Critical Health Psychology, 2003). Two crucial components of a critical approach to psychology are, firstly, a goal of helping to bring about a radically better society and secondly, a challenge to mainstream psychology's values, assumptions and practices through questioning of the status quo (Crossley, 2000c; Fox, 2000). Several texts have emerged recently addressing criticality in the psychologies including critical health psychology, critical discursive psychology and critical social psychology (Parker, 2002; Prilleltensky & Nelson, 2002; Hepburn, 2003; Murray, 2004b; Parker, 2004; Tuffin, 2005).

## Disability studies

There has been a strong message from disability groups for problems to be seen from the perspective of people with disability and chronic illness and their families. What is unacceptable to people with disability is a failure to acknowledge their lives "in the round" and the misappropriation by professionals of power to make generalizations "about their lives, their feelings, preferences and responses to disablement" (Jordan, 1998, p. 476). Oliver (1993) stated that research on disability could not proceed in isolation from disabled people:

*Strategies have to be devised to ensure that research on disability provides an accurate and fruitful account and this can only be done by ensuring that the experience of disability is fed into the project by disabled people themselves.*

p.66.

Reaction to a medical model of disability and illness, particularly in the United Kingdom, has led to the development of a social model of disability. This stands in contrast to the view that disablement is localized within and a problem of the affected individual. The social model considers disability as a socially created problem constructed as a lack of opportunities, choices and rights, and a consequence of the attitudes and barriers imposed by a non-disabled society (Pound, 1998). A society which does not take into account the needs of people with impairments effectively excludes or disables those people (Tregaskis, 2002). Oliver (1996) considers that the impact of the social model within professional arenas has been limited and that professionals still consider that disability resides within the individual. Individual therapy is therefore aimed at curing or changing an individual's behaviour to compensate for the disability. He also highlights the change that working within a social model can bring in relationships between professionals and people with disability involving dialogue and sharing of expertise.

Despite the strength of the social model within the disabled people's movement, there has been an appeal in recent years, particularly from women with disability, to extend the social model of disability to include impairment (French, 1994). Crow (1992) calls for a renewal of the social model of disability with an aim to "bring back impairment" (p. 3). While disability theory has opened up debates about integration and inclusion, there is an exclusion of individual and personal accounts. Tregaskis (2004) recommends that disability studies can learn from feminism by giving more attention to the personal experience of disability.

### **Qualitative inquiry**

Social scientists have attempted to duplicate the methods of the physical sciences but their ability to research psychological concerns has been challenged (Chamberlain, 2004). This has led to a "qualitative revolution" and an acceptance of qualitative research approaches (Denzin & Lincoln, 1998, p. vii). Defining qualitative research begins by gaining an understanding of its complex history, some of which has been explored in the previous chapter in the locating of the self. Denzin and Lincoln (2000) detail seven phases in the history of qualitative research. Influential to the project is, firstly, the moment of blurred genres in which social scientists began to look to the humanities for models and theories and blurred, interpretive genres emerged. Secondly, the crisis of representation where research and writing became more reflexive. A third influential moment, a triple crisis, identified problematic issues including the ability to capture lived experience, using

traditional criteria for the evaluation and interpretation of qualitative research, and how research impacts on change and society (Denzin & Lincoln, 2000). Rogers (2000) suggests that the promise of qualitative research in psychology is its potential “to represent human beings as whole persons living in particular social and cultural contexts” (p. 83). The questions that this research project asks are about meaning and this cannot be grasped as we can a thing or a substance; meanings change and each social situation produces subtle differences and consequences (Ezzy, 2000). Hence, the influence of qualitative inquiry to this project.

### ***Autoethnography***

The crisis of representation challenged assumptions about being able to capture lived experience and about models of truth and meaning. From this crisis emerged alternative ways of writing and the consideration of writing as a method of inquiry (Denzin & Lincoln, 2000; Richardson, 2000). One form of writing is autoethnography; highly personalized texts of an autobiographical genre in which authors tell stories about their own lived experiences as a topic of investigation (Ellis & Bochner, 2000; Richardson, 2000). Richardson (2001) maintains that people writing in the social sciences always write about their lives; despite trying to suppress their voice in writing, “. . . it keeps erupting in their choice of metaphors, topics, and discourses” (p. 34). In autoethnography the self is considered as a source of data when writing about others’ life experiences and from a relational perspective, it is difficult to see how we can study the Other without studying ourselves (Koch & Harrington, 1998; Etherington, 2004). Autoethnography is said to address the issue of speaking for the Other because the autoethnographer is the Other (Richardson, 2000).

Not without its critics, autoethnography has been described as a “rampant subjectivism” (Crotty, 1998, p. 48) and Morse (2002) is critical of its potential to overwhelm a study:

*I call this conceptual broad siding – a form of concept tunnel vision. In effect, the personal experience derails the inquiry or, at least, seriously impedes it.*

p. 1159.

While Tierney (2002) once had concerns about the “unreflexive absence” of the author, he now has concerns about the “unreflexive insertion” of the author and the potential for overlooking the critical research relationships between researcher, researched and reader (p. 391). Ellis (2002) responds that writing always involves the Other in the context of social problems and social actions

although this may be implicit. Autoethnography is one alternative form of data presentation that influences this project. Other forms of writing are influential as well as visual forms, motivated initially by making data acceptable to and inclusive of people with aphasia. In offering further alternatives, Eisner (1997) identified the potential of the multimedia capabilities of the computer to provide text, image, music, and combinations of these (see Jones, 2004a).

### *Participatory inquiry*

Heron and Reason (2001) outline two main problems in traditional research: a lack of connection between a researcher's thinking and the research participants; and the researcher's theoretical focus which "doesn't help people find out how to act to change things in their lives" (p. 179). Acknowledging this, research approaches focusing on participation are gaining increased attention. The roots of participatory research are in projects located in developing countries where involving local communities in research and planning was found to be cost and time effective. The distinction between traditional and participatory approaches is the balance of power; in participatory research communities are involved in the entire research process in a bottom-up approach (Cornwall & Jewkes, 1995).

The disability movement has called for changes in the social relations of research by putting the control in the hands of the researched not the researcher (Oliver, 1997). Along with this is the need for different methodologies to be adopted. Inclusive research practices include emancipatory and participatory research. Zarb (1992) identified the use of participatory approaches as only a first step towards emancipatory research. Principles of empowerment and reciprocity are embedded in emancipatory research, and while participatory research does involve people in a meaningful way and has progressed reciprocity, Zarb (1992) believes that it has done little to advance empowerment of disabled people. Chappell (2000) considers the implications for research with people who have learning difficulties and suggests that participatory research methods are more prevalent in the area because the nature of learning difficulties has an impact on how research is undertaken. Hence a role exists for non-disabled researchers but Chappell (2000) warns against the potential for tokenism and for creating a false sense of participation.

There are different models of participatory research ranging from making research more accessible and involving people as informants through to involvement of community members in developing their own priorities for research, analysis and producing information (Cornwall & Jewkes, 1995). Action research includes a range of approaches and practices dependent on different philosophical, psychological and political assumptions. It regards knowledge as a process that is living and evolving and originates from everyday experiences: "It seeks to bring together action and reflection, theory and practice in participation with others" (Reason & Bradbury, 2001, p. 1). Participatory action research was influenced by the work of Paulo Freire and principles of radical education reform. The researcher and the researched are considered to be equal and active participants in the research process and knowledge is transformed into a critical consciousness through "repeated cycles of action and reflection" (Brydon-Miller, 1997, p. 2). The basic tenets of participatory action research are: research begins in communities that have traditionally suffered exploitation or oppression; there is a goal of achieving social change; and it is a process where all participants contribute and are transformed (Brydon-Miller, 1997). Heron and Reason (2001) maintain that research should be with people rather than on or about people. They propose a co-operative approach to inquiry where the mutually exclusive roles of researcher and subject are changed and research is based on people working together as "co-researchers and as co-subjects" (p.179). They also suggest that a key quality of participative inquiry is that it is self-reflexive (Heron & Reason, 1997).

### *Reflexivity*

Qualitative research repositions the researcher; subjectivity is both assumed and appreciated. This brings with it the need to be aware of how the researcher's assumptions can shape research (Russell & Kelly, 2002; Chamberlain, 2004). Reflexivity is an awareness of these assumptions; awareness of our own values, our personal history, our social and cultural contexts and how these influence interpretations (Etherington, 2004). Reflexivity is also about ethical practices and decision making in research and Chamberlain (2004), in outlining levels of interrelated reflexivities, suggests that being reflexively aware is also to be critical. Considering the issue of power in research relationships acknowledges the role of reflexivity. This project is fraught with places where power is sited; my position as a researcher (and a therapist), my personal agenda for pursuing research, my linguistic abilities, my social position, my authority as the interpreter of other people's accounts, and my role as the author of these accounts. While it seems impossible to create non-hierarchical research,

being reflexive about the research process is one way of attempting to make the role and influence of power more transparent. Mauthner and Doucet (2003) point out that while *being* reflexive is granted importance in social science research, the practicalities of *doing* it receive little attention. As with autoethnographical research, criticisms of reflexivity concern the balance between self and research, and the potential to reduce the voices of participants.

### *The crisis of legitimation*<sup>25</sup>

Qualitative research texts present challenges to traditional criteria for evaluation. The legacy of the scientific method persists in terms such as validity, reliability and generalizability. There are a range of responses to this from advocating for retheorizing these concepts to arguing for abandoning them (Koch & Harrington, 1998; Denzin & Lincoln, 2000; Sparkes, 2001). Bochner (2000) suggests that the differences between how we judge what is good, what is useful and what is not from our different perspectives are unresolvable because of the ways in which we understand the world. He also suggests that we have often worried more about our scientific standing rather than whether the work is “insightful, meaningful, and useful” (p. 267). A key issue is that quantitative approaches require an adherence to methodological rules and standards which do not have the same relevance to inquiry-guided research (Agen, 2000; Sparkes, 2001). So what criteria can be proposed for appraising qualitative studies, particularly interpretive research? Mays and Pope (2000) identify several techniques: triangulation (two or more different methods of data collection are used); respondent validation (the research accounts are returned to participants for their validation); a clear account of data collection and analysis; reflexivity; attention to negative cases (the exploration of contradictory data); and fair dealing (the research design incorporates different perspectives). Riessman (1993) suggests four ways to approach critical issues of quality in narrative analysis: persuasiveness (this criterion asks whether the interpretation is reasonable and convincing and if claims are supported by the participants’ accounts), correspondence (credibility is increased if the participants can affirm the researcher’s account achieved by taking the results back to participants), coherence (this is based on the three kinds of coherence in Agar and Hobbs’s (1982) approach) and pragmatic use (this refers to the extent to which a study becomes the basis for others’ work). So what makes a good narrative? Questions of quality include: does it contain abundant and concrete detail, does it make a contribution to understandings of our social world and social processes, does it have aesthetic merit, is there adequate reflexivity, does it have emotional credibility in making an

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<sup>25</sup> Denzin & Lincoln, 2000, p. 17.

impact on the reader, does it engage the reader to think with the story and does it express a reality and authenticity of experience (Connelly & Clandinin, 1990; Bochner, 2000; Ellis, 2000; Richardson, 2000)? Jones (2004b) offers some starting points for reflecting on qualitative works in a narrative way: dialogical (how is a dialogue produced between researched and researcher, reader and researcher?), experiential (how does it induce a sense of "shared habitus"?), reflective (how is the researcher made transparent?) and narrative (how is it a good story?) (p. 107).

### Locating the strands

These influences overlap but they all contribute to locating the project and add to the theoretical scaffold as shown in Figure 4.2.

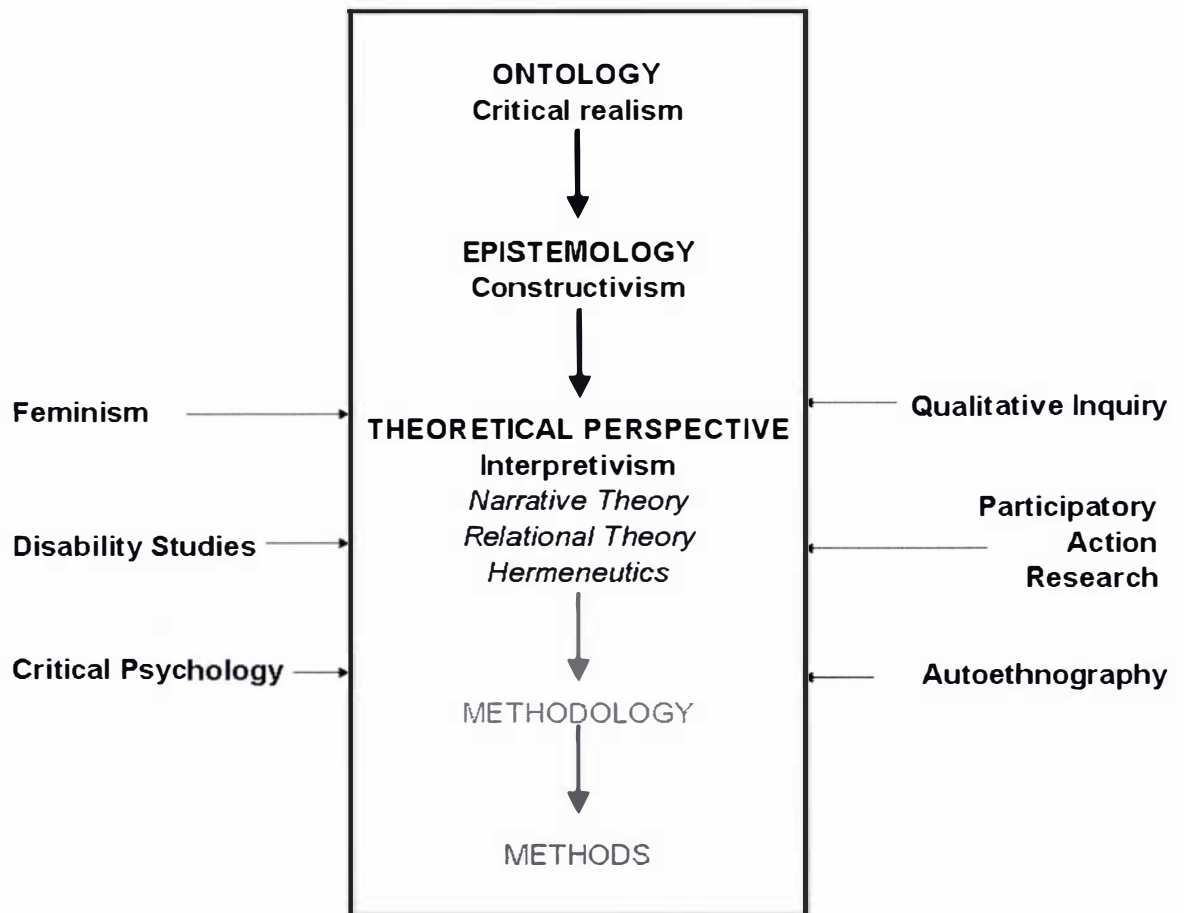


Figure 4.2: Advancing the theoretical scaffold

(Adapted from Crotty, 1998, p4).

### Summary

This chapter completed finding a location for the project by introducing other influential perspectives. While not specific to self and identity or aphasia, they contribute to the project's development. As this has occurred over a long period of time with recourse to a large and diverse body of literature, there may be other influences I have not specifically identified. The motivation was to locate a process that would support addressing the research questions and pay attention to how research is carried out. The next section, Section C, is about finding a way of doing the research. It focuses on completing the project's methodology. Chapter Five, the first of this section, revisits narrative inquiry, particularly its relevance to identifying a method and an analytical approach for researching self and identity.





SECTION C

FINDING A WAY

Chapter 5: Narrative inquiry

Chapter 6: Developing and doing

## Chapter 5

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## Overview

This chapter is the opening chapter in this section, "Finding a way". Along with Chapter Six, it completes the research methodology. This project has a focus on self and identity and, as developed in Chapter Three, the self of the project is a relational and storied self in dialogue with the world and all its historical and cultural influences. Narrative theory has been specifically identified as an important contribution to the project. However, narrative inquiry is a broad field that builds on this theoretical understanding. This chapter explores narrative practices further with the aim of identifying how the research can be developed to advance an understanding of the impact of aphasia on self and identity. While it extends and builds on this earlier introduction to narrative theory in Chapter Three, it also integrates the subsequent discussion in Chapter Four of the other theoretical influences which all have links with narrative inquiry. Some definitions are proposed and narrative genres relevant to research into self and identity are introduced. A tool, or method, for exploring self and identity arises from these discussions and an approach to analysis is then identified. Together with the preceding chapters, this chapter provides the justification for my choice of research methodology. The chapter culminates by completing the theoretical scaffolding of the research process: the methodology and associated methods.

### The tangled weaves of narrative<sup>26</sup>

*The task of a narrative psychology and of a narrative social science, is to explore the different stories told, not only for the insight they provide into the actual character of the experience described by the storyteller, but also for the insight they offer into the identity of the storyteller and of the culture in which she/he lives.*

Michael Murray, 1997, p.1.

Over the last twenty years, the social sciences have seen a "narrative turn" with an increased interest in interpretative work and considerable attention has been given to narrative practice and personal experience in research (Atkinson, 1998). The study of narrative is strongly interdisciplinary and narrative studies are reported within a range of disciplines including literature, linguistics, cognitive

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<sup>26</sup> From Goodley, Lawthom, Clough and Moore (2004).

science, sociology, ethnography, history, anthropology, psychology and theology, and from a diversity of theoretical perspectives (Riessman, 1994; Goodfellow, 1997; Quasthoff, 1997; Brockmeier & Carbaugh, 2001). In psychology, there is increased research attention to personal stories and their social significance (Polkinghorne, 1996; Josselson & Lieblich, 2001; Kirkman, 2002).

Bamberg (1997) claims that this increased interest in narrative demonstrates a weakening of the difference between perspectives that emphasize the role of the individual in constructing herself and the view that it is social practices that are dominant in the construction process. Narrative, according to Bamberg (1997), provides a bridge. Although there is disagreement about what exactly narrative comprises, most authors acknowledge that, at least in western societies, narrative is about sense making and communicating meaning (Chase, 1995). The study of narrative is not considered a separate discipline. Rather it can be viewed as a problem-centred area of inquiry and, from that perspective, it is an umbrella term including a range and diversity of approaches (Mishler, 1986a; Mishler, 1999). Returning to Crotty's (1998) theoretical scaffolding and placing narrative within this allows us to understand the relationships between epistemology, theoretical perspective, methodology and methods as shown in Figure 5.1. This helps to identify the difference between narrative as a form of analysis and narrative as a focus of analysis (Zussman, 2000). Narrative can be regarded as a theoretical perspective, as a method of analysis, as method for gathering data or as data (Polkinghorne, 1995).

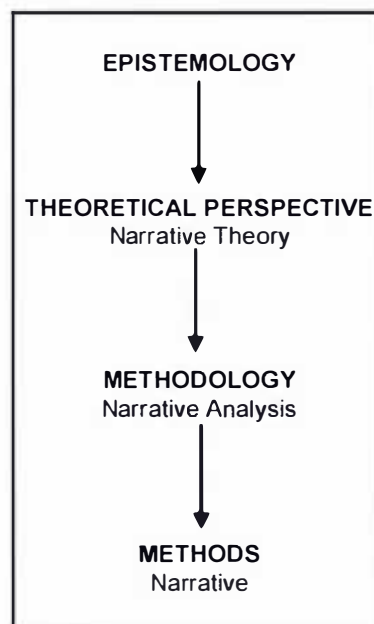


Figure 5.1: Theoretical scaffold for narrative

*(Adapted from Crotty, 1998, p. 4).*

While it is not possible to draw exact boundaries between narrative as theory, method or data, it is useful to try to clarify these blurred boundaries (Kirkman, 2002). While the following text is presented in an orderly manner, I acknowledge that definitions, understandings and boundaries are less than clear. There is a balance to be maintained between wanting to create a coherent story but not wanting to oversimplify the complexities and present narrative practice as less problematic.

### **A narrative approach to psychology**

A narrative psychology has different goals to traditional psychology. Based on the premise that we live in a storied world, it is concerned with understanding and with the structure, content and function of stories (Sarbin, 1994; Murray, 2003). Kotre was the first to propose a narrative psychology with his work on archetypal stories in 1984 (Kirkman, 2002). Subsequent to this was Sarbin's (1986) seminal work. This influential text gathered together essays related to a narrative psychology and was the first project to do this. It included Gergen and Gergen's (1986) application of the literary device of narrative to account for human action over time, considering the narrative forms of stability, progression and regression.

More recently, narrative psychology has been incorporated within the social constructionist movement in psychology (Murray, 1995). Sarbin (1986) proposed narrative as a root metaphor for psychology generally and Crossley (2000b) focused a narrative psychology on the study of language and stories that represent the self, based on her research with people living with serious illness. Parker (2004), in proposing radical research approaches in qualitative psychology, suggests that a narrative psychology, may allow us to "bring history alive again so that it is not merely recounting the chronological order of past events. Then the work turns into action research, for the way we grasp the past has a direct bearing on the way we can break from the present and make the future" (p. 86).

### **Some definitions**

Despite significant difficulties in achieving a clear-cut definition of narrative, we need to consider context and disciplinary background when attempting to locate the meaning of what it is (Murray, 2000; Riessman, 2003). The context for this project is the personal narratives of people with aphasia and therefore the definitions presented here relate to these stories. However, as acknowledged

throughout this project, people exist within a social and cultural world which also has its dominant narratives (Polkinghorne, 1988). As a researcher, I bring psychology's narratives to the process and as a clinician, narratives of aphasia, disability and professional power.

### **What is narrative?<sup>27</sup>**

While more clarity may emerge when different approaches to narrative analysis are discussed, most of these share a basic understanding about what narrative is. Simply, a narrative has a beginning, middle and end. Polkinghorne (1996) defines narrative as the "storied linguistic production of a person's emplotted configuration of life events into episodes or a whole life" (p. 78). Three key features of narrative emerge from this definition. Firstly, emplotment. This is a concept from the work of Ricoeur (Rankin, 2002). It is a narrative device that explains the purpose of events. The plot gives meaning to experience by turning unrelated events into a coherent story. When emplotment occurs events take on narrative meaning. Secondly, sequentiality. While a narrative is made up of parts, these parts do not have a meaning of their own. Meaning is created by the sequence as a whole (Bruner, 1990). Thirdly, temporality. People use temporal means to structure a plot (Bruner, 1990; Riessman, 1993; Polkinghorne, 1995; Ezzy, 2002; Kirkman, 2002; Murray, 2003).

A story also needs to be told in a way that makes sense to others with attention to form as well as context and according to cultural conventions. Narrative emphasizes human agency but stories are always part of social relationships (Brockmeier & Harré, 2001; Kirkman, 2002; Riessman, 2003; Parker, 2004). Finally, narrative calls for the narrator's voice and perspective (Bruner, 1990). Several features of narrative that distinguish it from other qualitative research include a focus on the individual, the personal nature of the research process, the practical orientation of the research and an emphasis on subjectivity (Hatch & Wisniewski, 1995). While narrative has a communicative function and it is a way of sharing information with others, Mello (2002) regards narrative as also providing a process for social and cultural cohesion. Another key function is that of negotiating relationships and connecting self and others.

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<sup>27</sup> For the purposes of what follows, I treat "narrative" and "story" as synonymous.

## Personal narratives

Oral or personal narratives are a form of discourse, a particular genre of sense making and self-presentation. Not all forms of talk are narrative and there are non-narrative forms of discourse (Labov, 1997; McCabe, 1997; Riessman, 2003). It is thought that narrative is the first discourse ability to be acquired in childhood and there is evidence that narrative comprehension is one of the earliest skills to emerge in children. It is an ability that continues to improve into adolescence (Bruner, 1991; Quasthoff, 1997).

While they may differ in complexity and context, Ochs and Capps (1996) detailed an extensive list of the genres of personal narratives ranging from stories, novels, diaries, letters, memoirs, gossip, legal testimonies, eulogies, medical histories, to jokes and satire. Bruner (1991) considered genres to be the kinds of conventional narratives that we recognize as representing human predicaments including romance, tragedy, comedy, farce and satire. While they are a type of telling, they also have the ability to shape our way of thinking. It is also recognized that there may be other forms of narrative including musical, pictorial and silent dramatic representations (McCabe, 1997; Bell, 2002; Radley & Taylor, 2003). Two influential genres of narrative that are the concern of this project are life story and illness narratives thus opening the way to considering how the project should approach research in self and identity.

## Life story narratives

*If you want to know me, then you must know my story, for my story defines who I am.  
And if I want to know myself, to gain insight into the meaning of my own life, then I,  
too, must come to know my own story.*

Dan McAdams, 1993, p.1.

As with narrative itself, life stories have become an increased focus in social science research. McAdams (2001), a moderate constructivist, describes a rapid growth in stories and narratives in psychology. I describe life stories as a genre of narrative and agree that "while all life stories are narratives, not all narratives are life stories" (Hatch & Wisniewski, 1995, p. 114). I also make a distinction between "life history" and "life story". A life story focuses not only on what happened but also on how stories are told and the construction of meaning (Rosenthal, 1993; Hatch & Wisniewski, 1995). Bruner (1990) suggests that our autobiography is an ever-changing draft that we carry with us and that it is only understandable to self and other by the interpretations that are



available to us through the culture we live in. A life story is therefore a social construct that enables us to attend to the social (and cultural) as well as the experiential world (Rosenthal, 1993). It is an expression of our sense of self and organizes our understanding of our past, present and future (Linde, 1993). It is argued that in the telling of our life story, we also become responsible for our lives (Crossley, 2000b). Self-construction is part of the "mundane work" we do to maintain and negotiate our social world (Faircloth, Rittman, Boylstein, Young & Puymbroeck, 2004, p. 403).

McAdams (2001) proposes a life story model of identity. Developed from Erikson's concept of identity formation which suggests that identity is first confronted in late adolescence and young adulthood, this model argues that identity takes the form of an internalized and evolving life story and highlights continuity and change over the lifespan.

### Illness narratives

Stories of illness and disability as a catalyst for self-change have been explored in the literature on narrative. By creating a story about their illness or disability, it is proposed that people can begin to understand the meaning of it (Murray, 1997). Illness, especially chronic illness, has been considered as a disruptive experience when the assumptions that people have about life are challenged. It is suggested that illness narratives, or pathographies, have a role not only in preserving selfhood but also have a political role in challenging the dominant medical voice (Sakalys, 2000). Recent findings challenge the image of a passive individual in dealing with chronic illness. Instead the person is seen as actively seeking to restore meaning in illness and has her or his "own complex theories about health, illness and medicine" (Williams, 1996, p. 32).

For Frank (1995), illness damages a person's sense of where she/he is and where she/he may be going. Stories become a way of "redrawing maps and finding new destinations" and almost every contemporary illness narrative contains some reference to the "new" person that illness has produced out of the old self (p. 53). Illness narratives, then, appear to be a way for people to organize and construct meaning to achieve coherence in a life affected by loss and change (Kleinman, 1988; Fife, 1994). They are also a way in which health professionals can describe therapeutic processes and possible outcomes after illness or trauma within a larger therapeutic story (Mattingly, 1994).

What role do illness narratives have? Hydén (1997) identified several possible functions of illness narratives in chronic illness: narratives have the ability to construct a world of illness as well as reconstruct a person's life history, they can provide explanation and understanding of illness, they can act as a means of affirming identity and they can move the experience from an individual to a collective level. Over the last decades, particularly in Britain, several key themes have emerged from studies of meaning and experience in chronic illness and in disability: biographical disruption, the role of narrative reconstruction and the negotiation of self and identity (Williams, 1999). Bury (1982) introduced the concept of "biographical disruption" (p. 169). This is not just a disruption of a sense of self but also of social relationships which all influence a person's ability to deal with illness. Williams (1984) chose the concept of "narrative reconstruction" to explain how people address this disruption and understand their illness as part of a larger interpretive process. People's accounts are attempts to "establish points of reference between body, self, and society and to reconstruct a sense of order from the fragmentation produced by chronic illness" (p. 177).

Nearly two decades on from the initial defining of biographical disruption, Williams (2000) outlined the challenges that postmodernism and disability theory present to this idea. A focus on the "suffering self" (p.46) is considered to be a modernist concept while disability theory sees disablement as an outcome of social oppression rather than residing in the body. According to Williams (2000), biographical disruption may fail to take into account aspects such as disability in early life and the idea of "biographical continuity" (p. 61). The reliance in the literature on the concept of biographical disruption has also been challenged by recent research (Faircloth, Boylstein, Rittman, Young & Gubrium, 2004). Analysis of qualitative interviews with people at different times after a stroke introduced another conceptualization, "biographical flow", as a way of describing the integration of the stroke into a biography that continues over time and space, particularly when the stroke is associated with ageing (p. 256).

Several typographies of illness narratives have been suggested. Frank (1995) proposed three narratives that characterize a person's understanding of the illness and its course. Restitution stories address illness as being temporary while chaos stories are the opposite. They are classified as chaos because there is considered to be no narrative order. Quest narratives are based on a person's belief that there is something to be achieved by the illness experience. Robinson (1990), in his analysis of the life stories of people with multiple sclerosis, followed Gergen and Gergen's (1986) framework. He found that he could analyse the accounts according to the three broad life trajectories: stable, progressive and regressive. Hydén (1997) believed that these typologies were based on a small

number of genres and he suggested, instead, basing a typology on aspects of the illness narrative. He developed a typology of three types of illness narratives based on the relationship between the narrator, the narrative and the illness: illness as a narrative (corresponding to a personal experience narrative), narrative about the illness (how the illness is talked about, for example, by professionals) and narrative as an illness (where there is an inability to form a narrative in conditions such as Korsakov's syndrome). Davies (1997) characterized the experience of people living with human immunodeficiency virus (HIV) according to three temporal orientations. She described these as "living with a philosophy of the present"; "living in the future", and "living in the empty present" (p. 566-568). Ezzy (2000), also researching with people with HIV introduced the concept of polyphonic illness narratives. Polyphonic means "many voiced" (p. 613) and these narratives are about embracing the ambiguity and uncertainty, and the unpredictability of life. They depict the "often contradictory goals, values, temporal assumptions and attitudes" (p. 613). So where does this take us in this project about self and identity in aphasia.

### Researching self and identity

The project is influenced by these narrative genres and the role that they have in the narrative construction of self. How then might we research self and identity? The self of the project is a relational and storied self in dialogue with the world with all its historical and cultural influences. It has already been identified that the project is grounded in a relational constructivist approach within which identity is considered to be both the product and process of self-narrative construction. Our identity is the telling of our life story within which we select the events, the characters and the themes we want to include or exclude. We take up different positions through our narrative and we also privilege some voices while silencing others. In this way, there is never a "single, fixed, final or true life story to tell, nor a single way to tell it" (Botella et al., 2004, p. 122).

The project seeks to explore the changes in self and identity in people with aphasia and this requires gaining subjective perspectives. From the discussion of life story narratives and illness narratives and considering the research questions, the method for exploring self and identity for the project would most appropriately be a life story interview gathering narratives from people who are living with aphasia. A life story interview may be one of the most effective means for gaining understanding of how the self evolves over time (Atkinson, 1998). These narratives capture not just the personal but also give insight into the social, cultural and historical context of lived experience.

As a genre of narrative inquiry, they offer a different way of constructing the relationship between researchers and participants; more personal and collaborative (Ellis & Bochner, 2000). The earlier discussions about the tensions between self and social remain in my thinking. As I make a decision about drawing on the life story interview, I consider Gergen and Gergen's (2000) observation:

*To focus research on the individual's experience, feelings, identity, suffering or life story, is to presume the primacy of the individual mind. To employ methodology that attempts to give voice to 'the other' is already to favour a metaphysics of self/other difference.*

p.1041.

I believe now that the life story narrative as a relational endeavour addresses some of the concerns about the "primacy" of the individual. The telling of a life story is not an individual action; it remains a joint action. It brings in many voices and it tells stories about the social and cultural history of an evolving narrative. Having arrived at the point of identifying a method with which to begin to attend to self and identity, how might a life story be analyzed?

### Narrative analysis

*Any methodological standpoint is, by definition, partial, incomplete, and historically contingent. Diversity of representations is needed. Narrative analysis is one approach, not a panacea; it is suitable for some situations and not for others. It is a useful addition to the stockpot of social research methods, bringing critical flavours to the surface that otherwise get lost in the brew*

Catherine Riessman, 2003, p. 342.

### Approaches to narrative analysis

Narrative analysis is not a specific method in itself and approaches to narrative analysis are as varied as are the theories that motivate narrative research (Chamberlain, Stephens & Lyons, 1997). However, they share an interest in the analysis of lives and lived experiences (Bamberg, 1997). I considered the range of approaches that I perceived to be most commonly used in the research literature I was reading. When none of the previous frameworks seemed functional for my purposes (and perhaps, my assumptions), I thought about how I might present them. There is a risk in reducing the approaches to a mere set of instructions or a composite of similar methods (Chamberlain, 2000).

Consistent with early discussion about the nature of social research (Crotty, 1998), doing narrative research involves firstly identifying an epistemological location which informs subsequent decisions about methodology. Goodley, Lawthorn, Clough, and Moore (2004) laid out these concerns through the presentation of four life story narratives. For each story, they tracked the ethical concerns, relationships with participants and methodology through to the assumptions of knowledge held by the four researchers as a way of rendering life stories as a product of a particular epistemology.

Another consequence of attempting to identify the common approaches to narrative analysis and then to set about "classifying" them is to become highly prescriptive and to undervalue the iterative nature of research and the possibility for transformation. Research within a qualitative paradigm is progressive, reflective, dynamic and evolving. The writings of key authors are an indication that there is also change over time and that modifications of approaches do occur (Labov, 1997; Riessman, 2003). Several key life story researchers (McAdams, 1993; Lieblich, Tuval-Mashiach & Zilber, 1998; Crossley, 2000b; Plummer, 2001) are not prescriptive in their reading of narratives. While they may make reference to incorporating other approaches (for example, Plummer, 2001, includes grounded theory) or set out a step by step guideline or question schedule to guide analysis, most do not specify a particular analytical approach. Judging these works alone by whether they offer a systematic approach in these cases clearly undervalues the theorizing that supports their work and the interpretive nature of the process. Mindful of these concerns, but also wanting to achieve a sense of clarity to background my own methodological decision making process, I have chosen to base the following presentation of narrative analyses on key analysts and their associated disciplinary locations. This is not entirely satisfactory as they are not necessarily mutually exclusive but it allows for the consideration of some of the assumptions underlying a disciplinary orientation. What I was searching for was an analytic approach that could be used with a range of communicative abilities including severe aphasia where verbal expression would be limited. It had to acknowledge not just the co-construction of the life story narrative but also the relational nature of meaning making within the interview. I also wanted an approach to analysis that would fit within a research process that was more inclusive. The process of exploring a range of approaches helped me be much clearer about the approach that was needed epistemologically and methodologically.

*William Labov and Joshua Waletzky (1967): a sociolinguistic approach*

I have considered Labov and Waletzky's model (1967) in detail because it is frequently employed in narrative analysis and it continues to be an influential approach. It is regarded as the first systematic attempt to study interview narratives (Mishler, 1986a). Labov and Waletzky's model is considered to be a defining work in narrative research and many subsequent narrative studies have utilized their framework for analyzing oral narratives of personal experience. Their work (sometimes referred to as Labovian sociolinguistic analysis) was significant in establishing that narrative could be understood within a formal framework. A narrative includes four structural parts that are ordered and an unordered part that may appear anywhere. The ordered parts are the abstract (an optional initial summary or evaluation of the narrative), orientation (provides information about the narrative's characters, time, place and circumstances); narrative clauses (tell what happened next) and an optional coda (which brings the narrator to the present, indicating the end of the narrative). The evaluative material may appear anywhere and illustrates the point of the story showing why it is worth telling. The evaluation is considered the most interactionally significant part of a narrative as it is when negotiation is required between the narrator and the listener as the narrator signals how she wants to be understood and what the point of the story is. Evaluation also indicates to the listener what kind of response to the narrative is wanted (Labov & Waletzky, 1967; Linde, 1993; Riessman, 1993; Nicolopoulou, 1997).

While there are limitations to the formalist aspects of their work, Labov and Waletzky's (1967) contribution to the study of narrative includes, firstly, an acknowledgement of narrative as social phenomena. It is an activity that occurs in the context of interpersonal communication. Secondly, the concept of evaluation, in establishing the meaning of the narrative for the storyteller, has an interpretive function and enables us to gain an understanding about why people tell and respond to a story and the impact of that story (Daiute & Nelson, 1997; Nicolopoulou, 1997). Labov also modified the earlier work by giving more attention to the social meanings of reported events, drawing on the work of Goffman (Mishler, 1986a). What Labovian analysis does not achieve is an analysis that accounts for narrative as a symbolic form. Nicolopoulou (1997) suggests we need to see narrative as a vehicle of meaning and we should be looking further than just a technical analysis of narrative structure.

We should be considering analytic tools that include interpretive and sociocultural perspectives: "The study of narrative calls for aesthetic, not merely linguistic, analysis" (p. 190 - 191). My decision not to employ a Labovian approach was related to the interpretive nature of the project and the need for a sociorelational approach. I also believed that some participants would not have the linguistic abilities to provide the corpus that would be needed for this type of analysis.

#### *Elliot Mishler (1986): a sociological approach*

An early and still very significant influence in narrative is Mishler's (1986a) text on research interviewing. His critique of mainstream methodologies, particularly standard survey interviewing, motivated his proposal that meaning is expressed in and through discourse and that one important way of constructing meaning is through the telling of stories. His studies were particularly focused on narratives within interviews. Mishler (1986b) based his approach to analysis on a Labovian approach. The full response is analyzed and a skeleton plot or core narrative is extracted. The core narrative is given a title which summarizes the point of the story and is an interpretive act. Analysis is only part of Mishler's (1986b) overall introduction of narrative interviewing. His work continues to be significant in its contribution to narrative study. While I was familiar with Mishler's work and his thinking continued to be very influential, for reasons as outlined with a Labovian approach, I did not feel that it fully met the needs of the project.

#### *Catherine Riessman (1993): a sociological approach*

Riessman (1993) extends what she describes as the Mishler-Labov model which is informed by literature and sociology. A full transcription of an interview is completed and then the boundaries of narrative segments are identified. These segments are then structurally analyzed using the Labovian model. Some decisions remain dependent on the analyst's own perspective, as not all narratives are suitable for this approach. Riessman (1993) considered another two strategies for analysis. Drawing on the work of Bell (1988), one strategy involves identifying the core narrative (based on Mishler, 1986b). The second strategy is informed by Gee's (1991) work on the analysis of poetic structures. Riessman (1993) warned that linguistic form may become the object of analysis when the process is an interpretive inquiry. Although not highlighted by Labov, Riessman's approach is based on the collaborative and interactional nature of storytelling. Riessman's contribution to narrative inquiry extends beyond her analysis framework. She proposed five levels

at which representational decisions are made in the research process: attending, telling, transcribing, analyzing, and reading: "Simply stated, we are interpreting and creating text at every juncture, letting symbols stand for or take the place of the primary experience, to which we have no direct access" (p. 15). While Riessman's overall approach and extensive writing on narrative practices have influenced my work, I did not feel that it alone gave me an analytical approach that would fulfill the requirements for an analytic approach for this project.

***Michael Agar and Jerry Hobbs (1982): a cognitive anthropological approach***

Coming from a background of Artificial Intelligence and anthropology, Agar and Hobbs's (1982) approach is a response to what they considered to be the lack of formal methods for accessing culture from text. While life story interviews are valued, they detected problems when language analysis moved beyond the sentence level: "But what do I do with all this stuff" (Agar & Hobbs, 1982, p. 2)? The central focus of their work is the narrative strategies used to produce a coherent story. They analyzed three kinds of coherence: global (how the utterance is related to the speaker's overall conversational goals), local (the relationship between an utterance and the effect the speaker is trying to achieve in parts of the text) and thematic (the parts of the text, or themes that occur repeatedly) (Agar & Hobbs, 1982; Mishler, 1986b). The strengths of this approach are in its analysis of coherence and its maintenance of some of the complexity of narratives. One of the main reasons for not using this approach is that there is a tendency for the interview to be treated as a monologue with minimal interviewer participation (Mishler, 1986a).

***James Gee (1991): a linguistic approach***

Gee (1991) agrees that it is erroneous for an analysis to separate the text from the context as in formalism but he believed that narrative inquiry has underestimated how much meaning is available in the linguistic structure of a text. He used some basic poetic strategies to organize narratives, moving from the parts to the whole. There is a focus on the prosody of spoken language (stress and pitch) to draw the researcher's attention to the rhythm of the narrative. Gee (1991) used the literary language of stanzas and strophes and he considered five levels of structure that play a role in interpretation and meaning (Mishler, 1995; Murray, 2003). I was interested in Gee's focus on context and on prosody but its linguistic emphasis would make it less suitable for the analysis of the life story narratives of people with aphasia.



***Gabriele Rosenthal (1993): a sociobiographical approach***

Rosenthal's (1993) work has grown from sociological practices in Europe and is based on work by Schütze and the method is called a "hermeneutical case construction" (p. 61). A life story is regarded as a social construct which encompasses social reality and the subjective world. The method seeks to understand biographical presentations in narrative and involves five distinct steps. It considers life history (the lived through experience and actual events of a life) as co-producer of a biography with the life story (the narrated life story as constructed by the narrator). One of the main missing features of this approach was attention to relational aspects.

***Tom Wengraf (2001): a psychodynamic sociobiographical approach***

The biographic-narrative-interpretive method involves a narrative interview and analysis of the chronological life and the interview story. It is based on Rosenthal's work and assumes that narrative expresses both conscious and unconscious processes. The focus is on individual experience within historical and societal contexts. Interviewing and analysis are presented as a systematic approach and training in the method is available (Wengraf, 2001; Wengraf, 2004). This approach, in its supporting detail, initially had merit for the project and the method was fully developed in a text by Wengraf (2001). A published case study using this approach was an opportunity to gain further understanding (Wengraf, 2004). The case study use of the concept of defended subjectivity (with the potential for divergent perspectives between the participant and the researcher) established it within a more psychodynamic orientation.

***Wendy Hollway and Tony Jefferson (2000a): a psychoanalytical approach***

This approach is a social psychological discourse analysis using a psychoanalytic framework and is based on the thinking of Klein as an approach to a psychosocial subject with a core concept of unconscious conflict (Jones, 2000; Hollway, 2001; Frosh, Phoenix & Pattman, 2003). This is an attempt to understand subjectivity not only produced through social discourse: "Psychoanalysis, with its core notion of a dynamic unconscious, can conceptualize people's actions as unconsciously, as well as consciously, motivated and conflictual. This is an essential step if the psychic side of the psychosocial is to be given weighting with the social" (Hollway & Jefferson, 2000b, p. 137). Although I concur that narrative expresses both conscious and unconscious processes, I did not see

myself as offering a psychoanalytic interpretation of the participant's life stories. Again, I was seeking a more relational (and participative) process and one where, although not entirely possible, there was at least a goal of working towards equalizing relationships. For these reasons, I did not consider Wengraf's or this approach.

The next three approaches are included not because they appear or have been referenced frequently in the literature but because they are connected to current debates around what narrative and narrative analysis might mean in the aftermath of postmodernism. While I have not used them they still remain part of an ongoing dialogue for me.

*Stanton Wortham (2001): a linguistic anthropological approach*

Wortham (2001) outlines a systematic approach to analyzing narrative discourse, specifically autobiographical narrative by reflecting on how language positions speakers interactionally. He provides a detailed background on his theoretical approach to narrative construction and on his dialogical approach to discourse.

*Peter Emerson and Stephen Frosh (2004): a critical psychological approach*

Emerson and Frosh's (2004) work is one of the most recent and it is historically positioned in the current discussions in psychology arising from postmodernism. They situate their interest in critical narrative research in the context of psychosocial studies which is concerned with identity but avoiding the traditional social-individual division (Frosh, Phoenix & Pattman, 2003). They illustrate their approach through a case study as it develops and responds to the joint nature of meaning making. The text is a reflexive act and the ongoing dialogue between theory, method and application is apparent. Different transcriptions occur of the same text at different times in what they describe as "intensive and extended micro-work" and analytic movement (p. 144). They employ Labovian analysis, Riessman's (1993) approach and Gee's (1991) linguistic tools. In common with other discursive approaches, this critical perspective is informed by social constructionism and deconstructionism.

***Ian Parker (2004): a radical narrative psychological approach***

Parker's (2004) approach is grounded in discussion about narrative psychology as an approach to radical qualitative research. In this approach narrative is not reduced to "a search for intentions, naïve realism, constructivism and the reduction of narrative to the individual" (Box 6.1). Parker (2004) provides a stage-by-stage analytic process as a summary utilising a theatre or cinematic metaphor: production schedule, auditions, casting, improvised scripting, performance, and reviews. Also considered is the story of the research as narrative.

**Voice centred relational method**

In considering a range of analytical approaches to narrative, while not quickly identifying a solution, afforded me clarity about what it was I wanted from an analytic approach. It was apparent that I was seeking a process that identified the relational nature of conversation and of meaning making. While some aspects of approaches satisfied some aspects of the project, I did not feel the more frequently cited approaches did this. For the research questions related to self and identity, I was seeking an analytical approach that would deal with both the life story narratives of people with aphasia and my own voice in the project. I had already used an approach based on the works of Mishler (1986a), Bell (1988) and Riessman (1993) in the earlier project. I did not want to categorize or quantify by way of coding rather I wanted an approach that would make the relationship between researcher and participant central to the process (Tolman, 2001). It needed to be an analytical approach that could also attend to data that was not verbal and could be used with people with a range of communication disability. While some participants were verbal, others used alternative communication resources to develop their life stories including photographs, objects in their environment, the context itself, written responses and non-verbal communication.

The focus of this project was the life story narratives of people with aphasia attending to what people with aphasia tell about the impact of aphasia on self and identity and how they do their telling. Shotter's perspective that language is sociorelational has significance for the understanding of self in this project. His notion of "joint action" (Shotter, 1993, p. 7) where words and actions not only take their meaning from the context but they actually create the context is also significant to how we consider self and identity in emergent relationships. An approach to analysis for this project

would also have to have the potential to enable the consideration of such joint action. As it is also about the self of the researcher, my search was for method of analysis that would allow all voices to be heard. The shift in my thinking about self over the development of the project is reflected in my need to locate an approach to analysis that would allow the relational nature of the research project to be dominant.

I turned to feminist writings which are grounded in listening to women's experiences and consider research to be the product of what occurs between the researcher and the researched (Way, 2001). I became interested in the work of Gilligan and colleagues, developed from analyses of identity and moral development originally carried out by Gilligan (1982) from a feminist perspective. Brown, Tappan, Gilligan, Miller and Argyris (1989) describe this developing interpretive method as a guide in the reading of narratives in a project about moral conflict and choice. They drew on the works of Mishler, Dilthey and Ricoeur. The method was developed partly as a reaction to growing discomfort with coding approaches to qualitative data and to the desire to develop more complex ways of examining qualitative data (Gilligan et al., 2003). The method was not about coding responses but rather a way of reading a text that drew attention to the interpretive nature of the process. Multiple readings of a narrative were recommended with the initial reading establishing the story from the narrator's point of view. Subsequent readings used "different interpretive lenses to locate self and voices of care and justice" (Brown et al., 1989, p. 148). In the course of their research into girls' development and women's psychology, Brown and Gilligan (1992) further developed the method as a way of working in psychological research that upheld others' voices and their own and led to the creation of a voice-centred relational method (VCRM): "Our goal was to create a collaborative and relational method that, rather than upholding the usual lines of division, provided a way to come into relationship with another person" (p. 15). This is called the "Listening Guide" and is used as a guide to analyse and interpret qualitative interview data (Gilligan., 2003, p. 157). It was based on the assertion that narrative plays a role in the organization of experience and, as a method, it is sensitive to the relational nature of research. As a feminist approach, it was concerned with issues of power and relationship in research (Way, 1997; Tolman & Brydon-Miller, 2001). The theoretical and methodological foundations that underpin the voice-centred relational method have their origins in clinical and literary approaches, interpretive and hermeneutic practices and relational theory.

Brown and Gilligan (1992) maintain that voice is essentially relational. The voice, with its range, its pitches and rhythms, is embodied. It creates a connection between psyche and body and in language between psyche and culture. Voice is a "pathway that brings the inner psychic world of

feelings and thoughts out into the open air of relationship where it can be heard by oneself and by other people" (Brown & Gilligan, 1992, p. 20). The "Listening Guide" offers a way of listening to the different voices that make up the voice of a person within a specific relational context (Gilligan et al., 2003). Brown and Gilligan (1992) pose several questions that underlie the multiple listenings: who is speaking, in what body, telling what story about relationship, from whose perspective and in what societal and cultural framework? They associate the centrality of voice within this work with Linklater, a voice practitioner primarily concerned with the voice of the actor. Linklater maintains that the voice exercises within her approach set out to reveal the personal, psychological and emotional connection between the speaker and the voice (Linklater, 1976).

Research cited in the literature using the VCRM has been increasing and those researchers who have used variations of the voice-centred relational approach have adapted the method in alignment with their topic, their theoretical background, and the context within which their work is placed (Mauthner & Doucet, 1998; Way, 2001). The projects have been varied: investigating the views of older women with dementia (Proctor, 2001), understanding what it means to be an older perioperative nurse (Letvak, 2003), understanding women's experiences of motherhood and postpartum depression (Mauthner, 1995, 1999), explaining self-injury in adolescent girls (Machoian, 2001), exploring femininity in rural working class girls (Brown, 1997), exploring gendered processes of domestic responsibility (Doucet, 2000) and understanding adolescent girls' narratives about sexual desire (Tolman, 2001). While the VCRM is grounded in women's experiences and it has almost exclusively focused on women and girls, it is now being used in research with other participants (Way, 1997; Way, 2001): understanding how women and men deal with a social pressure of silencing in taboo subjects (Kiegelmann, 2001) and explaining boys' friendships (Way, 2001). The VCRM would meet the needs of the research questions concerning self and identity in aphasia for the following reasons: it was inclusive of other approaches to narrative analysis (for example, the analysis of the plot in the first step of the "Listening Guide"), it did not focus primarily on linguistic aspects and could therefore be used with people with linguistic impairment and it attended to the relational nature of self construction both in participants' narratives and in the research relationship. With a commitment to voice, it could be adapted for people with severe aphasia where prosody and gesture become an even more vital part of communicating the self and it provided a systematic approach to an interpretive act.

Having identified that stories would be gathered through the life story interviews and analyzed through the VCRM, I was still presented with the issue of how these stories would then be

represented in the text. The methodology, my clinical background of working with the individual, my desire to retain the power of the personal accounts, my desire to foster a relational approach to research and the small number of participants involved in the research meant that I did not want to lose the voices of the participants by reducing their stories to common themes or issues, not that these are not important or significant to the project. These, however, were some of the reasons that encouraged me to consider developing narrative case studies from the individual interviews. Acknowledging the emergent nature of the research project meant I also held some of these methods in tension as I navigated the process.

### The case for the case study<sup>28</sup>

*... the case study may be the only tool by which social scientists can provide the truly disadvantaged with a voice.*

Karen Winegardner, 2004, p. 17.

Case study methods have been used in education and the human services because of the nature of research questions and also because they allow researchers to engage in research with individuals (Janesick, 1998). Case studies are extensively used in the clinical realm where the "case" may be a person, a disease, or the biography of a person with a specific disease. The case is a powerful teaching tool; valuable in the teaching of clinical skills as well as reflective practice and dealing with ethical issues (Marshall, 1999; Clark, 2002). While the case study has had a long history in social science research and many qualitative researchers have used the case study approach, there continues to be different interpretations and multiple meanings (Bergen & While, 2000; Winegardner, 2004).

Very simply put, "a case study is a study of a case" (Marshall, 1999, p. 380). A "case" may be an individual, a phenomenon, or an organizational unit. Is a case study an approach or a method? Marshall (1999) considers it an approach which may use several methods including interviews, gathering of archival data, or focus groups. Stake (2000) regards it to be a "choice of what is to be studied", not the methods by which we choose to study it (p. 435). Yin (2003), a leading advocate of case study research, defines a case study as an empirical inquiry that "investigates a contemporary phenomenon within its real-life context especially when the boundaries between phenomenon and

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<sup>28</sup>The title of the book by Feagin, Orum & Sjoberg (1991).

context are not clearly evident" (p. 13). A case study approach is appropriate when "a 'how' or 'why' question is being asked about a contemporary set of events, over which the investigator has little control" (p. 9). A research design can be based on a single case or a number of cases as in a collective case study or a multiple case design (Stake, 2000; Yin, 2003).

There are different ways of categorizing case studies and they are dependent on the epistemology of the researcher. While the philosophical perspective of most researchers who use the case study method is interpretive, it can also be used in positivist (as presented by Yin, 2003) and critical frameworks (Winegardner, 2004). Stake (2000) focuses on variations in methodological orientation to the case and, although he proposes different types of case study, he recognizes that people and reports do not always fit neatly into such categories: "I see these as heuristic more than determinative" (p. 438).

Radley and Chamberlain (2001) consider that, if health psychology's main contribution is to provide deeper understandings of illness and interventions, then the case study has a particular relevance; conceptually, clinically and methodologically. They recommend that the case is something to be explored in researching health and illness rather than merely a tool. They set about to deconstruct the "case" and provide an alternative definition to the case as a method, an empirical unit, and the case as a product, a theoretical construct. What is central is, instead, how "individuals portray themselves as exemplars of a class or are so portrayed by others" (p. 326).

### *Features of case studies*

Lewis (2003) summarizes a variety of sources to identify some facts associated with case studies: only one case is selected (although there may be several), the study is detailed and intensive; the phenomenon is studied in context and multiple data collection methods. While this project corresponds to the first three features, it was never designed to involve the use of multiple data collection methods. The data were to be narratives obtained through life story interviews. However, as the project developed additional "data" were recognized as valuable and resulted from being in context. Meeting with participants over a period of more than twelve months provided ongoing conversations and exchange. Contact was maintained through letters, cards, fliers, telephone calls, e-mails and face-to-face contact. Completing interviews in people's homes provided orientation to their personal environment. It also provided participants with additional

resources for telling their stories: photographs, books, people and possessions. During some visits, other friends and family called in, increasing the opportunity to observe and participate in people's lives. All interviews were videotaped and this produced a richness of data that was unanticipated based on previous experience with audiotaped interviews. Therefore, although the design did not include multiple collection methods, these occurred naturally and spontaneously and as part of the ethnography of the project.

### *Choosing a case study approach*

The decision about how to bring the analyses together evolved as the research evolved. At the stage of planning the research, I had no pre-conceived idea about how this would occur. Hence, the discussion about a case study method has been placed at this point because this is temporally where the decision to use case studies emerged as method and therefore completes the methodology for the project. While it may appear that this decision was late in the process, it was actually already present in my thinking and in the way the process of ongoing contact with participants was managed, the individuality of the interviews and the way in which the analysis was performed. As a practitioner, case studies have always been recognized as a useful way of answering questions about practice. I chose a case study approach because I wanted to understand more about how aphasia affects self and identity for people with aphasia. The people involved in the project all had aphasia post-stroke but they were not a homogenous group. They presented a wide range of communication disability requiring an individualized approach to the interviews and to analysis. I wanted the outcome of the research to be of value to the participants and also to practitioners working with people with aphasia and their families. I felt the case study approach honoured the participants' involvement in a way that would allow them to make links between the interviews, the feedback and the final product. My orientation is interpretive; I have an interest in personal experience and the insider's perspective and I am a health care practitioner which brings with it a concern for working with individuals.

### *Bringing the cases together – problems of generalization*

Lack of generalization is an often-used criticism of case study research (Stake, 2000). Eisner (2003) contrasts statistical generalization with naturalistic generalization which is what we perform daily in our decision making based on our experiences and may well arise for a single event; "N=1" (p. 24).



Rosenwald (1988) advocates for a multiple-case study research where psychological processes and social facts are brought into “conversation” (p.239) in addressing what he describes as the separation of personality psychology from social psychology. A focus on the uniqueness of the individual isolates human beings and works against the theorizing of a person as socialized and continues to maintain this segregation of individual and society. In responding to how then to move away from psychology’s methodological individualism, Rosenwald (1988) proposes a model that seeks to understand the individuals better “both singly and together, by recognizing them in complementary and problematic engagement” (p. 244). The multiple-case study method sets out to gain an understanding of the unique and shared experiences of individuals (Cressy, Harrick & Fuehrer, 2002). There is an intensive focus on subjective factors in the production of social knowledge. Each case, or life, contributes its own understanding. It is the synthesis of multiple viewpoints that produces social knowledge: “To be sure of obtaining a useful synthesis, we want observers at a range of vantage points rather than crowded on one side only” (Rosenwald, 1998, p. 246). Although the synthesis is grounded in the participants’ stories, it is ultimately, the researcher’s construction (Burgess-Limerick & Burgess-Limerick, in press).

My context, the life story method and the focus on narrative and storied accounts underpin my choice of a multiple-case study method. The study of cases in this narrative approach is the study of meaning making and this has epistemological resonance with constructivism and the assumption that there is no one singular and fully knowable reality; our understandings instead are embedded in our social and interpersonal contexts (Brandell & Varkas, 2001). Finally, as the synthesis of the stories is my construction, I am also an N of 1 throughout this process. I remain a learner moving from person to person, gathering understandings about others’ lives and my own life.

### Untangling the theoretical strands

These last three chapters have focused on locating the parts of the project and then finding a way to begin the research to address the research interest identified particularly in Chapter Two. While Figure 5.2, representing the completion of the theoretical scaffold for the research process, looks tidy and straightforward, the experience would contradict this neatness and clarity. However, it is laid out as a basis on which to judge the process of the research in action. All steps of the process are based on weaving the strands together. The scaffold provides an orientation for the reader and the tools with which to review the evolving process.

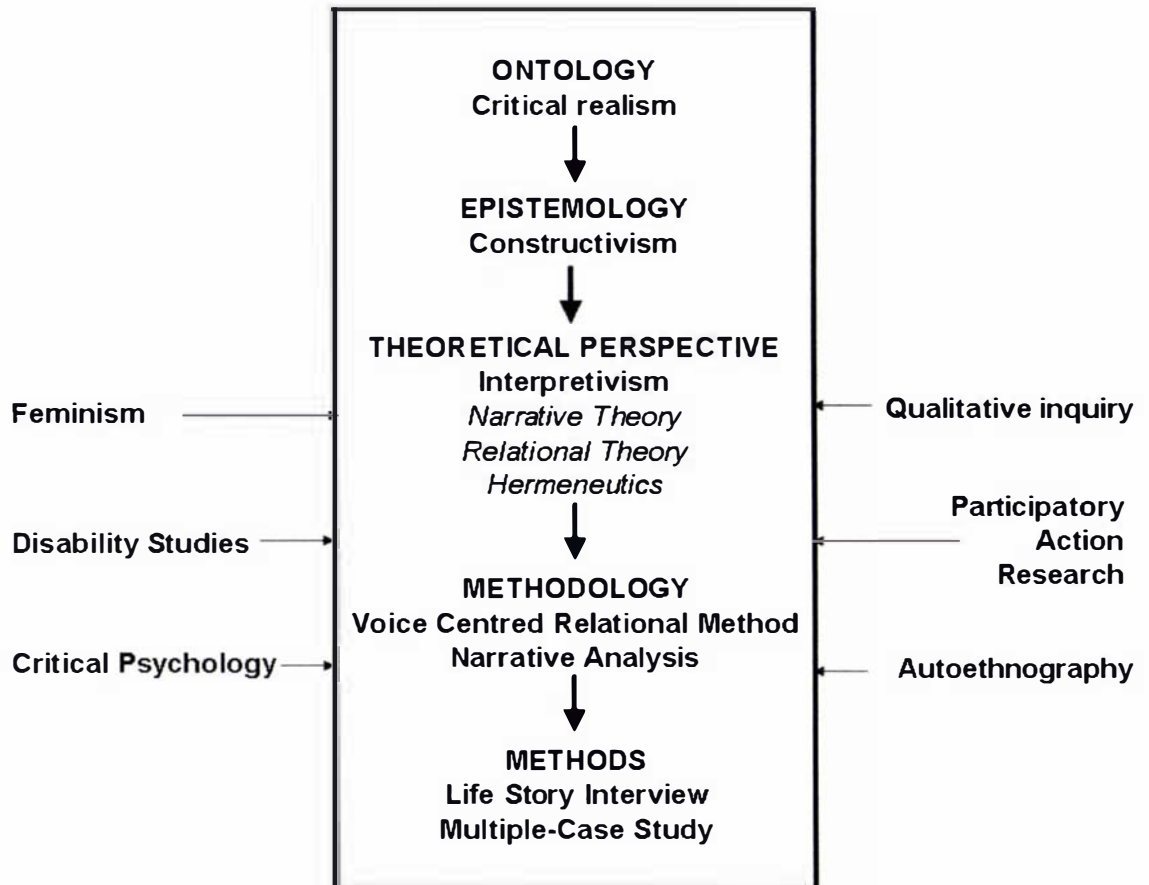


Figure 5.2: Completing the theoretical scaffold

(Adapted from Crotty, 1998, p. 4).

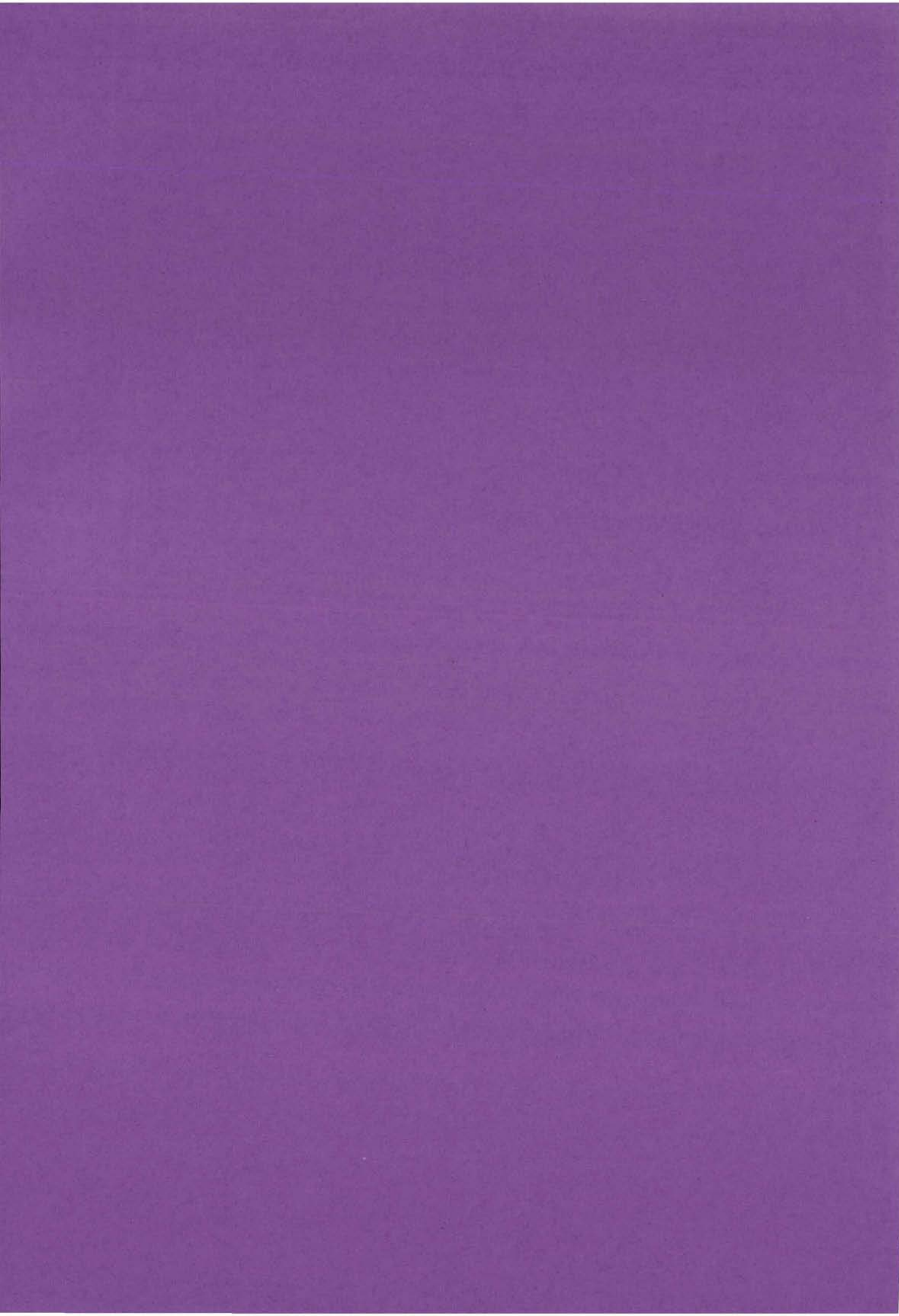
#### A cautionary note: the tyranny of the narrative

Riessman's work in narrative spans over twenty years but, in acknowledging the critiques of the field, she too admits to some discomfort with the popularity of the genre; hence the "tyranny of the narrative" (2002, p. 4). She considers the key criticisms to be, firstly, the questioning about social structures within which personal narratives are produced. Atkinson's (1997) criticism of illness narratives is that they place a value on the personal perceptions of the authors that ignore the authority of dominant narratives. He is also critical of work that he believes transforms research into "an almost therapeutic and emancipatory aspect" which goes beyond methodology (p. 334). While Zussman (2000) supports the concept in narrative of giving voice to people traditionally denied

voice, he also believes it is essential to attend to the social structures within which those voices are located and especially to attend to other voices that “may impose a story - and impose a self – on the autobiographer” (p. 6). A second key criticism that Riessman identifies is narrative’s idealization of individual agency and assumptions about an interior self. Atkinson (1997) sees this as a failure to attend to social context and social consequences where narratives are understood as an “individualized view of the self” (p. 339). His concern is that such narratives are regarded as privileged kinds of data and they lack systematic social analysis. He believes that this is when there is a danger that narrative goes beyond “the realms of analytic methodology and becomes a surrogate form of liberal humanism and a romantic celebration of the individual self” (p. 335). Parker’s (2004) suggested that the threats to narrative were naïve realism, constructivism and the reduction of narrative to the individual. Riessman (2002) seeks to address these concerns by calling for the location of narratives within their social and historical context. She also recommends that we go beyond a focus just on verbal communication by also questioning our own positions as interviewers and researchers. An assumption that this type of research can reveal or make heard voices of those traditionally silenced does not necessarily mean that it can transform those voices (Stein & Mankowski, 2004).

### Summary

This chapter described in detail the efforts to understand the nature of narrative and its contribution to this project. From this foundation and a relational constructivist perspective, life story interviews were identified as a method to address the research questions related to self and identity in aphasia. The VCRM was explored as an appropriate approach to the analysis of these narratives. A multiple-case study method was also proposed for the project and, finally, the methodological scaffolding was completed representing in a linear way the weaving together of the many strands which form the process. With this chapter and the preceding chapters as a foundation on which to begin to locate and find a way to “do” research with people with aphasia, the next chapter completes the project’s methodology by providing details of the process of doing the research.



## Chapter 6

### Developing and doing

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*Verbal communication*

*Written language*

Creating aphasia-friendly research resources

*Information and consent forms*

*Life story prompt book*

*Maintaining written contact*

Creating aphasia-friendly environments

Videographic data

Ethical considerations

Inviting participation

*An inclusive process*

*Who to invite to participate?*

*Sampling decisions*

#### Taking part

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*The importance of non-participation*

The interviews

*Interview resources*

Maintaining contact

## Dealing with the data

Transcription: From talk to text

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*Analytical interest*

*Considering the relationship to the audience*

*An approach to transcription*

Analyzing the stories

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## Defining, refining and redefining

The process

*The question of a pilot study*

Supporting activities

*Reflection*

*Enfolding literature*

Praxis and research: more blurred boundaries

## Summary

## Overview

*..all researchers need to be concerned with describing their procedures. When they spend more pages explaining why they did not deploy particular methods than on describing their own conceptual and analytic moves, they leave behind them too few footprints to allow others to judge the utility of the work, and to profit from it.*

A. Michael Huberman and Matthew Miles, 2002, p. xi.

Because there are many ways to structure and carry out a qualitative inquiry, this chapter is an attempt to leave behind some “footprints” by describing the project’s methodology in detail (Mertens, 1998). It develops the research process further by building on the work of the previous chapter which considered the importance of narrative inquiry to the project and identified the use of a voice centred relational method (VCRM) for the analysis of life story interviews within case studies. The present chapter considers the step by step process of doing the research from the preparatory stages through to the interviews, transcription and analysis. Finally, some reflections on the overall process conclude the chapter.

## Preparing the way

### Aphasia-friendly principles

It was not possible to anticipate the communication requirements of prospective participants. The very nature of aphasia, as well as the project’s approach to sampling, as described below, meant that I could not assume that participants would have a specific type or severity of aphasia. However, there were some aspects that could be addressed in preparing for a research process that aimed to be inclusive of people with aphasia. While never formally defined, aphasia-friendly principles are considered to be those that reduce the disability associated with aphasia and increase the inclusion of people with aphasia (Pound et al., 2000). Although “aphasia-friendly” most often refers to written information, such principles are also part of creating a positive communication environment.

In preparation for gaining ethical approval from the Massey University Human Ethics Committee, I considered what this meant for people with aphasia. One of the five main principles in the Code of Ethical Conduct for Research and Teaching Involving Human Subjects (Massey University, 2002) is the principle of informed consent. The key points are that care should be taken to ensure that participants are fully informed and have given informed consent freely. Information should be provided in a manner and a form which participants can understand. Meeting the intent of these principles, however, was more complex than I initially thought and developing the research process for people with aphasia meant attending to verbal communication and written language.

### *Verbal communication*

People with aphasia may have difficulty not just with verbal expression but also with understanding spoken language. For the research to be viable and for people with aphasia to be included, communication within and about the project needed to be aphasia-friendly. In clinical practice, strategies to enhance communication have been developed together with people with aphasia. There is always the potential for some behaviours to also hinder communication. Key points for aphasia-friendly communication are summarised in Appendix B. These are based on the principle that aphasia masks the communication competence normally revealed in conversation. Many people avoid conversation with people with aphasia because they are unaware of their competence. Aphasia-friendly communication, therefore, involves firstly acknowledging that the person with aphasia is competent and then negotiating and revealing that competence in conversation through partnership (Kagan, 1998).

### *Written language*

People with aphasia may also have difficulty with written language. This can range from being unable to read through to having difficulty recalling information that has been read. There were several key stages in the project where people were required to manage written material: when they first received the information sheet about the project, reading about the project and their rights in order to give informed consent, during the project when the interview questions were also presented in a written form and during the time of feedback where transcripts are commonly returned to participants for feedback. There was also incidental correspondence during the project to stay in contact and also to inform participants of any changes. Reliance on people's ability to read



in a project that is spread over time and over geographical distances can be high and the impact of reading disability can be underestimated. The levels of literacy and linguistic skills required to read for understanding standard information sheets and consent forms can therefore become potential obstacles to ensuring informed consent for people with aphasia unless some compensations are made. Braunack-Mayer and Hersh (2001) state that aphasia does not make people incompetent but there continues to be the potential to exclude them from decisions involving their care. They pose three reasons for this: aphasia is not generally well understood; as a language disorder, aphasia can mask competence; and logistical reasons such as allowing time may make involvement more problematic. While it is possible, Kagan and Kimelman (1995) recommend against using a proxy decision maker or proxy respondent for people with aphasia. It may actually reinforce an assumption of incompetence and any decisions that are made may not concur with the person with aphasia's own decisions.

Increasingly, there are now examples of researchers exploring and addressing this issue by considering how written information may be made more aphasia friendly (Hersh & Braunack-Mayer, 2000; Braunack-Mayer & Hersh, 2001; Hilari, Byng, Lamping & Smith, 2003; Parr, 2004). Although current opinion suggests aphasia-friendly written materials are useful, there is need for further research into what principles make material aphasia-friendly and what combinations are the most effective (Eames, McKenna, Worrall & Read, 2003; Rose, Worrall & McKenna, 2003). While wanting to provide material that is accessible is a noble goal, Rose et al. (2003) make a salient point that it is still important that the material is not degrading or disrespectful: "Health professionals need to evaluate under what circumstances it may be more important to preserve self-esteem or to increase comprehension" (p. 390).

### *Creating aphasia-friendly research resources*

#### Information and consent forms

A standard information form (Appendix C) and consent form (Appendix D) were developed with associated aphasia-friendly forms for the information form (Appendix E) and consent form (Appendix F) were produced using the guidelines summarised in Figure 6.1 (Bloomberg & West, 2001; Rose et al, 2003; Parr, 2004). This was done with input from a graphic artist who also helped clarify what the forms needed to achieve. In retrospect and with the learning that has taken place

throughout the project, I would now take more time to develop the forms in partnership with people with aphasia.

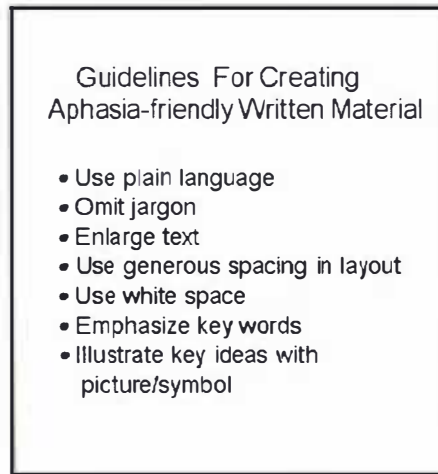


Figure 6.1: Guidelines for aphasia-friendly written material

As the forms were to be people's first introduction to the project and to me, they needed to look professional and to communicate that time had been taken to consider what people might require. They needed to look adult-like and be respectful to people's intelligence. While clip-art was an option, I was not able to find pictures that had shared commonality of style. The important information from the standard forms was developed into text that was less complex. The artist then created forms incorporating the adapted text and his associated picture supports (Figure 6.2).

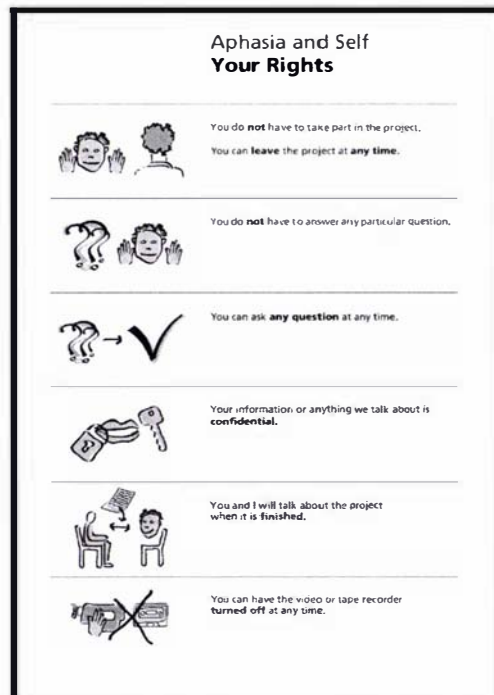


Figure 6.2: Example of aphasia-friendly information form

Attention to communication (written and spoken) has been specific to people with aphasia as part of this research project. There is, however, potential application for the principles to also apply to other situations that people with aphasia may be in and also to other groups of people including people with literacy problems, dyslexia, English as a second language, intellectual disability, dementia, and visual or hearing impairment. The Code of Health and Disability Services Consumers' Rights covers rights related to health and disability treatment or services, participation in teaching and participation in research. Right 5 in the Code requires that all consumers have a right to effective communication as shown in Figure 6.3 (Health and Disability Commissioner, 1996). This confirms that providers (for example, clinicians and researchers) must treat people as individuals with unique communication needs (Bray, 1999).

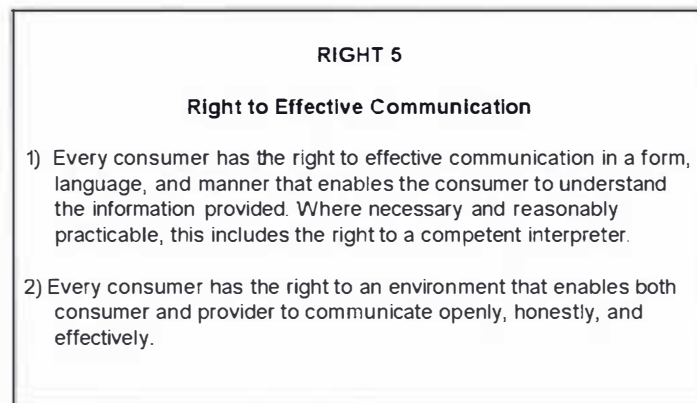


Figure 6.3: Right 5 (Code of Health and Disability Services Consumers' Rights)

### Life story prompt book

The life story interview is supported by prompt questions (Appendix G) presented orally to participants as part of the interview. In approaching interviews with people with aphasia, these questions needed to be made accessible in case of difficulties in understanding spoken language. A prompt book was developed to support communication in the interviews (Appendix H). For some people some of the pages were also sent to them prior to the interview to help them gain an understanding about what the interview would involve and to give them an opportunity to gather any resources they might wish to use to help tell their stories. Each question was presented individually on one page following the guidelines for creating aphasia-friendly written material (see Figure 6.1). Although the aphasia-friendly information and consent forms were developed with the support of a graphic artist, clip art was used for the prompt book. The main reason for this was initially the time factor. However, because the range of questions was diverse and the options for

pictorial representation reduced, the use of clip art actually made the process more flexible. Over the course of the project, I was able to change some of the pictures following people's feedback and adapt them if necessary in preparation for an interview. For example, I changed the gender of people in the pictures to match the gender of the participants. Also, by the time we reached the interview when the book was to be used as a resource, relationships were already developing, people had met with me and we had possibly reviewed some of the material in the book. I was therefore less concerned about any potential negative impressions that the printed material and pictures would make as I was when the forms were the first contact with the project. Examples of two pages from the prompt booklet are shown in Figure 6.4.

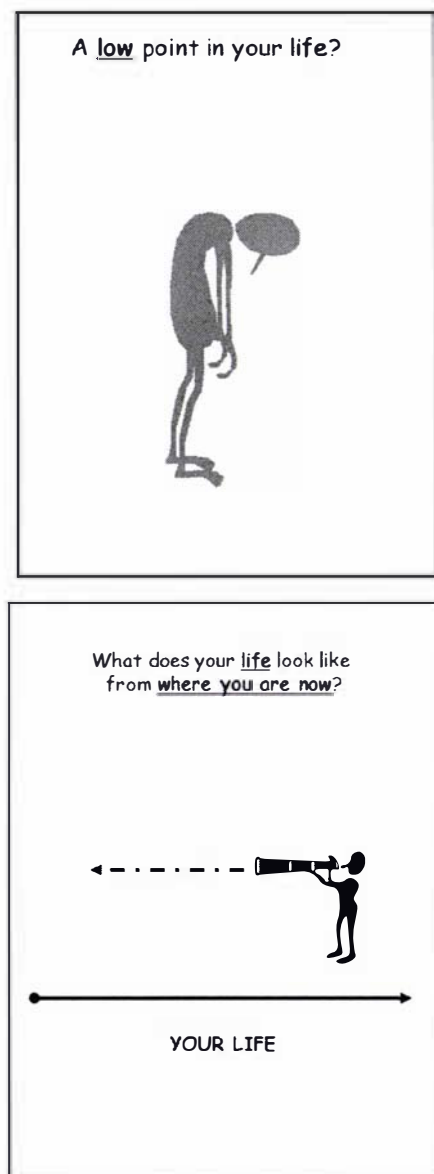


Figure 6.4: Sample of pages from life story prompt book

## Maintaining written contact

Given the time and distance over which the project took place, there was a need for additional written communication with participants and also with those people who chose not to participate. While this took the form of generic material such as the consent and information forms as well as fliers, individual written communication in the form of e-mails, cards or letters were used to support face-to-face and telephone contact. While I used aphasia-friendly principles in all written communications, I also designed the letters and e-mails so that they would be easily identified as related to the "Aphasia Project". To indicate that the correspondence was about the project a picture of a cosmos flower and Comic Sans as the font were used on all correspondence (Figure 6.5).

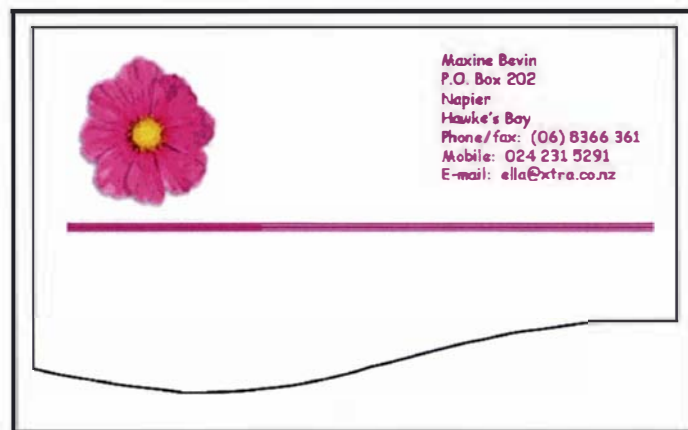


Figure 6.5: Example of Aphasia Project letterhead

### *Creating aphasia-friendly environments*

We can actively support an aphasia-friendly communication environment by considering what parts of the research process may create barriers and what can be done to reduce these barriers. By specifically targeting written material, the tangible aspects of meeting the needs of people with aphasia were addressed. By being aware of communication skills (Appendix B) and considering what an aphasia-friendly environment involved, the reduction of potential obstacles to including people with aphasia were highlighted. What could not be prescribed in the planning of the project was the way in which negotiation of communication with each individual participant would occur.

## Videographic data

A decision was made at an early stage to use videographic recordings of interviews. While audiotaping would have captured the linguistic as well as the paralinguistic<sup>29</sup> aspects of communication of participants, it would not have captured nonverbal behaviours. These also contribute greatly to meaning making: gesture, eye gaze, facial expression, touch, proximity and posture. These nonverbal communication aspects have been said to account for about fifty five percent of the meaning that people gain from conversation and is the principal means of rapport building (Caris-Verhallen, Kerkstra & Bensing, 1999; Hobbs, 2004).

I could not project the overall verbal abilities of people who would become involved in the project. As I had chosen not to exclude people with a more severe aphasia (should they choose to be involved), I knew from clinical experience that the gathering of verbal information alone would fail to capture the communication abilities of people. Body language, writing and drawing as well as using other communication resources (such as communication books) can be used by people with aphasia to augment their verbal communication. Therefore videotaping was decided to be the most appropriate way of recording the interviews.

## Ethical considerations

Ethical approval was given by the Massey University Human Ethics Committee before any contact with people with aphasia was initiated. The President of the Stroke Foundation of New Zealand was approached about contact with the Foundation's membership through the Field Officer Service, indicating that ethical approval had been given. Although a more formal approach was not required from me, the President sent my request to the Foundation's Medical Director for his opinion and this offered another level of safety for people who would take part in the project. Ethics in qualitative research have tended to address gaining ethical approval at the beginning of a research project and then following standard ethical guidelines. There has been less attention, however, to the ethical implications of conducting qualitative research including methodological and theoretical concerns. Creating guidelines for ethics in qualitative research is difficult because ethical concerns are always arising as the research process unfolds and there are possibilities of

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<sup>29</sup>The paralinguistic aspects comprise the properties of speech which can alter meaning including rate, speed, pitch, volume, tone, emphasis and vocal sounds such as sighing, laughter and crying.

recurring ethical dilemma throughout the entire study (Janesick, 1998; Ezzy, 2002). Birch, Miller, Mauthner and Jessop (2002) therefore argue that dialogue about ethical matters needs to take place throughout the research process. This project presented a series of ethical dilemmas, some of which were identified at the outset but some emerged during the process in. The initial two key ethical concerns identified were regarding the ethics of doing research with people with aphasia who might be considered vulnerable and the ethics of narrative research involving the exploration of subjective experience and meaning. I have chosen to speak to the additional ethical issues as they have arisen by weaving them into the discussions of the individual stories presented in the next chapter.

### Inviting participation

#### *An inclusive process*

An important goal of the study was that it would encourage a more inclusive process because people with aphasia are often excluded from research projects (Hilari, Byng, Lamping & Smith, 2003). Often a criterion for exclusion in research into stroke-related<sup>30</sup> issues is communication disability. This is described in a variety of ways: severe speech impairment, lack of communication skills to complete a questionnaire, inability to talk, language difficulties or inability to understand the informed consent process (Pound & Gompertz, 1998; Bendz, 2000; Ellis-Hill et al., 2000; Maclean, Pound, Wolfe & Rudd, 2000; Aben, Verhey, Strik, Lousberg, Lodder & Honig, 2003). The exclusion of people with aphasia in stroke research has been identified as a potential weakness in research designs particularly those investigating the psychosocial impact of stroke (McKenzie & Chang, 2002; Turner-Stokes, 2003). Even in a project aimed to be inclusive of people with aphasia, people with severe communication disability were excluded because the methodology was not appropriate (Parr et al., 1997; Parr, 2004).

An associated issue is the use of other proxy respondents such as close relatives or healthcare providers as alternative sources of information in research with people with aphasia. Cruice et al. (2005) investigated whether family members and friends could act as reliable informants for people with aphasia on quality of life measures. People with aphasia and their proxy respondents were

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<sup>30</sup> Stroke is the foremost cause of aphasia.

interviewed separately and proxy respondents were asked to answer questions as they thought that the person with aphasia would respond. They found that proxy respondents' ratings of their partners' quality of life were significantly more negative than people with aphasia rated themselves. While they make cautionary remarks about statistical reliability, this research is of interest both to research and clinical practice.

### *Who to invite to participate?*

This project initially set out to firstly include people with aphasia who indicated that they wanted to take part. Several decisions, however, were made at the outset of the project about who would be approached to consider participation:

- People who had aphasia concomitant with other neurological impairments (such as traumatic brain injury, progressive aphasia or dementia) would not be approached. While it is not a common sequela of a unilateral stroke, etiologies other than a single stroke can result in an impairment of self-awareness. The research questions are specific to self and identity in aphasia following a stroke.
- Participants invited to consider participation in the project were to be people in the community who had had aphasia for at least two years following a stroke. This would mean people would no longer be in a period of major change that is anticipated in the early stages after a stroke and they would be able to share experiences of living with aphasia.
- Participants would not be approached directly through speech-language therapy services. This was so that the research would not be associated, or be seen to conflict, with therapy services.
- As one of the main outcomes sought was a process that encourages a more participative research approach with people with aphasia, severity and type of aphasia were not identified as criteria for exclusion.



### *Selection<sup>31</sup> decisions*

The selection of the participants for this project is best described as criteria based, or purposive, sampling whereby people participate because they possess particular characteristics “which will entail exploration and understanding of the central themes and puzzles which the researcher wishes to study” (Ritchie, Lewis & Elam, 2003, p. 38). The power behind this sampling is that the sample should be information rich (Morse, 1998).

This project sought to understand the impact of aphasia on self and identity for people with aphasia through life story interviews. It did not seek to select participants on the basis of a particular presentation of aphasia (for example, Broca’s aphasia or conduction aphasia) or severity (for example, mild, moderate or severe) for several important reasons. Firstly, a more inclusive approach to research participation was a primary goal. Secondly, the conceptualization of self and identity espoused in this project includes the self as relational and storied in dialogue with the world and identity as the changing and evolving story of the self. Sampling on the basis of the different classifications of aphasia implies a philosophy of reductionism where a phenomenon is considered in its parts. However, communication and self and identity and the relationship between these phenomena, are complex actions which are not independent of the social world.

Thirdly, if sampling had involved classifying either the type or severity of aphasia, more formal assessment would have been required. I believe that a formal assessment process, additional to the research interview, would have reinforced the perception of my role as therapist and introduced other dynamics and power relationships additional to those already present in research. More importantly assessment would have influenced the nature of the developing relationship with participants and focused attention on the individual’s impairment rather than the relational nature of communication. Fourthly, people with aphasia rarely identify themselves as having a particular diagnostic classification of aphasia and, in fact, people often do not use the word “aphasia” to describe their communication disability. Therefore, involving participants in diagnostic assessment in order to categorize the aphasia would have little relevance to them.

Fifthly, the working assumption is that people with aphasia have an evolving narrative or an autobiographical story through which self and identity are constructed. Excluding people on the

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<sup>31</sup> Polkinghorne (2005) suggests that “selection” is a better description than sampling in qualitative research (p. 139).

basis of severity would infer that people with severe aphasia do not, rather than challenging how this narrativising is achieved in the presence of a severe communication disability. I had also considered literature where narrative methods had been used with people with learning difficulties where the emphasis was on overcoming barriers that impeded the involvement of "inarticulate subjects" (Booth & Booth, 1996, p. 55). They suggest that researchers "should attend more to their own deficiencies than to the limitations of their informants" (p. 67).

Sixthly, while this project does not claim to represent the clinical population, a desired outcome would be its contribution to the clinical realm. In a clinical setting, there is no sampling procedure in place. People are not selected for intervention based on the type or severity of aphasia. There may be some treatment decisions, however, that are made which are influenced by these factors but these would be taken into account along with other information such as co-existing conditions, personal wishes and responses to treatment.

How many is enough?

It has been argued that in an emerging research design the number of participants needs not be established ahead of time (Seidman, 1991). However at the outset of the project, for my research proposal and for my own planning, I established that I would complete a minimum of ten interviews with people with aphasia. I projected this based on my past experience with interviews with people with aphasia where there was a considerable amount of time involved in dealing with the material produced from an interview which was about personal experience. Given this current project's planned methodology, I considered that this was a reasonable projection. I was flexible, however, and wanted to see how the process developed and whether there would ultimately be a need to complete further interviews or reduce the number of interviews. The aims of the research were to further understand the impact of aphasia on the construction of self and to explore the use of more participative research approaches with people with aphasia. The first aim involved considering the number of participants needed to gain an understanding of the impact of aphasia on self and identity and this was held in tension with the second aim which was to develop a more inclusive approach to research with people with aphasia. This process was much more time intensive than was anticipated. It involved a minimum of one visit to participants including the interview itself and a maximum of four visits while managing travel to other districts to achieve this. Participants all received a copy of a draft of the narrative that was developed based on their involvement in the

project and most provided either verbal or written feedback. Adapting written material to make it more accessible to people with aphasia with reading disability was also time consuming. This all impacted on the final number of participants who became involved in the process as discussed later in this chapter.

## Taking part

### Making contact

Participants from the lower half of the North Island who were interested in talking with me were contacted following referral from the Stroke Foundation's Field Officers. The Stroke Foundation of New Zealand provides information and support to people who have had a stroke, their family/whanau and support people. There are currently about seventy stroke clubs in existence in New Zealand and about forty Field Officers who provide ongoing support to people affected by stroke (Stroke Foundation of New Zealand, 2004). I intended to prepare an aphasia-friendly flier to distribute to the Field Officers; however my initial letter to the Stroke Foundation was quickly distributed before I could do this. Consequently, the information that the Field Officers used to identify people was only about the proposed project outcomes and had no exclusion criteria. Three Field Officers subsequently contacted me directly and I made contact with a further two myself. One couple made contact with me independently after hearing about the project through their local Field Officer.

Fourteen people expressed an interest to the Field Officers and were provided with the written information and consent sheets including copies of both the standard text and the aphasia-friendly forms (Appendices C, D, E and F). A crucial part of the project was to make sure that people understood what they were committing to if they decided that they wanted to participate. Hence, I met with all the people who were interested at least once before any interview took place. For some people we completed an interview the same day or the next day but for other people the initial meeting was followed by a longer period of time for them to decide whether or not they wanted any further involvement or whether they had any further questions. This was sometimes more than several months.

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### *The importance of non-participation*

My initial meeting with all fourteen people took place in their homes sometimes on their own or with their partner. One person resided in a rest home. Of those fourteen, nine people decided that they wanted to participate further. The people who decided they did not want to take part in an interview did so for a variety of reasons. One person let me know at the time of our initial meeting; the others let me know their decisions by telephone or e-mail. At no point did I try to persuade them to reconsider and I fully understood their reasons. Several people were within a year of their stroke and were still involved in active speech-language therapy. Two people took time to read the interview questions and expressed a reluctance to talk about their lives because of a sense of privacy or felt it would be too painful to talk about themselves. One person commented that it was a time to look ahead and not back. All of these people were attending local stroke groups for social communication and I let them know that there would be an opportunity for information about the outcomes of the project at a future time.

Although this process was very time consuming and over a third of the people with whom I initially met decided not to go ahead with an interview, this was important to the tenor of the project. People needed to firstly have time to think about the project and to gain an understanding of what an interview would entail. They needed to have some idea about what being involved in the project would mean in the longer term. They also needed to have the opportunity to meet with me. From my perspective, the initial meeting was a time to think about the communication between us and also to think ahead to how an interview might best be organized. Because of my clinical experience, some informal "assessment" occurred in the initial meeting. Because I was committed to focusing on the communication between us and how we negotiated joint understandings, I was interested in the barriers to communication and the skills that were present that made communication between us (and others) successful. I was struck by people's willingness to be involved even if they chose not to participate further. Communication disability, my status as a stranger and the personal nature of the life story interview did not appear to be obstacles for those people who chose to take part.

Times were arranged for interviews with the nine people who had decided to take part and one person, when I rang to confirm our meeting time, chose not to go ahead with the interview. Due to the communication disability and the absence of face-to-face contact, I was not clear as to why there had been a change of heart but I respected the response. In total, eight people took part in an interview. The initial contact and interviews began in September 2003 with all but one interview

being completed by April 2004. The final interview took place in July 2004. The process leading to the completion of the interviews is outlined in Figure 6.6.

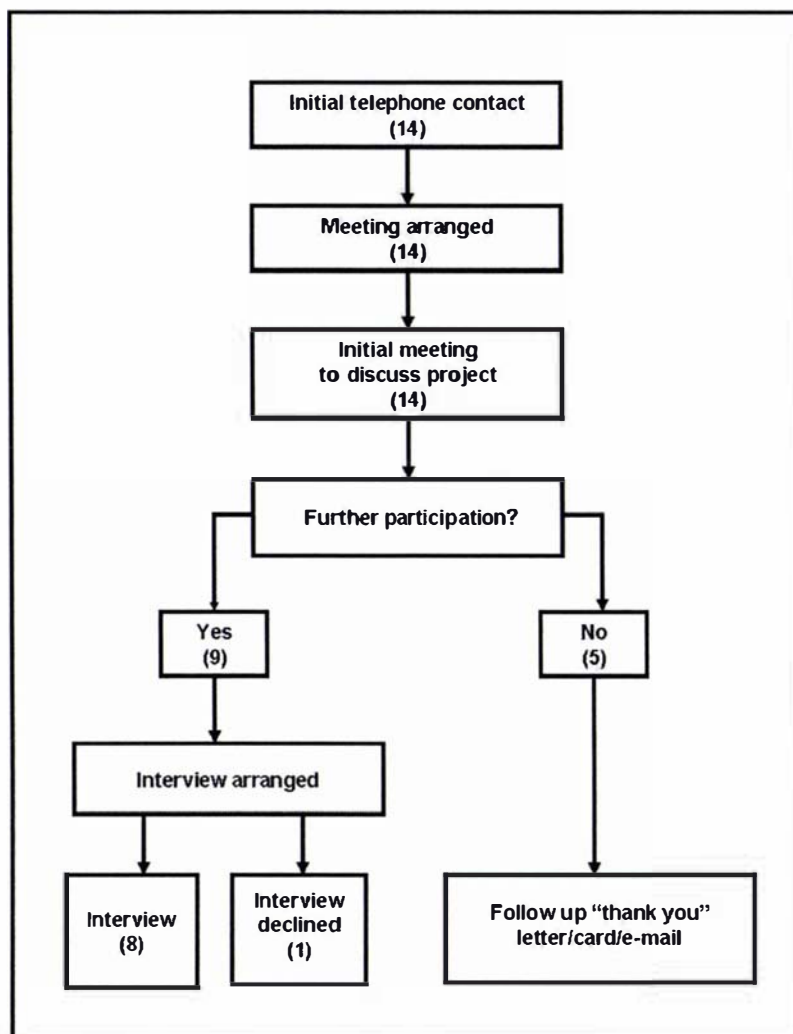


Figure 6.6: The participation process

### The interviews

Eight people, five men and three women, each took part in a semi-structured in depth interview. These participants, who will be introduced in the next chapter, had all been living with aphasia for almost two years and up to eleven years. Their ages ranged from the late fifties to the late seventies. Not only was each interview different because of the individuals involved and our relationship but the way in which the interviews were organized needed to attend to individual communication abilities and social context in order to maximize participation. Although the format of the interviews was arranged around the life story interview questions as shown in Figure 6.7 (and

Appendix G), there needed to be flexibility and in some interviews the questions were all presented while in other interviews they acted as a guide.

<b>LIFE STORY QUESTIONS</b>	
<b>General</b>	
<ul style="list-style-type: none"> <li>•Tell me about your life. Begin where you like and include whatever you like.</li> <li>•If you had the opportunity to write the story of your life, what would the chapters be about? Chapter 1? Chapter 2?.....</li> </ul>	
<b>Details</b>	
<ul style="list-style-type: none"> <li>•Tell me about a turning point in your life, wherein you underwent a significant change in understanding yourself</li> <li>•Tell me about a high point in your life</li> <li>•What about a low point, the worst moment in your life?</li> <li>•What's your earliest memory?</li> <li>•An important childhood memory?</li> <li>•An important adolescent memory?</li> <li>•An important adult memory?</li> <li>•Who have been the most important in you life?</li> <li>•What does your life look like from where you are at now?</li> <li>•If you could have your life over, what would you do differently?</li> <li>•How do you explain what's happened to you over your life?</li> <li>•Tell me about your plans and dreams for the future</li> </ul>	
<b>Self</b>	
<ul style="list-style-type: none"> <li>•How would you describe yourself when you were younger?</li> <li>•How would you describe yourself now?</li> <li>•How much have you changed over your life?</li> <li>•How?</li> <li>•What is your philosophy on life?</li> <li>•Looking back over your life story (with chapters and characters) can you pick out a major theme or message of your life?</li> </ul>	
Adapted from Atkinson (1998), Gubrium (1993); McAdams (1993)	

Figure 6.7: Sample interview questions

The questions were drawn from several well established works on life story interviews. They included initial questions aimed at a very general overview which served as an introduction. Next there was a group of more detailed questions about experiences, events and people. The last group of questions was tailored to exploring more specific notions of selfhood (Gubrium 1993; McAdams 1993; Atkinson, 1998). This format allowed people with more verbal abilities to develop the direction of the interview. For people with severe aphasia the structure was helpful in making the interview more accessible.

I did not plan to ask a specific question about the impact of aphasia on participants' lives. I did not want to assume, or communicate, aphasia as a "biographical disruption" (Bury, 1982) but rather I

wanted to allow the life story narrative to develop. I did not specifically talk of “life before aphasia” or “life after aphasia” or introduce a concept of an “old self” or “new self”. I believed that if the impact of aphasia was significant to that story in that interview at that time then it would be part of the telling. There were, however, conversational opportunities when in some interviews aphasia was explored more directly. The format of the life story interview acknowledges the dimension of time through its structure, through the nature of the questions and, in some interviews, we also physically created on paper a time line. These all gave an opportunity for discussing the impact of aphasia in participants’ lives and reflections on life before and after the stroke.

### *Interview resources*

The interviews were supported by several key resources. All the interviews were videotaped and this took place in either people’s dining rooms around a table or in people’s living rooms. The video camera was positioned to always include the participant and myself; if a spouse or partner also took part in the interview, the video camera was positioned to include everyone. For several people, from my observations and their comments or gestures, the video camera was initially prominent and this was probably not helped by my need to check the cameras at different points during the interview as well as listening for the warning sign to indicate when the video tape was nearly full. For most part, though, I believe the video camera became less obtrusive as the interview proceeded. The interviews lasted for at least an hour with several extending to two hours.

While I had the interview questions as a prompt for each interview, the life story prompt booklet was also used with all but one of the participants. Although it was designed primarily for people who had difficulty with understanding spoken and written language, it was useful as a point of reflection during the interviews and appeared to help people when they were considering the questions. It seemed to take the pressure off communication by allowing people to spend time reviewing the pictorial material rather than having to maintain eye contact if the time between my verbal question and the participant’s reply was lengthy. I sent two people copies of some of the questions to give them an idea of what the interviews would involve and this also enabled them to prepare for the interviews by gathering together photographs and books that became important resources for the interviews. Because all of the interviews took place in people’s home, the environment was a resource in itself. People referred to articles and objects in the house, pictures in photograph albums and on the walls, and also indicated information by connecting themselves with

the environment outside the home. This allowed people to signify events in their lives by the objects representing those events including trophies, certificates, craft items and family pets.

### **Maintaining contact**

The project was spread over a long period of time and also over a geographical area which necessitated travel. The initial contact and interviews began in September 2003 and were completed in July 2004 although I met with people again with my last face-to-face contact taking place in the middle of November 2004. The project was formally completed at the end of April 2005. While I would now develop a more consistent approach to maintaining contact, I found it difficult to create the collaboration I had aimed for. The obstacles were mainly time and travel but verbal communication and difficulties with written language made non face-to-face communication more challenging. Ideally, following an interview I would have liked to have been able to return with a transcript and with feedback about the overall discoveries. The project, however, was not so straightforward. Transcription procedures and approaches to analysis were emerging elements in the project and I made some major methodological decisions as the project began to develop. This was most closely related to the practical aspects of contact with people and the interviews. For example, while I had planned in the initial stages to approach the analysis of the interviews using a narrative analysis approach that I had developed in my earlier project, I had to rethink this.

Over the course of the project, I was also developing a deeper understanding of the relational nature of the interviews and, more generally, of communication through exposure to the literature and to the interplay between the literature, my reflective practice and the interviews themselves. This has been introduced in the earlier dialogue about the VCRM and will be further discussed in the section on analysis but it is an illustration of what Morse (1997) calls the uncertainty and risk of qualitative inquiry. Other difficulties included how to return the interview transcripts to people who have difficulty with understanding written language and also how to explain the emerging understandings about self and identity when these were not fully formed. The eight individual life story interviews that form the next chapter will highlight these issues and how they were addressed.

While maintaining contact about the interview was individual to each participant, I also sent out generic fliers. The aim of these fliers was to primarily keep in touch given the time between personal contacts, let people know how the project was going generally, and also to inform



participants of changes. Figure 6.8 is an example of one of the generic fliers. When the analyses had been completed, further contact with participants involved sending a draft of what I planned to include in the final writing and then either receiving written comments back from them, telephone contact or personal visit.

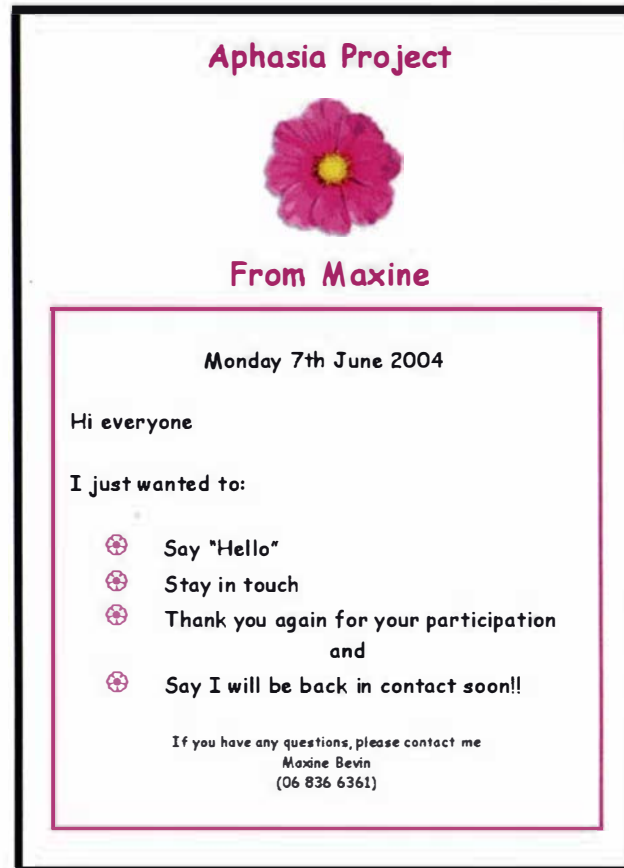


Figure 6.8: Example of generic flier

### Dealing with the data

Following the interviews, the videographic material was transcribed and then analyzed. At each stage decisions were being made, particularly in the initial interviews, about the processes that best enabled the research questions to be addressed. Developing systems for transcription and analysis was not about finding a recipe and locating an existing convention, it was about acknowledging the theoretical issues and methodological implications of doing qualitative research (Lapadat, 2000; Linde 1993).

## Transcription: from talk to text

In the preparatory stages the matter of transcribing videotaped records of interviews with people with aphasia seemed clear-cut. I would write down what I heard and saw. While prepared for a labour intensive process, I did not initially consider the transcription and the sharing of the transcripts<sup>32</sup> in the thesis document to be problematic. I had had experience with transcription in my clinical work and also in my initial research project. However, clinical transcription was for the purposes of linguistic and/or phonetic analysis of a language sample and research had involved narrative analysis with participants who were verbal and I used audiotaping. Subsequently, challenges began to emerge. Firstly was when I began to transcribe the first interview and then again when I considered how I could guide readers to make sense of transcripts and enable them to hear the voices in the interview interaction, although now reduced to text. Decisions around transcription are dependent upon context (Muller & Damico, 2002). The participants all presented with different communication skills and a form of transcription was needed that would take into consideration not just verbal expression but all aspects of communication including voice, gesture and writing. Linde (1993) identifies three considerations in approaching these decisions: theory, analytical interest and relationship to the audience. These provide a way of clarifying the decision making.

### *Theory*

The act of transcription tells about how we see the relations between reality and representation, and meaning and language and as such are constructions that speak of our theoretical assumptions (Mishler, 2003). My theoretical background is interpretive. It includes the acknowledgement of the relational nature of self construction and the recognition of narrative as a way of understanding the world as well as making sense of the actions of people within it (Sarbin, 2000). This theoretical background has implications for how transcription can gain entry into the interactions between people and the joint action of meaning making.

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<sup>32</sup> I have chosen to adopt Müller and Damico's (2002) use of the term *transcript* for the product and *transcription* for the process.

### *Analytical interest*

My analytical interest, therefore, was how the transcription would marry up with the theoretical assumptions and support the analysis. There is an increasingly wider focus in practice and research in communicative disorders in recognition of communication breakdown residing in the communicative event rather than in the person and the acknowledgement of communication as a collaborative endeavour. This has been accompanied by a growing acceptance and use of qualitative methodologies (Tetnowski & Damico, 2004; Müller & Guendouzi, 2002; Damico, Simmons-Mackie, Oelschlaeger, Elman & Armstrong, 1999). However, the most common qualitative methodologies cited in research in aphasia are conversational and discourse analyses. This project proposes a narrative analytical approach and while both conversational analysis and discourse analysis could well be used with the “data”, the assumptions are different.

Video technology offers potential opportunities in qualitative research and is becoming increasingly looked upon as a valuable tool (Bowman, 1994; Morse & Pooler, 2002; Rosenstein, 2002). However, it is still relatively uncommon and researchers conducting video based research have tended to develop their own systems to record visual and tactile behaviours (Heath & Hindmarsh, 2002).

Müller and Damico (2002) whose research interest lies in conversational analysis propose a “toolkit” approach to transcription which is multilayered and can be used in various combinations (p. 312). This includes a primary layer (the transcription of all utterances), a gesture and gaze layer, a prosody and voice layer, a discourse layer and a clinical analysis layer. They propose that such a system will make the process of transcription more manageable. They acknowledge the interpretative nature of transcription and the visibility of the transcriber, but what I identify as absent is a reflexivity that is associated with an interpretive account. Such a “tool kit” assumes objectivity and that we can truly represent communication in a transcription. Communication, however, remains a complex, contextually based and integrated action occurring between people in the construction of meaning. For these reasons, I had aligned myself with the VCRM as a way of analyzing the interviews and that has implications for the transcription process.

### *Considering the relationship to the audience*

The main audience in this process is the reader of the thesis who will have a shared understanding of the part language plays in the social construction of reality and will recognize that transcripts are therefore not a direct representation of the original phenomena (Müller & Damico, 2002). Although participants are also potentially a key audience, aphasia has, to varying degrees, made reading inaccessible and alternative ways of presenting information has been explored. I am also part of the audience as I return again and again to transcripts in the process of analysis and interpretation. Transcription, rather than a means of representing talk, becomes an interpretive and constructive act in which I am also positioning myself (Lapadat, 2000). Given these relationships, the theoretical footing and an interest in narrative and a relational methodology, the transcripts should invite a reader into a conversation that was had by certain people, in a certain place in a time in the past. The transcripts are not ad hoc but are a result of the decisions I have made through the process and they should not obscure my part in making sense of the conversation (Allred & Gillies, 2002).

### *An approach to transcription*

Lapadat (2000) makes the point that transcripts are theoretical constructs and not neutral representations of reality: "They are interpretive implications that follow seeing qualitative data as contextual and constructed" (p, 209). Following the interviews, I completed an initial transcription as soon as practicable. I improved my skills in transcribing videographic material as I progressed from interview to interview. Research with people who do not have aphasia has the potential to produce lengthy passages for transcription and analysis (Riessman, 1993; Mishler, 1995). This was not the case for the project's interviews. However, given the range of aphasia that people had and the use of video recording, transcription was still lengthy and labour intensive. While some people were predominantly verbal in their communication, others relied on a combination of verbal, voice, and nonverbal means including gesture, drawing, writing and environmental resources.

As already discussed the VCRM involves multiple listenings to the data; listening to who is speaking, in what body, telling what story about relationship, from whose perspective and in what societal and cultural framework (Brown & Gilligan, 1982). Therefore the approach to transcription needed to be linked to the way in which the data would be analyzed. While transcribing the talk was imperative, prosody, gesture, position, facial expression and eye gaze were also important to the

concept of “listening” to and for voices. The VCRM is also based on relational theory and so all participants’ voices needed to be present in each transcript. While I initially projected that this would include myself and the participant, in three of the interviews the participants’ partners also took part.

While computer assisted qualitative data analysis software would have provided some advantages in the comprehensive storage and formatting of data (graphic, audio and text) as well as the potential to “manage” information over all the interviews, I did not feel that this level of sophistication was needed as I was not seeking to code a large amount of data across large numbers of cases. After much exploration and trial and error, I was able to import the videotaped images into the computer and, using the “Tile Windows Horizontally” function, I could simultaneously observe the images in a window at the top of the screen and word process in the bottom window using Microsoft Word. To begin with I transcribed verbal, vocal and non-verbal behaviour as well as recording narrative comments using a template (Figure 6.9).

Counter	Transcript	Notes

Figure 6.9: Initial transcription template

The time from the videotapes was recorded in the “Counter” column, beginning at “00.00” which gave both minutes and seconds so that particular sections of the videotape could be quickly re-located as needed. Communication behaviours (verbal, vocal and non-verbal) were recorded in the “Transcript” column with an associated line number. Comments and reflections were transcribed in the “Notes” column of the transcription template either at the time of transcribing from the videotapes or during later reviews. After several interviews, however, I removed the notes column and instead recorded comments and reflections in an exercise book, one for each participant. This

worked well but also made it easier to then use the template for the analysis approach suggested in the VCRM. All verbal behaviours were recorded verbatim and included pauses and overlapping talk. I tried to use normal punctuation including question marks, exclamation marks, commas and full stops to represent speech. I wanted any excerpts used in the analysis to be able to be read without the reader needing to access a specific notation system. However, there was still a need to communicate other aspects such as a word not being understood or said with emphasis and this required further explanation. A transcription key was developed to meet the specific needs of the project based on other transcription systems used in the literature (Balandin & Iacono, 1999; Heath & Hindmarsh, 2002; Linde, 1993; Poland, 2003). It is located in Appendix A and it is reproduced here in Figure 6.10.

<b>TRANSCRIPTION KEY</b>		
<b>Notation</b>	<b>Explanation</b>	<b>Example</b>
Number in margin	Line number of transcript	30. Maxine: I went home
-	Hesitation	I went - home
<b>xxxxx</b>	Emphasised word	I <b>went</b> home
x:	Prolonged sound	I w:ent home
(?)	Word not understood	I (?) home
/xxxxx/	Possible hearings/paraphasia	I /sent/ home
(xxxxx)	Narrative information	(She looks at the floor) (Long pause)
Fillers	Orthographic	Mmm Ah Oh
[	Overlapping talk	Maxine: I went home Mary: [I went home

**Figure 6.10:** Transcription key

The notation was chosen to allow a better understanding of aphasia as well as the interactional aspects in conversation. It was my hope that the presentation of any excerpts of the transcripts in the final narratives would increase an understanding of the obstacles of language impairment and an understanding of the way in which meaning making occurred despite these barriers. Non-verbal

behaviours were transcribed in a narrative form and all participants were included in the transcript. The use of a narrative description rather than the “tool kit” approach of a coding system was an outgrowth of the theoretical assumptions of the project. While some notation was required the overall aim was to create a transcript that would impart the sense of listening to a conversation where all voices are present as the following excerpt shows:

745. **Lisa:** *Yeh, it was on the left side*
746. **Mark:** *(He traces his hand from the top of his head, down the left side of his face, and then down his left arm and his leg) See.*
747. **Maxine:** *'Cos what hand do you use? What hand would you normally use?*
748. **Mark:** *(He lifts his paralyzed left hand with his right hand). /Ay/? (And he looks over to Lisa).*
749. **Lisa:** *The left (and she nods at his left hand).*
750. **Maxine:** *You're a left hander, aren't you?*
751. **Mark:** *[Yeh, yeh (and clenches the fist of his right hand).*

It has been suggested that the transcription of spoken language, in its informality and incoherence, may actually suggest lower intellectual abilities and therefore risk labelling people or groups of people as such (Lapadat, 2000). Having returned transcripts to participants with attention to how we both might “sound”, I did not receive any negative feedback about the way the text was perceived.

While the transcripts were a step in the process preceding the analysis and the main task was to transcribe, it was the beginning of interpretation, particularly in the form of the narrative descriptions that accompanied the text. Decisions were being made about the level of detail to include associated with what I had regarded as important. My choice of language was also an act of interpretation. In the above excerpt my choice of “clenches the fist of his right hand” implies a different meaning than “makes a fist”.

Morse and Pooler (2002) in their discussion on analyzing videotaped data present a useful example of the analysis of a handshake. At a technical level a handshake would be described behaviourally as an action but through inference from shared meaning and experiences, it is labelled as a greeting which is the purpose of the action. This is then extended to what assumptions can be made about the handshake, what is inferred if we know about the roles of the participants, the relationships

between them as well as the function. The inferences about a handshake between business partners are different to those between enemies. So in the act of transcribing when I provide narrative information, some interpretation is already occurring.

### Analyzing the stories

Although it is possible to say that, technically, the transcription process preceded the data analysis, every point of contact made with participants throughout the entire research process and the “contact” with the raw data have been part of the ongoing development of understanding and new insights. For example, the initial telephone calls or e-mails to interested participants, the follow up meeting when the project was introduced, the interviews themselves, the research journaling and the opportunities for follow up and feedback were all important parts of a whole and illustrate the difficulty in separating analysis out as a discrete stage. Compartmentalizing the process discounts the “messiness” and has the danger of depicting the process as a purely linear one. The early stages of data analysis can be “messy and confusing” but this is where we are beginning to learn from the data as we learn about it: “But while this sense of not knowing and of openness is exciting, it is also deeply uncomfortable” (Mauthner & Doucet, 1998, p.122).

The data analysis stage of the research process is still, for the most part, neglected and guidance in the literature about how transcripts are analyzed is lacking. There is little detail about why researchers choose particular methods and how theoretical and epistemological orientations are translated into approaches to data analysis (Doucet & Mauthner, 1998; Mauthner & Doucet, 1998). The suggested reasons for this “most vulnerable spot” (Mauthner & Doucet, 1998, p. 123) include lack of space available for detailed description of the analysis process in published material, the dominance of positivistic research approaches, the equating of computer data coding with qualitative analysis and difficulties in articulating what are subjective and interpretative processes. As feminist researchers, Mauthner and Doucet (1998) acknowledge the critical issues of listening to women and of understanding their lives but are concerned that there are limited examples of how this is operationalised in the analysis of data. While reflexivity in methodology and epistemology seem to have been well explored, there is still little attention to reflexivity in the data analysis stage. The dilemma for researchers is how to analyse data that reflects participants’ voices while also identifying the researcher’s role in shaping the process (Doucet & Mauthner, 1998).



*The voice centred relational method: "Listening Guide"*

As introduced in Chapter Five, the VCRM is known as the "Listening Guide"<sup>33</sup>. As a guide to analysis it is sensitive to the relational nature of research and it is used to interpret qualitative interview data when narrative is considered to play a role in organizing of experience (Tolman & Brydon-Miller, 2001; Gilligan et al., 2003). As I approached the analysis of each interview, I was also adapting this method to reflect my own background in communication disability, psychology and my research interest in self and identity and aphasia.

## Engaging in analysis

Doucet and Mauthner (1998) believe that when we are engaged in the process of analysis of qualitative data, we are, in fact "confronted with ourselves and with our central role in shaping the outcome" (1998, p. 3). Even when we draw on specific methods of analysis, we still use and interpret these in our own individual way influenced by our personal, political and theoretical biographies. What follows then, is how I have adapted and used the VCRM to understand self and identity in aphasia. Although I found it useful to consider how the VCRM had been applied in other research, in order to develop an approach specific to this project and the participants, I drew on four main resources for the VCRM: Brown and Gilligan, 1992; Mauthner and Doucet, 1998; Brown, 1997; and Gilligan et al., 2003. I also adapted an approach to the analysis of personal stories developed by Fraser (2004). She uses key questions to guide researchers through the process of analysis without offering a formula or recipe. While these authors are not specifically referenced, their work is incorporated in the approach I have developed.

I was aware as I began to work with the VCRM that "As voice depends on resonance or relationship in that speaking relies on, and is affected by, being heard, this method is intended to offer a pathway into relationship rather than a fixed framework for interpretation" (Gilligan et al., 2003). The method provides a guide rather than rules to be followed. Most applications of the VCRM are based on at least four sequential readings of transcripts with each reading, or listening, aimed at allowing the researcher to develop a relationship with a person's distinct and multilayered voice. Gilligan et al. (2003) recognize that as with any other analytical tool, people will develop different

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<sup>33</sup> In this project, the key tasks were not just listening (and reading) but also included watching (in order to "listen") particularly for people with more severe communication disability.

ways of carrying out the four basic steps to address the needs of the study and the research questions. I initially considered four listenings or four steps related to the project and to my understanding of the VCRM. I developed the steps around guiding questions (Brown & Gilligan, 1992; Mauthner & Doucet, 1998; Brown, 1997; Gilligan et al., 2003, Fraser, 2004). As I began to work with the videotapes and the transcripts, I included two more steps. Each step involved some interaction between the videotape and the transcript although there were times when just the transcripts formed the data. I have used “data” to cover both videotapes and transcripts and then specified if I am referring to just one. After listening to and watching the videotapes many times, it was also almost possible to hear the voices in the transcripts.

*Step 1: Listening to the story the participant tells*

Listening for the plot<sup>34</sup>

The first part of this step was to listen for the overall story or plot:

- What is the story the participant is telling
- What are the contexts of the stories being told
- What is happening?
- What are the main events and how do they unfold?
- Who are the characters?
- What are the subplots?
- Are there any recurrent images, metaphors, themes, words, events or contradictions?
- Are there absences or things not being expressed?
- Are there silences and what do they signify?
- Are there emotions experienced through the telling?
- What are the vocal inflections and what do they signify?
- What non-verbal behaviours are used and what do they signify?
- What is the larger social context within which the stories are experienced?

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<sup>34</sup> This part is common to other approaches to qualitative analysis including Riessman’s work (Mauthner & Doucet, 1998; Gilligan et al, 2003)

I also drew on my experience with an approach based on the works of Mishler (1986a, 1986b), Bell (1988) and Riessman (1993) in the earlier research project. I found that it was helpful to develop a time line or a life history map to support the creation of the plot and understand the life history as part of the life story interpretation.

#### Listening for the research relationship

The second part involves listening for how I respond to the participant and the narrative by “identifying, exploring and making explicit” my own thoughts and feelings; by actively focusing on my responses to the person and what she/he is expressing (Gilligan et al., 2003, p. 160):

- What is my position?
- Where am I socially located in relation to this person?
- What power do I bring with me?
- How do I identify with this person?
- How do I distance myself from this person?
- In what ways are we similar or different?
- Do I feel a connection with this person?
- Where am I confused or puzzled?
- What are my emotional responses to the narrative?
- Do I have any further insights about myself from listening to the person and the narrative?
- How might my responses affect my understanding of this person and of her/his narrative?

As suggested by Brown and Gilligan (1992), the following steps involved highlighting the transcripts with coloured pencils to trace the particular listening focus.

#### *Step Two: Listening for the self*

This step is one that attends to locating the self in the data. I used a highlighter (pink) to trace through the first person voice; how the person talked about, experienced and felt about her/himself? This was mainly identifying the use of personal pronouns such as “I”, “you”, “we” as well as “one”. With people with more severe communication disability, I attended to any

paralinguistic or non-verbal behaviours that I thought signified the "I" (for example, the person pointing to her/himself). When there was a partner also present in the interview, I listened for how the person spoke about their partner. The guiding questions were:

- How does this person speak of her/himself?
- How does this person experience her/himself?
- How does this person perceive her/himself?
- Is there an active "I" telling the story?
- What is the social location of the "I"?

Gilligan et al. (2003) have now included the construction of "I" poems as this second step. Their research is the only literature I accessed that incorporated this step in the VCRM. "I" poems involve underlining every first person "I" in chosen passages along with the verb and any important associated words. These are then pulled out and arranged in order like a poem. The main reasons they propose this approach is to encourage the researcher to listen to the first-person voice in all its cadences and rhythm. Also they believe that this is a key way of coming into relationship with the person and it prevents the researcher distancing her/himself. I did not follow this process in a committed way because the nature of aphasia means that the linguistic representation of the first person such as pronouns or proper nouns may be impaired or absent. Also repetition of words in aphasia may not necessarily be as significant in the text as they would be for a person without language disability. Finally, longer passages of text were not common in the interviews.

### *Step Three: Listening for other*

For this step, I traced the words or actions that spoke of interpersonal relationships in green:

- Who does the person speak of: family, relatives, children, friends, colleagues?
- Are there personal, social or cultural constraints to such relationships?
- How does the person speak of these relationships?

*Step Four: Listening for aphasia and stroke*

I decided that this step would focus attention on the person's experience of aphasia and stroke which I highlighted in blue:

- What does the person tell about the experience of aphasia and stroke?
- What stories are told about aphasia and stroke?
- What stories are told about the experience of speech-language therapy?
- How does the person talk about aphasia and stroke?
- How does aphasia manifest itself in our conversations?
- How does aphasia impact on our conversations?
- How do I talk about aphasia and/or stroke?

The VCRM involves at least four sequential listenings and I had originally planned to complete these four steps, as outlined above, with Step Four the final step in the analysis. However, in working with the transcripts and reflecting on the research and the research questions, I still felt there were missing elements and I included two further steps.

*Step Five: Listening for the process*

As I was completing the analysis of several interviews, I was also developing a chapter for the thesis recording the theoretical perspectives. I identified an increased clarity in how I wrote about the location of the project but I was interested to hear if this was evident in how I spoke about the research with participants. In acknowledging the difficulty in explaining a heuristic process, I considered a further step attending to how I spoke about the research and traced these in yellow highlighter. I listened for how the research process was talked about, understood and developed:

- How do I explain the research process?
- How do I talk about the research process?
- How do I talk about the life story interviews?
- How do I talk about narrative?
- What assumptions am I making?
- What theoretical perspectives am I giving voice to in practice?

*Step Six: Listening for relational practice*

While I felt that the steps that had been developed thus far and included were a strong feature of the research in their contribution to addressing the research questions about self and identity in aphasia, I was still not sure that they would help people *act* differently (Brown et al., 1989, p. 164). I was thinking about the practical outcome of the research particularly for speech-language therapists working together with people with aphasia. How would this analysis and my conclusions add anything to the way in which we *act* in relationship with people with aphasia. I had developed a strong commitment to relational theory over the course of the research and I felt that this had a contribution to make to the therapy world. But I could see that the analyses could possibly be viewed as a form of conversational analysis but with a “layer” of interpretation and meaning.

There are many illustrations of collaboration and co-construction in sense making but they do not tell us about the meaning making or the identity construction that occurs in these encounters and conversations. Many times, particularly during transcription, I valued the way in which conversational analysis had moved our understanding of aphasia forward and given emphasis to the interaction between people rather than the focus on the individual. If self and identity are constructed within our social relationships, how does this operate in practice? My concern therefore was not questions about interaction but about meaning making and the development of a relational approach. What are we doing together that creates a shared reality and enables us to develop our relationship? What is it that we do or say that talks of the joint action of communication? I therefore decided to include a sixth step that involved listening for what could be considered relational practices. How can we capture “being” and the creation of a meaningful, shared understanding rather than “doing”? These were then underlined in the transcripts in red pen:

- What are the verbal behaviours we use that are relational and that foster relationship?
- What are the verbal behaviours we use that are obstructive to relationship?
- What are the nonverbal behaviours we use that are relational and that foster relationship?
- What are the nonverbal behaviours we use that are obstructive to relationship?

An example of a transcript page with the coloured highlighting and tracing is shown in Figure 6.11.

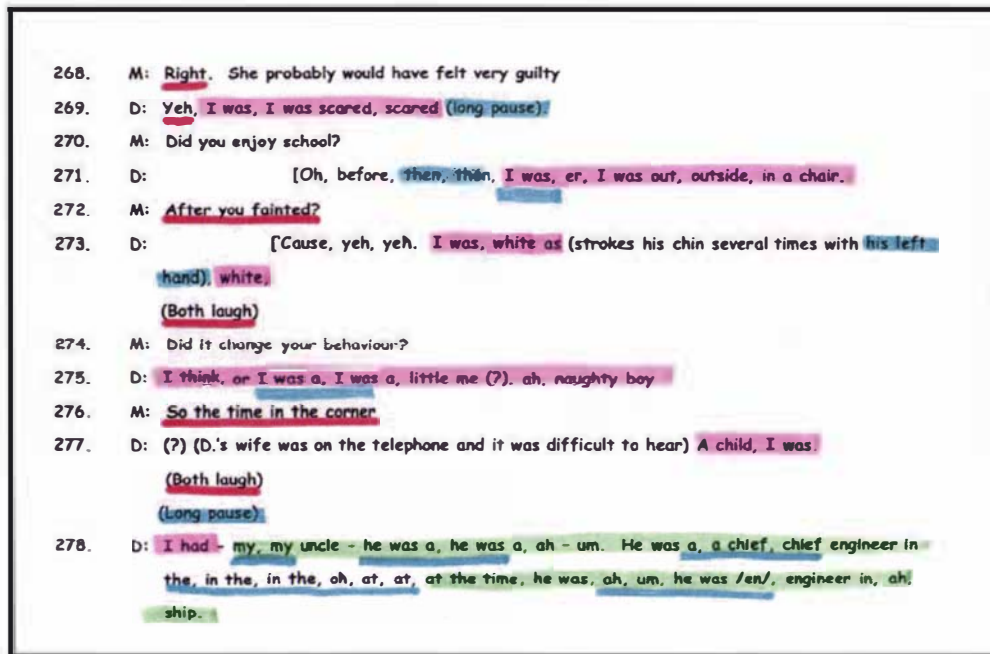


Figure 6.11: Example of transcript page

### Composing an analysis

Having completed the analyses of the interview transcripts, the next task was to consider how to condense the new understandings into an interpretation of the interviews. There were several questions that also guided this process (Mauthner & Doucet, 1998; Gilligan et al., 2003, Fraser, 2004):

- What did I learn about the research questions through the process?
- How have I come to know this?
- What is the evidence on which I base my interpretations?
- Have the research questions changed?
- Have I distinguished the participants' accounts from my own?
- Are the interpretations I have made fair?
- Do my analyses maintain a respectful tone towards participants?
- Does my writing recognize my subjectivity and its influences on the interpretations?

I had elected to use each interview as a case study and I developed a narrative interpretation of the analysis of each interview which brought together each participant's experiences with me and the research questions adapting a data analysis proposed by Way (1997). She used narrative summaries

to condense interview stories while using extensive quotes from participants. She then used these summaries to identify themes across interviews which formed the basis for the "Listening Guide". Instead, I used the narratives as a final step. The separate readings all contributed to my understanding and rather than code the interviews into dominant themes, I maintained a sense of the individuals' voice in dialogue with me, with her/his other relationships and with the social and cultural milieu. I wrote in a style that I felt suited each participant as the narratives would be returned to them for feedback. I tried to balance a conversation between my voice and the participant in a way that also told of the relationship. Interspersed with the interpretive narrative were excerpts from the interview either as a piece of dialogue or as distinct comments only. I also wanted to find a way of integrating the ongoing learning and discoveries that were occurring throughout the process and any issues that arose. Peshkin (2000) presented an account of a study with accompanying reflections he called "problematics" (p. 5). These were complementary to his text but were also a way of making transparent what lay behind the researcher's process of interpretation. Life stories of individuals will always be individual; life stories of people with aphasia will always be individual as well; however they will weave in the many voices of the participant, the researcher and those people with whom the participant is in dialogue. I did not try and capture only commonality or reduce the data to universal themes; rather I have tried to attend to individual voices in dialogue with their social worlds. In creating the narratives, I am also respectful of the participants who were to read my interpretations of our interview. I am also respectful of the insight and skills that any other readers bring to their reading of the narratives, both as individual stories or as a whole, along with their own listenings and interpretations. The narratives, which are presented in Chapter Seven, may well tell as much about me and my assumptions as they do about the participants. They will always be my account of the conversations and are open to other interpretations.

### **Defining, refining and redefining**

The process was not as deliberate as this text would show; the process has been anything but linear with each step raising further issues thus creating opportunities for refining the process and for the reshaping of the research. The commitment to identifying ontological and epistemological assumptions has enabled an acceptance of the fluid nature of the process; to take steps to understand, adjust and attend to conflicts that have arisen and to feel confident that the quality of the project is enhanced by the outcome of these matters because it is theoretically grounded.



## The process

Towards the end-stage of gathering the interview data and beginning the analyses, I set out to create a flowchart of the process as a pictorial representation of what was happening. However, it did not “fit” easily into this format. Ultimately I arrived at a diagram that captured at least some of the dynamics (Figure 6.12). What the diagramming revealed was a koru shape; the spiral of plan, do, check, act of action research

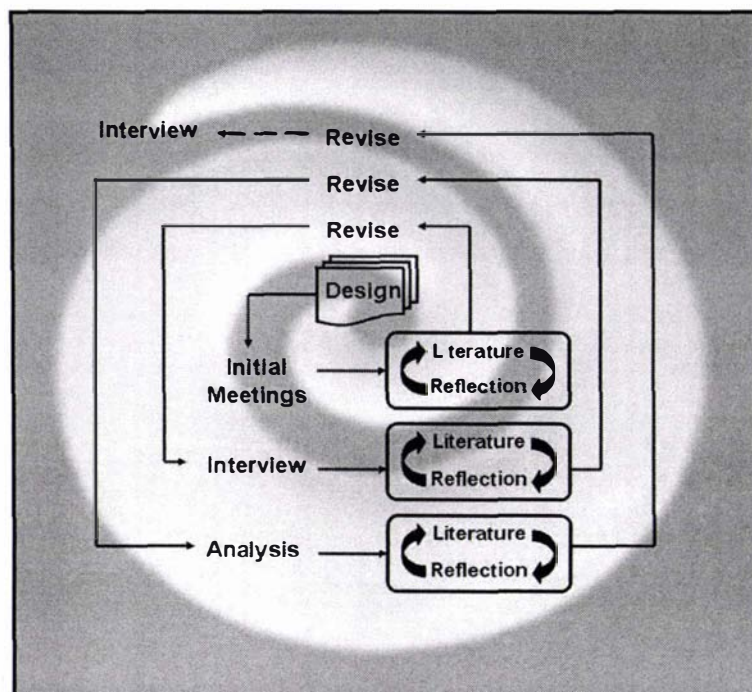


Figure 6.12: Research process

It represents the way in which each stage of the research process including the initial meeting with a participant, the interview and the analysis was supported by reflection and by connection with the literature. Each contact was an opportunity to consider the overall direction of the project and to adjust the process. My readings in qualitative inquiry introduced me to discussions about the use of pilot studies and while I did not decide to carry out a pilot study, the question about whether or not to pilot has been an important contribution to my understanding of qualitative inquiry and also to this project's evolution.

### *The question of a pilot study*

The term pilot study can be used to refer to either a trial run in preparation for the main project or it can also refer to the pre-testing of a research instrument including a questionnaire or an interview guide (van Teijlingen & Hundley, 2001). This suggests that pilot studies can be used in both quantitative and qualitative approaches; the difference in qualitative research being that pilot interviews are not necessarily excluded from the data and may still contribute to the findings (Arthur & Nazroo, 2003). Sampson (2004) considers that pilot studies are under-utilized, under-reported and under-developed in qualitative research perhaps because there is a tendency to associate them more with positivist methodological approaches. There is also a tendency to use pilot studies as an initial qualitative approach to an unexplored topic using it to assist in the design of a later quantitative phase (van Teijlingen & Hundley, 2001). Sampson (2004) believes that their value is much greater than this and that well conducted pilot studies should also include an analysis phase and she suggests that pilot studies could be reported in reflexive research accounts. This is supported by a call to encourage researchers to report issues arising from all parts of a study including the pilot study and the resulting improvements made to the research design and process (van Teijlingen & Hundley, 2001). In her ethnographic work, Sampson (2004) identifies that a pilot study can warn of research problems and questions, highlight gaps in data collection, and allow the researcher to take into account broader issues such as ethics and researcher health and safety. Janesick (1998) recommends the inclusion of a pilot study in qualitative research projects. Because of the demands and time commitments involved in a qualitative study she suggests that preinterviews and observation can help to focus the particular area of study, begin the development of relationship links with participants and reveal new insights. In later writings, Janesick (2000) rejects the term "pilot study" as being too limiting for qualitative inquiry and instead, using an overall metaphor of choreography for qualitative research, labels this background work as "stretching exercises" where the researcher has the opportunity to practice interviewing, observation, writing and reflection (p. 386).

Despite this literature, I decided not to include a pilot study for this project for several reasons. The Honours project, although a complete study in itself with different research questions, gave me access to a range of issues related to alternative methodologies that have been incorporated into the current project including ethical issues, reflexivity and an increased understanding of narrative inquiry. I had already explored a narrative approach in this earlier project and the findings suggested that narrative analysis may be used to explore meaning and change in people with

aphasia. As an interviewer, I had the experience with this project but also, as a clinician, I had a background in clinical interviewing. I was already familiar with aphasia and I had considerable clinical experience working alongside people with aphasia. A researcher with less opportunity for interaction with people with aphasia may well have made a different decision. The interview schedule was developed from several well used tools (Gubrium 1993; McAdams 1993; Atkinson, 1998) and I felt confident that the questions and the format would be effective facilitators for a life story interview.

Most importantly, the participants, although they all had aphasia, were certainly not homogenous and therefore altering the process to achieve a more standard approach would have compromised flexibility and jeopardized inclusion. There needed to be some license to allow for the process to be adapted to each participant's communicative and social needs. Also, the nature of qualitative inquiry involves uncertainty and risk along with an excitement intrinsic to the process (Morse, 1997). Therefore, I did not see that a pilot study would improve the research and the influence of action research principles on this project seemed to underscore the need for such preliminary work. Morse (1997) argues that pilot studies do not help researchers to address the vague nature of initial research questions. She maintains that that is the essence of the qualitative inquiry where there is often very little known about the proposed topic. She also comments that too little data make qualitative analysis difficult and therefore reporting on a pilot study when the analytic work has not been completed is actually reporting on unfinished work.

I have regarded all steps of the process as contributing to the research questions and of importance to the developing outcomes. Ongoing reflection was imperative to the process but this also involved access to the literature as a part of developing the process. Although this indicates that changes were made, these were in response to issues, reflection and engagement with the literature. The underlying theoretical perspectives were augmented and honed by the process and by the literature. Figure 6.13 is a representation of the process in a three dimensional way with layering of the interviews. It acknowledges movement within and between layers.

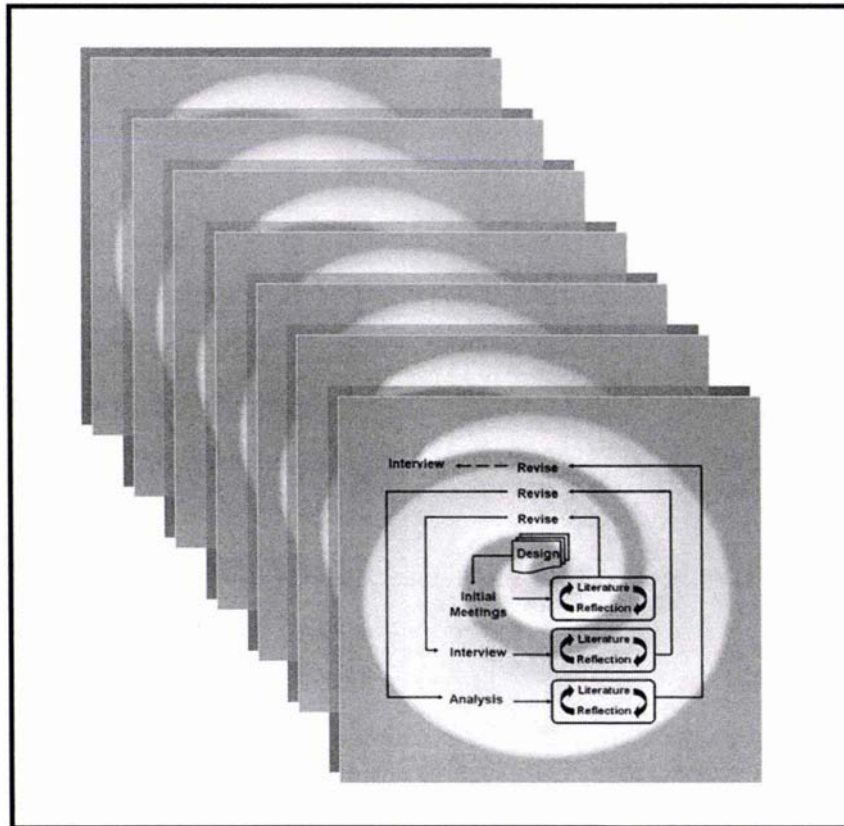


Figure 6.13: Overall research process

### Supporting activities

In capturing the process in this way, key supporting activities were isolated, as shown in Figure 6.14 including regular and ongoing reflection and reviews of the literature.

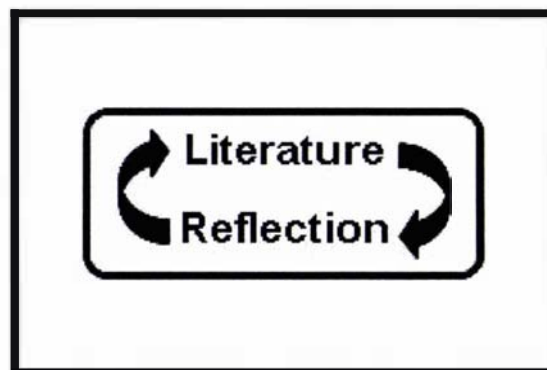


Figure 6.14: Activities supporting research process

## *Reflection*

A key activity supporting the research process was personal reflection and one of the main tools I used for this was a reflective journal. Reflective journalling is a practice used in qualitative inquiry (Janesick, 2000). It is also an approach used in clinical practice and in clinical supervision and has its roots in Schon's (1983) work on reflective practice. Reflective practice acknowledges all sources of knowledge that contribute to how we understand experiences including theoretical, personal and practical sources. I had also been introduced to the concept of keeping a reading journal in my prior studies in health psychology. As part of this project, I kept a research journal to record activities (both completed and planned), reflections on those activities and experiences, self questioning, ideas, observations and my reading interests (both current reflections and recommendations or reminders for future reading). I also included comments and feedback from supervisory contact and meetings, from the participants in the project and from other people with whom I talked in my efforts to make sense of the process. All entries were mainly in a narrative form but I also used poetry, lists and shorthand notes.

Most of the journal entries were in books either A5 or A4 size but I also vacillated between these and notes in a folder on the computer. The medium was usually dependent on what I was doing. It was often much easier and more convenient for me to use a book. It gave me greater flexibility about where and when I could write. It also allowed me to paste in notes that I may have hastily written at other times on whatever was at hand. I then did not need to duplicate by word processing at a later stage. However, if I was already working at the computer, it was sometimes more spontaneous to word process. In retrospect, the word processed entries are clearly more organized, grammatical and spelled correctly<sup>35</sup>. Figure 6.15 is an example of a word processed journal entry.

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<sup>35</sup> These entries are also more legible!

Friday, 8 August 2003

My first visit was to a rest home and, when I called into see the woman, she was fast asleep on the bed. Several attempts to wake her by name and I realised that I shouldn't persevere for the sake of my purposes. What was in her environment that told me about her - there was nothing that would suggest aphasia. Certainly a stroke - her posture in sleep on her bed - almost as though she had been tossed there and remained where she fell, her head slightly askew against the wall beside her bed. And a wheelchair sitting in the middle of the room, neither coming nor going. Perhaps the paper magazine of word searches might have hinted of aphasia but it could also suggest an activity to fill in time. I find rest home environments make me sad. A person's life reduced to one room. I left without waking her but I left thinking about what it might mean to her life story to be involved and what she might think of doing this.

I came calling  
Looking for your participation  
In a project  
About aphasia.

I have no idea of your aphasia  
And in sleep  
I can't hear your talk  
Of dreams and wishes.

I found you lying,  
Asleep on a bed  
In a single room  
In a rest home.

I can't create you  
From your environment.  
There are no signs  
Or evidence of a personal life.  
There are no pictures  
To record your life.

Your body positioned  
As if tossed there  
And you caste,  
Unable to move to  
Comfort stroke affected limbs.

And I leave you as I found you.  
The only words spoken  
By me  
Softly calling your name  
And silence.

I wonder about your involvement  
And how it might feel  
To be recounting your history  
From a place in which  
You may not want to be.

I am reticent  
Do I need to return?  
An obligation to follow through  
But who will gain from this?

Figure 6.15: Example of computer journal entry

Most entries though have been in books by preference. In a book form I was able to incorporate additional written material from other sources that I felt were relevant. These included excerpts from journal articles, journal abstracts, song lyrics, quotations, newspaper articles, letters and e-mails. A page from one of the journals is shown in Figure 6.16 as an illustration.

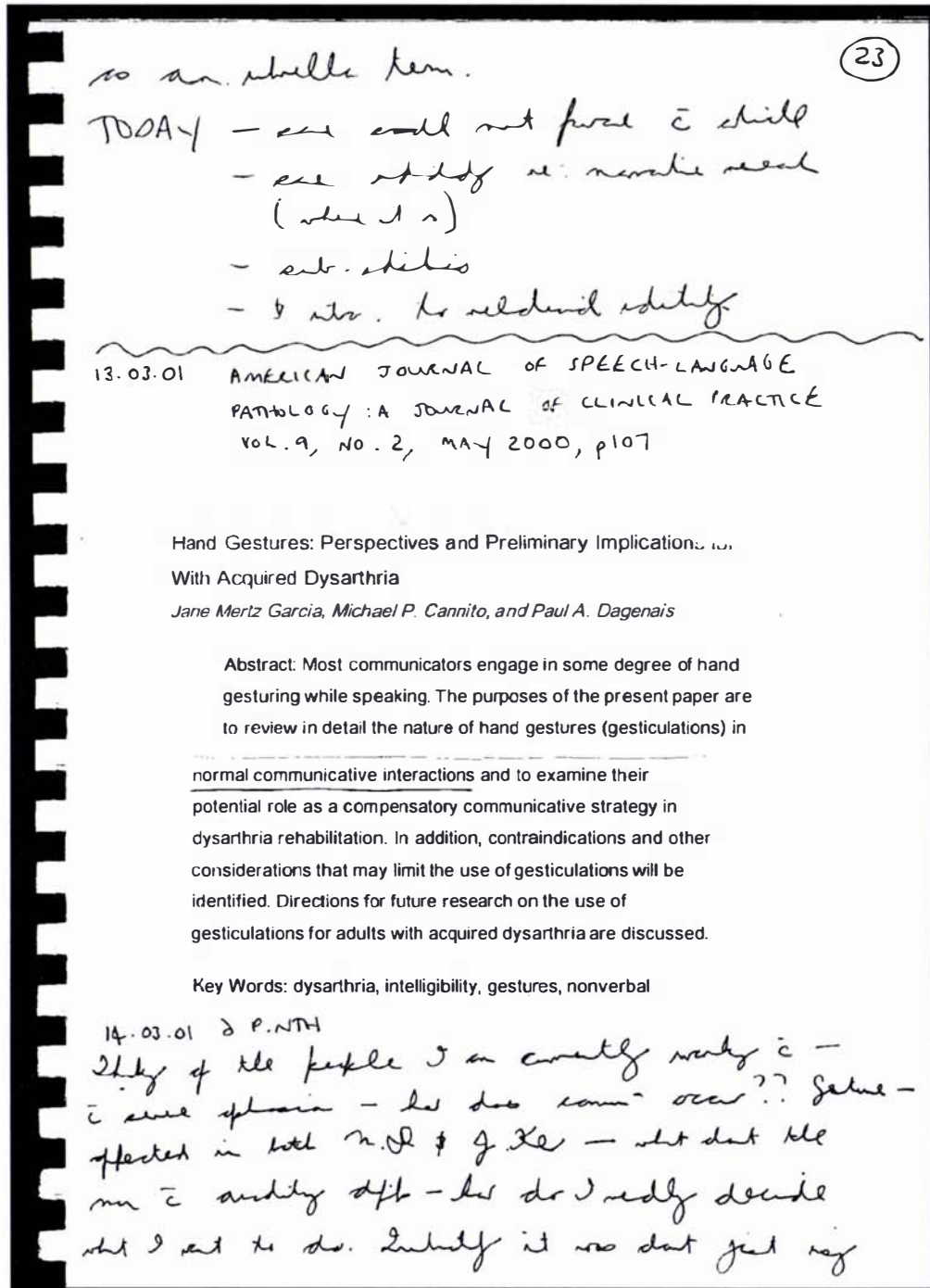


Figure 6.16: Example of journal page

I also kept another more “visual” journal although at times the two overlapped. I used this journal to sketch ideas in picture form and/or diagrams for example, to develop mind maps for the process, for planning and for problem solving. An example of a mind map for articles that could be developed from the project is shown in Figure 6.17. These tools did not replace conversations and discussions about the process. Rather, they provided another way of meaning making and are in harmony with the project’s grounding in narrative inquiry.

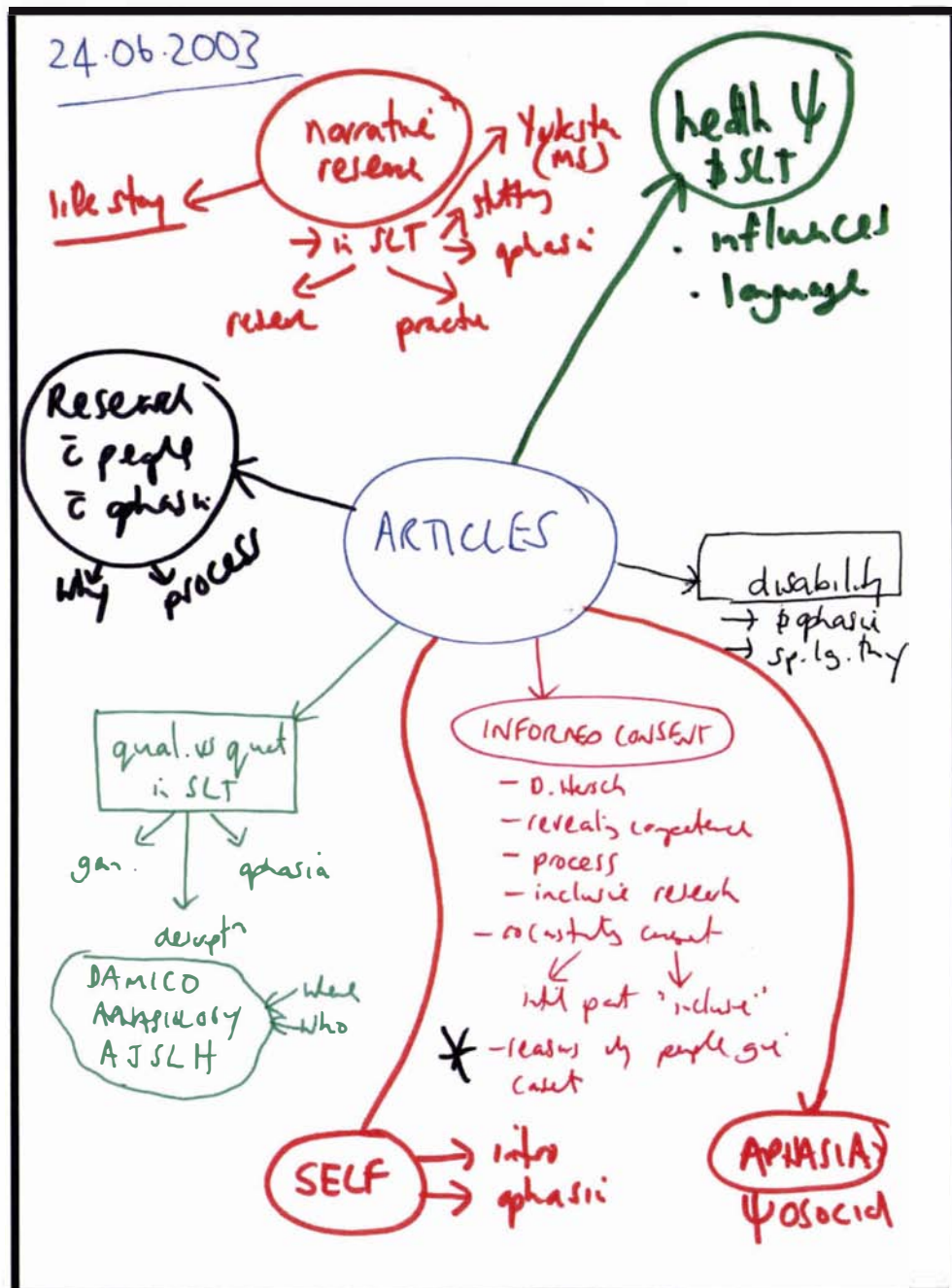


Figure 6.17: Example of visual journal page



### *Enfolding literature*

I also adapted a concept introduced by Eisenhardt (1989) in the context of her case study research and theory building which she calls "enfolding literature" (p. 544). She suggests that the ongoing comparison of emergent concepts, theory and hypotheses with the existing literature is a critical feature and should include both similar and conflicting literature. Through this, confidence in the findings can be increased but also any conflicting literature, Eisenhardt maintains, is an opportunity for more creative thinking. Qualitative research and, in particular, narrative inquiry are developing fields. They overlap and are entwined with other areas of social science research. The literature is extensive and continues to grow in ways that motivate, challenge and ultimately enrich this project. Hevern (2004) in his search of databases found an increased interest in narrative by psychology and other social science researchers which began in the 1980s and gathered strength in the last part of the 20th century. He cites a comparative growth of the percentage of all citations concerned with narrative in the PsycINFO™ database from 1967 until 2001 of 2569%. In my apprenticeship in qualitative inquiry, reviewing and reflecting on the extant literature has played an important role in both supporting the previous research as well as the development of new ideas, perspectives and interpretations. It has also provided opportunities to revisit and reconsider earlier concepts that I may not have fully cognized in my initial reading (Paré, 2002). The project has been strengthened by these supporting activities as I have been able to modify and develop the overall process through reflection and the enfolding literature.

### **Praxis and research: more blurred boundaries**

Throughout the stages of designing of the project, the development of the information and consent forms, my initial meetings with people interested in the project and the subsequent interviews, it was necessary to be very clear that I was not in the role of a speech-language therapist but rather that of a student researcher. The foremost reason for this division between practitioner and researcher was to ensure that participants would not expect a therapeutic benefit from taking part in the research. That is, they would see not the project as a form of therapy and therefore a commitment to improve their own or their partner's communication skills. That remains ethically important. However, as I talked with people in our interviews, as I transcribed the videotapes and as I started to write, I was increasingly aware that the boundaries between therapist and researcher were less than discrete. My speech-language therapy background was an advantage in exploring

the language of aphasia and in talking with people about stroke and aphasia. But I could not strip away part of my self, my way of being, embedded over many years of developing working relationships and friendships with people with aphasia. The motivation for the research was from the world of practice and I was always committed to an outcome that would be relevant to those with whom I work, both colleagues and people with aphasia. Trying to present a divided self was not an easy or a practical decision. I became interested in how I managed these blurred boundaries and how much of the therapist was evident in the stories and how that might have influenced, positively and negatively, the interviews for the people with aphasia.

### Summary

This chapter has completed the methodology of the project. The preparation for the project has been described and the active research process presented. It has not been a step by step progression. Instead the pattern was one of flexibility and change. The next chapter is focused on the participants' interviews. While the interviews explored self and identity in aphasia through life stories, they also raised issues that are important in considering research with people with aphasia and issues in considering a qualitative strategy. The analyses of their interviews and the issues that the research process in action raised are presented as interpretive narratives.

## SECTION D

### EXPLORING LIFE STORIES

Chapter 7: The stories

## Chapter 7

### Exploring life stories

#### Overview

#### Margaret

##### The story

*Meeting*

*Preparing*

*Communicating and negotiating*

*Picturing a life*

*Sharing a history*

*Communicating self*

*Summarising*

##### The process

*Exploring the edges*

#### Owen

##### The story

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*Living a life*

*The stroke*

*Dealing with it*

*Making light of it*

*Constructing stories*

*Talking in context*

##### The process

*Relationships: research and practice*

**John**

The story

*And what of aphasia?*

*Sketching a life story*

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*Outside the formality*

*Talk in context*

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**Bill**

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*Before the interview*

*Whose story?*

*Communicating about the self*

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The process

*Thinking individual, becoming relational*

**Mavis**

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*Bridges to recovery*

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**Mark**

The story

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*Collaborating on a life story*

*Transcending severe aphasia*

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*Listening (and watching) for meaning*

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*Inclusive research*

**Kilroy**

The story

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*Laying out a life story*

*A life uncomplicated*

*Telling of self*

*What of the other?*

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*Creating a summary*

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**Mary**

The story

*About the stroke*

*About the interview: sense-making through collaborating*

*About a life*

*Theorizing aphasia*

*Theorizing self*

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## Overview

*Life stories express our sense of self – who we are, how we are related to others, and how we became that person. They are also one very important means by which we communicate our sense of self to others and negotiate it with others.*

Charlotte Linde, 1993, p. 219.

This chapter presents eight accounts of people's experiences of living with aphasia; in particular, the impact of aphasia on the construction of self and identity. While these stories arise from life story interviews with these eight participants, they are now removed from the original tellings. I have constructed each narrative from the initial interview, from the videotaped record of the interview, from the process of analysis and from my ongoing contact with each participant. I have gathered the pieces together in a structured and storied way for the retelling. The narrative, however, will remain my interpretation of each interview, the responses to the questions that informed the life story and also to my changing understanding as I moved from interview to interview. I am aware that these accounts are also open to revision and re-interpretation (Navarro & Zeni, 2004)

The stories are a way of honouring difference. Although the participants share an experience of aphasia, for each person it brings with it different language impairment in terms of presentation and severity and different experiences in terms of personal history. The narratives do not necessarily repeat or enlarge on the shared similarities in living with aphasia although I think they are there in the reading of the stories as a collective narrative; rather I have tried to construct a narrative that speaks of the person within their specific personal, social, cultural and historical context. It is my hope that my voice does not reinforce a form of ventriloquism or obscure participants' voices.

Interaction with each participant throughout the research also highlighted issues that I considered to be problematic or a discovery that needed further exploration. These included questions about informed consent, the nature and ethics of qualitative research, the difficulty in separating the researcher from the practitioner and incorporating alternative forms of writing. Following the interpretation of each participant's story, I have attended to these issues arising from within the research process and research relationships.

Margaret

*I can't remember.*

Margaret, 444<sup>36</sup>.

## The Story

### *Meeting*

Margaret was fifty seven when we met and she had had a stroke seven years earlier. The Stroke Foundation Field Officer gave me Margaret's contact details and expressed concern that there were no agencies in the community to provide her with further social communication opportunities. Margaret was living at home with her husband and her three adult children also lived locally. She provided support for her daughter when she was working by looking after her grandson. I called to see Margaret at home to talk about the project.

Margaret spoke in short phrases ("I don't know", "And those ones", "I can't", "I can't remember", "This one here") and she had difficulty retrieving content words which interfered with verbal expression. I heard the aphasia as non-fluent, with significant word recall difficulties, associated with apraxia of speech and she also had some difficulties with reading and writing. At times, she was frustrated by an inability to express what she wanted and perhaps also my inability to always understand. She reluctantly resorted to pen and paper and, although her written language was affected by aphasia, she was often able to supply a key noun, or at least part of it, which was sometimes enough to facilitate my understanding and this greatly assisted communication between us. I encouraged her to write, trying not to be directive but when she had difficulty telling me something, I saw the benefits to our conversation in her writing to communicate.

Margaret had made a good physical recovery following the stroke as supported by the crafts that she showed me: small flowers formed from ribbon, home spun wool and knitting, and soft toys. When we talked directly about aphasia, she became tearful. In wanting to give her the opportunity

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<sup>36</sup> This refers to the number of the line in the transcript.



to decline participation in the project, I asked if she wanted more time just to think about it but she pointed to the information sheets and said "I would like to". I was confident Margaret was able to consent with the support of the documentation but I was also aware of how difficult it was to inform someone fully about a project that was interpretive and evolving. We also talked about using items that she had which would provide other ways of telling about herself including photographs and the resources within her home.

### *Preparing*

This was the first interview and while I knew of Margaret, I did not know what her communication skills were until we met. I was thinking while we talked about how we would approach the interview given her communication. After our meeting I developed the aphasia-friendly prompt book to be used to support the interview. All the initial questions (see Appendix G) were presented in a picture format as well as in writing (see Appendix H). I was prepared for the interview and had practiced several times with the technology of the videotaping. I had organized the resources including pencil and paper along with the prompt folder. Margaret, too, was equally prepared. She had two photograph albums on the table when I arrived and, although I had probably mentioned that she might like to use resources such as photographs, I had not expected her to be so organized. Margaret's photographs formed the basis of the interview along with some speech, gesture and writing.

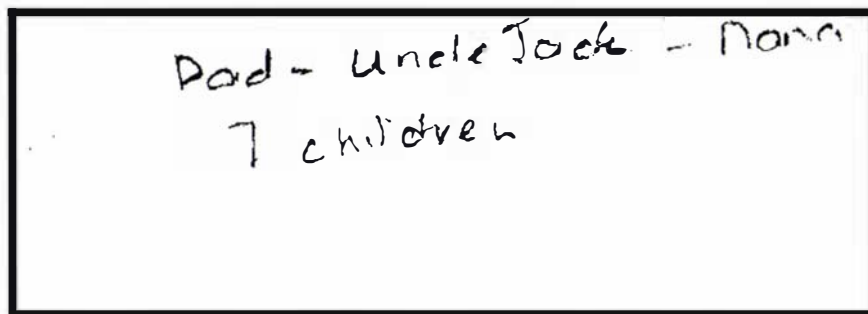
### *Communicating and negotiating*

Margaret's verbal expression was mainly phrases that acted to start a sentence ("I've got", "I don't know", "I have", "I know") but she had difficulty with retrieving the key words such as a name or noun or a verb. While she might start by saying "I can't remember", she would sometimes then write a word that would then open up our conversation. Drawing on experience with other people with aphasia, I mostly interpreted "*I can't remember*" as a way of encompassing not memory problems but difficulty with accessing language. Margaret wrote a list of seventy words during our interview mostly in relation to her photographs. They were mainly proper nouns including people's names ("Jack") and places names but also included relationships ("cousin<sup>37</sup>", "Nephew") as well as

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<sup>37</sup> The words are written as Margaret wrote them as upper or lower case.

ages ("10 mth", "5 yr") and some descriptive words ("married"). Margaret's own transcript of the seventy single words is a static record of our conversation. However Margaret moved backwards and forwards throughout the interview making connections between new words and words she had written previously. In introducing relatives in a family photograph, she made the connections for me by going back to where she had written "Dad" earlier which she followed by writing "7 children" indicating the size of her father's family. She went back and drew a hyphen after "Dad" and then wrote "Uncle Jack". She drew another hyphen and completed it with "Nana" (Figure 7.1). Margaret used the text she had created well with moving back to words she had written earlier and creating links almost like a family tree of relatives, friends and locations.



Dad - Uncle Jack - Nana  
7 children

Figure 7.1: A scanned example of Margaret's writing

Margaret wanted to tell me about the events in her life. She wanted me to know about her family and her history along with the important events in her life. If I look to the text she created in her writing during our time together, they tell very little of the nature of our conversation. They are a list of words. If I return to the video, however, it captures her hesitation when I am wrong, my hesitation when I do not understand, her presentation when we talk of the stroke and aphasia, and her humour when I make yet another mistake:

745. **Margaret:** *I know (and she laughs as she points to a man in a photograph). Um, this one here, is, ah (and writes "Priest" beside "John" which she had written earlier*

746. **Maxine:** *A priest?*

747. **Margaret:** *No, no (laughing)*

748. **Maxine:** *That's a surname (and we both laugh).*

749. **Margaret:** *No!*

I had made an assumption that he had become a priest. Her emphatic response of "No" told me clearly he did not have the qualifications to be a priest and that it was his surname not his vocation. A similar negotiation occurred around her nephew's name when I misunderstood:

1233. **Margaret:** *(She looks through photographs) Those ones – um (she writes "Clive" beside "Nephew", joining them with a hyphen).*
1234. **Maxine:** *They're in Clive, now?*
1235. **Margaret:** *Yes, no. Yes, but /?/ don't, is (and she points back to "Clive").*
1236. **Maxine:** *Is your sister in Clive?*
1237. **Margaret:** *Yes but her (and laughs and goes back to what she has written).*
1238. **Maxine:** *Her new – no.*
1239. **Margaret:** *New (and points to her nephew) is called, this one (and points back to "Clive").*
1240. **Maxine:** *Oh, called Clive.*
1241. **Margaret:** *Yeh. God (and we both laugh)!*

While Margaret wrote some words or parts of words accompanying other communication skills, my part was to make it verbal so I could check with Margaret if I had understood. While aphasia created obstacles to easy communication it did not prevent a story being constructed with available skills and resources and it did not prevent our relationship developing. It involved a process of negotiation but sometimes it took time for the information to slowly build to create understanding:

336. **Margaret:** *And, that one (and she starts to write). Oh. Um (looking away and laughing)*
337. **Maxine:** *A brother?*
338. **Margaret:** *Yes, it is but it's a – (long pause). Mmm – I can't.*
339. **Maxine:** *Anything that would give me a clue?*
340. **Margaret:** *Um, it's/core/, um (and she points out the window, puts hand to her mouth and then starts to write again "Auckland").*
341. **Maxine:** *He's in Auckland now?*
342. **Margaret:** *Yeh. But those were one, one (points back to photograph and returns to where she had written he brother's name, draws a hyphen then writes "Apo". She crosses /p/ out and replaces it with /d/ leaving "Ado")*
343. **Maxine:** *When he was born, did he go to Auckland?*
344. **Margaret:** *No. He was there and, brought, down, with this, um (there is a long pause and she looks away).*

345. **Maxine:** *Was he unwell?*
346. **Margaret:** *No, no.*
347. **Maxine:** *No.*
348. **Margaret:** *No. It was just -*
349. **Maxine:** *Is he adopted?*
350. **Margaret:** *Yes.*
351. **Maxine:** *Okay.*
352. **Margaret:** *[Yes.*

Our interview involved developing a shared understanding as we moved through the photographs and the events of her life that resources made available to us. There were probably many things that we did not and could not share but Margaret was active in responding to the life story questions and in leading me to some understanding. Margaret's early history was in nursing and we had talked about her training in the early stages of the interview. When she later she wrote "Night - Mat" as we talked about her working life before her children, I was already contextually "primed" to guess at her working night duty in a maternity ward. Margaret used both "embodied resources"<sup>38</sup> and environmental resources; facial expression, gesture, rate of speech, laughter, changes in pitch, repetition of words, pointing, eye contact or looking away while she was recalling a word, photographs, objects within her home and environment including using the pencil to signify when she had finished talking by placing it down and looking at me. This list speaks of a range of skills and of Margaret's resourcefulness. However, it fails to replicate the complexity of communication when these resources are used in concert. This influenced how I chose to transcribe. I did not use a particular coding for the variety and combinations of resources. I instead chose to represent it in a narrative form. At one point Margaret showed me a photograph of a wedding but to indicate they the couple were no longer together, she placed her hand over the couple in the photograph, saying "No, and they" as she shook her head negatively.

The speed of communication also carried with it messages about importance and urgency given that Margaret often took time to recall and then express an idea. When I asked Margaret about what her philosophy was, she quickly pointed to her wedding ring and said "*Marriage*" (1623). The timing of this action and its simplicity was much more significant in the context of our earlier conversation about family and friends who were no longer married. She was able to summarise a

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<sup>38</sup> Goodwin, Goodwin & Olsher, 2002, p. 3.

value of importance to her without access to the complexities available through non-aphasic linguistic resources. Reliance on Margaret's spoken or written text alone would have diminished Margaret's ability to tell a story. Most important was not simply noting Margaret's use of these skills as an isolated action but rather the action between teller and listener and a willingness of both to work towards understanding one another. These all enable us to "hear" a lot more.

### *Picturing a life*

Margaret's interview was firstly about herself but it was also about her family, relatives and friends. She made connections between these as she deftly used photographs to take me through the passages in her life. We moved from photographs to writing and back to photographs. Sometimes Margaret would turn back the page of writing to return to an earlier word or go back to a previous photograph to make another link to aid my understanding. The concept of chapters was not useful in this interview but Margaret's photograph albums and her use of them created a chronology that reproduced the chapter structure. Photograph albums as cultural tools are commonly organised as a chronicle of life events. They are mostly about people and occasions although some are about places or memorable scenes and they preserve continuity.

I observed moments where Margaret paused looking at a particular photograph. I interpreted these moments as recollection or reflection that I could not share. While aphasia made it difficult to do this sharing, it was also an opportunity for Margaret to choose not to share. The photographs, while they evoked memories for me about events common to our life in New Zealand, were much more pertinent to Margaret as they were about her and her involvement with people and events. What appeared as static frames of the past become active in Margaret's collecting and connecting of them into a life story. I thought about just how much of her life was omitted though as our interview was controlled by the resources we had at hand, by Margaret's use of the resources and our joint understandings. Parts of her life were not available although she indicated that she had other photographs elsewhere. However, this would have occurred in any interview. A different time, a different need or a different listener would result in a different account. The aim, however, was not to capture a life as lived rather the meaning of those events for participants and, in her selection of photographs, Margaret had created her own meaning. In the absence of a photographic reference, Margaret used written words and once towards the end of the interview Margaret drew a sketch. I had asked her about dreams or plans for the future:

1468. Margaret: *Um (as she looks up and ahead then raises her left hand up to scratch her head, returning to write. She draws a square with another square in the top right hand corner, like a house). Um. And this, this off.*
1469. Maxine: *A section?*
1470. Margaret: *Yeh (and goes back to write "Farm")*
1471. Maxine: *A farm?*
1472. Margaret: *Yes (and puts the pen down and looks up at me).*

I did not fully understand and we engaged in a lengthy process of checking whether or not her and her husband actually already owned the farm. I continued down this pathway asking numerous questions about where it was and who was looking after it. Finally, Margaret returned to the picture, and laughing, and wrote beneath it "Lotto" (Figure 7.2).

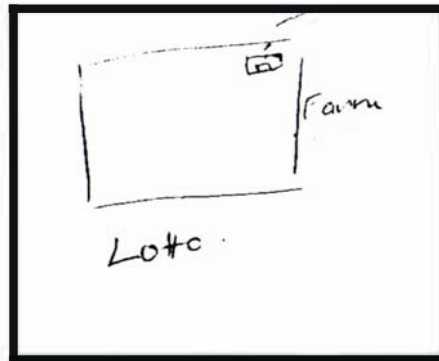


Figure 7.2: A scanned example of Margaret's drawing

### *Sharing a history*

I knew none of the people in the photographs Margaret showed me and I was not familiar with the places but the albums, their layout, the age and quality of the photographs, and even the positioning of people in some of the more formal photographs reminded me of my own background. I recall photography by Christopher Beade that graced many living room walls in the fifties and sixties. Margaret was also about the same age as my older sister and both had trained to be nurses. Some of the events in her history reminded me of my own sister's history: the teased hair, the obvious eyeliner and the ball gowns of the sixties. Living in New Zealand also has had its own culture of family days at the local show, ballet lessons for girls, family holidays, christenings and

the celebration of twenty-first birthdays, engagements and weddings. These created a background for our joint understandings. On the surface, negotiating understanding was about negotiating language but it was also about negotiating our relationships as she tolerated my mistakes.

### *Communicating self*

How did Margaret communicate her sense of self? Her communication resources were embodied resources. She used herself to communicate about herself and her relationships within her social world. Within the photographs she was a social person. She was a child with her family and it was important to her to name her relatives and to place them in a period of time in her life and a location. She was a young woman socializing and attending functions with friends and she was a bride and a mother. She was a sister on holiday with her sister and their families. When I asked her how she would describe herself now, she pointed to her spinning wheel and her handcrafts and later wrote "*Craft*".

While analysing Margaret's transcript using the VCRM of highlighting in colour different aspects of the research questions, I found that in order to gain a sense of what was happening and Margaret's account, I also had to highlight my questions and my responses. Unlike research transcripts where there is often a large chunk of a participant's text in response to an interviewer's questions, Margaret's communication meant a high level of interchange between us so her experiences of self were interwoven with my questions or my negotiating meaning:

1505. **Maxine:** *Okay (as I return to prompt book which shows a picture of some school children<sup>39</sup> and reads "Describe yourself when you were younger"), how would you describe yourself when you were younger? What kind of a person do you think you were?*

1506. **Margaret:** *(She looks at the prompt question and picture and pauses for a long time). Um, um. (She pauses again). I don't know (and there is another long pause).*

1507. **Maxine:** *Any words, or ideas you could use to describe what you think you were like as a younger person?*

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<sup>39</sup> Following this interview I changed the picture to make it less suggestible and not associated with such a specific location but I acknowledge that it would have been impossible to create a completely neutral set of pictures.

1508. **Margaret:** *(There is a long pause as she looks down, hand to her mouth, picks up pen. She then puts it down, points to the picture which shows the school children) Mmm. This, oh, no. This one (and she shakes her head negatively), I didn't, those (shaking her head again)*
1509. **Maxine:** *At school? You didn't enjoy school?*
1510. **Margaret:** *(She looks directly at me) Yep.*
1511. **Maxine:** *Did you hate school?*
1512. **Margaret:** *Yeh (and she laughs).*

About a quarter of the words Margaret wrote were related to herself whether it was a place she had worked or lived, the years she attended ballet or the age she was when she met her husband. These also had a relational aspect to them. The remaining words were related to people but they all shared a common link; they were in relationship to Margaret. They were included because they shared part of her life. The writing was mainly restricted to nouns but working together with other resources and with the listener, Margaret was able to create a network of people that made up her life.

While using "I" a lot in her expressive language, a transcript of their occurrence alone did not reveal a lot about Margaret's sense of self although they highlighted the effect of her language impairment ("I don't know", "I can't remember", "I can't", "I couldn't", "I didn't know"). She talked about herself in relation to others but she also referred to herself by pointing to herself:

154. **Margaret:** *That was my/mah/ (as she points to herself and nods affirmatively). That one, was from me (pointing to herself again).*
155. **Maxine:** *That was your dog?*
156. **Margaret:** *Yep.*

The important events in her life story involved other people: her friendships were an important childhood memory, being present at the birth of her grandson was an important adult memory, and her wedding was a high point.



*Communicating aphasia*

1296. **Maxine:** *And any, Margaret, (and I open the prompt book) and these are just sort of questions, any, anything you would have called a low point?*
1297. **Margaret:** *(She draws breath as if through her teeth and she nods affirmatively). Yes (she looks upwards and starts to cry).*
1298. **Maxine:** *Okay.*
1299. **Margaret:** *(She picks up the pen and starts to write, looks away with tears welling in her eyes) Um (she is very emotional as she return to writing and after a time writes "7" then points to herself).*
1300. **Maxine:** *You've written "Seven". Seven,*
1301. **Margaret:** *[Yes (and she holds up her left hand displaying five fingers and her thumb and index finger on the right hand with the rest of her fingers folded into her palm).*
1302. **Maxine:** *years?*
1303. **Margaret:** *This (and points to her throat then points back to what she has written and points to her throat again while she nods affirmatively).*
1304. **Maxine:** *Are you talking about the stroke?*
1305. **Margaret:** *Yes.*
1306. **Maxine:** *Okay. That would be the low point (and Margaret looks back towards the interview book). Okay (and I turn to the next page in the prompt book). Anything that you would have called, like a turning point, you know, where you actually made a change or, um?*
1307. **Margaret:** *(She slowly nods her head negatively) No (and points to "7" again and she looks tearful).*
1308. **Maxine:** *Probably with the stroke again,*
1309. **Margaret:** *Mmm.*
1310. **Maxine:** *a big turning point.*
1311. **Margaret:** *Yep.*
1312. **Maxine:** *Okay.*
1313. **Margaret:** *Mmm (still tearful).*

Margaret described her aphasia with and within her body. She pointed to a place in her body, her throat, where for her the aphasia resided. Margaret did not have the language to describe the impact of the stroke and aphasia. It was clear, however, from her presentation and the indication of seven years ago that it has been a distressing time. Seven years also pointed to its ongoing presence in her life. The impact of a stroke and a severe expressive aphasia for Margaret at fifty probably did not require extensive probing. It was apparent from her account that she had a wide social circle and the effect of a communication disability was likely to have effects on this social world and her sense of self.

Some of the questions were difficult for Margaret and I to negotiate particularly when they required a more descriptive response than that available through naming. I thought about how to be less leading perhaps by creating rating scales or giving a choice of single adjectives both spoken and written (e.g. when asking about describing oneself by offering alternatives such as "Shy?", "Sporty?", "Friendly") but these would always represent some selection bias. Therefore some questions were directive because there seemed no other way of developing them and they were reduced to binary choices. I was also less sure about the interpretive quality when I had positioned a choice and sometimes I discontinued my line of questioning out of respect and where I could not find another way to support successful communication:

1662. **Maxine:** *Okay (and I close the book). If you think about, like, your aphasia. You've had some speech therapy,*

1663. **Margaret:** *Mmm.*

1664. **Maxine:** *and things like that. How are you? Are you the same person (and she begins to nod her head negatively) as you were before your stroke?*

1665. **Margaret:** *(She laughs and seems emotional).*

1666. **Maxine:** *Okay. What's, what's kind of different do you think? What are the things that you would think would be different?*

1667. **Margaret:** *Um. I (and she looks to her left). Don't know. No (and she shakes her head negatively. Long pause). I don't know (and laughs).*

In the time since the stroke and in living with the aphasia, Margaret had a busy family life with commitments and remained involved in her craft work. Following our interview, and her husband asking about any other opportunities in the community, I invited Margaret to join in a small aphasia project team facilitated in a community setting and aimed at social communication rather than

formal therapy. She willingly attended and while it was difficult to know how much benefit she felt she gained from it, she was a positive contributor to the group as a whole. While that was in abeyance, she continued at the centre with the goal of gaining further computer skills.

### *Summarising*

The act of transcription  
And I watch again  
As our conversation develops,  
Through gesture and writing,  
Through expression and voice.

And I see myself  
Vacillate between listener  
And therapist.

The first interview  
And some fears.  
My hesitation  
And your emotion  
As we talked  
About aphasia  
And stroke.

But you remained  
Keen  
To take part.

So I watch the moving pictures  
Of our interview.  
Some smooth transitions  
As you lead me through photographs;  
Your telling in speech and writing,  
Bound together with  
Subtle changes in position,  
Gesture  
And voice.

Then there are jagged moments  
Of misunderstanding  
When my desire to understand  
Is obscured by my many  
And too frequent words.  
My mind racing  
To gather up all the clues

And to make meaning  
Of any movement,  
Or change of tone  
And  
To check back with you.

Your careful agreement  
Followed swiftly by  
Disagreement  
And I know once more  
I have misconstrued  
A word  
Or the context:  
A name not a location,  
A name not a vocation,  
A "yes" not a "no".

But we continue to work together  
Trying to create some accord,  
Some accuracy  
With faulty symbols  
Between us  
Whether from me  
In my fluency  
Or from you  
In aphasia.

And yet sometimes  
You save face for both of us.  
You let me believe  
For a short moment  
That I am right.

Backwards and forwards  
Negotiating your story  
Between us.

November, 2003

## The Process

*"Risking the scorn of modern-day deconstructionists, let me suggest that the craft of writing fiction or verse is quite different from the craft of social science. In any event, if I want to read a good poem, why on earth should I turn to a social science journal?"*

David Silverman, 1997, p. 241.

As part of the analysis of Margaret's interview, I created the preceding research poem as an alternative way of representing part of the data; a reflection on the interview. While I did not do this for every interview, I found that when there was something about the interview relationship or a moment in the interview that I wanted to describe, it was somehow more helpful to me to explore that through poetry and to augment the narrative. While it is challenging to identify what makes a good narrative, it is probably more difficult to identify what makes good verse and there will be a range of responses from a range of readers. There is always the risk, as there is with other forms of writing, of "narcissistic navel-gazing" (Chamberlayne, Bornat, & Wengraf, 2000, p. 17). So why use poetry?

### *Exploring the edges*

Eisner (1997) uses the expression of "exploring the edges" to describe the use of alternative forms of data representation as other possibilities to display what has been learned (p. 9). I have used a poetic form as an alternative to other textual genre to enhance voice and understanding. Poetic expression encourages different word choices based on semantics but also on the sound a word creates in its form and positioning. Different rhythms are created through the words but also by the way the lines are constructed or the text arranged. This textual form (although it is often intended to be a spoken form) attempts to account for an experience in its wholeness (Willis, 2002). Poems are not used as objective and generalizable data; instead they are considered as in-depth data to explore complex relationships (Langer & Furman, 2004). Cahnmann (2003) suggests that using a poetic approach involves studying "our own written logic, technique, and aesthetic" (p. 32).

There are, of course, problems with proposing alternative representations. They may create ambiguity through the potential of multiple interpretations and they may be used and perceived as “substituting novelty and cleverness for substance” (Eisner, 1997, p. 9). However, the research poems within this project have a place and extend on the interaction with literary forms in representing lives. They are still a representation just as the narratives are and are open to interpretation. Willis (2002) talks about the writer disappearing into the poem so the poetic voice, and not the writer’s, is heard. My hope is that it speaks of a relational act between Margaret and me and that it also becomes a relational act between writer and reader permitting a better understanding of the context within which the narrative was developed. Within this context of people with language impairment I consider the ability to use a poetic form to change language sound and appearance to suit my needs. I am reminded of Chris Ireland’s poem in the opening chapter. In living with aphasia, she is able to use her language to express notions in a way that only aphasia makes possible:

*...we have poetry, that linguistic achievement whose meanings are paradoxically non-linguistic. Poetry was invented to say what words cannot say. Poetry transcends the limits of language and evokes what cannot be articulated.*

Elliot Eisner, 1997, p.8.

## Owen

*But each morning I wake up on the mornings, and say, ah, another bonus again day to go.*

Owen, 470.

## The Story

*In the beginning*

Owen's interview was the second interview of the project and we had made contact through the local Stroke Foundation Field Officer. He was sixty eight years old and he had had a severe stroke eleven years earlier. His aphasia would probably be described as "mild". There was some loss of fluency and hesitation as he took time to formulate what he wanted to say or took time to recall a word. There was also, at times, a slight imprecise or slurred quality to his speech most probably related to a mild motor speech impairment resulting in a subtle change to the organization and sequencing of the motor movements for speech. He had regained his ability to walk but "*I never got any use, back in the right hand*" (758). Owen and Julie, his wife, met with me before the interview to talk about the project. Owen's attitude was one of "*Go for it*" if it could help others. Julie did not feel that there had been any change in Owen's personality and that coping with the stroke in their lives meant that "*You adapt*". It was very easy to establish rapport with Owen and he was happy to be involved in a videotaped interview. He was interested and interesting and the subsequent interview was relaxed.

*Living a life*

*It mean I, it's been, it means that I have had a, a fairly pleasant sort of a life*

Owen, 1042.

I began our interview with an open-ended request for Owen to tell me the story of his life and he took the lead. His initial quip was: "*Well, I was born!*" (47). From there he talked about his early days as a very sick baby, the youngest of eight which set the scene for his story:

53. **Owen:** *Ah, I was sick (and he leans forward and looks directly at me). Very (shaking his head negatively) sick.*
54. **Maxine:** */A/, as a baby?*
55. **Owen:** *[Yep, yep. As a baby. Mmm. My mother had - more or less been told, well (and he pauses), he's going to die.*
56. **Maxine:** *Okay.*
57. **Owen:** *And - got me through it. Mmm. I, I came from, head on from there. Yeh.*

Through numerous stories, Owen talked about his own family, school, sport, work, his marriage to Julie and their family. However, there were several significant changes during his working life. A serious injury to his right hand when he had just started working was one of the main turning points in his life. It saw him move from field work into a clerical career. After some stability, there were then changes brought about by restructuring prevalent in the eighties within his work environments. He survived these phases of restructuring but it was at a particular stressful period of transition when he was completing documentation for one organization as well as starting with the new branding that he had his stroke. One of the approaches to the interview is to divide the life story into chapters, just as in a book. Owen was clear about where his chapters began and ended as he worked through his life story: the first chapter was before going to school, the second chapter his school years, the third was the accident to his hand and associated adaptation, and then the fourth chapter was his working years. He proposed that chapter five would be *"the result of the stroke and the, the - trouble I have had"* (392). For Owen, there were no other chapters, instead: *"Each /chah/ - each chapter, is, today. I think of today"* (551).

### ***The stroke***

With a long history of debilitating migraine, the stroke was preceded by headache: *"It /whoh/, it was - was pretty, horrific, in fact. Um, it had got to, uh, uh, migraine"* (422). The resulting stroke was severe and Owen was unconscious for nine days. He knew that he was not only most unwell, but that he actually might not *"come through"* (414). Being visited in hospital sometimes two or three times a day by his general practitioner and being moved into a separate room communicated and reinforced to him the seriousness of his situation:

395. **Owen:** *I had pneumonia (he pauses and laughs softly). I couldn't speak (and he turns his left hand over). I couldn't eat (and he repeats the action with his left hand). I couldn't (laughing) do anything (and again, he repeats the action with his left hand as to signalling that it was just one thing after the other). I wasn't in /eh/, any – I /whoh/, I had a separate room up at the hospital, you know what they (laughing),*
396. **Maxine:** *[Yeh.*
397. **Owen:** *Yeh (he laughs).*
398. **Maxine:** *[Usually a good sign*
399. **Owen:** *[It is (laughing)*
400. **Maxine:** *that things are pretty grim.*
401. **Owen:** *Uh, my daughter, who's a nurse by the way,*
402. **Maxine:** *[Right.*
404. **Owen:** *just mentioned the other day about it, (?), the fact that they put me in a separate room. "/Dih/, did they think I wasn't going to /geh/ (laughs), come out of it?" "Yeh, that's right" (laughs).*

I was curious about the affect that the communication disability had on Owen's life and his sense of who he was, particularly in the first months after the stroke given the severity:

706. **Maxine:** *So how did those three or four months feel? When you're, you're right in there, right in there.*
707. **Owen:** *Well, hih, I don't know whether the fact that I had, had in mind, what I was going to have a go at (and he pauses). You know, to get - and speech therapy back (?), got (and he waves with his left hand away from him over his right shoulder) ranked (?) in the –*
708. **Maxine:** *Speech, speech therapy got?*
709. **Owen:** *Got tucked away in (and he waves over his shoulder again as if indicating at the back of his mind), ah, here.*
710. **Maxine:** *Okay.*
711. **Owen:** */Thih/, /thih/, other things were very, very important, and one was to walk.*
712. **Maxine:** *Okay.*



713. Owen: *Yeh (and he laughs).*
714. Maxine: *So, speech therapy wasn't the highest,*
715. Owen: *[Yeh.*
716. Maxine: *You had other things that,*
717. Owen: *Yeh.*
718. Maxine: *Okay.*
719. Owen: *I, I had to walk.*

Although his commitment to speech-language therapy was not perhaps as great as the commitment to being able to walk again, he liked the speech-language therapist with whom he worked while still harbouring some reservations about the value of therapy to him:

655. Owen: *Yeh, the, the, used to be terrible. And (he pauses) – the (and clears throat). Putting the /wih/ words (and he gestures writing in the air in front of him), you know, the, the, do the crossword puzzles. Um, do the, ah (and he gestures writing again), complete the sentence and,*
656. Maxine: *Right.*
657. Owen: */Hah/, (laughing). All, would have been much easier, /nih/, not, not to have had them.*
658. Maxine: *It would have been much easier not to have them?*
659. Owen: *[Yeh (laughs). Never get any speech (and he points to his mouth and laughs). But I stuck it.*

As I listened to Owen's accounts of therapy, I thought about the many therapy sessions I have planned, carried out and evaluated. How many times, particularly in the early days of developing an understanding of aphasia, did I encourage feedback from clients? Did I have the experience to risk hearing such responses? I am not sure if Owen, at this early stage, would have had the language available to him or the benefit of the ability to reflect at a distance and to articulate this view. Also his empathetic understanding of what he considered as a "terrible time" that speech therapists had may have restrained him from sharing this.

*Dealing with it*

*Ah, then, that was – I, just box on, right through.*

Owen, 1039.

Owen described himself as having always been tenacious (“*At work wise, sports wise, house wise*”, 1125). In his rehabilitation, he was insistent that he would walk again and that “*no way was I going to waste my time in the wheelchair*” (723). He took great delight in being able to relinquish the chair and to say to the hospital “*Take it away!*” (732). Because he was in hospital for a period of four months, despite his aphasia, he seemed to have developed close links with the staff with whom he worked. He still saw some of the people who had been part of his rehabilitation when visiting the hospital and was generous with his praise and acknowledgement of the efforts that went into his treatments. His return home still saw him attending some outpatient treatments but he attributed changes in his communication to having contact with others. About eighteen months after the stroke, Julie initiated contact with the local bowls club on his behalf and although reluctant, he went:

780. Owen: *So, so cart me up there.*

781. Maxine: *Carted you up there.*

782. Owen: *Carted me up there. I didn't really want to go. Ah (and he clears his throat). No (then he pauses). For a, two years. I never said a word. No (and he clears his throat). It, has done a lot for me, being with, other people.*

783. Maxine: *Mmm.*

784. Owen: *That*

785. Maxine: *[I can't imagine you not saying a word for two years!]*

786. Owen: *Yeh (as he nods), ah, I was quite, quite willing to, to (closes his mouth firmly and hunches his shoulders as if keeping quiet). People would ask me questions, I'd answer "Yes" or "No" (and he moves his hand from one side to the other). And (continuing to move his hand from side to side) that's bout it.*

787. Maxine: *[Okay.*

788. Owen: *A:nd, wouldn't say, well, "How are you?" (and he extends his hand out so me). "How are (?)" (as if replying). You know.*

789. Maxine: *Okay, so the, the social stuff.*
795. Maxine: *So you, you went to the bowls, sort of about eighteen months after,*
796. Owen: *[Yeh.*
797. Maxine: *And for two years you (and I gesture holding my hands close to me as if keeping silent)*
798. Owen: *Yeh. Very,*
799. Maxine: *[bit your tongue. What was your speech like in that time?*
800. Owen: *No (as he shakes his head negatively). It was hopeless.*
801. Maxine: *Okay.*
802. Owen: *[Yep, yep, it was hopeless. Then, it developed (as he made circular movements in the air with his hand moving upwards).*
803. Maxine: *Right.*
804. Owen: *My, mainly through (and he makes small circles with his hand in front of him) – contact, with – others (and he motions to his right side as if to someone sitting on his right).*
805. Maxine: *Great, mmm. Yep.*
806. Owen: *Made world of difference.*

### ***Making light of it***

*Oh, yeh, any wonder what to get rid of, migraine? I've got it. You can have my stroke.*

Owen, 1072.

While expressing the gravity of the situation, Owen often followed a story of the seriousness of it all by joking. Sometimes laughter and tears come easily after a stroke and for some people there is difficulty containing these emotional expressions, not because of excesses of sadness or joy but simply because of damage to specific areas of the brain. There was no right time to introduce a question about whether or not some of Owen's laughter was technically what is labelled "emotional lability" and I chose not to in the context of our interview. Rather I considered the use Owen made of humour and laughter during our conversations and observed an ability to balance

both the seriousness of what had happened with his stroke with an ability to describe the funnier, or lighter, side of these experiences. He described a speech-language therapy activity that would have been designed to improve his word recall:

649. Owen: *And that was the - admittedly the, they used to, take, /hah/, terrible time, you know, for me, with /hol/, holding up pictures. What is it (and he mimes looking hard at something)? Like, you know, a carrot. I could never remember what a carrot was (and he laughs). It's not a *parsnip*,*

650. Maxine: *(I laugh).*

652. Owen: *[no: (and he pauses). It's, um, (he laughs), it's not a radish (pausing again). No: (and he laughs again).*

654. Maxine: *Close (and I laugh).*

655. Owen: *But - you know, I'd have an idea (and he waved his index finger), that, but I could never think of carrot. You know, carrot. Carrot (laughing again).*

I listened to his description and to his humour but I know I have done exactly the same type of activity with people with aphasia in a therapy session in an effort to facilitate word recall. He gave me a window into being a recipient of such activities. In some way, Owen's humour saved me from my own critical reflection on the futility of it all and he opened up a space for me to laugh, both with him and at myself.

### *Telling stories*

While it would have been possible, with Owen's verbal expression, to have just relied on audiotaping, he made full use of non-verbal communication as well as being very adept at varying vocal tone, emphasis and speed to illustrate his point, sometimes in quite dramatic ways. He had a strongly preserved ability for storytelling despite any limitations that the aphasia imposed. While body language is a vital part of our communication, Owen did not just supplement his verbal communication with supporting movements; his body language was in partnership with his verbal story telling throughout the interview. His storytelling was active. It involved all of him in the reconstruction of his memories. His skill lay in the theatre of movement and pantomime, of timing and emphasis and in the effective use of strategies such as repetition of words and actions. He told an energetic story about his initial inability to talk and swallow and his approach to it all:

633. Maxine: *Anything that you'd call, like a, a low point (and I pause slightly for Owen to answer)? Anything that's you'd say this, this*
634. Owen: *[Yeh (and he nods his head affirmatively as he looks ahead and laughs quickly). The stroke. (He laughs again). There's no doubt about it (as he shakes his head negatively and looks at me).*
635. Maxine: *Okay.*
636. Owen: *[When I came to from that, I was – I was, dead. I, I (and he places his hand to his throat), completely, lost, my, voice (he accentuates each word with a slight nod of his head as his voice slowly drops to a whisper).*
637. Maxine: *Right.*
638. Owen: *I could only answer with numbers (and he leans towards me).*
639. Maxine: *Okay.*
640. Owen: *Ask me a question, and I give you a number.*
641. Maxine: *Ah.*
642. Owen: *And no, I just couldn't (shaking his head negatively). Not (and he pauses), and also (as he moves his left hand to his throat) - the liquid diet.*
643. Maxine: *Right.*
644. Owen: *Oh, that was terrible. Ah (and he laughs). You - drunk stuff that (and he holds his hand as if cupped around a glass and tips it slightly towards himself), mixed like wallpaper paste, you know (and he quickly laughs). And had three months of that.*
645. Maxine: *Okay, so that was with your*
646. Owen: *[Be, be, yep.*
647. Maxine: *swallowing. Not being able to swallow*
648. Owen: *[Yeh, yeh.*
649. Maxine: *in those early days.*
650. Owen: *Yep. I was given, a, /hah/ (and he points to his mouth with his index finger), ah, see if I could - a test (and he points again to his mouth with his index finger. He then moves his finger in a pathway from his mouth down to his throat as if tracing the path of the liquid barium during an x-ray. He completes this by resting his open hand on his throat), you*

know (*imitates an effortful swallow and then makes long noise as if he was regurgitating something*). No (*as if someone else was indicating a negative outcome of the test and he laughs*).

651. **Maxine:** [So, so /dih/ did you, did you have some x-rays?
652. **Owen:** Ye:s. Yeh.
653. **Maxine:** [Of your swallow?
654. **Owen:** [Yeh, yeh. I, I had about four of those.
655. **Maxine:** Okay.
656. **Owen:** [And they tested, and tested, and retested (*nodding his head each time as if to accentuate the repetition*), until I was all up. And, ah (*and he looks down*).
657. **Maxine:** Did you think you were going to – swallow (*and I move my hand as if move my hands one in front of the other as if making steps forward*), again?
658. **Owen:** (*He breathes out*).
659. **Maxine:** Did you think (*and my voice gets softer*)?
660. **Owen:** [Look (*and he leans back in his chair, looks ahead and then gently hits the arm of the chair a couple of times*). /Hah/ (*and looks at me*) – everything was - is, ah, is, is, (*and he clears his throat and looks down, leaning forward*). This, the state I was in. It was, I was (*and he gently clenches his hand, then opens it and moves his hand, palm down, upwards and forwards in the air several times as if taking one step at a time*) - making do with a, day to day (*as he taps out each word with his hand on the arm of the chair. Then he silently gestures opening and closing his hand at the same time as he moves his body backwards and forwards as if slowly clawing his way forward. He looks at me with his teeth clenched as if it is hard work*). Just (*and laughs as I nod in agreement*), that, in it. It
661. **Maxine:** [So in your mind (*and I point back to myself as if pointing to a place inwards*),
662. **Owen:** Yeh.
663. **Maxine:** that's how you were managing (*and I push my glasses back*).

664. Owen: *[That's all, that's all I had thought in my mind (as he points to his head), was (and he pauses looking ahead as he waves his hand from side to side). Okay (and he looks directly at me). We'll try it (he speaks softly and places his hand down firmly on the arm of the chair). We'll try it (as he repeats the action with his hand, his voice getting louder). We try it (and he repeats the movement then returns his hand to rest on his right hand).*

In some of his storytelling, he took up the voices of others and I watched myself assuming the role of audience, listening quietly with very little changes of body language or position and no need to reinforce or clarify<sup>40</sup>:

*But anyway (and he hold his hand out to the side as if to indicate he has more to say), speech therapists (and he looks at me), must have – a terrible time (and he pauses as looks straight ahead). I'd see this girl, going round looking for Joe Bloggs, you know (and he moves his head around as if searching and looks down at the floor). "Have you seen /soh/, Joe Bloggs (and he imitates a well spoken voice)?" (He pauses) "No: (and he shakes his head negatively assuming his own voice). "Haven't seen him (and pauses). Saw him, about quarter an hour ago, but don't know where he's gone". "He's hiding somewhere" (in a voice as if an aside from a pantomime)*

Owen, 646.

### *Constructing stories*

While the life story provided some structure and was used across interviews, so much of what was talked about was not structured. It involved both of us responding to each other to construct the story between us, both in our roles within the interview and also because of the aphasia:

916. Owen: *Yeh. Um (pause). The – no - it's got me completely (and he takes a long pause).*
917. Maxine: *Any hints or clues?*

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<sup>40</sup> I have removed any reinforcers I used within this narrative.

918. Owen: *It happened, in 1948 (and he laughs). And we had – the school, um, stay home from school.*
919. Maxine: *Right.*
920. Owen: *This was the country.*
921. Maxine: *Okay.*
922. Owen: *For way over three or four months, in the home.*
923. Maxine: *Right.*
924. Maxine: *So it's something that happened /nay/ nationwide?*
925. Owen: *Nationwide. Um –*
926. Maxine: *To do with the war or -?*
927. Owen: *[No, no. (Holding his hand up as if to stop me while he was thinking).*
928. Maxine: *Polio?*
929. Owen: *Yes, that's the one!*
930. Maxine: *Okay, okay.*
931. Owen: *[But, yeh, the polio and*
932. Maxine: *[I don't know where I got that from.*
933. Owen: *Yeh, you got it.*

## The Process

### *Relationships: research and practice*

Owen had severe communication disability following the stroke and speech-language therapy was one of the therapies he received as part of his rehabilitation. Inpatient therapies tend to be intensive and it is understandable that a different depth of relationships can develop between therapists, clients and their families that may not occur in other healthcare contacts. While Owen was more motivated to getting back his mobility, he continued to attend speech-language therapy. This was despite some reservations but he liked the therapist and was empathetic about the difficult nature of her job. He made an agreement with the therapist that he and his wife would meet up with her again when she left:



661. Owen: ... *when she went back, over to X, ah, I had a card from her.*
662. Maxine: *Right.*
663. Owen: *But there's no address, where she'd sent it.*
664. Maxine: *Ah.*
665. Owen: *So it finished.*

This is a reality of practice; of developing relationships through the work, through gaining knowledge about one another and through the therapeutic relationship. This made me think about the ethics of the relationships we develop during research, particularly during narrative research involving personal experience and researcher subjectivity. It is not a neutral process for the participants or for the researcher. A relational approach is based on relationship and this implies authentic engagement with people. Apart from the personal nature of interview about subjective experience, the research process for this project involved several face-to-face contacts with participants in their home and ongoing contact with both the participants and their spouses. We have shared part of our lives over the period of time of the project. We have also come to know one another and to share an interest in the project. My relationship with participants and my sense of responsibility to them have also influenced the analytic and interpretive process. I plan to take back the final conclusions to participants after the project is finished. While I may feel at this stage that I will still maintain contact with participants either personally or through discussions about any future writing based on the project, I will be interested to see how this process develops and how I will look back on this from a future point.

## John

*And as I've, a – I'm an introvert, the loss of my voice is really no great moment.*

John, 498.

### The Story

#### *And what of aphasia?*

John was a retired lawyer and aged sixty seven when we first met. He was the third participant to complete a life story interview with me. We first made contact by telephone following a letter from his local Stroke Foundation Field Officer. John's initial query was whether or not he was what I was "looking for". His communication had improved since his stroke in 2002 and he appeared to have only mild communication difficulty. My "criteria" for participation in the research were that people identified themselves as having aphasia and that they wanted to be involved.

We decided to go ahead with an interview and it was at this stage that John gave me a speech-language-therapy report that had been completed about three weeks after the stroke. It indicated that John had initially had "severe expressive and receptive dysphasia and was unable to vocalize". As he improved, it became clear that he had "dyspraxia of speech with some mild dysphasia". Dyspraxia of speech is classified as a motor speech disorder and not a language disorder, as is aphasia. It is characterized by difficulties initiating, planning and sequencing the muscle movements necessary for speech in the absence of any muscle weakness. There is, however, lengthy debate in the literature about whether or not apraxia of speech is also part of a non-fluent (or Broca's) aphasia.

From our contact, John's dyspraxia was probably the main difficulty affecting fluent communication and presented as some hesitations and an equalizing of stress in sentences. There were some minor grammatical errors as markers of a mild aphasia. Writing had been a strength from early on and understanding of written language had continued to improve:

571. John: *I've, ah, read a lot. I've*
572. Maxine: *[Yes.*
573. John: *I've – that's been one side of – um – until the last five, four or five months. I have not been able to read.*
574. Maxine: *Right.*
575. John: *Um –*
576. Maxine: *And what's that, that – is it related to your, your, your aphasia, not being able to*
577. John: *[Yeh.*
578. Maxine: *Okay, so*
579. John: *[Um, I don't, um – I /dih/ – um -/toke/, /token/, um, /tokt/, don't take it in.*
580. Maxine: *Okay. But it's, are you saying it's improved in the last five month?*
581. John: *[Oh, yes.*
582. Maxine: *Yes.*
583. John: *[Yes.*
584. Maxine: *Yes.*
585. John: *Oh, yes.*
586. Maxine: *Yeh, great.*
587. John: *Um, about – I, I – wasn't able to read a newspaper for*
588. Maxine: *[Right.*
589. John: *the first f:ive, /ih/, four or five months.*
590. Maxine: *Right.*
591. John: *And I, wasn't able to read – um, magazines.*

While aphasia (and the impact of aphasia on self and identity) was the key focus for the project, my description of John's communication and the written report seemed focused on the impairment. However, John's own descriptions of his communication skills post-stroke provide a much better indication of its impact on his life. Like all the other participants, John never talked about "aphasia". Rather, he talked about what had changed, what was difficult and what had improved since the stroke.

Along with the changes in his ability to read and the early return of his written language, he described his verbal difficulties, *"the lack of speaking"* (178), as a *"bit of a pain"* (503) after the stroke. John's physical abilities were not greatly affected by the stroke: *"I'm perfectly able to /co-ordinate/, /coh/, ordinate – my physical being"* (565). Therefore, I have interpreted comments about the stroke to be directly related to the changes in his communication. Given his professional background, it is possible to make assumptions about John's communication abilities before the stroke, both for his work but also for his social life derived from his social status. While acknowledging the ongoing improvement in his verbal communication, John and I also talked about how the changes in his communication were impacting on his everyday life<sup>41</sup>:

*Um, it's been a /hanicap/ socially, um, but – um – but I'm not worried /uh/, about that. Well – um, um (long pause) - to a gathering of people, um – um – I'm not able to express, um – what I think. And, um, I'm not able to take part, in a conversation? But I can play golf. I, I'm, playing twelve holes of golf again. And I'm able to /commen/, /municate/ at the, at that level. Um, but I'm – um – sadly lacking in input over a social gathering. Um, it's not too, great, but, um, but, the, the, - I'm communicating reasonable well, /ih/, between you and me. And, um, I have times where I cannot communicate as well. I get left behind.*

John, 514 – 554.

### *Sketching a life story*

John's linguistic abilities and the interview context made it possible for him to verbally express who he was and to be an active "I" in the telling of his story. He and I worked our way through the prompt questions with some detours as John developed his story. I assumed that John, with his professional background, brought to the interview an understanding of the interview process as a social form. After details about his early life, John's narrative was one of his career and his working life. Linde (1993) comments that occupation plays an important role in defining self in Western culture. Choice of profession is often used as an interview topic because of its acceptance as an essential part of self-presentation: "... it suffices that occupational choice is a major theme for life stories and one that is appropriate for conversation between speakers who are not closely related" (p. 57).

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<sup>41</sup> For the purposes of understanding John's experience of his communication, only his comments are summarised from a section of the transcript without my intervening reinforcements or clarification.

John described his first seven years as a time when his family experienced a variety of changes. His mother died during the birth of his only sister when he was two and a half years old. They were subsequently cared for by a woman who was employed in this role until his father returned from war and remarried. John was sent to boarding school where he talks of himself as “*an introvert on the Myers Briggs personality scale*” (53-55). John was not sure what he wanted to do when he completed his schooling and he finally pursued a career in law, a profession that was his father’s and grandfather’s before him. This initially appeared to be by default and John also described a waning of interest in law in his middle years. However, he talked about one of the high points in his life being, along with his marriage and the birth of his children, the time when he qualified in law. He also acknowledged its contribution to his overall development as a person: “*But, um – I’m very /gih/ grateful for the ah, the experiences that ah, ah law has given me*” (691).

Work formed a major part of his life after training and he reflected on its place in his life:

209. **John:** *Um, because /f/, um, (clearing his throat) the greater part of my working life, ever since I, um, got into law, which was about twenty five,*
210. **Maxine:** *Right.*
211. **John:** *and, until I – um, the, /f/ for the next 20 years I became a workaholic, I, (breathing in), um - and ah, that is the, period of my life which, ah, have, I have, um, some regrets over*
212. **Maxine:** *[Hmm, mmm.*
213. **John:** */bih/ because I /w/ was not, um, able to put, in more, to the children.*
214. **Maxine:** *Right.*

In his mid forties, John became a church goer and became very “*wrapped up in it*” (201). During this time, he became involved in voluntary work at an addiction agency. This saw John go through training to become a voluntary counsellor:

228. **John:** *And I did, twelve months, um, training,*
229. **Maxine:** *Right.*
230. **John:** *to be voluntary counsellor,*
231. **Maxine:** *Great.*

232. John: *[and I almost became, well (clearing his throat) I thought about, um, counselling,*
233. Maxine: *Yes, yes.*
234. John: *as a profession,*
235. Maxine: *Right.*
236. John: *but it was too late. Um - but, um -um, and we went through (breathing in) weekends training and ah - um, growth weekends or, all sorts of*
237. Maxine: *[Hmm, mmm*
238. John: *weekends training, and I did, twelve months, counselling, after that, until the, (agency) reorganized,*
239. Maxine: *Hmm, mmm.*
240. John: *um - and I regard that - period, /thih/ the greatest, um, development for me*
241. Maxine: *[Mmm.*
242. John: *as a person.*
243. Maxine: *Mmm. Mmm. So although you were doing it for others,*
244. John: *Yeh.*
245. Maxine: *the, the actual personal, development and, and awareness through the, the process, was a,*
246. John: *[Yeh*
247. Maxine: *a, a, positive.*
248. John: *Yeh.*
249. Maxine: *Yeh. Oh.*
250. John: *[So that was really worthwhile.*
251. Maxine: *Yes. Ah.*
252. John: *And I ceased to be ah (breathing in), um, have a hang up, a religious /hih/ hang up, after that training.*
253. Maxine: *Right. Okay.*
254. John: *[and I became much more balanced.*
255. Maxine: *Right, right.*
256. John: *[(Laughs)*
257. Maxine: *[Right, yeh.*

While theological studies remained an important part of John's life, he made major changes in his approach to his faith which he touched on later in our conversation when we began to talk about his philosophy on life:

822. **Maxine:** *So that's, that's probably a significant thing in, in the way in which you have managed, all the things that have occurred, um, is a, is a, is a philosophy that has some spiritual,*
823. **John:** *[Oh, yes. Yeh.*
824. **Maxine:** *Um-*
825. **John:** *Yeh.*
826. **Maxine:** *weight there. Mmm.*
827. **John:** *I'm a very, radical – um – radical, um, believer or /s/*
828. **Maxine:** *[Right.*
829. **John:** *um - opposite to fundamentalist,*
830. **Maxine:** *Right.*
831. **John:** *strain.*
832. **Maxine:** *Okay. Okay*
833. **John:** *(Laughs)*

Associated with these changes, John also experienced a welcome shift in his role at work with him taking on other responsibilities although this was not without its stresses. Just before the stroke, John had begun to reduce his work commitments. However, the stroke "*put the kibosh, on me, practicing law, and I have /neh/ never been happier since*" (150). John was able to create closure by completing his work obligations after the stroke because he was by then able to write. He did not think he could have brought everyone else up to speed without this because expressing himself verbally was very difficult at that stage. While there have been changes with the stroke, when we talked, John identified it as a positive change as it removed him from work and he was able to pursue other interests including becoming "*a full time gardener*" (154):

492. **John:** *Um (clearing his throat) – well – um, I /kin/ can tell you - um – reasonably clearly – um -that it's - um - not made very much difference because um, I am very positive about having given up work.*
493. **Maxine:** *Right. Right.*

494. John: *Um – (clearing his throat) I have – um, my wife Jill,*
495. Maxine: *Right.*
496. John: *is provided transport, for me and, as well as companionship.*
497. Maxine: *Right.*
498. John: *um - so I've lacked nothing there. And as I've a - I'm an introvert, the loss of my voice is really no great moment.*
499. *(Both laugh)*

I thought about what I interpreted as John's resilience to the stroke and to the changes in his communication. Maybe this had some relationship to the "meaning making" he had already engaged in through his own journey in life and in developing his ontological beliefs. From my listening and his telling, he had thrown his energies into studying theology in his forties and then began to explore a more radical approach, at a later stage, to Christianity through his counselling training and through the personal counselling associated with this. Maybe an understanding of the changeability of life and the experiences of self-understanding provided a framework for acceptance as John encountered further changes in his life. Despite these changes and the stroke, there is a coherency and continuity in John's telling of his life story.

His earliest memory was when he was about two and was working and "*fiddling around in the garden*" (428); then when he considered what he might change about his life, he reflected that he might have liked to have followed a more scientific career path such as horticulture or agriculture and at the time of our interview, he was able to say that "*I'm a full time gardener as, as, it's, really blissful*" (154).

John acknowledged that while the impact of the stroke was of "*no great consequence*" (710), if he had not had a partner or had incurred physical disability as the result of his stroke, it would have been "*worse by far*" (715). He, however, was in a long-standing partnership and was physically able to resume social activities such as golf that allowed him to maintain social relationships and hence his personal and social identity.



*Joint action*<sup>42</sup>

As I considered my contact with John, I thought about Shotter's (1993) notion of language as sociorelational and dialogical; that the meaning of an utterance is dependent on subsequent utterances within a relationship and the ongoing dialogue. Shotter (2005) advances this with a notion of a "sense of collective-we between us" (p. 103). It is only within such a shared reality that we are able to express to one another who we are and to achieve this there are interactive responsibilities to our joint action. John and I were essentially strangers but had some shared understandings of communication disability associated with stroke. My understandings of aphasia were as a therapist and novice researcher while John's was very much an insider's perspective. Did we develop a collective-we between us and, if so, how did we achieve this? The interview as a life story had a format and it was guided by prompt questions; I remained the asker of the questions and I used the questions to direct, redirect and, at times, steer the interview. Also our backgrounds in terms of age, profession, gender and history were different. Despite this, the interview offered opportunities to make connections and I believe we both had an understanding of our interactive responsibilities and a desire to develop a meaningful conversation where we could express who we were.

Some of the "tools" for developing a shared reality rest within the subtleties of our expressions: gaze, facial expression, eye contact, gesture and tone of voice accompanied sometimes by our verbal language. I am aware that once I reduce my conception of a shared reality to transcribed text, some of the responsiveness is already lost or "dead". Shotter (2005) quotes Wittgenstein to highlight that "understanding a sentence lies nearer than one thinks to what is ordinarily called understanding a musical theme" (p. 128) and therein lies the difficulty in trying to replicate a living act, long passed, in a static form. Reviewing our interview material, I listened and looked for times when the movement of the conversation showed the dialogical nature of our interaction. In the following segment, John was talking about going back to work after the stroke specifically to complete work on his files by writing in long hand because he was not able to communicate well verbally:

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<sup>42</sup> John Shotter(1993)

189. **John:** *Yes. So, I was able to /pring/, the partners up to speed and, take ah over, the tasks, that I, had been involved in.*
190. **Maxine:** *And was there any, as, as you were, communication /im/, verbal communication improved, was there any time you thought, oh, oh I would like to go back into the office?*
191. **John:** *No.*
192. **Maxine:** *[(Laughs)*
193. **John:** *[No, no.*
194. **Maxine:** *[No hesitation! (Laughs)*
195. **John:** *No (Laughs)*
196. *(Both laugh)*

The responsiveness is created through the interplay between us. There could be no prediction of the responses or the way in which they were to be produced by either of us but each response becomes part of the developing story between us. The presence of humour, of shared laughter, John's repeated repetition of "No" and my acknowledgment of John's swift responses, in contrast to the hesitations sometimes present within his delivery, these all carried with them the shared reality of the meaning for him of not returning to work.

Although I was present as the interviewer, John was able to highlight for me, and thereby allow me to articulate aspects of the process at work. While we were talking about the training he underwent, I was making connections with my research experience and John put voice to this, opening a space for me to identify it:

258. **Maxine:** *So what was it through the, the, the training you think /thah/ that made that change?*
259. **John:** *(Breathing in), awareness.*
260. **Maxine:** *Right.*
261. **John:** *Um, yeh.*
262. **Maxine:** *Okay.*
263. **John:** *And good - stuff, um, /silt/, /slike/, psychological stuff.*
264. **Maxine:** *'Cos that's the thing about, um, the, the training, is that you, you, you spend a lot of time working on the, the you in there,*

265. John: *Yeh.*
266. Maxine: *you know,*
267. John: *[Yeh.*
268. Maxine: *in order to be able to, to work along side other people, I suppose.*
269. John: *Right.*
270. Maxine: *Mmm.*
271. John: *And, exactly, what you have been doing,*
272. Maxine: *Mmm.*
273. John: *for (laughs), for yourself.*

### *The private "self"*

The nature of interviewing, of narrative research and particularly of a life story interview gain entry into private and sometimes painful spaces in people's lives and there is no established way to either anticipate these moments or prepare people, including the researcher, for their occurrence. After a recounting of his career and then his retirement from work after the stroke, John quietly remarked that their youngest daughter had died four years earlier. This was unexpected for me within the interview and I perceived it to be, for John, an emotional moment. I felt somewhat like an intruder at that point as John took time to reposition himself. I felt awkward about my gaze and the presence of the video camera. It is clear from the increase in my quantity of speech at this point of the interview that I was trying to regain some footing. I also noted how I omitted additional questions about low points, wanting to avoid further intrusion and also treating what he had shared carefully. How we would have negotiated this without the context of an interview or without a video camera running may have been quite different. It did however open up our conversation once the interview had ended.

### *Outside the formality*

When our interview, as such, was completed and the video-recording had been turned off, we continued to talk. John was curious about comments made during the interview that he wished to pursue and about the nature of the project. He quickly took charge of questioning. I easily settled into the role of interviewee. It seemed natural and I began to enjoy the opportunity to relax and

let the conversation take its own direction. It was a chance to talk about the project and to share thoughts and ideas. Aphasia and/or dyspraxia were forgotten as John took charge and roles changed. Maybe that was because of the mildness of John's communication impairment but maybe it was also about the level of relating that had already been established by the questions I had asked as part of creating a life story, questions that were personal and hardly superficial. John had already commented that I had not asked many "stroke related" questions and I sensed, at times during the interview, that some questions might have been perceived as too personal and perhaps potentially invasive. Perhaps this enabled him, then, to cut across the context of stranger meeting stranger and enabled him to talk to me about my own sense making. He turned the conversation to an earlier reference to my nephew's death and asked if it had influenced my study. In retrospect, I had no idea at that stage how relevant Marcus's death was to the project's development and to my own subjectivity within the project. Discussion ensued about philosophies of life and John shared authors and texts that were influential for him. While the interview produced "data" for analysis related to the interview questions, the informal act of conversation and relating after the video was turned off also produced data about John's life story and his experiences of aphasia, about myself, about the nature of communication and about the nature of the project.

### *Talk in context*

I considered John's communication difficulty to be mild; John described it as a "*handicap socially*". This was more evident in our conversations outside the interview. Our conversation ended with me chatting about my travels and then John, in closure, introduced me to his wife. He created a connection between us by his preface that I was also interested in travel, as she was. I listened to the conversation between his wife and I gather momentum and thereby begin to exclude John by its speed and its unpredictability. Whilst the videotaped interview had been paced by John's communication needs and my role as interviewer and listener, now the informal conversation between his wife and I, two speakers without aphasia, picked up speed. We covered an enormous amount of territory with constant changes of turn and topic and John's earlier comments in the interview about getting "left behind" were evident and were an insight into what John had already so succinctly described. His expressive language, however, enabled John to take part in the verbal construction of a life story and in the process, self construction. It has enabled him to carry on with social activities while acknowledging that there are restrictions that occur as the

result of his communication difficulties and the temporal dynamics of social interaction imposed by more fluent speakers. The interview assigned us specific roles that we both recognized without any discussion interviewer and interviewee. However, these roles change when the context is one of a shared conversation and the impact of aphasia becomes more evident when the person with aphasia competes against speed and time for a conversational space regardless of the quality of the relationship between participants. The interview context was an appropriate context with which to explore John's life story but if I had not had the opportunity to move beyond the interview context, I may have well minimized the influence of aphasia overall in John's social life.

### *Seeking feedback*

As part of the process, I sent John a draft of what appears here. His was the first feedback I sought and, because of his reading ability, I was able to send him the draft narrative in long-hand for his comments. He promptly returned the draft in which he made some minor but pertinent changes in the text related to details and to word choice. In a covering letter, he mentioned the videotaping and the plans for what would happen with this once the project was complete. I followed this up with a telephone call.

It has been over a year since I had spoken with John and I was aware of a subjective improvement in the fluency of his communication. I talked about returning the videotape to him along with the completed transcript and final narrative. While we talked about many things, I asked him how he had found the interview and the process. He felt that, although some type of recording was necessary, we did not need to videotape the interview. In thinking about the process after completing all the interviews, the transcription and the analysis, in his case I agree. From the outset, I had made an unconditional decision that the interviews would be videotaped. I would now judge the necessity for visual information as well as verbal on an interview on a person-by-person basis. Transcribing John's interview required less narrative comments about the visual data and there was a focus on the text which would have been adequately captured by audiotaping alone. John also made a final comment that we tend to forget about our past and that the interview and reading the draft were reminders of the journey had also helped to "shape where I am going".

## The Process

During my contact with John and the subsequent time spent in analyzing the interview, there were questions and issues arising that challenged my view of what the research was about and how it was developing. One issue was how to explain an evolving project and the place of the interview particularly for the purposes of gaining informed consent.

### *Informing for informed consent*

*Um. The questions you /ah/, ask, um – are not very, um, stroke related.*

John, 697.

I sensed a reserve in John as we began our interview which I had not been aware of in our initial conversation nor was it present in our concluding discussions outside the interview. What was it that signalled what I perceived to be this reticence? It had something to do with an increased formality in language, the way the interview began to take shape, pauses and increased delays between questions and responses as well as shorter answers. My first thoughts were that the setting up of the video camera and subsequent recording changed the dynamics between us. Retrospectively from John's feedback this was influential. I could have also put this down to John's personal presentation. However, on reviewing the videotape and the transcript over the course of the analysis, I realised that the interview was not what John had anticipated. He made the comment at a point forty five minutes into the interview that the questions I was asking were not very stroke related. He had also prepared a written list of observations before the interview: "*I – just jotted down here when you first – um – approached me*" (739) and these were specifically stroke related. Although I had sent him the standard information and consent sheets, John had planned for us to talk about his experiences of the stroke and his aphasia but perhaps not for a more in depth consideration of his life story. We had entered the interview with our own ideas about what it would entail and the interview therefore became a site of negotiating what it was about. I wonder now how this could be more clearly achieved, considering the need to gain "informed" consent at the outset of the research interview.

It is difficult to explain a project when it is heuristic and when each interview yields new information or insights that directly influence the next step in the process. Qualitative research is not easy to lay bare and to simplify. But it is problematic for the issue of informed consent which is

gathered at the beginning of the process and not always renegotiated throughout the process. There may still not be a clear understanding of exactly to what a person is consenting. Kagan and Kimelman (1995) question whether the consent form has become more important than the actual consent procedure: "... genuine informed consent requires a more dynamic dialogue or process" (p. 71). Although the information and consent sheets need to be carefully designed to be "aphasia-friendly" to support informed consent, I realised in talking with John that there was a difficulty in communicating the essence of an interpretive endeavour which is itself in evolution. The difficulty was definitely not about John or even about aphasia; it was about a research process which is ongoing, reflexive and contextual (Goodfellow, 1997). I considered how I could, in returning John's story to him, also address some of the gaps of which our interview had made me aware. I chose to do this in a letter accompanying a draft of what would appear in the final writing; the contents of the letter are reproduced here:

Dear John

It is a long time since we first met and completed our interview! This process has taken much longer than I anticipated. I have enclosed a draft of what is planned for the thesis but I would like to know what you think before I include it. I would also like you to change anything with which you do not agree or delete anything you want excluded. I have tried to create anonymity by changing some of the identifying information. I hope that works. Our interview is one of eight that I have developed for the thesis.

Our interview was my third interview and I think, as I listen back to the videotape, neither of us was entirely clear about where it would lead. In fact, about forty five minutes into the interview, you said to me that I had not asked many stroke-related questions. I can see that even though I had prepared an information sheet about the project, it was not easy to describe exactly what it was about and hence your most appropriate question. I have continued to think about this: how to explain the nature of a project that is in fact taking shape over time. I have tried to write about this too as it is an important issue for other people doing this kind of research. I have included here some information (including the formal referencing) that might be helpful background to reading the draft.

### Self and aphasia

Aphasia (or "dysphasia") is the language impairment post-stroke and it refers to a group of symptoms ranging from mild to severe. It encompasses spoken language, understanding, reading, writing and gesture. It can have a profound effect on an individual and his/her social world. There is a growing body of literature that indicates that the experience can bring about some profound shifts in personal identity. It can affect every part of the person including the ability to cope socially, feelings of loss and possible depression, and a change in the sense of self (Sarno Taylor, 1993)

### Research in self and identity

How do we research about self and identity? From my perspective, the sense of self and identity are not a static rather they are dynamic activities and are continually evolving. As such, we need alternative research methods than those traditionally used in a formal science model (Polkinghorne, 1988).

### Narrative research and the life story

Narrative psychology is interested in the application of narrative in the discipline of psychology (although it draws from studies in literature, linguistics, sociology and anthropology). Narrative or storytelling is a very human activity and stories give us insight into the identity of the storyteller (Murray, 1997). The self is understood as a developing story used to interpret and account for our lives (Polkinghorne, 1988). Narrative research is suited to exploring the reconstruction of personal identity following illness or trauma (such as stroke). Life story narratives may be one of the most effective means for gaining understanding of how the self evolves over time. These narratives capture not just the personal but also give insight into the social, cultural and historical context of lived experience (Stake, 2000). Narrative research also reveals the identity of the researcher who is involved in the process.

With this in mind, I chose to complete life story interviews with people with aphasia. I chose to not focus directly on the impact of aphasia on people's lives, rather to let people talk about their lives generally and then listen for stories of aphasia within that life story. The broad outcomes for the project were:

1. To find out more about the impact of aphasia on a person's sense of self and identity through a life story interview; and
2. To develop a process that includes people with aphasia.

Our interview has contributed on both counts and I used the experience to help improve the research process as I met with other people. I also have some suggestions now that I think will be useful to other people involved in research with people with aphasia in the future.

Please, please feel free to change anything and to make any comments about what you read. I would be like to catch up at some stage to give you feedback about the completed project but will ring you before I include anything in the thesis. If you want, you can also send any suggestions for changes on the extra copy I have enclosed.

Best wishes 2005. Thank you again for your involvement in the project and I value any feedback you have about how I have told the story of our interview.



In the interviews that followed John's, I also set out to be much clearer about what the interviews would involve. I made a point of always meeting face-to-face with people before the interview and almost always allowed for an intervening period of time for them to decide whether or not they wanted to take part. Lists of the questions or examples of the "aphasia-friendly" prompt questions were provided before some of the interviews. Subsequent to John's interview, I followed up a telephone call with a visit to a woman who had aphasia who had expressed interest in the project. She had wanted to talk with me because she thought I sounded "nice" on the telephone. I left a copy of the interview questions with her and asked her to think about whether or not she wanted to be involved further. She e-mailed me several days after my visit: *"I've read the list of questions you left me and have thought about it quite a lot and decided that I wouldn't like to be filmed. I know it's confidential, etc, but I'm conscious of how I sound now and also feel reluctant to talk about my life. I think I'm probably quite a private person"*. From the vantage point of the project's completion, I would consider being more transparent with participants about "not knowing" as a starting point for discussions about the emergent nature of qualitative research (Bone, 2005, p. 2).

## Bill

*But the stroke would be your biggest disappointment.*

Nella, 631.

### The Story

Bill was seventy two years old and he had had a stroke almost ten years earlier just before he turned sixty three. He had had a celebrated career as a jockey before his retirement which took him and his wife, Nella, all over New Zealand and to Australia, South Africa, Japan, Singapore, Malaysia and Hong Kong. He had mixed with many people during a forty year career that saw him at the top of his profession. He had met dignitaries including the Queen Mother and had received the Most Excellent Order of the British Empire (M.B.E.). He had also had an autobiography published in 1976 and he was inducted into the New Zealand Sports Hall of Fame in 1990. So his stroke was indeed a great disappointment in a very full and rewarding life. However, one of the motivations for Nella and Bill to be involved in the research project was that they wanted people to know that life does go on after the stroke.

### *What's in a name?*

At every stage of contact with Nella and Bill, I talked about a pseudonym for them both as part of the ethical considerations for the project. From the beginning, they both saw no real reason to not be known as themselves. I considered developing a pseudonym myself but I was still concerned as to how I would be able to ensure their anonymity given their illustrious career in horseracing, the significance of this to Bill's life story and Bill's distinctive and perseverative phrase "Himma gotta go". Before sending them a draft of what I had written from our interview, I talked once more about possible pseudonyms. Although not forceful, Nella was definite that neither of them felt the need not to use their own names, checking again with Bill. Their main reason had always been if it could help someone to know that Bill had had a stroke, then it was worthwhile. The last time I broached the subject again, Nella recounted recently overhearing a conversation between a man who had just had a stroke and nursing staff. The man was asking "why me", why had he had a

stroke when he was fit and well and had never smoked. Nella said that Bill had always been very fit before his stroke and had no contributing medical problems, therefore it might be helpful for other people to know this and also to know how Bill had “got on” with his life. She referred to how Christopher Reeves had been able to increase people’s awareness of spinal injuries but also had been able to show people that he had carried on with his life. So Nella and Bill appear as themselves.

### ***Before the interview***

When I met with Bill and Nella to talk about the possibility of an interview, we spent time talking about the project and also about Bill’s life. He had right sided weakness as a result of the stroke and although he was able to walk, he was unable to use his right arm and hand. His verbal expression was severely impaired; he used some single words and a repetitive phrase “*Himma gotta go*”. Early in our meeting, I was already making assumptions about how difficult the life story interview would be for him but, in that first visit, I also became increasingly aware of Nella’s key role in presenting Bill and his views to the world. Over a first meeting which lasted almost three hours, Bill had no obvious difficulties with concentration and was an active contributor to the time spent together although Nella was the primary communicator. From the beginning, Bill directed Nella to the things he wanted me to know or to the things that he wanted to share. He did this by his tone of voice, his repetitive phrase (“*Himma gotta go*”), through negating or affirming Nella’s responses and by pointing. We looked at the many photographs that were displayed in a large games room and at other trophies and awards in the rest of the house. He continued to direct Nella to photos and Nella would tell me the story associated with the photos. Occasionally Bill would add a single word (“*Japan*”, “*Ballarat*”, “*Westport*”). Nella would almost reflexively comment, in between her sentences, when Bill retrieved a word, “*Good, Billy*”. It appeared a very fluent process and Nella seemed at ease and familiar with this communication style. She remarked that the occurrence of some single words was a more recent happening.

I perceived Bill to be someone with a good sense of himself. While he expressed real frustration with the aphasia through his voice, gesture and facial expression, he was keen to communicate and he was an active initiator with Nella’s collaboration. The games room was a living life story but also Nella had collected every newspaper cutting since 1959. She had four large scrapbooks that contained every article and picture that had been published up until Bill’s retirement. These

also feature many pictures of Nella indicating that Bill and she were visibly seen by the media as a couple. Bill's autobiography was dedicated to Nella: "For her total dedication to my career".

We talked about the project, about it being a life story as well as exploring his experiences of living with aphasia. I suggested sending through some of the kinds of questions that the life story would involve and I gave, as an example, that we might talk about some of the important people in his life. Without facilitation or hesitation, he leaned over and placed his hand on Nella's arm. For all three of us, the power of this was clear. I thought about how Nella and Bill seemed to manage the impact of the aphasia on their life and I considered the significance of their lives before the stroke. Bill had been one of the last century's most successful jockeys. He continued to enjoy widespread recognition for what he had achieved and who he was. These experiences as well as the love and support of his wife would have built a strong sense of self worth and perhaps this all helped Nella and Bill in their adjustment to the effects of the stroke and of aphasia. I was present when several visitors called in; people associated with racing and they appeared to have a shared history with Nella and Bill. Seeing people interact with Bill made me think that he was still held in high regard and his competence was never questioned. Also Bill maintained an active presence in communication; he was social, he included himself, he was inclusive of others and he retained a good sense of humour. Racing colleagues had named a horse "Him A Gotta Go" after Bill's repetitive phrase which was as a tribute to Bill but it also signalled to me an acceptance of the aphasia being something Bill had and not who he was and the construction of the impairment of aphasia in an affirmative way.

### *Whose story?*

Before the interview, I had already acknowledged the importance of Nella to Bill's successful communication and the need for her to be involved in the interview as well. The time spent together in the beginning was vital to establishing how the interview might be completed. The previous three interviews of the project had been carried out with just the individual participants and myself present so when I began the interview with Nella and Bill, I was less sure of the shape the interview would take. I had already seen the way in which Nella and Bill worked together to allow communication to be, for the most part, successful. There were communication failures but this usually ended in Bill acknowledging the frustration but letting it go. I had already recognized the closeness of their lives and the shared nature of their narratives. Separating out whose story it

was would be difficult however both Nella and Bill, in this joint production, emerged as individuals but with a shared narrative:

1733. **Nella:** *One time, he was actually, um, in the sauna, this was on every week 'cos he had to get in the sauna to get the weight off,*

1734. **Maxine:** *Right.*

1735. **Nella:** *and he come in one day and he said, look, I can't do that. I'm not, I'm not going to, take any more weight off, I can't do it. I says, oh, look, I said that horse is a good horse, I said, you know, you'll win on it. I said, I'll come out in the sauna and, and, you know, and (laughs). So I went in the sauna with him. And, (laughing)*

1736. **Bill:** *[Faint.*

1737. **Nella:** *anyhow, he came out and he was frightened I was going to faint – very good, Bill.*

1738. **Bill:** *Yeh.*

1739. **Nella:** *He was frightened I was going to faint, you see, and I said, no, I'll be right. So, anyhow, out he comes, he loses all his weight, and home the horse came, you know. But I had to go and ring up the owner and tell him, yes, he can ride it, you know, because he wasn't going to.*

### *Communicating about the self*

In the VCRM, the second listening is to listen for the “I” statements so as to hear the first-person voice and to hear how the person speaks about her/himself. Relying on a pronoun made this impossible with Bill’s language impairment but it did not mean that Bill’s “voice” was not present or was not heard. How did Bill then talk about himself? He was not passive within communication contexts and I saw and heard how Bill orchestrated telling about “I”. Although Nella provided some of Bill’s history (and their shared history), Bill led Nella to tell a story he wanted by giving clues and feedback. Sometimes this might have been by pointing or by gesture, he may have used the resources available during the interview including his biography by locating a particular page or photograph, or he may have used a single word. He directed Nella by using “yes” or “no” and the vocal intonation, the loudness and the repetition of these two words conveyed whether or not she was on target. It was not just with Nella, he used these skills to help

me make sense of his story. While there is literature discussion of the notion of “speaking for another”, Nella automatically checked where the story was going and whether or not Bill was in agreement with how she represented him:

660. **Nella:** *I think coming north improved his career,*
661. **Maxine:** *Right.*
662. **Nella:** *even though he was successful,*
663. **Maxine:** *Yeh.*
664. **Nella:** *all the way.*
665. **Maxine:** *Okay.*
666. **Nella:** *It got him a better opportunity, that's the word I'm trying to think of.*
667. **Bill:** *[Yeh, yeh, yeh,*  
*yeh.*
668. **Maxine:** *Okay.*
669. **Nella:** *Is that alright?*
670. **Bill:** *Yep, yep, /oo/, /himma gotta go/ (points to Nella and then to himself and looks at me)*
671. **Nella:** *You carry on, Nella (and we all laugh). I shouldn't be doing this, should I?*
672. **Maxine:** *No, no. Whatever works.*
673. **Nella:** *[It's hard 'cos I know what he wants to say.*
674. **Maxine:** *Yes.*
675. **Nella:** *Well, I think I do.*
676. **Bill:** *Yes, yes. Oh, yes, yes, yes (nodding affirmatively and pointing to Nella).*
677. **Nella:** *You tell me if you think I'm wrong.*
678. **Maxine:** *Do you think Nella's telling your story well?*
679. **Bill:** *Yes! Oh, yes (and moves back in his chair)! /Himma gotta go/!*

Bill's communication involved the interplay of techniques that he had developed. These included tone of voice and expressiveness, the use of “yes”, “no” and “himma gotta go” and their repetition to create a different meaning, the use of facial expression and gesture, some single words and reference to the props in his environment. When we were talking about an important adult memory, Bill replied, shaking his head negatively “*Racing. Racing. Racing*” (967). As Nella qualified, riding and all it involved took up a major part of his life and there was little time for

anything else. Communication was not just the outcome of the use of specific techniques; it was the outcome of the use of these in relationship with and in response to Nella's communication. While this was a reminder of their interdependence in how communication was negotiated, Bill was still tenacious in having his voice heard. We talked about his community work and the many times he gave talks in many places:

996. **Nella:** *Except he had one or two hairy rides in /mow/, in two seater planes to get to these places.*
997. **Maxine:** *[To actually access,*
998. **Nella:** *Oh, yes.*
999. **Bill:** */Him, him, himma gotta go/ (and points out the window to his right).*
1000. **Nella:** *[Yes, in Otaki.*
1001. **Bill:** *Otaki.*
1002. **Nella:** *Yes.*
1003. **Bill:** */Oo:/, /himmma gotta go/ (and he sweeps his hand down over the table and up again as if imitating a plane).*
1004. **Nella:** *They'd sent down a three seater plane, (laughs), for him from Hamilton and we had to, they had to come in and park down in a paddock, you know, like, and in a paddock, not park, land in a paddock and we had to chase all of the sheep away.*
1005. **Bill:** *[/Himmma gotta go/.*
1006. **Nella:** *And then, of course, we had to do exactly the same thing to get him off the ground again (laughs). I think by the time he was leaving, he didn't know if he was ever going to come back again.*
1007. **Bill:** */Him, him, him, himma gotta go/, um, (pointing to Nella) /cam/, um, /tamel/, no, /tamilton/,*
1008. **Maxine:** *Hamilton?*
1009. **Nella:** *[Hamilton, yeh.*
1010. **Bill:** *Yes. No, no, no, no, no. Hamilton. Yeh. To, oh, /himmma, himma gotta go/ (looking to Nella).*
1011. **Nella:** *Well, that's where you were going that time, you were*
1012. **Bill:** *[Yeh, yeh, yeh, yeh, yeh, (pointing*

- to the table).
1013. **Nella:** *[I don't know what club it was.*
1014. **Bill:** *[/hingga gotta go/. No. No. No (pointing to the table and very definitely shaking his head negatively and shaking his hand from left to right).*
1015. **Nella:** *Oh, was it a racing do?*
1016. **Bill:** *Yes, (points at the table several times) yes, yes, yes, yes (and looks down at the table and moves the book slightly). Oh - no (despondently).*
1017. **Nella:** *Oh, Bill (as if disappointed she has not been able to identify the place).*
1018. **Bill:** *Um (looks up at Nella), oh. Hamilton, no (shakes his hand from left to right and then points to his left).*
1019. **Nella:** *Was it somewhere else, Bill?*
1020. **Bill:** *Yes, yes, yes (and points to his left, moving his hand in front of his body as if indicating direction or location).*
1021. **Nella:** *Oh, I thought,*
1022. **Bill:** *[Hamilton – Taumarunui! (and raises his hand above his head) Yes, yes, yes.*
1023. **Nella:** *[Oh, very good. Taumarunui.*
1024. **Bill:** *Yes, yes, yes.*

Bill presented as being a modest man. Despite the accolades and his professional status and despite the aphasia, he managed to communicate humility. I considered how this was achieved both as a complex personal characteristic but also within the limitations that aphasia produced. Often when we talked about one of the many major achievements in his life, he would merely shrug his left shoulder. Nella told the story of Bill as a young boy saving a person from drowning:

1318. **Nella:** *You saved a boy was it, or a girl's life?*
1319. **Bill:** *[Yeh.*
1320. **Nella:** *I can't remember. Swimming and they were drowning or something.*
1321. **Bill:** *[Yeh, yeh. Twelve. Twelve.*
1322. **Nella:** *[And then someone took him home,*
1323. **Maxine:** *She was twelve?*



1324. **Nella:** *Yeh.*
1325. **Bill:** *Yeh, yeh.*
1326. **Nella:** *Oh, when you were twelve.*
1327. **Maxine:** *Okay.*
1328. **Nella:** *Before you left Greymouth and, um,*
1329. **Maxine:** *Right.*
1330. **Nella:** *and someone took the child home after they got, you know,*
1331. **Maxine:** *Mmm.*
1332. **Nella:** *and got it settled, and, um, they, I think they took the credit it for it, didn't they?*
1333. **Bill:** *Mmm (and nods).*
1334. **Nella:** *Yeh.*
1335. **Nella:** *Still, you know.*
1336. **Bill:** *Mmm (and lifts his left hand up and shrugs his left shoulder).*
1337. **Nella:** *You know yourself.*

Again, despite success and tributes, when I asked him if there was anything he would have done differently, he reflected not on himself alone but on his brother as well. Nella's knowledge was imperative to the story but also they worked together until the moment when Nella was able to make the connections between what Bill was saying and what he wanted her to say, all based on a history of stories shared and stories still alive in the telling:

1093. **Maxine:** *(Turning to the next question in the prompt booklet) If you were looking back over your life, okay, and you could change things, would you make any changes? Over your life? (Pause). Things you would have done differently, or changed?*
1094. **Bill:** *Mmm. Um. Well, /him, him, him, himma gotta go/. Bob, Bob. /Him, him, himma gotta go/, (pointing to his book and clicks his tongue in annoyance). Oh,*
1095. **Maxine:** *Something to do with your brother?*
1096. **Bill:** *Yeh. /Him, him, himma gotta go/. Um. Johnny (and points to Nella), Johnny, ah,*
1097. **Nella:** *Anderson?*

1098. **Bill:** *No, no, no, no. Um, Johnny, (pause). /Him, him, him/,*
1099. **Nella:** *[What? Hobbs?*
1100. **Bill:** *No, no, no, no. Um, /him, him, himma gotta go/, um /jelly/, Dowling. Dowling (pointing sharply at Nella)!*
1101. **Nella:** *Johnny Dowling?*
1102. **Bill:** *Yeh. /Him, him, himma gotta go/.*
1103. **Nella:** *Oh: You're talking about, Bill, like, you're talking about your premierships?*
1104. **Bill:** *Yeh, yeh, yeh.*
1105. **Nella:** *No, what Maxine's asking you is –no. I know what you mean (and she pauses as if some understanding is emerging). Oh, (and she stretches her arms across the table towards Bill), is that what you would have liked to have done? Like you and Bob to have won the fifteen premierships, over the fifteen years?*
1106. **Bill:** *Yeh, yeh.*
1107. **Nella:** *But Johnny come in between and,*
1108. **Bill:** *[Yeh, yeh.*
1109. **Nella:** *What Bill's getting at is, for fifteen years him and his brother held the premiership, you know,*
1110. **Maxine:** *Right.*
1111. **Nella:** *it was on top, between the two of them. One won it for nine years, the other one won it for seven. So, ah, over that time, the only person that broke the sequence,*
1112. **Bill:** *Yeh.*
1113. **Nella:** *was Bob's brother-in-law, ah,*
1114. **Bill:** *Yeh.*
1115. **Nella:** *Bill's brother's brother-in-law. He was a jockey too.*
1116. **Maxine:** *Right.*
1117. **Nella:** *And he actually won the premiership,*
1118. **Maxine:** *Ah.*
1119. **Nella:** *and broke the sequence.*
1120. **Maxine:** *[And you would have liked it to have been,*
1121. **Bill:** *(And Bill nods affirmatively).*
1122. **Maxine:** *yeh.*

*Listening for others*

Nella and Bill's life was, both before and after the stroke, filled with many people including family, friends and colleagues. They had both maintained a very active interest in horse racing. They regularly attended race meetings, following their horse and taking part in the social activities associated with the sport. People continued to be important to them and Nella believed this was also essential to assist Bill getting on with life and living with the stroke:

1395. **Nella:** *No, I think his nature is quite good. You know. He's able to /ack/ – accept it and that (and she pauses). And you've got a lot of friends, haven't you?*
1396. **Bill:** *Yeh. Mmm.*
1397. **Nella:** *[They come round and see you a lot. I think racing gives you a lot.*
1398. **Maxine:** *[Well, you've been, you'll, that name will never change, will it (as I turn to the next question)?*
1399. **Nella:** *And I think you, you – you know, um, having been in racing, you've always got someone there to, um, that you can - come round to visit you or something like that, you know, I mean,*
1400. **Maxine:** *[Mmm.*
1401. **Nella:** *you've got memories and, of all the things.*
1402. **Maxine:** *[Shared, shared memories.*
1403. **Bill:** *[Mmm.*
1404. **Nella:** *[Yes. Yes. And sometimes there's someone, racing people come in and, and you know, you go back to the old times and that's, I think this was a big,*
1405. **Maxine:** *[Right.*
1406. **Nella:** *help (pointing to Bill), you know.*
1407. **Maxine:** *Yeh.*
1408. **Nella:** *Mmm.*
1409. **Maxine:** *Well, that's part of you, isn't it?*
1410. **Bill:** *Yeh, yeh.*
1411. **Nella:** *Yes.*

However, the aphasia also brought with it frustrations:

1524. **Maxine:** *Just – the last one is just, just about the talking difficulty. How, how do you think, you know, how's it affected things for you, since your stroke? The difficulty with talking (and I place my fingers across my mouth).*
1525. **Bill:** *Mmm, well, Nella, /him, him, himma gotta go/. Um, /him, him, himma gotta go/ (and gestures around the room).*
1526. **Maxine:** *Around home?*
1527. **Bill:** *[Yes, yes, yes.*
1528. **Maxine:** *[And Nella? Fine?*
1529. **Bill:** *Mmm. /Him, him, him, himma gotta go/ (and d shakes his hand from left to right and frowns).*
1530. **Maxine:** *Other people? Friends?*
1531. **Bill:** *Oh, yes, yes (but not definite).*
1532. **Nella:** *It's frustrating when we get friends,*
1533. **Bill:** *[Yeh.*
1534. **Nella:** *coming round, especially when I say racing friends, when they're talking about racing and what's happened or what had happened, you know, the past,*
1535. **Bill:** *Yeh.*
1536. **Nella:** *in looking back he can't, he feels – you feel you want to put your bit in, don't you?*
1537. **Bill:** *[Yeh, yeh, yes, yes (and raises his index finger in the air).*

### *Of the stroke*

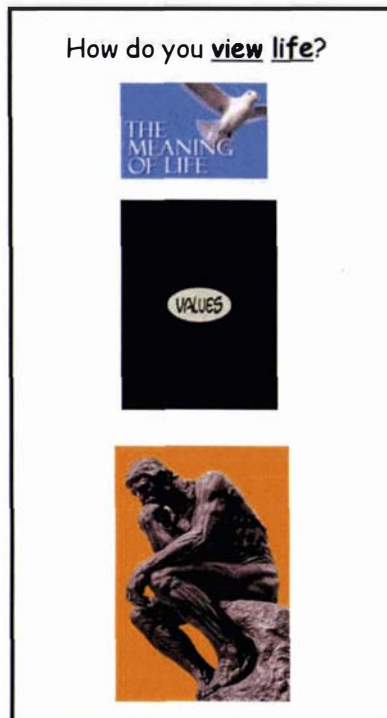
The impact of the stroke in their life was major and both Nella and Bill expressed this. Bill continued to be troubled by pain on the side affected by the stroke and this was a frustration for him. His ability to spontaneously produce some single words was at times a surprise to myself but also to Nella within his overall communication. In talking about the stroke one of the props that Bill used was a time line which we had created for the interview, marking out from birth to an indefinite future. It acted as a way of structuring our talk:

1079. **Maxine:** *Okay (and I turn to the next question). This is a, a toughie but if you're standing here, so here we are in two thousand I suppose and you look back over your life, what does it look like?. If you look back over your life, what do you think of your life?*
1080. **Bill:** *Ten years (and he bangs his hand straight edge down as if cutting the time line ten years ago coinciding with his stroke).*
1081. **Nella:** *Oh (as if surprised).*
1082. **Maxine:** *With the stroke.*
1083. **Bill:** *Yeh.*
1084. **Maxine:** *Yes, okay. But if you think of the whole life before that, what does it look like?*
1085. **Bill:** *(And he holds his hand palm upwards as if showing something) /Him, him, himma gotta go/, yeh.*
1086. **Maxine:** *Okay?*
1087. **Bill:** *Mmm.*
1088. **Nella:** *A good life.*
1089. **Bill:** *Yeh, yeh.*
1090. **Maxine:** *But you put the stroke in as a (and I imitate his slicing of the line).*
1091. **Bill:** *Yeh.*

While some assumptions can be made about Bill's sense of self based on his life story, the shared interview also was a location where Bill's competence was accepted, maintained and reinforced. The degree of impairment was minimized, at times, by the negotiation skills between Nella and Bill and their ability to create the stories between them and it became easy to be caught up in the story rather than the telling. While Bill's language was severely impaired, his ability to talk about himself and his life, both independently and in concert with Nella was not.

1458. **Maxine:** *(Selecting the next questions and turning it round for Bill to see) Now this is a - hard one to explain. It, it, it's really about do you have a philosophy or some views on life? What do you believe about life or what gets you through life? That kind of, it's a hard question.*
1459. **Bill:** *Oh, /Him, him, himma, himma gotta go. Um. Um. Christ and /himmma gotta go/.*

1460. **Maxine:** *You have, you, you believe in God?*
1461. **Bill:** *Yeh. Yeh.*
1462. **Nella:** *[Yeh.*
1463. **Bill:** *And um, /him, him, him, himma gotta go/ (and he points to a picture on the prompt page<sup>43</sup> which has the word "values" within it). Values.*
1464. **Maxine:** *Yeh.*



**Figure 7.3:** Prompt page for philosophy of life question

## The Process

### *Thinking individual, becoming relational*

When I first met Nella and Bill, my initial assumption was that the interview questions would be difficult for Bill but I also saw that he and Nella had a style of communication that together they presented Bill's story (and increasingly as I identified through the interview), their story. However, during the interview, I began to feel that Bill could verbally contribute much more, given time and

<sup>43</sup>The page is shown in Figure 7.3.

support. Nella, however, tended to build on Bill's verbal communication attempts and I constructed it as "speaking for" Bill. On reflection, I could hear myself subtly trying to challenge this and I see this now as the influence of my therapy background and the strong hold of an individualistic approach. As I worked to be inclusive of Bill and as I tried to give him the opportunity to "say" more, I failed to understand the nature of what was happening. This was a major turning point for me doing the project. I had increasingly been reading, writing and thinking about the relational aspects of communication and self-construction yet in practice I was still attributing communication success to be Bill being able to "say" what he wanted. But this story was also very much Nella's story. Bill's success was also very much their success. Bill was instrumental in providing directions for Nella in her telling of his (and their) story. Nella and Bill had also shared the years since the stroke, with some professional intervention for his aphasia and they had developed communication patterns to enable them to continue to share their lives, enabling Bill to maintain his identity and narrate his evolving story in the presence of severe aphasia.

## Mavis

*And so, I think you should, I think in life, you should try to help other things, help, help to, and to take part of it, lots of things. Yeh.*

Mavis, 203.

## The Story

From our first contact, Mavis was enthusiastic about being involved in the project and we met one day with me returning the next to complete an interview. She had had a stroke in 2001 when she was seventy. At the same time as she had her stroke, her husband, Anthony, died suddenly therefore she returned home with the effects of her stroke and widowed. Mavis was right handed and the stroke had affected her left arm and hand<sup>44</sup> and she had aphasia.

### *Communication as a goal*

Mavis's speech was fluent and while she had some word finding problems, she had an idiosyncratic way of negotiating with the listener. The joint searches for words were made easy by her positive approach:

65. **Mavis:** *Yeh, like we, and for four years, before I came to New Zealand, I was in the, ah, army, not the army, but the army - /tee/, um, the ones you look after /ih/, um, in the ah, /terra/ /terra/ /terra/ terryterry - tear*

66. **Maxine:** *[Territorials?*

67. **Mavis:** *That's right.*

68. **Maxine:** *Yeh. Okay.*

69. **Mavis:** *[You've got it.*

484. **Mavis:** *So I used to, ah, in the local, local paper, it said they wanted people on the*

<sup>44</sup> While "crossed aphasia" is significant as a rarity for a therapist for Mavis this was of no significance to her living with aphasia.



-/chih/, "C", "H", "E", "X", "C", "X"(and she spells out loud as she writes letters on the back of the prompt book with her finger), check, check (and looks up at me).

485. Maxine: *Check?*  
 486. Mavis: *Yeh, what you're saying (and points to me).*  
 487. Maxine: *Check-out?*  
 488. Mavis: *Yeh, yeh.*  
 489. Maxine: *Check-out, right?*

Her goal seemed to be communication; not being correct or exact to the detriment of the conversation but to preserve communication between us. Several times during the interview she also used a previous joint production as a short cut later in our conversation. At one point, it took several attempts for us to locate the word she wanted:

1377. Mavis: *I'm not a scary, I'm not a /s/, /sh/, shy person at all,*  
 1378. Maxine: *Right.*  
 1379. Mavis: *but there's a main difference between shay and, um, um – um - what's the difference between shy and?*  
 1380. Maxine: *[Confident?*  
 1381. Mavis: *What's that?*  
 1382. Maxine: *Confident?*  
 1383. Mavis: *Yeh, yeh. Well, no. Not really confidence about. Sometimes it's, ah -/in/, can't think of the word. Um - /shoh/, um – um (and has her eyes closed as she thinks) – not confidence, um –*  
 1384. Maxine: *Comfortable?*  
 1385. Mavis: *[/s/, self, self. Self (and points to her self and then writes invisibly on the sofa)- /con/, /conshih/,*  
 1386. Maxine: *[Esteem?*  
 1387. Mavis: *No, self, self /consh/, /conshilly/,*  
 1388. Maxine: *[Self confidence?*  
 1389. Mavis: */conshish/ (and points to me).*  
 1390. Maxine: *Self conscious.*  
 1391. Mavis: *Yeh.*

Further into the same conversation she did not spend any extra time negotiating the word for a second time. Instead she signalled our shared understanding:

1409. Mavis: *For one minute, for one minute I won't be shy at all. But sometimes, if I first come on, if people, look different or, um. I used to find that quite difficult,*
1410. Maxine: *[Right.*
1411. Mavis: *difficult to do that sometimes. When the, I think that when the children, when you've got, when all they've got, and you haven't got not so many adults around, and there aren't so, um – I could never understand why I didn't want to do certain things,*
1412. Maxine: *Mmm.*
1413. Mavis: *Because I felt /un/, /un/, that word you were saying.*
1414. Maxine: *Self-conscious.*
1415. Mavis: *Yeh, yeh, I did.*

Later, in an e-mail after the interview she wrote:

*Some people doing speech work try to make me talk more slowly, but to me the words seem must be quick as I always talk. I can't help its natural.*

Mavis did not talk about speech-language therapy specifically within the interview but after taping she told me about an episode during her hospitalization that I understood to be some form of assessment. She described being taken into a room with two people and feeling that she could not do anything, that she had failed and that she would never be able to do anything. When I asked her how it could be different, she said that it was too early and that she should have told them that it was too early for her to do the test. This she could still recall three years later and her comment is pertinent to considering therapy as a social practice. Her identity as a patient in a hospital and as a person with aphasia exposed her to different practices. Without a “voice” she was unable to change a practice about which she could have told us that she was not ready to undertake.

*Bridges to recovery*

Mavis had played bridge before her stroke, a game which she loved. She describes beginning to play again after the stroke and how it also became a way for her to understand her progress and her improvement after the stroke<sup>45</sup>:

*Well, I was quite, when I first, when I had my – stroke, of course I could not do anything at all like that and, um – for /sih/, for - for six, months (and she holds the fingers up on her right hand), I couldn't do, I could not even, um – I /kih/, I /kih/, I could do not, lots of things because. So then, then they /dee/, then they decided, let, let, let, give, take her some - cards so I tried to get cards. And at the time, I could not know what is diamond or club. I didn't know what they were. I didn't know what they even looked like at all. And then the numbers, numbers were so difficult. I couldn't say - what names it was, what numbers and everything. But I kept trying to, trying to do it. So, gradually I think, when your (pointing to her head), brain is learning to things, it comes back. So, I was very lucky because, a friend of her, a friend had been very, had been sick and she wasn't going to play bridge because she been so sick. So, then she /tore/ me, it was another place in –local one, where, where um - older people and not many people come. So she took me as well, to take me. That was /a/at the beginning. That was, I - I tried to. At the beginning, I couldn't do it. I tried at home, at home, at home, everything. And gradually things were coming back (pointing to her head). And it's amazing how much it does. And so in the end of it, I couldn't actually can play bridge now. Again. . I can do it - I'll never be, as good as I was then, but what I can do I find was fine, because I can, I can learn, I can – all of a sudden now, even now, I'll think of a thing I could do, I could do again (pointing to her head) (264 – 282).*

She also identified the changes in her game with her bridge partner to signify the changes in her abilities and in her communication:

308. **Mavis:** *Which I like, of course. Now I realise, one of the thing, um, making me better, shows m I'm looking better, now with my partner, now I want to – regard, I want to, argue for her (and points to me as if indicating she has "found" what she wants). Argument. I want to argue to her, I want to say, no, don't say it that way, do it this way.*

309. **Maxine:** *Right.*

310. **Mavis:** *[I would never have been scared to do that, but now I can say that.*

<sup>45</sup> The fluency and the quantity of Mavis's speech meant that sometimes I was providing only reinforcement such as "Right" "Okay" or "Yes" as she talked. I have removed these from some passages to maintain the flow of her story.

311. **Maxine:** [So you obviously  
feel, pretty much that, that you're
312. **Mavis:** [Yeh.
313. **Maxine:** *switched on with the game, you,*
314. **Mavis:** [Yeh. That's right. That's, that made me much  
better because,
315. **Maxine:** *Yeh.*
316. **Mavis:** *it just shows me I'm looking better now that I can say, you can argue.*
317. **Maxine:** *You can challenge a bid.*
318. **Mavis:** *Yeh.*
319. **Maxine:** *Yes.*
320. **Mavis:** *Yeh. You've got the right,*
321. **Maxine:** [Yes. Yeh.
322. **Mavis:** [that's a better word than arguing. Yeh.

Within the search for a specific word, Mavis was able to express herself but she was also able, as in her last comment (line 322), identify a word that would better describe what she wants. However, she did this with no sense of being corrected or of failing but rather as part of the flow of conversation.

### *Joining in*

Mavis talked about her travel to New Zealand with her husband-to-be, the early days of building a house and making new friends that grew into life long friendships, her involvement with her family and her very busy life. Among other things, she got involved in Brownies and she supported her children in sport, getting up many mornings at five thirty to take them to swimming training and also becoming involved in helping with swimming. Even when she was playing bridge, she also got involved in other aspects: *"And ah, and then, of course, I, I started to do all the things you do there to help there. I did do it- with my computer, and help with the computer thin"* (237). She felt that being involved was important and also important following the stroke:

*And, so, so I did all that for many years. So my, my life, although I didn't work, I was a very busy person. I always been. That's probably been one of the things now, now that I've had this stroke, I still think you can join things because, if you don't take part of anything, you don't get any -a I do feel that difficult at the /bee/, difficult to do it now but now I can do it again (some emotion in her voice?). And I think a lot of people don't – join. They don't want to, they don't want to join. They're not joiners. A lot of people who either join and people don't want to (and she moves her hand from left to right as if indicating opposites) but I reckon, it makes your life much more interesting and also, you learn to /lie/, new, new people, all the time in you life, even now like that. Yeh (softly and with ? emotional). So really all those years, since I was - for always (and scribes her hand as if back to the past), for always, all been who person like, to, join things, and be, and help, and help people. (167 – 183)*

### Turning points

*And think now, ever since I've had a stroke, I think that is making it better as, helping me as well, because, because of what happened then.*

Mavis, 616.

As we moved through Mavis's life story, she came to a point where she prefaced her story with "Well, I haven't told, something I've got to tell you which it was a big thing. Great, huge big thing to me. When I was married for twenty seven years (drawing "27" on the book with her finger), when I was twenty seven years, my husband decided he didn't want to be a /mih/, married any more" (452). For Mavis this was a terrible time; she had just had her first grandchild and she was nearly fifty. A year before this happened, when her youngest child was sixteen, she had decided that she should be doing something else. However, as she was leading a very busy life, she did not want to take on something that made her too busy so she got a part-time job at the check-out of the local supermarket. When she and Anthony separated, she felt the first thing that she needed to do was to get full-time employment. She then began work as a bank teller and continued until her retirement:

540. **Mavis:** *I could take all those old people and help them. I used to do it /?/. And the bank people used to know, if Mavis doesn't know, if there's no, if someone's got a - problem, Mavis will have it.*
541. **Maxine:** *Right.*
542. **Mavis:** *Give it,*
543. **Maxine:** *(And I laugh)*
544. **Mavis:** *give them to (and pointing to herself), look after Mavis.*

545. **Maxine:** [Shuffle them down to
546. **Mavis:** [Because I liked  
doing that.
547. **Maxine:** Yes, ah.
548. **Mavis:** [And when I first, I never think, when I first got my – the job, I could not  
understand, I could not believe, that I loved it so much that you, at the end of  
the week, you got a /?/, you got a, you got the, you got paid for doing it.
549. (We both laugh)
550. **Mavis:** It was so good. I still enjoyed it.
551. **Maxine:** Yeh.
552. **Mavis:** I still, right at the end, I always loved it.

While she described her husband leaving as being “horrible” (618), she also believed that it was actually the best thing that had ever happened to her, that she started to do things for herself and that “I was never scared of anything” (612). She considered her separation as a turning point; a time when “I became a different person. And much of it, much of it was better for me” (1314 – 1316):

*I, I reckon what happens, I know that’s a funny thing to say now, but because those, that what happened to me, made me a much different person, a much different person. It made me more, um, um - much more, ah, became myself, much more about me. More about me, yeh. (464-472)*

When we talked further about how this happened, she was initially unsure: “I don’t know. Suddenly – I know. Yes I do know, it was going to England. The England thing that happened to me” (1326). Mavis, several years after her separation, travelled back to England for six weeks revisiting friends and family: “And it was, I never know my life was absolutely wonderful” (589)

1362. **Maxine:** So a key changing, a key time of change, for, for how you saw yourself.
1363. **Mavis:** Oh, definitely, definitely.
1364. **Maxine:** [Yes, yes.
1365. **Mavis:** I was more of a, a – well, when you hadn’t worked for twenty five years, or  
when, um – it’s hard to say about myself, really, um – um – you really feel  
the idea, I can do anything. That’s who you feel like.
1366. **Maxine:** [Mmm, mmm.

1367. Mavis: *That's who you think, that's what you think.*
1368. Maxine: *Well, some people probably don't ever achieve that in their lives, do they?*
1369. Mavis: [No.]
1370. Maxine: *You know, so –*
1371. Mavis: *(She pauses). But I don't, um, but I do think that, um –*
1372. Maxine: *How would you have described yourself before this, you know, you're saying, that, that you, you felt you could do anything and this, this change in yourself, how would you have described yourself before that (And I sweep my hands as if indicating the before, the past).*
1373. Mavis: *Well, I'm funny because in some, in some respects, um – as my husband always used to think, why you so scared of everything, why you so scared other things?*

Mavis associated this sense of no longer being scared of things and of feeling that she could do anything to her separation and then to travelling on her own. She also related this to how she coped with her stroke:

*When I first had my stroke, bus from that bus I hated to tell the bus drive. I hated `to tell them now and think about it all day before I go. Shall I go or shall I go? Oh, no, I don't want to go. Now I can, I can manage for that. Well, you've got to learn that it takes a while to get better, doesn't it? (1433 – 1435)*

Anthony and Mavis were still in contact during their time of separation and they still saw each other with Anthony always joining the family for family celebrations. Then ten years later, "we came back together again" (566). Mavis also felt that this was horrible from the point of view that people did not understand why. She talked, though, of sharing so much and that they were actually very good friends who did a lot together: "He loved his bridge. I like my bridge. He played golf. I played golf" (673) and "We liked the same things. We talk. We, we, we /adreed/, we agreed about so many things" (687).

While Mavis had been able to identify the significance of her separation, of her working and of her travel as a turning point and a change in her sense of who she was, she did not signal a major change in how she would describe herself since the stroke:

Now. Well, I think I'm the same person really I've ever been. I'm exactly the same as I was. What you're saying up there (and points to her head) is what is there. What is – all. I'm still, still the same person. I don't /thih/, this, (pointing to the words above picture with the question mark). I feel that the, ah. The things about thinking about myself, I still, still the same, I think, really. I don't think I'm much, much different. It might, cannot – do some things. (1683 1691)

### Of friendships

*And I think having friends is very important*

Mavis, 967.

In the early years of establishing a home and family, Mavis and Anthony lived in a newly established suburb and with babies and no transport, people in that developing community became closely connected sharing similar experiences:

953. **Mavis:** *And those people become our great friends, are still my best friends (points to herself).*
954. **Maxine:** *Okay.*
955. **Mavis:** *It was like a family, it was like a family.*
956. **Maxine:** *[A community. Yes.*
957. **Mavis:** *Exactly. Yeh, it was great.*
958. **Maxine:** *[Yeh.*
959. **Mavis:** *And those friends have been very – friends are like a -been, been my life (pointing to herself).*
960. **Maxine:** *Right.*
961. **Mavis:** *Friends have been very, part of my life.*
962. **Maxine** *Okay.*
963. **Mavis:** *And been very good.*
964. **Maxine** *Right.*
965. **Mavis:** *[We've all been good friends together.*
- 
988. **Mavis:** *Even when I had my stroke, some of those people as well those people who were friends up there,*



989. **Maxine:** *Yeh.*
990. **Mavis:** *they they, because you've had a stroke, sometimes people some people don't know what to tell you that does happen. Some people are not sure whether to talk to you or not it's very difficult.*
991. **Maxine:** *Yeh.*
992. **Mavis:** *So those friends all those year away some of the best.*
993. **Maxine:** *And stayed, stayed.*
994. **Mavis:** *Yeh. And all those ten years Anthony wasn't there, they were always always take me everywhere,*
995. **Maxine:** *Yeh.*
996. **Mavis:** *'Cos I tell you one thing, I don't know if people ever realize when you are one person on your own you are younger, especially when Anthony wasn't here, people don't always take you, don't always um, ask you if you're going for dinner to someone's house, sometimes they don't ask you.*
997. **Maxine:** *Whereas if you had still been a couple,*
998. **Mavis:** *That's right. I'll never forget they've been such great friends.*

### *Of losses and dreams*

*I don't think, I haven't got any plans. But dreams. Ah, of course, I have dreams.*

Mavis, 1681.

Mavis talked about her dreams for her children to be happy and to have a good life with good partners. She also draws her dreams from her losses. Reading had been important to her; she loved history, she was actively involved in genealogy and reading was important to her. So the loss of the ability to read was difficult for her and her hope was to be able to read again:

*Dreams. I would like, my dream would, one dream would be able to, to, to, um – be able to read, the books, again. I love, love, love reading. I love reading. Yeh. And I miss it. Miss it. Because, when you read, read, you, your dreams are up in these, head (and points to her head and looks upward). And, and, and all those things, like watching T.V. I know you can but the same, not the same, but dreams are. A good book, takes your life with you. Takes your, takes your, takes your out of yourself. (1655 – 1663)*

Subsequent to our interview, almost six months later, I contacted Mavis to finalize how I could return the draft narrative of twenty pages to her. We had talked earlier about her reading difficulty and perhaps using a life history map. However, over that time, she had realised that her reading had improved. She had spent a long weekend on her own with family and friends away and she had picked up an historical fiction book and found that at one o'clock the next morning, she had still not put the book down. She was delighted to know that she could now read books again. This also made easier my returning the narrative but it also opened up an important part of her world again and I recalled her earlier comment: *"Well, you've got to learn that it takes a while to get better, doesn't it?"* (145).

### *Of location*

As I talked with Mavis and I reviewed our conversation many times, the social and historical location of Mavis's life story became more prominent in my listenings: her immigration to New Zealand as an adventure when she was in her early twenties in the beginning of the 1950s, bringing up five children in a developing suburb, an active involvement in the community and in supporting her children, not working outside the home until her fifties, her subsequent separation and her discovery of who she was through the changes thrust upon her and even her access to the computer, the internet and e-mail are all placed in the context of a social history. It speaks of the changing role of women in society and of self-discovery, of the changing expectations of relationships and of marriage and of our changing communities. Mavis talked about those early days of child rearing and living in a developing suburb in the fifties and sixties:

971. Mavis: *that's actually we had no, we had no cars no cars well Anthony had a truck but we had no, no, no to none to um, um, we could not ah we were far away from the/chops/, shops and everything.*
972. Maxine: *Right.*
973. Mavis: *And so, we all to try it, to try it together.*
974. Maxine: *Did you all share, like, were you all having children?*
975. Mavis: *That's why I feel sorry for people today,*
976. Maxine: *Yeh.*
977. Mavis: *life is much although we hadn't got, hadn't got any money at all,*
978. Maxine: *Right.*
979. Mavis: *nothing at all, but life was very good.*

And her own evaluation of looking over her life:

*So I was very. I reckon I've been very luck in my life now I'm still being lucky. Lucky, in founding this house now. Like to be able to walk to the mall, walk all those things, yeh. Still make – if you think you're lucky, makes, makes you feel better, doesn't it? (1012-1018)*

## The Process

### *Confidential and anonymous?*

*You're, you're the only person I've told that.*

Mavis, 783.

During the interview, Mavis shared with me aspects of her life that she said she had not shared with anyone else. The nature of the life story, the opportunity for personal reflection and the presence of a supportive listener are all conducive to self-exploration and the subsequent telling. Although I believed that these experiences contributed to Mavis's self narrative, I resolved not to include them as specific details. Rather I hoped that the overall presentation of her story also wove in many experiences in her life, not all of which were detailed in the interpretive narrative. Listening for voices rather than listening for a "plot" alone was also a rationale for this decision.

While I do not believe that the things we talked about were in any way particularly private or intimate, I balanced what they would add to the narrative presented here and whether or not they were actually present anyhow in the tenor of Mavis's life story. I prioritized the trust that we had developed within our contact and inclusion of other information would have required much more time together to dialogue about the necessity of including or excluding information. The draft narrative was returned to Mavis for her review before it became part of the thesis and she will receive back the full transcript and the videotape when the project is completed.

This example asks us to consider the private self and the ethics of narrative research. It also, however, involved my questioning of the practical aspects of confidentiality and anonymity as I analyzed and constructed all of the individual stories. It highlights the methodological problem of the approach I used and of placing the resulting narratives in a public domain (Mauthner, 2000).

From the beginning of my contact with people, confidentiality was a point of discussion particularly in reviewing the information sheets. The standard, long hand version of the information sheet contained a paragraph about protecting confidentiality and included:

*The tapes and written records for the research will be identified by the use of a pseudonym and it will not be possible to identify you by name in any reports that are prepared about the study.*

The aphasia-friendly version of the information sheet contained two references (as shown in Figure 7.4) to confidentiality

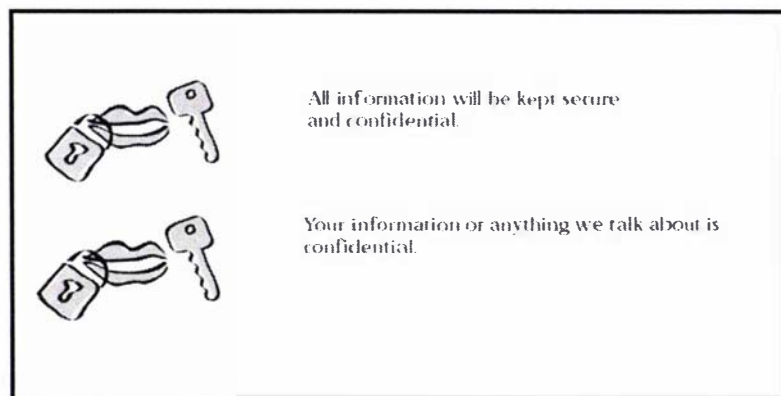


Figure 7.4: Confidentiality references in aphasia-friendly information sheet

As the project developed, I was very conscious of these commitments and made sure that all information was kept secure and confidential and that I maintained confidentiality about people and about their life stories. However, I became increasingly aware as I met with people, as I started to make decisions about the form of the final thesis and how the narratives would be presented, that I might not be able to ultimately ensure anonymity for all the participants. Through their stroke groups, several of the participants knew that other people with aphasia with whom they had contact were taking part in the project. Although I was careful in my discussions as I visited people, participants were often curious about who else was involved. Also, over the time of the project and through the stroke groups, some participants were meeting and talking with others without the same stringent ethical guidelines required by a researcher. While only one participant requested a copy of the completed thesis and was interested in the other seven stories, it would be possible for people who knew one another to identify people by some defining features through reading the other narratives. Even each person's distinctive communication

patterns would possibly also act as an identifier unlike the transcribed speech of people without aphasia. While I could have altered some of the more factual information, such as occupation and age, doing so would also have changed the context and would have disturbed the social, cultural and historical aspects of self construction. I also found myself thinking about how a pseudonym could also shift the orientation of the story; a pseudonym of "Ziggy" for an eighty year old man has a different constructional influence than a pseudonym of "Tom". Of the eight interviews, the participants involved in two elected to have their own names used.

I sent each participant a draft of my narrative of her/his individual interview. People were encouraged to make any alterations and to delete any information they were unhappy with and wanted excluded. This added an additional level of care in the construction of the narratives as I became aware of what and how I was writing about the participants and myself, and how it would be to be a participant reading the narrative. Some of the participants had reading disability associated with their aphasia and I attempted to provide a form that would be more accessible for them (a pictorial life history or a life history map). There was of course a difference between such formats (a life history) and my long hand narrative (a life story narrative) as an interpretive process. I also provided the long hand narrative so that participants' partners would know what had been written and perhaps together with the person with aphasia would be able to provide feedback. Throughout the project I had the ability and the authority to present myself in a way over which I had control; participants, apart from the opportunity to amend the draft narrative, did not. Again, while the process of qualitative inquiry was difficult to explain at the out set, the process of interpretive work was also hard to clarify.

## Mark

### The Story

Mark, aged seventy seven, had severe aphasia as the result of a stroke five years earlier. It had affected verbal expression but also, at times, there were some difficulties understanding spoken language. Written language was also severely impaired and not a viable alternative to speech. Communication involved a limited number of single words ("No", "Yes", "See", "Look", "Jesus", "Ay?", "Dee") and some infrequent and isolated words which occurred spontaneously and were sometimes slurred in quality. At times, he repeated out loud some short words. Although I initially had reservations about completing an interview, given the severity of Mark's aphasia, we went ahead. Over the course of the interview, the transcription and the analysis, I came to see just how he used what limited language he had and how he made use of the other resources available to him through the interview; either those in his home or the props that were created for the interview. Even though I knew he would be unable to read it, I developed a narrative from the interview as though I was talking to Mark. I considered this to be an appropriate vehicle for me to be able to summarize our conversation and my interpretation which I felt recreated the sense of subjectivity; Mark's, Lisa's and mine. As well it gives a sense of a developing relationship despite Mark's severe aphasia.

### *Mystory*

We met twice. The first time was when I visited you and your wife, Lisa, to talk about the research project. I had no prior information about you except that you had had a stroke and you had aphasia (talking difficulty following a stroke). When we met, I established that aphasia made verbal communication difficult. In a conversation, you seemed to be understanding and you indicated if you did not. Reading and writing were not easy although sometimes if you saw a word written down, it might help you in saying it. I wondered whether or not the research interview would be too difficult for us to complete: a life story interview with questions about your life and what you tell of your self and identity in living with aphasia.

I had made contact with you and your wife through The Stroke Foundation. I had indicated that I would be happy to meet with anyone who was interested in talking about the research project. I was now initially nervous that you would want to be involved and what that might entail. I was also conscious of my desire to make the process as inclusive as possible and so this ambivalence made me uncomfortable. People with aphasia are often excluded from research so I did not want to also practice that exclusion if you wished to be involved. We went through the information sheet and the consent form and I tried to be clear about the project and what you could expect (although I was still finding my own way to talk about the project). I chatted with you and Lisa about the stroke and about your lives. I was aware, at times, that she and I talked around you and I watched you frequently look to Lisa when my questions were difficult to answer. As I listened and talked, I was also actively trying to find my feet and to find the best ways for us to communicate.

I was aware of the limited time available to build up a relationship. Although I thought you were happy to meet me and we seemed to establish a good understanding, I sensed your hesitancy about your participation in the project. I knew your wife was more enthusiastic. You, however, were very keen to show me how your walking was progressing. When I left, I said that I would ring your wife after you had both had time to talk. If you wished to take part, we discussed sharing the interview between the three of us as we had our conversations in that first meeting. I told you I would send some of the questions so that you would have time to prepare.

As I drove home, I thought about the notion of inclusive research and aphasia, particularly when verbal expression is severely compromised. How could we "do" an interview which is heavily weighted towards being able to "tell" your story? It was not the first time I had considered this but it was now no longer an academic question and it came with responsibilities and challenges. As I thought back, I was reassured by the "props" that were available to you in your home that would support your telling; the environment, the many photographs of your family that were hanging on the wall and displayed on the shelves and also the presence of your wife of fifty four years. I thought about shared stories and shared lives and wondered if we did meet again, how the process would work. But, at that stage, I still sensed that you would choose not to take part.

However, several weeks later I rang your wife and she indicated that you wanted to do an interview. We arranged a time and I sent examples of the questions. We then met again for an interview and our video recording began with the two of us sitting around the table in the living room and Lisa joined us with morning tea. Ready on the table were loose photographs and photograph albums and pen and paper in preparation for the interview. I also brought with me the book of prompt questions and pictures. What follows is the story that the three of us crafted in the hour we spend together. You did this through the tools you had available. Sometimes you might say a word, you might point at something, your voice changed in its pitch, rate and loudness to convey your meaning and you involved your wife when you needed to. I drew a time line on A3 sheet of paper as a way of introducing the life story format for us to talk around (as shown in Figure 7.5).

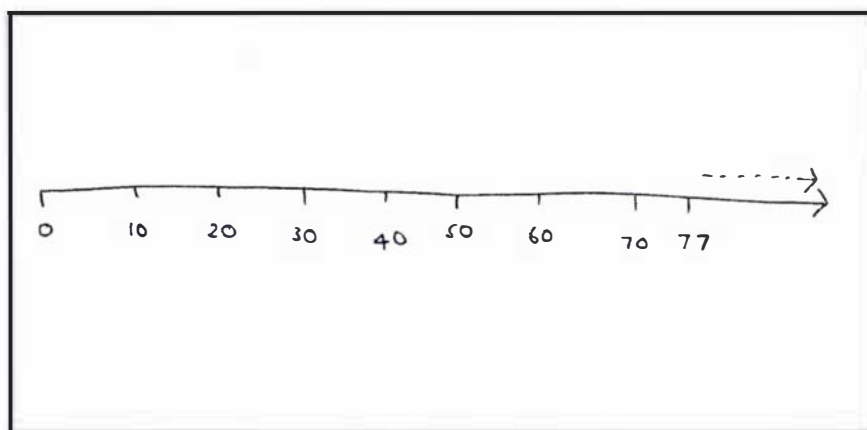


Figure 7.5: Time line prop for interview

I hoped that my experience with aphasia and my first conversation with you would enable me to make the ensuing conversation a shared one. There were times when you gave up because you could not express an idea but sometimes Lisa and I failed to understand or we moved on too quickly, leaving your communication attempt incomplete.

*You were born in X, one of five children. You were delivered by your grandmother, a midwife, whom you called "Mum" and you lived with her for quite a while. She is credited with saving your life as you were only three and a half pounds at birth. In your school days at X in X, you played rugby and it is said that you were always "in the cart". One year, you got the medal for the boy that never bears malice! Your photos show you at school and during your football days. Many of the people you shared those experiences with have since died, some at a young age.*



You left school at thirteen and, because you were too young to begin an apprenticeship, you worked in a slipper factory. You were small for your age and this made you an easy target for teasing by the factory girls. You began a building apprenticeship in the late nineteen forties and your working life continued until you were sixty. You took a break, however, from carpentry when you finished your apprenticeship and took up driving for a carrying firm. You married Lisa fifty four years ago and when you got married, you bought a house and moved to X and went back into carpentry, working for a branch of the same firm with which you did your apprenticeship. For the last decade of your working life, you taught carpentry. Despite official retirement, you still kept on building and you were always doing something. Your seventies brought some complications with your health and you had abdominal surgery and then had a stroke when you were seventy two. A year after the stroke, you had to go back to hospital for surgery on your hip.

The stroke was severe and you spent seven weeks in hospital. The stroke caused left sided weakness and being a left hander, you also experienced aphasia (talking difficulties). Initially, it was suggested that you would need to go into a rest home but you wanted to get home. In order to return home, you needed to be able to walk. Photographs record your recovery and show you, in the early stages, requiring three people to support you. Now although you have a wheelchair, you are able to walk short distances around home with the aid of a stick. You have thrived being able to watch all sports on television as you were able to follow and enjoy it from very early after the stroke.


Family has remained important to you as has your faith. Sadly, you lost your first child, a year after you were married but you have eight adult children and your family now includes grandchildren and seven great grandchildren. Although some of your family now lives in X, you still catch up with one another and there is always someone calling in. When you look back over your seventy seven years, the only thing you would change are the years where you have experienced problems with your health and with the stroke. Considering the future, you think about your family, your wife and your home.

I put this story into a form that would be useful to you with supporting graphics and text (an example is shown in Figure 7.6). I hope it is.


### Health

- Always healthy
- **Stroke**

Walking




Talking



### Working life

Driving



Building and teaching




Figure 7.6: PowerPoint slides for Marks's life history

### *Collaborating on a life story*

We could not have done what was done during the interview without involving Lisa. They had been married for fifty four years and so much of Mark's story was also Lisa's. To have not acknowledged and incorporated this would have been to create an obstacle for Mark in being able to tell about his life. I had already completed one interview with both partners taking part and I had already gained insight into the way in which communication is enhanced by this collaboration in severe aphasia. It would have been easy to have relied solely on Lisa to recreate the facts of Mark's history but throughout the interview Mark was active and involved in negotiating the story with Lisa and myself. Very early on Lisa got Mark to show that he could say some words such as where he was born or the names of people. However, this lessened during the interview and while Mark sometimes said some words, it was spontaneous and without prompting and the focus became one of communication not talking.

Just after the beginning of the interview, Lisa asked if she should talk and I put the question to Mark. His reply was definite and he accompanied "Yeh. Yep, yep" (74) with pointing to Lisa to confirm this. What was required on Lisa's and my part was to be attentive to the changes in how Mark used his verbal skills and gestures along with gaze and facial expression to allow him a voice within the interview. While this was more natural for Lisa, it took some time into the interview for me to feel that I was more fluent in developing the conversation together with Mark. Mark involved us by gaining attention through "See" or "Look" but also achieved this through drawing attention to a photograph or the timeline or the act of handing a photograph for one of us to look at and to start to talk about.

Mark had had very limited speech-language therapy and Lisa had said earlier on that it "*didn't go very well*". Regardless, Lisa and Mark had developed good communication on top of what I assumed to be an already strong relationship and communication style before the stroke. She included Mark in her conversation and preserved a strong sense of his competency. There was also a closeness demonstrated in their eye contact, their shared humour and physical contact. Lisa summarised where they had arrived at: "*It's peace (and she stretches her arms wide), ah, it's a peace of mind and I think, we've kind of found that, you know. Like, what we've all been through now and we just enjoy every day (1632 - 1634).*"

*Transcending severe aphasia*

Although we all worked hard to understand one another, communication between us was not always successful; there were times when Mark would attempt to express something but then he would sit back in his chair with an exasperated “Ah” or throw his hand up and shake his head negatively, as if to say either “Leave it” or “I give up”. Sometimes it was related to him not being able to develop his message and at other times it was related to Lisa and I not being able to follow his lead. Completing the analysis, however, was revealing for me as I had the opportunity to look in much greater detail at Mark’s ability to transcend, at times, this severe communication disability and communicate things of importance to him. While the photographs were familiar to him, the time line was a new tool but Mark began to use it as a reference point to initiate ideas, to give us a lead and as a continued prop throughout the interview:

652. **Maxine:** *Okay. And we’ve headed towards (as I point to the present time on the time line) - time picks up speed, doesn’t it?*
653. **Mark:** *Um, um (and he moves forward and points to the seventy mark on the time line). See (and looks up at me).*
654. **Maxine:** *What happened around seventy?*
655. **Mark:** *(He shakes his head once negatively and holds his finger on the line). Ah: (and he drags his voice out as he draws his finger downwards at right angles to the line). See (and looks to Lisa).*
656. **Lisa:** *Your stroke?*
657. **Maxine:** *[Are you talking about your stroke?*
658. **Mark:** *Yep.*
659. **Maxine:** *Yes. Okay.*
660. **Mark:** *Seventy.*
661. **Maxine:** *At seventy.*
662. **Mark:** *(He nods). And (he rubs his finger along the time line),*
663. **Maxine:** *Okay.*
664. **Mark:** *Bloody hell. And,*
665. **Maxine:** *So you,*
666. **Mark:** *[Oh, and (he shakes his head negatively and sits back in his chair). See. /Dee/, see, /dee, (as he accompanies each word with a movement of his hand firstly over his stomach, then his right side and his left arm).*

667. **Maxine:** *The hip,*
668. **Mark:** *Yeh.*
669. **Maxine:** *and the,*
670. **Mark:** *[See.*
671. **Maxine:** *so you had a bit of a health (and I hold my hands up as if encircling a ball and move them from side to side), issue around that time.*
672. **Mark:** *Yeh (and he nods affirmatively).*

### *Negotiating meaning*

The interview relied on a negotiation of meaning and, while there were times when this failed, there were times that between the three of us, we were able to work towards understanding one another. Mark had indicated early in the interview that he was aware of the presence of the video camera. I had almost forgotten about it but there were several times where he looked and pointed at the camera. However, the success of negotiation lay within how we gather together what we saw and heard but it was also dependent on what was happening for us individually; what we were thinking about and how that influenced how we listened and saw:

1652. **Maxine:** *How has it gone?*
1653. **Mark:** *Oh (and he points his thumb towards the video camera).*
1654. **Maxine:** *You'd sooner be outside? In the sun (assuming he was indicating being outside)?*
1655. **Mark:** *Oh, yeh (and laughs). Oh, no.*
1656. **Lisa:** *[No, I think he's meaning the camera.*
1657. **Maxine:** *[I'm putting words in your mouth. The camera.*
1658. **Lisa:** *Yeh, I think he's looking at that camera (and she laughs and Mark points to it again and we all laugh).*

*Listening (and watching) for meaning*

While Mark's verbal expression was limited to a small number of words, he used these in ways to offer different meanings. "Yes" and "no" performed a variety of functions for Mark in communicating but also in directing the communication and expressing his emotions. We were looking at the pictures of his hospitalization after stroke when I asked him if these brought back memories for him. He looked at me and said "Yeh" in a very soft voice with a single quick nod to the side as if agreeing while indicating the enormity of it all (759). "/Oo/, yeh" indicated definite agreement, "Oh, yeh. See" indicated recognition such as in the photograph with a desire to share it. Whether the "yes" was associated with a smile or with laughter or simply with direct eye contact or with movement of his hand all carried meaning dependent on the context, the questions or what had been said before. Also when Mark interrupted with a "yes", it seemed to indicate an urgency of response and also accuracy on the part of the previous speaker.

If we come to know and understand ourselves through conversations with our past, present, and future projects, how is that achieved for the person with severe aphasia (Wolszon, 1998)? Lisa was able to summarise and verbalize the experience of the life story interview: "I think we should all do that every now and again, shouldn't we? It just makes you realise, makes you realise the good times" (1696 – 1700). However, for Mark the very tool needed to express his experiences was not easily available to him. While the photographs of his life and his family were already available, the experience of going through these in the manner of a life story was probably a novel experience. I watched him several times during the interview looking through the photographs while Lisa and I were talking. He had a small album of photographs related to the stroke and he flipped through these, pausing and perhaps smiling or shaking his head. Although not verbalized, some of those conversations about the past were surely present for Mark in his own meaning making. Sometimes he would use the photographs to initiate "talking" about them and about their meaning for him. At one stage, he selected a photograph of himself walking with the support of three people presumably in the very early days of his rehabilitation:

718. **Mark:** *See, see. Yeh. See, I gotta. See (I am standing by Mark and he holds the album up for a closer look).*
719. **Lisa:** *It was really amazing.*
720. **Mark:** *Oh. Oh (and he sweeps his finger over the photograph).*
721. **Maxine:** *Hard work, Mark?*

722. **Mark:** *Yep. Yep. Yep (and he pauses). Hard work.*
723. **Maxine:** *Hard work. Did you think you would be able to do it (as I return to my seat)?*
724. **Mark:** *No (and shakes his head, still looking at the photograph). I was. /Oo/. See (and he runs his finger over the three people assisting him to walk and then looks up at me).*
725. **Maxine:** *You've got three people there for support,*
726. **Mark:** *Yeh (and he points to the three people in the photograph).*
727. **Maxine:** *[In those days.*
728. **Mark:** *Yeh.*
729. **Maxine:** *And yet now?*
730. **Mark:** *(Gestures in a sweeping movement away from himself at floor level and smiles, looking pleased and looks up at me). See.*
731. **Maxine:** *Now - you've got a friendly stick,*
732. **Mark:** *Yeh, yeh (and gestures again away from himself and slightly round to behind him)*
733. **Maxine:** *but, but, not, not three people around you.*
734. **Mark:** *[Yeh. I – yeh, yeh.*

His description of the stroke took several forms throughout the interview: tracing his right hand down the left side of his body starting at his head and shaking his head negatively; touching his mouth with his fingers as if to indicate his aphasia; picking up his paralyzed left hand and letting it flop down; pointing to himself in a photograph after the stroke and at one point slumping back into his wheelchair, his head falling forward as if imitating losing consciousness. These were accompanied by sounds (/Oo/) or even words "I got, strokes" (922). When we talked about his coming home after the stroke, Lisa was telling the story of the early suggestion from medical staff that she should look for a home for him. With two of his daughters being nurses and his extended family returning home to see him, they decided that Mark should come home. From there, he was then admitted to the local hospital for rehabilitation particularly for mobility so that he could return home permanently. While we talked, Mark was looking through the photographs of his time in hospital and I asked him if he recalled that first visit home:

851. **Maxine:** *Do you have, do you recall all that, Mark? Coming home (while he's still looking at the photographs)?*
852. **Lisa:** *Do you remember that?*
853. **Mark:** *Um, ah (and he sits back in his chair and looks up at Lisa).*
854. **Lisa:** *I don't think he would have done because we don't really know at that stage,*
855. **Mark:** *Yeh, oh (he looks at Lisa and then looks down).*
856. **Lisa:** *whether he knew everybody (with a voice sounding as though tears are close to the surface),*
857. **Mark:** *Yeh (and he looks back at the photographs).*
858. **Lisa:** *but - he knew he was home (and she looks from Mark to me),*
859. **Maxine:** *Yeh.*
860. **Lisa:** *[didn't you, Mark (looking back to Mark)?*
861. **Mark:** *[/Oo/ yeh (and he looks up at me). Oh, yeh (and he draws in the air in a circular motion twice to his right with his index finger as if signalling where we were)*
862. **Lisa:** *[You knew you were home.*
863. **Mark:** *Yep (and he returns to the photographs).*
864. **Lisa:** *Yeh.*
865. **Maxine:** *Where you were meant to be.*
866. **Mark:** *Yeh (and points with a definite stab at the floor beside his wheelchair). Yeh.*

While it is much easier to signify a single concept through pointing or gesture, it is much more difficult to communicate ideas which are more conceptually complex. Mark had identified that his health and the stroke had been an issue for him through referring to the time line and through gesture and we talked about this further:

673. **Maxine:** *Was your health pretty good (as I draw my finger along the time line before the stroke)?*
674. **Mark:** *Oh, oh (and he points towards the time line on the table).*
675. **Maxine:** *You started off as a bit of a, a, a bit of the runt of the litter (as I point back to the very beginning of the time line).*
676. **Lisa:** *Yeh, yeh (and we all laugh).*
677. **Mark:** *Oh, yeh, yeh.*

678. Maxine: *[But, but, your health. What was it like over the years (and again I trace along the timeline with my finger from the early stage until his stroke)?*
679. Mark: *Um (and he pauses, looks at the time line and rests his hand on the timeline page but at no specific point. Then he raises his hand and extends it fully, pointing in front of him) /Swih/, /sih/, see (as he sweeps his hand around the dining room taking in the many photos of his children, grandchildren and great grandchildren that line the shelves on his right. Then he looks back at me)*
680. Maxine: *Yeh (and Arthur nods affirmatively several times and I start to laugh as I realise what he is meaning)! You produced pretty (I point with my thumb over my shoulder towards the pictures behind me as I am laughing)! That's good health! (And we all laugh). I won't go anywhere near there (and I hold my hands up).*
681. Mark: *Yeh (and he raises his thumb as he looks at Lisa and then down at the table smiling broadly).*
682. Lisa: *No, he was (she begins in a serious voice and then she laughs again as she also realizes what she is about to say), you were pretty fit, weren't you, Dad? (And we laugh again)*
683. Maxine: *Fit and healthy!*
684. Mark: *Yeh.*

### *Expressing the self*

In severe aphasia, uncovering how a person talks about her/himself requires listening and looking beyond the words. In reference to himself Mark would point to himself. He also used the photographs to indicate himself at different stages of his life be it as an apprentice or as a rugby player. He also referred to others in his life in this way as well.. His presentation of self was one of someone who wanted to communicate in spite of the restrictions of the aphasia. He initiated topics by gaining attention with "Dee" or "Look", or by pointing to something. He referred back to the time line as if to direct us to talk about a particular period in his life; we had been talking about his school years and he then ran his finger along the timeline and I asked if he was talking about his working life. He agreed and then pointed to 60 on the timeline.



This opened up an exchange enabling us to start to talk about his working life. He used his body to talk about himself; indicating the stroke, his inability to speak, his ability to walk, his connection with his family and his acknowledgement of the loss of people in his life. He also expressed his self in relationship with others. All this achieved by using all tools available to him but also by collaboration between the three of us.

## The Process

### *Inclusive research*

As has already been outlined, an important goal of the study was that it would encourage a more inclusive process for people with aphasia who are often excluded from research projects because of their difficulty with language. As one of the main outcomes sought was a process that encourages a more participative research approach with people with aphasia, severity and type of aphasia were not identified as criteria for exclusion. However, I had some reservations about how the process would work when Mark and I first met. I had a working assumption that people with aphasia have an evolving narrative or an autobiographical story through which self and identity are constructed. Mark's severe verbal difficulties and some difficulties, at times, understanding spoken language, challenged how to explore this where the ability to tell was severely compromised. The interview, therefore, involved all the props possible to allow Mark the tools with which to develop his life story. Lisa was an important communication "prop" for Mark and I also became a "prop" with my experience in talking with people with aphasia. The interview, as a result, was negotiated between the three of us. The use of proxy respondents such as close relatives as alternative sources of information in research with people with aphasia has been discussed earlier. I do not consider Lisa to be a proxy respondent speaking for Mark; rather she was involved in the interview as a collaborator with Mark and me in the construction of the life story. Mark was definite in his rejection of statements that did not represent his view, just as he signalled his agreement. The difference between Lisa and me in this process was her intimate knowledge of Mark's life as well as their own shared life, and shared communication strategies post-stroke.

So the interview was completed; a co-construction of a life story. A further challenge was, however, how to take back the transcription to Mark, a document of a hundred pages. Making this material accessible meant reducing the volume as well as considering exactly what relevance it would have to Mark. What was the outcome for him of completing this interview? I decided to recreate a life "history" based on the information from the interview. I took back a PowerPoint presentation (as in Figure 7.6) to Mark and Lisa which summarised his (and also their) life history. I also created a folder for Mark using printouts of the PowerPoint slides and gave this back to him. At that stage, we talked about the difficulty in finding appropriate graphics to accompany the text and explored how it would work to actually use the photographs that had been part of the interview as well as any other relevant ones. Lisa subsequently sent me the photographs and when the project is completed, I will substitute the impersonal graphics with Mark's photographs and return the folder to him. So the outcome for Lisa and him is the process of constructing a life story but also for Mark a folder which tells about him in a way that he may be able to use to supplement his conversations with others and preserve some sense of his evolving life story, of which the stroke is a part.

## Kilroy

*Life, ah, life is a dream*

Kilroy, 1403.

### The Story

#### Establishing ourselves

I first met Kilroy with his wife, Danielle, at his home to talk about his involvement in the project. He had a stroke almost five years ago and he had some remaining mild right sided weakness and aphasia. As I write this description I consider my words. I reflexively want to use words like "persisting" and "residual" but I veto them as clinical and they are not words that Kilroy and Danielle might use. While I asked questions highlighting his communication, Kilroy did not directly refer to his communication disability, if in fact he would discern it as such.

Kilroy was in his mid-sixties and lived at home with Danielle. Danielle talked positively about good rehabilitation support for them following Kilroy's stroke, both specifically from speech-language therapy and also from the wider rehabilitation team. Kilroy continued to take part in an aphasia group twice a month and he had conversation support through two people who visited each week. He had some problems with word recall and the retrieval of the sound patterns of words. There were also at times some difficulties with understanding spoken language. However, Kilroy's communication was successful given time and some joint negotiation of words. He was resourceful and gently persistent in communication. Our first meeting was very relaxed and Kilroy was happy to be involved in the project. On the basis of this, we decided to follow up with an interview the next day. We talked about a pseudonym and he joked about "Mr. X.". Later, he decided upon "Kilroy" and also suggested "Danielle" for his wife. I thought about how proper names are also significant to a time and place and how pseudonyms create a subtle disorientation for the reader. Where do these "people" belong, what time, what social context and what do the names evoke for the reader?

We met again for our interview and we sat in the lounge with the video camera capturing both of us. Danielle sat to the side and was a silent party to the interview. Kilroy gave a factual account of his life as the questions flowed. To begin with, he methodically recalled early memories of family, of living in England during the Second World War and of his early school years:

55. **Kilroy:** *Ah – it's about – (long pause and breathes out). I was in the, er, in the, in the, um, the er, air, air raid, shelter (looks back to me).*
56. **Maxine:** *Okay.*
57. **Kilroy:** *Yeh. In the, in the - just, just to - it's, er, it's er, it's um, dark and – ah damp, you know.*
58. **Maxine:** *Right.*
59. **Kilroy:** *From the, er –*
60. **Maxine:** *Was it an air raid shelter shared with people or, part of the /how/, you know, was it part of your home or?*
61. **Kilroy:** *No, it was – um, it's probably (pause), it's probably was the, er, /un/, the old /un/ Anderson Shelter. You know, it was, it was, er, um, you, you ah, you ah, dug, a hole,*
62. **Maxine:** *Right.*
63. **Kilroy:** *Big hole (and spreads his hands apart wide and we both laugh).*
64. **Kilroy:** *You put them, you get the, ah (and creates a half round movement in the air with his left hand), from, from the, er, the /min/, /min/, ministry of, of the, the, er s:upply,*
65. **Maxine:** *Right.*
66. **Kilroy:** *we get, er, um (and makes the half circle movement again), a /lock/, ah /corrih/, corrugated, corrugate, /corroh/, gated,*
67. **Maxine:** *Iron?*
68. **Kilroy:** *iron.*
69. **Maxine:** *Right.*
70. **Kilroy:** *Put it up over, put it up, off.*
71. **Maxine:** *Right.*
72. **Kilroy:** *Off and then, and, ah – /fin/, fill in, no. Fill in, top of the, er, shelter (looks back to me)*
73. **Maxine:** *So it's actually, it is underground.*

74. **Kilroy:** *Yeh.*
75. **Maxine:** *Ah.*
76. **Kilroy:** *Yeh.*
77. **Maxine:** *And dark and damp.*
78. **Kilroy:** *Yeh, yeh. Ah. Ah, it's about, er, about ninety four, forty three, forty four.*

### *A life uncomplicated*

Kilroy described what I construed to be “a life uncomplicated” as we meandered together through past events and explored future hopes. Even the events surrounding his stroke appeared to be just a part of his life and he almost seemed surprised to recall his stroke as a “low point”:

883. **Kilroy:** *Yeh, yeh. (Long pause). Um, low points? Well (long pause). Seven, seven, seventies (counting with his left fingers), no (and shakes his head). Eighties - no (shakes his head negatively). No, no low points. Nineties – no no, no. Very, very, very ah, very ah, happy.*
884. **Maxine:** *Ah, great, great (and we both laugh).*
885. **Kilroy:** *(Long pause). Oh, I I was, I ah, ah, I ah, be became, /ree/, redundant.*
886. **Maxine:** *Mmm, mmm.*
887. **Kilroy:** *That's, um, nineteen ninety, eight.*
888. **Maxine:** *Okay.*
889. **Kilroy:** *Er, seven, seven years,*
890. **Maxine:** *Mmm mmm.*
891. **Kilroy:** *ago. Ah (pauses), a low, ah, oh, a low. It's a /lih/, a low point (draws a dipping motion),*
892. **Maxine:** *Mmm.*
893. **Kilroy:** *Went (and then scribes upwards), just a, just a, just a drop.*
894. **Maxine:** *A dip (as I repeat his gesture)?*
895. **Kilroy:** *A drip, yeh.*
896. **Maxine:** *Yes.*
897. **Kilroy:** *(Pause). Um, like I got a /noo/, new job. Yeh. (Pauses). Oh (as if he's surprised. He starts to smile and looks over to his wife). Like I got a, got a, got a, a, /s:/, a /s:/, um stroke.*

I made an early decision that the interviews were to be about a life story as told and not directed to be an interview about aphasia. I hoped that the interviews would provide an opportunity for people to consider where aphasia and stroke were located in their lives without my assuming that they would have major ramifications on self and identity. Kilroy questioned whether or not the stroke was actually a low point:

900. **Kilroy:** *Low, oh (moves his head from side to side as undecided and laughs). Low ah, point. (Long pause). Um. I don't know, I don't know 'cos I, I – I wasn't, um, I was I /woh/, I was contented. /Con/, content?*
901. **Maxine:** *(I nod my head affirmatively).*
902. **Kilroy:** *Content?*
903. **Maxine:** *Content.*
904. **Kilroy:** *Yes, um, er (pauses). Ah -Danielle (pointing to his wife) was, very, very ah – oh, /wuh/, /wuh/, worries, /wuh/, worried.*
905. **Maxine:** *Is this to do with the stroke?*
906. **Kilroy:** *Ah - yeh.*
907. **Maxine:** *Yep, yep.*
908. **Kilroy:** *At first ah, was, was ah. The first week, the /hoh/, hospital, hospital,*
909. **Maxine:** *Okay.*
910. **Kilroy:** *I was um, (puts his head back and closes his eyes as if lying in a bed relaxing and smiles). I was, um, I'll come – I, I will come - /white/.*
911. **Maxine:** *In those early days in hospital, that was, Danielle was worried,*
912. **Kilroy:** *Yep.*
913. **Maxine:** *where you had that feeling, that you would come right.*
914. **Kilroy:** *Yeh.*

### *Laying out a life story*

Kilroy's responses to questions, his own incidental story telling, his inclusion of the social and historical climate of the stages of his life and his attention to dates, made it very easy, on later analysis, to systematically "draw" a picture of this life. Because Kilroy has a reading disability as

part of his aphasia, returning an eighty two page transcript of the interview to him would have been insensitive and exclusionary. Instead, a life history map (Hagland, 2004) was developed for Kilroy (as shown in Figure 7.7). This is essentially the plot of the story laid out in chronological order and by category. This was returned to him along with the case study narrative.

Year	Age	Geography	Family	History	School & Work	Friends	Leisure	Health
1941		Lived in burglarw house in X Road.	Father the captain of a "tramp", a coal ship.	World War II				
1944	3		Sister born					
1945	4			V. E. Celebrations				
1946	5	Moved to grandmother's business, a fruit shop Had own room.	Mother helped in shop		Infants' School			
1947	6		Uncle - chief engineer in a ship					TB & surgery
1948	7				Junior Class			
1955	14	Moved to New Zealand in June. Bought house in X			Started X School (4 <sup>th</sup> form)	Left friends in England Unhappy starting new school halfway through the year		
1958	17				Started work (Post & Telegraph)			
1965	24	Trip to England. Travelling around Boat trip there and back (Athens, Cairo, Panama etc).		Winston Churchill died. Rhodesian independence Vietnam War began	Special leave (got promotion while on leave) Night porter			
1968	27						Started model steamengine	
1971	30		Married					
1972	31		Family		Promotion - Training Officer			
1991	50		Father died					
1992	51						Started model of Golden Hind	
1998	57		Mother died		Made redundant (but got new job)			
1999	58							Stroke
2004	62						Completed model	

Figure 7.7: Life history map

Kilroy's life echoed events in history and also the influence of his geography in life changes. He was born in a coal mining area and Kilroy's family moved to New Zealand, partly because of Kilroy's health and contracting tuberculosis. As we talked, there were things he talked about that I only began to understand (and connect) in retrospect as I listened back to our videotape and

explored further. During our interview we negotiated, not just aphasia and a shared understanding but also about contextual information about Kilroy's life:

404. **Maxine:** *Is it still coal mining? Is there still mining in - ?*
405. **Kilroy:** *Oh. (Pause). No, no /?/. Many, many ah, collieries have ah, ah, closed, closed, closed down. Yeh.*
406. **Maxine:** *[Right. So the environment was quite affected, by, the coal dust?*
407. **Kilroy:** *T.B., yeh.*
408. **Maxine:** *Yeh. And, right.*
409. **Kilroy:** *The, the, ah, (tapping his chest) lung lung lungs, lung, er (long pause).*
410. **Maxine:** *I mean we know a lot more now, um, but in those, times, I guess, it was just, the way in which you lived, with, with it, with,*
411. **Kilroy:** *[Yeh.*
412. **Maxine:** *as you say, the, the, the /coll/ colliers, is it? Colliers?*
413. **Kilroy:** *Collier.*
414. **Maxine:** *Collier.*
415. **Kilroy:** *Oh, right. /Coll/ collier, collier (long pause). /Coll/. Um. Collier (and he stresses the word by tapping the syllables with his index finger),*
416. **Maxine:** *Mmm.*
417. **Kilroy:** *was a, ah - a ship that, that ah, carried, coal.*
418. **Maxine:** *I see, right.*
419. **Kilroy:** *[Collier, um. /Coll/, /see/, colliery (pause). Colliery? /Coll/?*
420. **Maxine:** *I'm not sure*
421. **Kilroy:** *(Long pause). Colliery - that's, that's, that's the (looks to his wife who has a dictionary for him). Can I? Yeh (laughs). The, the um, the /dish/, /dishionary/. /Coll/ - "C", "O", "L", "L" (spelling it out for his wife). "C", "O", "L", "L" (and his wife hands the book to me for Kilroy).*
422. **Maxine:** *Oh, right. Oh, that's a (I lift the book up and down indicating its weightiness and laugh handing it on to Kilroy who also laughs).*
423. **Kilroy:** *Cor. Ah (and he begins to sort through the pages).*
424. **Danielle:** *He was given that, from his son, after his birth, after his stroke.*
425. **Maxine:** *Right, right.*



426. **Kilroy:** *(Looking through the dictionary. My later searches reveal "collier" as meaning a ship designed to transport coal and also a coal miner while "colliery" refers to a coal mine and the buildings associated with it). /Coll/, collier. /Colly/ (as he continues to look through). /Coll//coll/, collier, oh (as he leans forward to share the entry with me and we both look at the dictionary).*
427. **Maxine:** *A coal mine.*
428. **Kilroy:** *Oh, no. A, coal miner, collier. A ship that /cah/, /cah/ (pause).*
429. **Maxine:** *So it works for the,*
430. **Kilroy:** *[Oh, oh, /coll/ collier - is a ship. Collier, /coll/ colliery,*
431. **Maxine:** *Is the coal mine,*
432. **Kilroy** *[Colliery*
433. **Maxine:** */Coh/,*
434. **Kilroy:** *[/Corry/, colliery.*
435. **Maxine:** *It's very, so "collier" and "colliery" - to do with coal, one's a*
436. **Kilroy:** *[Yeh.*
437. **Maxine:** *coal mine, and also that the ship, is the collier as well as, as,*
438. **Kilroy** *[Yeh.*
439. **Maxine:** *as the coal, coal miner.*
440. **Kilroy:** *Right.*
441. **Maxine:** *So your father was captain of one of ships, that carried the coal.*
442. **Kilroy:** *Yeh, right.*
443. **Maxine:** *Okay?*
444. **Kilroy:** *Colliery. Colliery? - "Y", "Y",*
445. **Maxine:** *On the end.*
446. **Kilroy:** *a - coal mine.*
447. **Maxine:** *So there were a few coal mines around the area?*
448. **Kilroy:** *Yeh, yeh (still looking at the dictionary).*

There was information that was new to me. I became sidetracked by finding out what an "Anderson" shelter was and about the coal mining history of the area in which he was born. I spent time locating information that would help me understand Kilroy's life story, both the context and specific words. I decided to share some of this background research with Kilroy and

Danielle. I visited them again several months after the interview with the purpose of talking about how I might best give Kilroy back the outcome of our interview that would take into consideration his reading disability associated with his stroke (and as shown in Figure 7.7, the decision was a life history map). At that time, I also took with me a PowerPoint presentation on my laptop which gathered together the specific aspects of Kilroy's life story that I had researched and from which I had learnt. I also printed the slides out and put these in a folder for his information. Figure 7.8 is an example from the presentation.

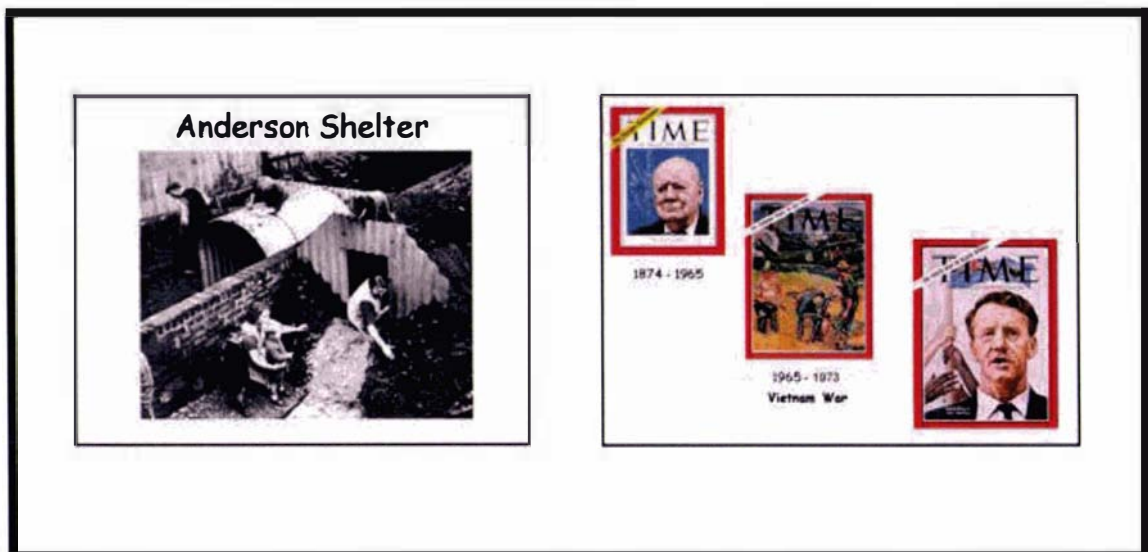


Figure 7.8: PowerPoint slides for life story feedback

### *Telling of self*

What did Kilroy tell about the impact of self on aphasia? He suggested that perhaps the stroke had an influence on his reaction to the situation he found himself in:

932. **Kilroy:** *I was ah, I was ah, (pause) placid.*
933. **Maxine:** *Have, have you always been placid?*
934. **Kilroy:** *Eh (and leans forward as if he hadn't heard)?*
935. **Maxine:** *Have you always been placid? Or, or was that a new side to you?*
936. **Kilroy:** *(Pauses) Yeh. I don't know (looking straight ahead). Probably my, ah,*

brain (and points to the right side of his head) is ah, is ah - stop me to come, come /wih/, /wih/, worry.

937. **Maxine:** *So with your stroke, you've stopped worrying?*  
 938. **Kilroy:** *Yeh. From,*  
 939. **Maxine:** *Okay.*  
 940. **Kilroy:** *[the, from the (pointing to the right side of his head)]*  
 941. **Maxine:** *From the stroke?*  
 942. **Kilroy:** *Yeh.*  
 943. **Maxine:** *Okay (and we all laugh).*

I listened to Kilroy talk about his life and I listened for what he tells me about his sense of self and who he was following his stroke. He did not tell me about major change and I listened to a sense of coherence of who he was and not just who he had become following the stroke.

1146. **Kilroy:** *I, I, I - I got, got few, few friends, you know. I, I ah, I ah, um - /ree/, /ree/, recluse,*  
 1147. **Maxine:** *Recluse?*  
 1148. **Kilroy:** *[/c/lose)*  
 1149. **Maxine:** *Recluse. No? I'm filling words I should be quiet.*  
 1150. **Kilroy:** *Yeh, ah. Recluse. Recluse (taking up the dictionary).*  
 1151. **Maxine:** *Recluse.*  
 1152. **Kilroy:** *That's a*  
 1153. **Maxine:** *[Someone, a bit hermit like.*  
 1154. **Kilroy:** *Yeh.*  
 1155. **Maxine:** *Okay.*  
 1156. **Kilroy:** *Recluse. Recluse (looking through dictionary). Oh. Um. "R", "E" "C" (after a time looking through the dictionary, he looks up and waves to the camera and we both laugh).*  
 1157. **Maxine:** *It's still there!*  
 1158. **Kilroy:** *Oh. /Riss/ - recluse. yeh, yeh. Retire, oh - solitary*  
 1159. **Maxine:** *[Solitary.*  
 1160. **Kilroy:** *Yes.*  
 1161. **Maxine:** *[Yes.*

1162. Kilroy: *(Continues to look at the entry in the dictionary). Right. Yeh (and reads from the dictionary). Likes (?) person who /loos/, who /loos/ retired from the world.*
1163. Maxine: *Is that how you're describing yourself?*
1164. Kilroy: *[Well, /n:/ no. /Hah/, half, halfway.*
1165. Maxine: *Halfway.*
1166. Kilroy: *Halfway.*
1167. Maxine: *Halfway reclusive (and we both laugh).*
1168. Kilroy: *I don't, I don't like um, ah, /clih/ clown, ah clown.*
1169. Maxine: *Crowds?*
1170. Kilroy: *Cloud, um, crowds.*
1171. Maxine: *Right.*
1172. Kilroy: *Crowds.*
1173. Maxine: *Right.*
1174. Kilroy: *(?)*
1175. Maxine: *And is that you before your stroke or?*
1176. Kilroy: *Yeh,*
1177. Maxine: *[Yeh.*
1178. Kilroy: *before.*
1179. Maxine: *[Was it before?*
1180. Kilroy: *Yeh.*
1181. Maxine: *Okay. Okay. Right. Reclusive. It's a lovely word but you're half, half, halfway (and I laugh).*
1182. Kilroy: *Yeh, yeh (and laughs).*

He told me about the importance of his wife, his family and his grandchildren. But he did not protest about his life:

1180. Maxine: *So if you're taking a look back, how does your life look?*
1181. Kilroy: *Oh. Oh, um, I've been ah, contented.*
1182. Maxine: *Mmm. Mmm. Yeh.*
1183. Kilroy: *Ah, haven't, um - /ex/, experienced war.*
1184. Maxine: *Right. Right.*

1185. Kilroy: [You know.]
1186. Maxine: Right. Yeh.
1187. Kilroy: Ah (Long pause). Oh, just, just a little - I got a, um, a a a /op/ operation (pointing to the left side of his neck),
1188. Maxine: Right.
1189. Kilroy: a broken - hip (pointing to his right hip). (?) ah,
1190. Maxine: So a few hiccoughs but
1191. Kilroy: [a strokes
1192. Maxine: A stroke.
1193. Kilroy: [Stroke. Yeh, a stroke. (Long pause). Um. (Long pause). Other, words, I was (?) be happy.

### *What of the other?*

There was an easiness about the interview and Kilroy's "fluency" in constructing his life story despite his aphasia. However, I was struck by the way in which the dynamics changed when Kilroy, his wife and I are engaged in a conversation. This has been highlighted in other interviews where the interview context assigns one person as being the listener and therefore maximizes the other person's opportunities for uninterrupted speaking. The lack of time pressures within the interview creates an optimum environment of shared conversation. However, outside that context, conversation is fast and turn taking is rapid and Kilroy's aphasia becomes much more of a barrier to communication. The interview was about Kilroy's life story but it wove in the stories of many others in his life; his wife, his children, his family and his friends. I heard little change in listening to stories of self as the result of the stroke when we completed our interview. However, I did not fully grasp from our interview the changes as the result of the stroke and the aphasia for Danielle as his wife and partner. There were changes in ways of communication and changes in responsibilities. When I visited them on the third occasion, Danielle was talking about a holiday they were going to take with family. For her, it would be an opportunity for a break as other family members could provide support for Kilroy while they were away. When just the two of them travelled together, she described it as being harder for her as she needed to be thinking for the two of them.

*The experience of narrative*

Our interview was an opportunity for Kilroy to revisit his past and consider his future. He appeared to take this seriously and he was quietly persistent in completing stories of importance to him when I had seemingly moved on. This highlights “narrative in action” and Kilroy also identified the role of narrative and story telling as the role of the “confessional”:

823. **Kilroy:** *Oh, that was, that was very, um. /Star/, I /tar, /start/um, I um, started at about, January, seventy two. I think it, it was /f:/ first, it was the first ah, my, ah, /m:/ marriage, you know.*
824. **Maxine:** *Right.*
825. **Kilroy:** *Yeh.*
826. **Maxine:** *That’s the first year of your marriage?*
827. **Kilroy:** *Yeh.*
828. **Maxine:** *[Right. Right.*
829. **Kilroy:** *Ah (long pause). I um, I didn’t, like the job.*
830. **Maxine:** *Right.*
831. **Kilroy:** *I, oh, I get, I get, ah - I became um, /ob/, /obstain/ - /obstin/ /obstin/ -*
832. **Maxine:** *Obstinate?*
833. **Kilroy:** *Yeh. Didn’t - I, I, your boss, get the, the ah, the um. my, my boss, he, my boss, get ah (pause). Tires away. Tire, tires – of, of me,*
834. **Maxine:** *Right.*
835. **Kilroy:** *you know (and he puts his hand across his mouth as if he should be quiet).*
836. **Maxine:** *(I laugh but I am unsure).*
837. **Kilroy:** */Con/, /confish/, /confishay/, /conf/ (looks over to his wife), ah.*
838. **Maxine:** *Confidential?*
839. **Danielle:** *[No. Confessions.*
840. **Maxine:** *Confessions!*
841. **Kilroy:** *Yeh.*
842. **Maxine:** *Well, and that’s the, you know, some the, the things that, that when we’re talking about our lives, some things are quite confessional, aren’t they (and I laugh)?*
843. **Kilroy:** *Yeh (laughs).*
844. **Maxine:** *So any other points that were low points?*

845. **Kilroy:** [(?), this, this, get this here (pointing back to the prompt picture and indicating he wanted to finish what he had started).
846. **Maxine:** *Okay, okay.*
847. **Kilroy:** [About, about August, he ah, he um, he ah, talked to me. "/Dih/, do you, do you want, do you want, to come back to, ah, radio section?" "Oh, yeh, good!" (Laughs). That's, that's, I like it. I like, the work,
848. **Maxine:** *Right.*
849. **Kilroy:** *at the /r:/ ah, /ray/ radio, section.*
850. **Maxine:** *And didn't like the training aspects.*
851. **Kilroy:** *Yeh.*
852. **Maxine:** *Okay. So by being a bit obstinate, you got your own way.*
853. **Kilroy:** *Yeh (nods his head affirmatively, slowly as if thinking about what I have said). Yeh, (?) (and we both laugh).*
854. **Kilroy:** *Yeh, that's about - so back, so back, back to, ah, radio section.*
855. **Maxine:** *Okay.*
856. **Kilroy:** *Happy.*
857. **Maxine:** *Happy (I laugh).*
858. **Kilroy:** (Laughs) *So, so, like, (?), um, /rep/, /ree/, /repair/, repairs of instruments.*
859. **Maxine:** *Right.*
860. **Kilroy:** *You know and ah -.*
861. **Maxine:** *And so*
862. **Kilroy:** [It's my,
863. **Maxine:** *responsible for your own?*
864. **Kilroy:** [Oh, it's my, it's - my/boh/. It's my boss (and points back to himself). No, ah, own, own boss.
865. **Maxine:** *You're your own boss.*
866. **Kilroy:** *Yeh, me. Yeh.*
867. **Maxine:** [Yes. Yes.
868. **Kilroy:** *It's good.*

*Creating a summary*

While I was involved in the dynamics of our interview conversations, I was wondering how this would form a part of the research project and how it would contribute to the interview questions about self and aphasia. It was not until the end of the interview and our last question, that I was quietly knocked off balance. What I had been considering to be straightforward reveals itself as complex and universal. As I reviewed the videotape and began the transcription and analysis, I tried to summarise the experience:

Life is a dream

I have spent many days  
Transcribing our interview.  
And I'm going through the motions of our talk,  
Now several months gone.

Trying  
To replicate  
In a textual way  
Our conversation.

We meander through  
Your recollections  
Of your life.  
I listen.

You take me to  
Parts of history  
And geography  
That I have never been.  
I am back in a war that wasn't  
Part of my life,  
An industry that has some connections  
With my own story and  
My grandfather's history of  
Coal mining.  
But in a different country  
And at a different time.

I can't help  
But make my own connections.  
As we separately weave our individual stories  
As we talk  
Together.

Your aphasia  
(If it is yours alone and not just between us)



Lessens  
As we both discover  
And rediscover  
The need to  
Talk.  
To trade stories  
To both have our part in this time.

And then,  
I decide  
That this is  
A life uncomplicated.  
Seemingly uncomplicated  
Even with stroke.

But it becomes much more  
As we talk  
Our interview slowly closes  
And I pose the last question  
About philosophies and values  
And  
You tell me  
Simply  
"Life is a dream"

Life stretching beyond  
The evening stars.  
Life  
Made minute by the vastness of it all.  
And you do it so  
Easily.

It slips into our conversation  
And I am caught off guard.  
It unbalances my assumptions  
About our reason for talking.  
And, within your words,  
I somehow forget my reason  
For being there.

We started with small things  
With memories of a childhood long gone  
And we made a pathway  
Out of recollections of a life  
But in the end  
As the tape wound through  
You reminded me of our  
Universal quest.

Not of what we did  
Of who we were  
At which time  
But of the enormity  
Of living  
In a vast universe

You remind me of  
The flow between  
Subject and object  
Between  
Interviewer and interviewee  
And of common  
Struggle  
To understand  
And to make sense.

And your achievement?  
"Content"  
"Happy"  
"A drop in the ocean"

I watch myself  
Compose myself  
As we conclude.  
I settle back into my role  
And proceed  
With the wind down  
And the reflection  
On it all.

Yet in those  
Hours  
I rediscover  
Some of the reasons for my being.  
As a therapist,  
Perhaps.  
And maybe as a researcher,  
But mostly as another human being.

Life is a dream

## The Process

### *Research ethics*

*"Paying attention to the power dynamics within the research relationship increases the likelihood that I will 'hear it like it is'"*

Niobe Way, 1997, p. 3.

Throughout the research process from the interview has been an awareness of the ethics of narrative research and particularly issues of power and responsibility. Kilroy has aphasia and I do not. As an interviewer and as the person who developed the research proposal, I also have the power of interpretation. I have the power in making decisions about what to include or exclude. I take Kilroy's narrative and display the pieces I feel give light to the research questions which are my research questions. Choosing to transcribe in a narrative form meant I also added another layer of interpretation even before deciding what to include or exclude in the final narratives.

In doing this and in finding a way to write the research that included my voice but did not overpower the participants' voices, I am also reminded of Fine, Weiss, Weseen and Wong's (2000) caution: "In the hands of relatively privileged researchers studying those whose experiences have been marginalized, the reflexive mode's potential to silence subjects is of particular concern" (2000, p. 109). I am also putting my voice to the participants' stories for what I believe are beneficial reasons. However, I am using these stories to build my own account. Klein (cited in Reinharz, 1992) suggests that although we cannot speak for others, "we can, and must speak out for others" (p. 16). An imbalance exists in the researcher-researched relationships and while speaking out redresses some of that imbalance, there is still the potential for perpetuating it and still objectifying people in research.

## Mary

*And I suddenly worked out that, um, that I was myself.*

Mary, 1496.

### The Story

The task of theorizing the self is well attended to by theorists from a range of disciplinary backgrounds. However, as we approach people in our lives, in our research and in our practice, we need to recognize that the people we make contact with also develop their own theories of self. Mary's interview is an example of this. She shared her own theory on her self as well as her theories on aphasia and the process of advancing her communication abilities.

I initially met with Mary and her husband, Ken, in their home to talk about the project. Ken had contacted me by telephone to express an interest in the project following information they had received from their local Field Officer. He felt that Mary's story was worth telling and it could be helpful to others because of her continued improvement past the time cited for recovery from a stroke. I then made a time to introduce myself and the project and three months later I returned to complete the interview. After the interview I spoke with Mary several times by telephone.

Although not actively involved in the interview, Ken was present and, for most of the time, he was reading at the other end of the room. At times during the interview, Ken offered information to support Mary's telling and he joined us for a short time when we had tea. As this interview was the last interview of the project, there was some sense of sadness for me as it signalled another step towards the completion of a stage in my life and it was a time to reflect on how the project had developed.

*About the stroke*

*'Cos it's quite amazing now, how much I can talk.*

Mary, 1816.

Mary had a stroke in 2000 which resulted in a subarachnoid haemorrhage and Mary was unconscious following this for eight days. Ken had been told initially that *"she may not last the night"*. Mary had retired in 1998 and after a full career in education, had started to pursue other interests including music and croquet before the stroke. She also experienced further ill health about two years after the stroke when she went into septic shock following surgery. This resulted in lengthy hospitalization and recuperation.

When we talked, Mary's verbal expression was deliberate and thoughtful. It took time for her to express her thoughts and, at times, fatigue appeared to influence her communication: *"But I found that, um – oh, I'm getting tired"* (457). Mary readily verbalized when she was having difficulty with word recall: *"I can't always tell exactly what it is"* (204); *"I can't even give you the name"* (838). Sometimes, she was apologetic, *"I'm sorry, I'm a bit hopeless"* (1012), while at other times she appeared annoyed when a word eluded her. She tried to tell me that her first degree was in geography: *"It was more like, ah, I did, do, do one, of areas of the world that had, things like (she sighs as if exasperated and then looks at me). Can't. I'm hopeless at the moment"* (1131). However, Mary was interested in the project, keen to be involved and willingly took part in an interview that lasted over two hours. She talked about some difficulties with understanding spoken language and used the example of listening to the radio and not always fully grasping what she had heard. Mary also had a considerable degree of right sided weakness as the result of the stroke and she experienced some restrictions with movement. She was right handed before the stroke and she now needed to use her left hand for all activities including writing. However, when we talked, she was feeling good about being able to walk for at least a kilometre on most days. She talked about learning to play the piano when she first retired but she was now not able to continue this following the stroke: *"And then I was very sad when I finally couldn't do that, because I haven't got a hand any longer"* (387). She expressed a desire to continue to improve physically: *"Well, I would desperately want to get out, going a bit more walking"* (1536).

*About the interview: Sense making through collaborating*

There were many examples of collaboration during our interview, mostly between Mary and myself, as an unfamiliar listener without history or context, but also between Mary and Ken. The shared responsibilities of communication were negotiated throughout the interview. The process of clarifying and constructing fell to both Mary and I as we managed our communication. The success of this lay with Mary's readiness to provide as much information as she could to assist Ken or myself with supplying the desired word and with the naturalness of this to her conversation: "What do you call it, a person who's in charge, but not?" (1387). For Ken and Mary, a shared history made this much easier and Mary appeared at ease with Ken offering the word for which she was searching:

436. **Maxine:** *What else did you do, or are you doing in retirement?*

437. **Mary:** *Um – I. And I can't give you the name, but Ken will be able to tell us (looking over to Ken). The name of the thing that I - Ken (and calls to her husband to get his attention). Where he can, the one that I do that he did. I was fastest, because the person who was with my, piano, was very interested in – (and pauses as if waiting for Ken to fill in).*

438. **Ken:** *Croquet.*

439. **Mary:** *Croquet.*

Ken could make this link because he knew it was Mary's music teacher who had suggested they might enjoy croquet. Mary's openness with her communication enabled us to talk about it and for a better understanding to be developed:

465. **Mary:** *Mmm. And then I get worried I can't always tell you what, I'm, doing because I can't always tell you.*

466. **Maxine:** *And I suppose that's a kind of joint responsibility as we talk and we've also got Ken as a backstop too.*

467. **Mary:** *Mmm, and he's wonderful.*

468. **Maxine:** *So,*

469. **Mary:** *Mmm.*

470. **Maxine:** *I think that, that between the three of us, probably.*

Mary, in managing her communication, also made it easy for conversational repair to occur naturally, both in terms of clarifying if she had not understood or correcting if I had not. In recalling an early experience on the farm where she lived as a child, I attempted to supply a word that I thought was contextually appropriate:

854. **Mary:** *And, and, so, going out and getting it. And I can remember, um, some things I wrote down (and she looks back to her notes), like, um - we, when I was about - three,*
855. **Maxine:** *Right.*
856. **Mary:** *maybe, and my, I would always go with my father. And I would, in, on the – and I would put, I would be in - a box, on the –*
857. **Maxine:** *Tractor?*
858. **Mary:** *No, no. We weren't - God (and she sounds surprised)!*
859. **Maxine:** *Oh, no! I've leapt ahead, have I, Mary - in technology (and we both laugh)?*
860. **Mary:** *Yeh.*
861. **Maxine:** *Horse?*
862. **Mary:** *A horse (laughing).*

Mary also allowed some slippage within our conversation. When I was unable to locate a word, Mary allowed my close approximation to suffice so that we could continue the story without a loss of significant meaning and without a loss to the conversational flow that would have occurred if we had continued to seek out between us the “correct” word:

992. **Mary:** *Ah. And I fell over, the cow's leg, I suppose it was. Uh, and I was had it (and she clutches her stomach). What do you call it when one falls over? And they can't, um, can't walk or /hurt/, or anything, 'cos they have –*
993. **Maxine:** *Fainted?*
994. **Mary:** *No.*
995. **Maxine:** *[No?*
996. **Mary:** *Well, in a way, it's a bit like that.*

Discussions between Ken and Mary after the interview revealed that Mary was “winded” when she tripped and fell.

*About a life*

Mary's life history is rich with people, places, travel and experiences. While the life story format provided some structure, a sense of continuity was maintained in her telling of her story. Mary talked about the early days in hospital after the stroke when verbal communication was more difficult; she found herself spending those times revisiting her childhood memories. More recently she has begun to write these memories down. Along with these, Mary had also prepared a sheet of relevant information for our interview and the notes that she had taken time to collate had a similar structure to the chronology of the interview format.

Her early life was on a farm and she was able to tell detailed stories about times and events that place her in a family with close relationships. Mary went on to graduate from university with a Master of Arts degree before she began teaching. At a later stage, she returned to study pursuing a postgraduate diploma which she then converted into a further Masters degree completing this in 1989. Although her mother had never had any formal schooling, Mary's career was in teaching and in school development. In the latter part of her working life, she became involved in educational administration:

699. **Mary:** *And one of the interesting things, for my life, I reckon always, that my mother didn't go to school ever.*
700. **Maxine:** *Mmm.*
701. **Mary:** *Because there was no: correspondence school. There was nothing like that.*
702. **Maxine:** *And interesting that that's where you should, your career ended up,*
703. **Mary:** *Mmm.*
704. **Maxine:** *was in a, in a, yeh.*
705. **Mary:** *In a way, it's a little bit why I, was pleased to go to something like that because, when, my mother was – thirty, forty (quietly), forty when I was born,*
706. **Maxine:** *Mmm.*
707. **Mary:** *and, and she had never been at school.*
708. **Maxine:** *So where did she: - learn the, the, the basics of, um -?*
709. **Mary:** *I think her father, ah, probably did quite a bit.*
710. **Maxine:** *Mmm.*



711. **Mary:** *Ah – /proh/, yeh, I think it was mostly what it was because they lived in an area where they couldn't go to school.*
712. **Maxine:** *Mmm.*
713. **Mary:** *Yeh.*
714. **Maxine:** *Did that influence her, um, her commitment to your education? Do you think?*
715. **Mary:** *No, no. 'Cos I think - I can remember, when I was about twelve, my father, my mother, being worried about, what, I used to say, things that I was doing, and she couldn't quite have that.*
716. **Maxine:** *Mmm.*
717. **Mary:** *'Cos she didn't have any, she hadn't been to school herself,*
718. **Maxine:** *Mmm.*
719. **Mary:** *so. I can remember, when was at (the name of a major distance education institution), and, I took her into the school where I was and also another school that I went to, just to feel what it was like,*
720. **Maxine:** *Mmm.*
721. **Mary:** *because she was so worried about that sort of thing.*
722. **Maxine:** *Mmm.*
723. **Mary:** *Mmm.*
724. **Maxine:** *Never having had the experience,*
725. **Mary:** *Mmm, mmm.*
726. **Maxine:** *and yet that's what we take for granted.*
727. **Mary:** *[And here she had this kid who did it all her life.*
728. **Maxine:** *Yeh.*
729. **Mary:** *Yeh.*

*Theorizing aphasia*

*Well, I find now when I'm talking to people, I can mostly just talk.*

Mary, 1833.

I entered the research with an understanding of aphasia based on my consideration of the research literature, my early study and continued clinical experience in working with people with aphasia. Mary and Ken also brought their own ideas and theories about aphasia. When Mary had her stroke there was an extreme shortage of speech-language therapists but Mary valued the input she received. Although Mary continued to attend a group for social communication opportunities, it seemed there had been no continued contact with a therapist. Given that Mary was now a distance from the stroke, this was probably a reflection of the services available as well as Mary's progress and her own insight into her needs. However, Mary was still having physiotherapy and had worked towards improving her right hand. Also Mary was, in fact, her own therapist; she was self-motivated and she knew what it was she needed to do to promote her own progress. She continued to actively work on her written language and she identified a need for continued contact with people by telephone as well as face-to-face to use her communication. She also came to aphasia with an extensive background in education, an understanding of literacy along with her own highly developed academic skills, and well developed theories about learning. Therefore Mary's focus on the importance of written language, both reading and writing, and the ability to relearn or regain skills make sense:

1954. **Mary:** *It's quite interesting, at one time, I could look at a book and possibly, I would look, four or five - pieces, for a very short time, now it's*

1955. **Ken:** *[Five minutes.*

1956. **Mary:** *And now I can read most of it.*

1957. **Maxine:** *Yes.*

1958. **Mary:** *And in not, not the big one (and shows the size of print being large with her thumb and index finger).*

1959. **Maxine:** *Right, right, in ?/.*

1960. **Mary:** *[And even now, I, of course, I can. At one stage, I couldn't, even, read, the paper, when I, when I was in hospital.]*
1961. **Maxine:** *Yes.*
1962. **Mary:** *[Some of the time, I would say, what's this?]*
1963. **Maxine:** *Mmm.*
1964. **Mary:** *What's the one right at the top?*
1965. **Maxine:** *The headline (and I laugh).*
1966. **Mary:** *[Yes. No, only the top.]*
1967. **Maxine:** *The top? The actual title?*
1968. **Mary:** *[Name of it.]*
1969. **Maxine:** *The name of the paper.*
1970. **Mary:** *Yeh, that's all I could do.*

While verbal expression often becomes a priority for people, particularly when it is more affected, the need for written language for some people remains essential to the expression of self and to quality of life:

515. **Mary:** *Well, every day, I do write a little bit with what I; I've been, for (?) a couple of years or more. Because I had, I had to write down something, and I haven't looked at it from the point of view of when I, sorry. Now I, I write quite a bit of what I (?) when writing.*
516. **Maxine:** *Yes.*
517. **Mary:** *But, at first, I couldn't do much, at all.*
518. **Maxine:** *So it's kind of a reminder – of, of, of how you've gone too. A very tangible reminder of the fact that, perhaps in the early days of doing it, you were writing a few things and now you're able to write,*
519. **Mary:** *Well, I can write other things but mostly, I thought it is important that, I, needed to write something, just to keep me, get me going.*

Ken also had his own ideas of what aphasia was for Mary as his spouse and through their shared journey of the stroke. Like Mary, Ken did not use the label of "aphasia" or perhaps it was not useful to them when they explored its own meaning to their lives.

1138. **Ken:** *Well, the big problem with her speech is, ah, the nouns,*
1139. **Maxine:** *Mmm.*
1140. **Ken:** *and it was interesting, we were walking down the drive the other day and she proceeded to name the manuka, and the lancewood. And this was, you know, quite a new development, ah, when, only in recent weeks has she reached for these nouns,*
1141. **Maxine:** *Right.*
1142. **Ken:** *and got them.*
1143. **Maxine:** *Ah.*
1144. **Ken:** *Um,*
1145. **Mary:** *What were those?*
1146. **Ken:** *The names of things. Yeh, one, one thing I, I was discussing with people how she couldn't find nouns and Mary then said, "What are those things that I can't get?" So I worked out that I had better stop talking like that (Ken and I laugh).*

Ken brought to his understanding of aphasia his history and knowledge of Mary's communication style and skills before the stroke and as well as their own communication style as a couple. He himself was also tertiary educated; he was a teacher and he had also pursued post-graduate studies. His expertise in English gave a place from which to theorize and understand Mary's communication following the stroke:

1221. **Ken:** *The other thing was the social speech and um, as opposed to the information speech,*
1222. **Maxine:** *Mmm.*
1223. **Ken:** *you know, all the, um, to and fro that makes communication possible. That was all there.*
1224. **Maxine:** *Mmm (and I turn to Mary again)*
1225. **Ken:** *It was the, the content side was that was giving all the problems.*

Mary and Ken both had their own understanding of narrative in the form of writing; Ken talked of his diary writing about Mary's stroke and Mary showed sheaves of paper on which she daily made a point of writing something. In the early days after her stroke it may have even been a small

quantity; as Mary described it: *"I think, some of the time, it would be just be, originally to say, it's a nice day"* (539). In latter times she had also been writing about her early memories. Both had an interest in the historical writings of their families. Ken had reproduced a book written by his mother when she was in teacher training and both Ken and Mary were beginning a project based on diaries that Mary's father had kept during the First World War.

Mary and Ken's views of the future potential for Mary's communication skills and physical abilities were positive and had a sense of forward movement. Mary considered that she was *"starting to get a little bit better"* (1794), *"things are not finishing now"* (1812), *"I'm still finishing"* (2018) and *"There's whole lots of things still to do"* (2020). Ken, describing Mary's style in personal relationships, could well have been describing her approach to her living with the stroke when he said *"You won't find Mary taking a step backwards"* (1922). He further commented: *"And, ah, she was always thinking, ah, what's the next step. And, um, you know, only yesterday, she said, do you think I'm getting a bit better, with my walking?"* (1996).

### *Theorizing the self*

*And I, I reckon, for a long time now, I'm an ordinary person.*

Mary, 1643.

Mary's verbal ability made it possible to consider how she spoke about herself in the interview; this was despite some difficulties at times expressing exactly what she wanted to say. She told of herself as a child, as a sister, as a daughter, as a student, as a teacher, as a leader, as a partner and as a friend. She talked of herself as someone who was committed to education, both her own, and those of the pupils and staff with whom she worked with commitment throughout her career. While Ken described Mary's communication style in her working life as *"very direct"* and *"assertive"*, this was also apparent in Mary's communication style even in the presence of aphasia. She was active in moving the interview on by directing me back to the process: *"So what are we else, are we (looking back to the prompt book)?"*; *"And I wonder what else I need to talk to"* (60). She politely brought the interview to an end when it becoming evident that she was tired by closing with *"Well, it's been very nice talking to you with you"* (2053).

There was an associated sense of agency in Mary's life story and through her telling. Recalling her childhood, Mary presented a younger self in a written recollection that is illustrative of how she saw herself. The early memories that Mary found herself revisiting after the stroke became part of her endeavours to improve her writing. When she was more able, Mary began to write up these early memories. These were then word processed and she shared some of these with me (an example is shown in Figure 7.9). Mary's presentation of herself as a child is one of agency and self direction.

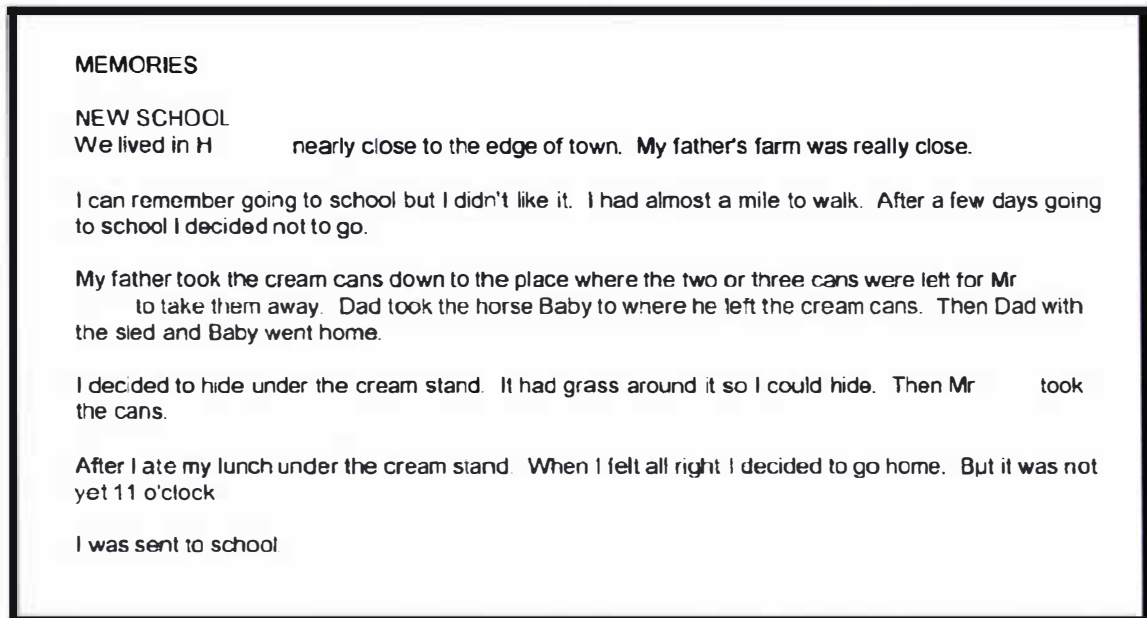


Figure 7.9: A scanned image of Mary's writing from Christmas 2003.

### The changing self

1454. **Maxine:** *If someone said to you, what were you like when you were younger? What would your family have said about you or-?*
1455. **Mary:** *Yeh. I'm not quite sure (and looks up at me). Because I think it wasn't until I was about fifty - I, really worked out that I was me.*
1456. **Maxine:** *Right.*
1457. **Mary:** *Mmm. Mmm.*
1458. **Maxine:** *You saying fifty? (Mary looks at me as if puzzled). Fifty years of age?*
1459. **Mary:** *How many?*
1460. **Maxine:** *Fifty?*

1461. **Mary:** *More forty.*
1462. **Maxine:** *Forty. Okay.*
1463. **Mary:** *Mmm.*
1464. **Maxine:** *You need all that time, before, don't you,*
1465. **Mary:** *Mmm.*
1466. **Maxine:** *to, to build up*
1467. **Mary:** *Mmm.*
1468. **Maxine:** *to who you are?*
1469. **Mary:** *Yeh. And I suddenly worked out that, um, that I was myself*
1470. **Maxine:** *Right. Okay.*
1471. **Mary:** *And, ah, I think I mostly, put it to, my first man. I was /mmm/ (and puts her head down to one side as if low or passive)*
1472. **Maxine:** *Right. So, some of the, the ,the crises in life actually helped you discover a bit about who you were.*
1473. **Mary:** *Oh, yeh, yeh. It was quite interesting*

Mary talked briefly about the ending of her first relationship when she was forty, its impact on her and the subsequent changes in herself. After this she accessed counselling and described this period of her life as one where she discovered what she considered to be “myself”. Mary also reinforced this sense of coming to know herself when we talked about people she considered had been influential in her life. She talked of her parents and a teacher who had been a mentor for her in her early teaching career. However, she described reaching a stage now where she had a sense of herself and perhaps the influence of others was less significant than it had been at an earlier life stage:

1412. **Mary:** *Ah. And, who else (as she looks down to her page of writing)? Well, of course, the one sitting over there (and she points to her husband and we both laugh). But I think, um, (pause). I think at that stage I would know what I wanted to be.*
1413. **Maxine:** *Right.*
1414. **Mary:** *For me.*
1415. **Maxine:** *Yes. That's, that's a really good point.*
1416. **Mary:** *[Mmm.*

1417. **Maxine:** *Mmm.*
1418. **Mary:** *[Mmm. Because, ah, it was me.*
1419. **Maxine:** *[Yes.*
1420. **Mary:** *Yeh.*

When we talked about how she saw her life if she looked back from the present, Mary then told me:

1557. **Mary:** *(Pause) Well. I mostly, can think of where I am going.*
1558. **Maxine:** *Okay, so you are thinking about the future,*
1559. **Mary:** *Yeh.*
1560. **Maxine:** *not necessarily dipping into –*
1561. **Mary:** *And it's been very interesting what, all the stuff that I've been doing.*
1562. **Maxine:** *Yeh, yeh.*
1563. **Mary:** *Ah, and especially of when, I was quite young.*
1564. **Maxine:** *Yes.*
1565. **Mary:** *Mmm.*
1566. **Maxine:** *And they're our building blocks.*
1567. **Mary:** *Mmm.*
1568. **Maxine:** *If you look back (turning over the page), Mary, same thing here. And we're looking back, would you do anything differently? Are there things you wished you'd done, or not done, or any changes you'd make if you looked back over?*
1569. **Mary:** *(Mary pauses for a long time as she looks down at the prompt picture). No, not particularly.*
1570. **Maxine:** *That's a really good place to sit.*
1571. **Mary:** *[It's more interesting. For – since I was about forty.*

We also talked about how she would describe herself in the present. Mary had a very simple and succinct response but still acknowledged the physical alterations introduced into her life by the stroke:



1475. **Maxine:** *How would you describe yourself now, Mary?*
1476. **Mary:** *(She looks down and after a while looks back up at me) That's me.*
1477. **Maxine:** *You. Okay, okay.*
1478. **Mary:** *But I get very annoyed sometimes.*
1479. **Maxine:** *About what?*
1480. **Mary:** *Well, I would like to, ah, get rid of having this problem (and she traces her left hand up her right side).*
1481. **Maxine:** *Okay, okay.*
1482. **Mary:** *Mmm. And I might get rid of it.*
1483. **Maxine:** *Okay.*

### The social self

*He aha te mea nui?  
He aha te mea nui o te ao?  
Maku e ki atu  
He tangata, he tangata, he tangata.*

*What is the most important thing?  
What is the most important thing in the world?  
I will say to you  
It is people, it is people, it is people.*

Māori Proverb.

Mary identified the importance of people in her life both through the associated stories of her childhood and family, her career years and her relationships with others. Her family history and her own memories featured as important in her narrative. She commented that from a very early age, *"even when I was, a, little kid, I thought people were important to me"* (1510). People continued to be important to Mary through her career, through her family and her friendships. Although Mary did not have children herself, she had ongoing contact with her own siblings' children and subsequently Ken's children from his first marriage. The points in her life that she considered to be low points were related to people; the loss of a significant relationship (*"I suppose it was when my, last man left"*, 1285) and the loss of significant friends (*"She and I thought, well, we would, might be able to sit, to be at one place and where we were. And then she died"*, 1300). Mary had a good

understanding of how people also have had a significant role in her accessing further changes in her life after the stroke. When we talked about plans for the future, improvements in her walking, talking and writing were a priority for Mary. She was clear that people and talking with people were what she needed to continue with her improvement in communication and to continue to develop as a person:

1582. **Mary:** *Ah – well, I, yeh, there'd be other people that I would need to talk, I need to have more people,*

1583. **Maxine:** *[Yes.*

1584. **Mary:** *that I can talk,*

1585. **Maxine:** *Yes, yep. Yep.*

1586. **Mary:** *because, ah, one of them's getting quite old,*

1587. **Maxine:** *Yep.*

1588. **Mary:** *and I think, well, in five years it might be /seh/, less that I have so I need more people.*

1589. **Maxine:** *And how do you think you'll, do that? I mean, what are the things that bring people into your life at the moment?*

1590. **Mary:** *Well, mostly, I need to, be talking with other people but it's going to take a little while*

1591. **Maxine:** *[Yeh.*

1592. **Mary:** *for me to get there.*

1593. **Maxine:** *Ah.*

1594. **Mary:** *Mmm. Mmm.*

During her working life, Mary had supported and counselled people with whom she had worked. She had also encouraged and helped others to complete advanced studies. Despite her aphasia, this remained a critical function for who Mary was; not only to talk with others as a way of improving her communication but also to be able to offer her own skills and support:

1170. **Mary:** *Yes. 'Cos two or three of them are very interesting people,*

1171. **Maxine:** *Mmm.*

1172. **Mary:** *and I, and I'm knowing things that they need to do (and she laughs).*

1173. **Maxine:** *Right. Rather than that, that early stage, where it's a bit of role reversal,*

1174. Mary: [Yeh.
1175. Maxine: *and people being helpful to you.*
1176. Mary: [Mmm.
1177. Maxine: *You're actually*
1178. Mary: [Yeh.
1179. Maxine: *have a different role.*
1180. Mary: [Well, one of them, ah, her man has left, her,
1181. Maxine: *Right.*
1182. Mary: *and so I've been helping, just talking to her and getting going,*
1183. Maxine: *Yeh.*
1184. Mary: *and the other friend is an, an older person who is not very well, and so –*
1185. Maxine: [Mmm.  
*And that gift is, is the gift of listening,*
1186. Mary: *Mmm.*
1187. Maxine: *isn't it?*
1188. Mary: *Yeh, it is. Listening*
1189. Maxine: *Because you don't*
1190. Mary: [Because I find that sometimes, when I was at the /univer/, well  
*anywhere was, /wih/, when I was start, at the (the name of a major  
distance education institution), there were often people in need of, things  
to help. Mmm.*
1191. Maxine: *And becomes part of your, it's, it's a blend of professional and personal  
skills.*
1192. Mary: [Mmm, mmm.

While Mary's communication was affected by the presence of aphasia and she is reminded, and reminded others, of the obstacles it created, she was able to develop a narrative that tells how she saw herself in the past, the milestones in changes in self and identity, who she considered herself to be now, and how she saw the future. She also highlighted the ongoing importance of people in her life and in particular, she was adamant that she needed people if she was to continue to improve her communication and to continue to develop as a person. However, she also identified the need for her communication and interactional skills to be available to help other people and not necessarily for her to be a recipient only of help and support.

## The Process

### *Speaking for another*

1974. Ken: *Well, the other thing out in the kitchen, um, you know was quite an achievement when she actually got the stuff out to make a cup of tea.*
1975. Maxine: *Yeh.*
1976. Ken: *And the next step was to actually make a cup of tea, and um, how long ago was it that you actually cooked up some scrambled eggs? She decided this was something she was going to do.*
1977. Maxine: *Mmm.*
1978. Mary: *(Mary looks at me) Something easy (and laughs).*
1979. Maxine: *Well, you don't want to take too much responsibility,*
1980. Mary: *[Oh, no, no, no.*
1981. Maxine: *do you (and we both laugh)?*
1982. Mary: *Why I do it when he can do it (and points to her husband)?*
1983. Maxine: *Yeh, that's, exactly.*
1984. Ken: *Ah, that was one of her other statements, "If I'd known how much you could do, you wouldn't have had it so easy before". And that, that was a stage when she couldn't get sentences out very easily but she got that one out (laughing).*
1985. Maxine: *[Yes. Yeh. Be, be careful about turning the tables. We might lose some things (and Mary laughs), that, that we, value.*

In previous interviews and earlier in this section, collaborative strategies as negotiating actions between conversational partners have been discussed. I was interested in these aspects of conversation not for the collection of data about specific behaviours but how they contributed to identity construction for the person with aphasia.

As already discussed, developing a life story with people who have severe aphasia necessitated the participants, their spouses, and me using a range of collaborative strategies. I saw the importance and necessity of this collaboration to the development of the life stories and the relational nature

of the interviews. However, Mary was much more fluent and more able to demonstrate agency in being able to talk of and for herself. Ken joined us half way through the interview when he made us a cup of tea and I noticed the discussions between Ken and me develop. I thought about whether we were beginning to exclude Mary as we talked and as she began to offer less. She was also tired at this point and later reflected, when we talked about the interview, that it had been fine, *“Except I get a bit tired, until I’d had a cup of tea”* (1604). So it may have been that Mary took this opportunity for respite as she had already completed an hour of the interview. Ken talked with me about Mary and Mary listened to the both of us, occasionally signalling agreement. Ken talked about the stroke and their shared history, and about Mary:

1244. **Ken:** *This is Mary, with her, with her. She is very disciplined, that she will write something everyday (pointing to her papers in front of us),*
1245. **Mary:** *[Yes, yes.*
1246. **Ken:** *because she feels that she has to write something everyday,*
1247. **Maxine:** *[Yeh.*
1248. **Ken:** *to keep herself tuned up.*

I initially thought about the action of “speaking for” the person with aphasia. This is considered to be a collaborative endeavour when it is instigated by the person with aphasia but it can also have a negative impact in the case of answering a question for the person or interrupting (Croteau, Vychnytil, Larfeuil & Le Dorze, 2004). In reviewing my own participation, there were examples of my own “speaking for” when I had made an assumption for Mary. Her own communication style, however, allowed for her to indicate disagreement:

1643. **Mary:** *And I, I reckon, for a long time now, I’m an ordinary person.*
1644. **Maxine:** *And, you’re, you’re, flexing, that kind of, um, personal, you know, you.*
1645. **Mary:** *Mmm.*
1646. **Maxine:** *You describe it, probably, as feminism, do you think?*
1647. **Mary:** *I don’t know (as if politely disagreeing).*

Rather than “speaking for” Mary, Ken in talking with me was “speaking about” Mary. Although he referred back to her, in the conversation with me he spoke about Mary in the third person: *“That was one of the reasons why she went to the (the name of a major distance education institution)*

*because she was a very clued up woman about administration*" (763). This "third personing" can only occur when there are more than two participants in a conversation. While I made initial assumptions about this excluding Mary, throughout the interview examples of successful collaborative strategies between Mary and Ken were evident. Ken was particularly involved in such "joint productions" incidentally during the interview when Mary actively enlisted and invited his input in her word searches.

Considering a relational view of the narrative construction of self and identity challenged my initial thinking about this and my initial goal to give "voice" to the person with aphasia. While that remains an objective within a narrative approach, through the analysis of Mary's interview woven in with the experiences of earlier interviews, I have come to appreciate the relational nature of identity construction and narrative; not just between the participants and myself but also between the participants and their partners. Their shared narratives existed before I entered to interview, the interview was a site for co-construction and the shared narratives will continue to evolve long after I have completed the project.

I wondered how it was for Mary listening to Ken's stories of her; hearing his positive regard for her and her life story, and the way in which she actively approached the stroke. I began to see Ken's narrative, not simply through the conversational analysis description of "speaking about" and the use of the third person, but as an act of co-constructing identity. I thought about how it might have been for Ken advocating for Mary in the early days after her stroke; negotiating with a raft of people who had entered their lives because of hospitalization, illness and rehabilitation. The need to introduce people to Mary's story, history, academic achievements, personality and expertise may have been a way of ensuring that people interacting with Mary supported her identity in a time of major change; a time when she was unable to demonstrate this herself verbally or physically. Ken talked of a particular nurse who cared for Mary while she was unconscious and the nurse maintaining that Mary should always be talked to as if she was able to understand and her permission requested.

These actions are important to how identity is strengthened rather than diminished. Erroneous assumptions about people with illness and disability and social interactions that reduce agency all contribute to the threats to identity. If we consider a relational way of being we start to reshape our assumptions. This does not reduce the criticality of such research and practice. The role of

power must be challenged and practices that reduce agency identified. Social dynamics and interactional patterns need to be addressed where they have a negative impact. However, a relational perspective affords us a way of researching and being with others that fosters an evolving life story for all participants including partners and the researcher. It highlights the interdependent human being influenced by the presence of the other while at the same time influencing the other.



**SECTION E**

**THE ACT (AND ART)  
OF SPLICING**

**Chapter 8: Gathering the strands**

**Chapter 9: Epilogue**



## Chapter 8

### Gathering the strands

#### Overview

#### Summary of findings

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Self and identity in aphasia

*How does aphasia impact on self and identity?*

*How do people with aphasia tell about self and identity?*

*What research methodology enables people with aphasia to tell their story?*

#### Implications for research and practice

Implications for research in aphasiology

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*Biographical responses to and self theories in aphasia*

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#### Limitations and suggestions for further research

#### Summary

## Overview

This thesis has explored self and identity in aphasia. It began by looking at what was known about self and aphasia and a theoretical perspective on self was then developed which led to exploring self and identity through life stories. These stories were analysed using an adaptation of the voice centred relational method (VCRM) and this process culminated in interpretive narratives. The project sought to further understand the impact of aphasia on the construction of self by exploring self and identity in aphasia using a narrative approach. It set out to do this using a more inclusive research approach with people with aphasia.

I have used a metaphor of splicing to describe the process. This sustains the notion of trying to weave together many strands to make a cohesive whole (Appendix I). The metaphor also extends to the starting point of two separate ropes: one the “knower” and the second, the “known”. This provides an illustration of the act of knowledge creation as “a subjective relational enterprise, always created and recreated between individuals rather than in isolation” (Josselson and Lieblich, 2001, p. 285). This chapter, then, is the concluding chapter in this thesis. It is about bringing all the pieces together in a way that closes the project but also sets an agenda for future research and clinical practice.

## Summary of findings

### Revisiting

The project grew from a practical setting. It grew out of a curiosity and a desire to be able to work better with people living with communication disability. The study and practice of aphasiology does not stand apart from its social and cultural location and the project was influenced by current thoughts on a social model of disability and the increasing application of qualitative methodologies in social science research. Specifically, the project was influenced by the growing attention to the importance of psychosocial issues in aphasia, particularly the importance of self and identity, as a balance to a predominant focus on linguistic impairment. The outcomes sought from the project were an increased understanding both of the impact of aphasia on self and identity and of the

construction of self and identity in aphasia. The project also sought to develop a process that gave voice to participants through an appropriate research methodology while also acknowledging the role of the researcher in co-constructing stories. While the project achieved its outcomes, the interpretative research process also allowed new understandings about the social nature of self, identity, clinical practice and research to emerge. While I began by considering “self” and “identity” as entity located within the individual, the opportunity to explore an extensive literature, design a research project and work together with people with aphasia through the life story interviews and subsequent analyses, enabled me to become aware of the importance to the project of a relational and storied self.

The following questions guided the project from the beginning and now provide a way of summarising the findings: how does aphasia impact on self and identity, how do people with aphasia tell about self and identity, and what research methodology enables people with aphasia to tell their stories?

### Self and identity in aphasia

#### *How does aphasia impact on self and identity?*

This was a key question for the project. Because stroke is an extremely personal experience and because I did not want to lose the voices of the participants by reducing their stories to common themes or issues, I developed narrative case studies from the individual interviews. The interpretive narratives of Bill, John, Kilroy, Margaret, Mark, Mary, Mavis and Owen therefore were presented as findings that can stand alone. However, I acknowledged that there was a need to bring these accounts together in a way that enables us to consider what we can learn from these people’s stories (including the researcher’s story). In the multiple-case study method there is an intensive focus on subjective factors in the production of social knowledge where each “case” contributes its own understanding and it is the synthesis of these multiple viewpoints that produces social knowledge (Rosenwald, 1988). So how do these stories inform our understanding about self and identity in aphasia which may then directly influence our research and practice with people with aphasia? I considered the research findings based on the literature on illness narratives and I considered how the framing of the project as a relational constructivist project draws attention to the relational nature of self construction.

### Biographical disruption or biographical flow?

I was familiar with the body of research on the narrative reconstruction of self after illness, including stroke, which talked of “biographical disruption” (Bury, 1991) and “narrative reconstruction” (Williams, 1984). The methodology did not include asking a specific question about the impact of aphasia on participants’ lives. I did not want to assume, or communicate, aphasia as a biographical disruption but rather I wanted to allow the life story narrative to develop and, if the impact of aphasia was significant to that story in that interview at that time, then it would be embedded in the presentation of the life story (Rosenthal, 1993). Therefore I did not specifically talk of “life before aphasia” or “life after aphasia” nor did I introduce a concept of an “old self” or “new self” in my dialogue.

I was also starting to come into contact with literature that challenged this notion of illness as a marked hiatus in a life story. Changes in self and identity are interpreted by each person individually within their relationships, their social situation, cultural context and their personal history. There were a variety of meanings of stroke and aphasia for people in the project which related to their sense of who they were and their personal and social identities. I risk minimising the individual skills, attitudes and relationships that each participant brings with them to a discussion of a reaction to stroke and aphasia by trying to aggregate their experiences. They each make a valuable contribution to understanding the impact of aphasia. For John it was a catalyst to make change and led to positive options despite the social handicaps of his mild aphasia. Margaret told of the aphasia with tears and identified the place in the body where the problem lay but she remained part of her family network and continued to pursue her family and personal interests. For Mavis and Mary there had already been personal crises long before the stroke which had altered their perceptions of who they were and they had emerged from these crises with a strong sense of being. They both continued to see improvement in their communication skills and were active in seeking this.

Owen had lived with migraine for a greater part of his life and it had been very disabling. He had also suffered a major injury early in his working career which had an impact on what his career options were. His stroke was severe and it was thought that he might not survive so for him every day has become a “bonus” day. Nella and Bill continued to look for opportunities for change but as Nella said it was just a matter of getting on with life but life would have been more fun if the stroke had not happened. Kilroy did not tell of major change in his sense of who he was after his stroke but he thought he had perhaps become more placid. Lisa and Mark had experienced the trauma of the

stroke but after fifty four years of marriage, Lisa could say that after what they had been through, they just enjoy each day. For some people the physical recovery, being able to mobilise or to walk again, was the most important concern and aphasia was not necessarily the priority for them in their goal to return home. All but two participants also cited the relevance of religion, church, God or spirituality in their lives. This was sometimes in response to a question about philosophy or in other discussions.

While the aphasia and the stroke were traumatic and made irreversible changes in people's lives, there was no consistency through the stories of a loss of self or biographical disruption that the early literature review developed. The narratives support more recent findings that challenge the image of a passive individual in dealing with chronic illness. Instead the person is seen as actively seeking to restore meaning in illness (Williams, 1996). For participants, there were major changes in social roles and opportunities which impact on the sense of self, but there was also a coherency and agency in the telling of the stories despite these changes in people's lives. Faircloth, Boylstein, Rittman, Young and Gubrium (2004) acknowledge that not all chronic conditions have the same effect on people's lives and that lives are not necessarily "disrupted". They introduced an analytic concept of "biographical flow" to better understand chronic illness as part of an on-going life (p. 245). They suggest that for some people there may be maintenance of a coherent pre- and post-stroke self as part of an ongoing life story. Stroke "does not always serve as a disruptive event, but instead melds into an enduring chronic illness narrative, part-and-parcel of biography" (p. 245). Carricaburu and Pierret (1995) propose a concept of "biographical reinforcement" in their research with HIV positive men where there was a reinforcement of their identities on the basis of what they had been before the infection (p. 66). Pound, Gompertz and Shah (1998) completed research with older people who had had a stroke and challenged the theory of "biographical disruption" in its applicability to people who have had other disruptive life experiences including illness.

### Loss in aphasia

Within the project, there was no specific talk of loss of self or a new self although there were references to loss. Mavis described the impact of the loss of her ability to read because reading had been an important part of her life before her stroke. There were changes associated with loss as with Margaret with severe aphasia. Bill certainly experienced losses in communication and also changes in his prominent role in the horse racing community. However, the relational aspects of his

life, his communication partnership with Nella and the maintenance of his social life may provide needed reinforcement for positive identity despite communication disability. As recounted, some of the participants had already experienced other disruptive events in their lives: work related changes, injury, bereavement, personal crises or turning points, or other serious illnesses. This does not minimise the impact of aphasia but supports other research which suggests that “accounts of the ordinariness of the event when placed in the context of their lives, contrasts with the commonsense of ‘grand narrative’ of stroke as an illness which creates havoc and devastation, presenting an altogether calmer picture of stroke as a ‘normal’ crisis” (Pound et al., 1998 p. 3000). While I do not determine my experience of listening to people with aphasia as stories of ordinariness, the project supports the need to consider different accounts additional to biographic disruption and loss for living with stroke and aphasia. The stories themselves give researchers, clinicians and others affected by aphasia other possible narratives of living with aphasia.

Given the participants in this project were mostly older and had been living with aphasia for two or more years, this outcome may reflect the composition of the group of participants. Margaret, as the youngest participant, expressed the most distress concerning her stroke and aphasia which occurred when she was fifty. All participants except one were in a supportive relationship and although Mavis was widowed she spoke actively of still being a person who joined in and helped others. Spouses and partners who were not involved in the interviews may give different accounts of the impact of aphasia on their lives. The people who chose not to take part may well have also given different accounts of their stroke and aphasia including biographical disruption given their age, proximity to the stroke and their reluctance to share because it was painful to talk about. It is much more likely that older people have experienced other life events that assist in stabilizing some of the impact of the stroke and aphasia or assist in making sense of it. There is also the element of the support available within close relationships and families following the stroke and the consequences might be more traumatic for someone without established or close connections.

### Self as theorist

What also emerged from the project was that in making sense of the impact on self and identity people developed their own understandings and hence their own theories. While a researcher is required to have an understanding of the theoretical background to the research problem, people with aphasia and their partners also have theories about stroke, aphasia and recovery. While I

developed an allegiance to models of aphasia that talk of disability being socially constructed, I am reminded by Margaret, that for her, she experienced aphasia as embodied; it resided within a place in her body when she pointed to her throat. Owen's theory of therapy, tempered by his resilience, was that it might have been easier if he had not had it. He also had theories on the type of therapy he was engaged in. John had counselling experience and it offered him theoretical tools with which to understand the stroke and its impact on his life.

Mary and Ken both had theories that resisted the medical discourse of recovery not persisting beyond three months. For Mavis, her theory on recovery was that you had to learn that it takes time to get better and she continues to do so. She also theorised that some of the assessments that were done with her were at a time that was too early for her to be tested. Nella felt that it was important for Bill to continue to use his brain and Lisa felt that not a lot could be done for a stroke so they got on with it themselves. These people all have theories about the stroke and aphasia and they are not simply passive in developing understandings and meanings. This supports that premise that people have their own theories about health, illness and medicine (Williams, 1996). There is also awareness of the cultural narratives that may be available to people within different age groups, for example stories of stoicism which may influence how accounts are presented.

#### A relational self

Despite severe aphasia and all the changes that are imposed, still being able to retain a sense of self is dependent not just on the level of communication or the functional abilities but on the social nature of our lives. Disability studies consider disability to be socially constructed with an emphasis on structural dimensions (particularly institutional structures and policies). Thomas (2004) and Reeve (2004) identify a new challenge to this social model and call for inclusion of the social relational dimension of disability as a well as structural. Social interaction with others and dealing with the reactions of others can affect psycho-emotional wellbeing and therefore affect a person's sense of self and identity and their participation in society. Bury (1991) says "the 'meaning' of illness lies in its consequence for the individual" (p. 453). From this project's theoretical base and from the life story narratives as "data", the meaning also lies within social relationships.

The project was framed by relational theory and my lens considered knowledge to be a subjective relational enterprise created and recreated between individuals rather than in isolation (Josselson &

Lieblich, 2001). I was therefore listening for relational acts within the life story narratives. A relational self was evident both in the stories being told but also in the telling of the stories. Although the stories were individuals' life stories they were also stories of and in dialogue with others, in the context of the time of their telling and they were part of a social and cultural world. While all the narratives were essentially part of historical periods and cultural contexts, the narratives of Mavis, Margaret and Kilroy's were chosen as examples of how these influenced their stories both in terms of the meaning of events in their lives but also of my understanding in our conversations.

All the participants' stories were populated by others and included stories of others in their lives and this is inherent in individual lives in social contexts. Specific to telling about self in aphasia were stories that also highlighted the importance of others in living with and making changes in aphasia. Mary and Mavis were very clear about the need for people in their lives if they were to continue to improve in communication and John acknowledged that without a supportive relationship the outcome of the stroke would have been worse. Owen attributed positive changes in his communication to having contact with others. Margaret's narrative was predominantly about the others in her life in relationship to her, while Kilroy maintained contact with two people who specifically visited him to provide conversational opportunities. One couple described a turning point when the minister at their local church directly addressed parishioners about the importance of keeping social contact with the couple. Bill continued to benefit from his racing contacts and Nella believed this was also essential to assist Bill in getting on with life and living with the stroke. Several participants wanted to be involved in the research primarily because they believed it might help others and a philosophy commonly cited by participants were versions of the Golden Rule.

### *How do people with aphasia tell about self and identity?*

#### Self construction in context with others

The research sought to understand how people with aphasia told about self and identity and therefore how self was constructed and negotiated within the interviews. As the project evolved there was a growing acknowledgment of the importance of a relational self to how meaning was achieved and how self and identity were constructed between the participants with aphasia, the researcher and others which included spouses. If we regard our sense of who we are and our social



identities as being constructed during our interactions with other people, how does this occur when language is impaired (Hagstrom & Wertsch, 2004)?

### Beyond aphasia

The range of communication disability in the project was from mild to severe. While interviewing skills emphasise the importance of good communication skills including finely tuned listening skills, the interviews with the participants with aphasia required attending to any communication behaviours that would enable the person to “tell” their story. This was fully explored in the methodology and within the narratives themselves. However, the ongoing engagement with the literature and the analyses of the interviews highlighted actions that I have called “listening beyond” aphasia. The act of listening to the stories being told rather than “listening to” aphasia as a linguistic act became the focus. “Listening beyond” aphasia involved understanding and negotiating the meaning of the stories rather than prioritising linguistic accuracy. This was particularly so for the participants with severe aphasia where the absence of expressive language meant negotiating understanding through all the available resources and identifying that other people are also resources in communication. Bill used his repetitive phrase<sup>46</sup>, which on the surface had no meaning, in different ways to achieve different meanings. At times it was an expression of frustration, of agreement or of wanting Nella to make further suggestions. The rate, volume and number of times it was repeated were important to Nella’s and my understanding. The context of what had been said before also contributed to the meaning. A “yes” or “no” for some participants had the opposite meaning and understanding involved listening to voice as well as attending to body language, facial expression and checking back with the person. The overriding goal in listening beyond aphasia was always developing and maintaining a relationship, strengthening our identities within that relationship and working together at understanding our shared time.

### Joint action

During the process of analysing the interviews I was also becoming much more relationally “aware”; my understanding of a relational way of being was no longer just a theoretical construct. At this stage I developed an additional “listening” to augment the voice centred relational method I had

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<sup>46</sup> “Himma gotta go”

adapted. I wanted to know, not about interaction, but about meaning making. I wanted to know what we were doing together to create a shared reality and what it was that we did or said that captured “being” in communication with another and the creation of a meaningful, shared understanding, rather than “doing” communication.

This partly involved the construction of the types of joint production and collaborative communication identified in the literature on conversational analysis (Goodwin, 1995; Perkins, Whitworth & Lesser, 1997; Damico, Oelschlaeger & Simmons-Mackie, 1999; Goodwin, 2000; Goodwin, Goodwin & Olsher, 2002). More importantly, though, it was also about moving beyond what words mean to “what the person means in saying them” and the notion of “joint action” (Shotter, 2004, p. 1). Shotter (1994) suggests that utterances are relational and therefore exist only in the interactive space between speaker and listener and, although speech is regarded as systematic and rule governed, there are actually no rules or principles for that space: “a uniquely creative response is required” (p. 4). The project regarded telling about self and identity as a relational activity but what was required was more attention to overall relational communication and a greater need for care in negotiating meaning in the presence of aphasia.

Mary’s licensing of my errors when they were not significant to the overall outcome or to our understanding served to preserve the flow of conversation and our relationship. Mavis wasted no time on trying to renegotiate a word that we had previously jointly produced. Her goal was communication and, accepting we had already developed shared knowledge about what the word was, she simply reminded me about “that word” and got on with communicating. Between John and me there were other examples of the responsiveness which is created through the interplay between speakers where each response becomes part of the developing story between one another. The presence of humour, of shared laughter, of word repetitions and of the speed of communication in a context all carried with them the shared meanings beyond the “text”.

### *What research methodology enables people with aphasia to tell their stories?*

The outcome desired for the project was a methodology that enabled people with aphasia to tell their stories through a more participative approach. There are two contributions that this project makes. Firstly, its exploration of more inclusive practices and secondly, its methodology.

## Inclusive research

While the research was inclusive of people with aphasia through the selection of participants and through a life story approach, it was at the lower end of the continuum of participative research approaches. The research questions were mine and analysis was completed without input from the participants although feedback was sought on the completed narrative interpretations. As much as possible inclusiveness was encouraged through the use of aphasia-friendly resources, ongoing contact and dialogue. Furthermore the interpretive nature of the analytic process and the linguistic demands of writing up created obstacles to a more participatory process. There is potential however to explore this further and also to explore the different types of research topics and questions that would generate more participation, particularly those questions that people with aphasia want asked.

I believe the life story approach sets out to create more equality in the relationships developed during the process, particularly when this is supported by relational theory. It also had some positive outcomes that were verbalised by participants. Owen commented that it was the first time he had had the opportunity to look back over his life and said he had moments of “Hey, that’s right”. Mary and Ken felt that the interpretive narrative gelled significantly with their own thinking. John felt that reading the final draft, which he received over a year after the interview, gave him the opportunity to consider his journey and that it also helped him to shape where he was going. The life story approach was able to be adapted for all the participants within the project and enabled people with aphasia, including severe aphasia, to tell their stories. The flexibility to adapt the process to meet the communication needs of each participant is an important contribution to a more inclusive research process.

## An enabling methodology

The research question was also about identifying a methodology that enabled people with aphasia to tell their stories. A life story approach was an effective research tool to enable people to tell about self and identity. While the VCRM is considered to be universal in its application (Gilligan et al, 2003) and the methodology worked with people with more verbal expression abilities, the challenge for the project was for this to also work with people with severe aphasia. The research was based on a working assumption that people with aphasia have an evolving narrative or an

autobiographical story through which self and identity are constructed. Including people with severe aphasia challenged how this narrativising was achieved in the presence of a severe communication disability. The life story structure provided a format but at times the questions were difficult for people with severe aphasia. For this project the VCRM was about listening to people's way of speaking which included the voice of the body as well. The participants used a variety of resources including embodied and environmental resources in a variety of ways. They were not identical and an inclusive approach respected their different communication strengths and difficulties.

Key to enabling people to tell their story was to see the relational aspects as vital to its construction; both in the nature of the telling and the negotiation of communication and in the nature of creating meaning between people. The participants with severe aphasia would not have been able to participate if the research had been one that removed the researcher's subjectivity, relied only on text or failed to acknowledge the significance of and work with individual resources. For Mark and Bill the important resources for them were their spouses and, while the story could not be told independently, their stories also told of interdependence and, even in the presence of severe aphasia, they both were active agents in the construction of the story. While communication was not always easy or successful and not all life story questions were able to be addressed, participants with severe aphasia were able to construct cohesive life story narratives using their resources and in collaboration with others. It also involved attending to the subtleties of communication with an assumption the participants were competent and the role of the active listener was to foster narrative agency. The VCRM allowed me to "listen" to the voices within the interview and to consider further the self in aphasia, not as an isolated construction, but as an ongoing construction in dialogue with others.

### **Implications for Research and Practice**

What we know about responses to chronic illness and disability and our understandings of narrative and relational theories are significant to the research and clinical realm. If we recognise research and practice as social practices, they are therefore also sites for identity construction. Having considered the project's overall findings related to the research questions, the final task is to apply these findings to research and practice. While this discussion is specific to aphasiology, it is also pertinent to other areas of communication disability.

### Implications for research in aphasiology

Based on the outcomes of this project a more inclusive research process for people with aphasia is possible through attention to the relational nature of research. If knowledge is considered a subjective relational enterprise then research is also a relational enterprise. This has implications for the way in which we engage with people within a research project, how researcher subjectivity is acknowledged as part of an interpretive research process, and how the ethics of research are managed throughout the entire process.

Frank (2005) determines that in fact research is at its most basic one person's representation of another. He proposes a dialogical alternative to research that seeks "static themes or lists of characteristics that fix participants in identities that fit typologies" (p. 968). Dialogical research emphasizes that listening to the participants' stories is an act of engagement and even the asking of research questions brings about self-reflection. The methodology used in this research project encourages consideration of research as a relational activity and therefore requires attention to the co-construction of knowledge and the ethics of such a commitment. One important implication of this project is the need to continually question what impact our research in its different stages will have and is having on the self and identity of participants.

Narrative inquiry using a life story approach is an appropriate methodology for exploring subjective experience and this project's design has implications for how self and identity with people with a range of severity of aphasia might be researched. While the process is lengthy and labour intensive, it reinforces the value of a process that is inclusive and aphasia-friendly. It allows a group of people often excluded from research to participate and to be able to tell their stories. This process also enables research involving more than one participant in an interview and is therefore more "aphasia-friendly" for people with more verbally compromised communication whose communication abilities are maximised through partnership. The inclusion of communication partners, while initially deemed a support for people with aphasia in this project, opened up a new way of thinking about the relational nature of communication. While this project has been about people with aphasia, the project's methodology has relevance also to research into subjective experiences in other communication disabilities and particularly the use of narrative and specifically issues of self and identity.

This project is strong in reflexivity. I believe that the interpretive nature of the research process requires reflexivity as a form of accountability and as a way of being able to “audit” the interpretive process and identify how the researcher’s subjectivity influences the final project outcomes. As I worked with the transcriptions and reflected on the interviews and the wider research implications, I highlighted issues through each interview and interpretive narrative that I considered to be problematic or a discovery that needed further exploration. This was a valuable way to account for the “messiness” of such research and identify issues as they arose.

### Implications for clinical practice in aphasiology

#### *Biographical responses to and self theories in aphasia*

We have discussed the individual responses to illness and disability and, within this project, to stroke and aphasia. The participants in this project developed individual accounts supporting the notion that biographical disruption is not the only response to stroke and aphasia. While this does not minimise the effects of living with aphasia nor does it suggest that for some people biographic disruption does not occur, it does however tell us something about how we might work together with people who have aphasia. We need to listen to and consider the theories that people bring to our therapeutic relationship. Their stories, their past experiences, their attitudes and reactions to these past events may well help us understand the possible reactions to stroke and to aphasia. We also need to understand that the person is not in isolation and some of the personal theories of self, illness, life events and now aphasia may well be shared narratives with spouses, families and others. We need to be careful that our judgements and our position as “expert” do not become obstacles to people being able to enter rehabilitation services in a way that respects their expertise and their history. We also need to be transparent and share our theories in order to develop a working relationship with people who may well have different theories, values and assumptions. While there are promising identity therapies for aphasia, I believe an important implication of this project is that it allows us to consider issues of self and identity as not a specific therapy we do but rather as a way of working and being with people who are negotiating meaning and self construction, as are we.

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### *The importance of communication in self construction*

Communication within aphasiology was considered to be primarily transactional where information is exchanged. Increasingly, though, it has been recognized that it is also interactional, a tool for social affiliation (Simmons-Mackie & Damico, 1995). Davidson et al. (2003) identified through naturalistic observation that aphasia impacted on the functions of communication including sharing information, maintaining and establishing relationships, and telling one's story. While telling one's story is the act of self construction and meaning making, the importance of this has not been identified or highlighted within aphasiology research. While aphasia impacts on the ability to exchange information and engage in social interaction, it also impacts on the ability to engage in self construction and meaning making.

There has been an increasing interest in the role of conversation in forming the direct basis of treatment (Armstrong & Mortenson, 1995). The emphasis in therapy is on interaction skills and training conversation partners (Kagan, 1998). While conversation is recognised as a collaborative and co-constructed event, it needs to be acknowledged that it is also the site of constructing meaning for people and that the therapist's subjectivity is part of the construction and interpretation (Bamberg, 1997; Quasthoff, 1997). This is particularly relevant in addressing issues of self and identity. A relational approach has implications for how we extend our understanding of the functions of communication from transactional and interactional to include communication as important to self construction. This requires us to think about how our therapy interventions can account for this function when working together with people with aphasia. Understanding that self construction is a dynamic process has implications for where our involvement with and responsibility to people living with aphasia actually ends. Communication is an essential part of self construction throughout our lives and this has implications for services for people living with aphasia in the long term in addressing changes in self and identity over the life span.

### *Reconceptualising practice*

An important implication from this research is the potential to reconceptualize our practice. Within aphasia therapy, recent developments in therapies that address identity have an important place in acknowledging the impact that language disability has on self and identity. While identity therapies in aphasiology are extremely valuable and important to developing a stronger sense of self and

identity in communication disability (Pound, 1999; Barrow, 2000; Byng et al, 2000; Pound et al, 2000; Pound, 2001; Hewitt & Byng, 2003; Khosa, 2003; Moss et al, 2004; Pound, 2004), self and identity are significant to any relationship that is developed between people where one is influenced by the other. All contact with people is in effect identity work and the implication is therefore not to specifically design only interventions for self and identity in aphasia but to foster a way of working together with people with aphasia that supports positive identity.

In our conversations and our more formal clinical activities both client and therapist are in the process of constructing their life story and their selves. We need to understand what it is that creates the context for identity work and for positive identity. This will enable us to also consider the converse; what it is within our therapeutic environment and relationships that has a negative effect on self construction and identity. This involves not only our interactions with clients, family and other health professionals but it also includes our choice of assessment approaches and our interventions. Identity therapy is about all we do in interaction with another. It is about how we position ourselves, how we identify the presence of power and how we communicate the values we bring to our interactions. Recent literature in speech-language therapy also substantiates this. Hagstrom and Wertsch (2004) suggest that identity as a social construction can be used to understand assessment and intervention processes in clinical settings and they emphasise the role of talk between clients and clinicians as central to the "identifying process" (Hagstrom, 2004, p. 225).

In response to these new and articulated understandings about self and identity, an important implication of this research project has been the embryonic development of what I have called a model of relational practice in aphasiology. This model brings together several themes current to practice in aphasiology as presented in the literature in Chapter Two and advances how we practically address the psychosocial aspect of self and identity in aphasia. These include the recognition of the importance of conversation and identity (Hagstrom, 2004; Shadden & Agen, 2004), the development of specific therapy approaches to address identity in aphasia (Pound et al, 2000), the call for increased participation of people with aphasia in authentic communication events (Chapey et al, 2001), the acceptance of a social model and more inclusive practices (Parr & Byng, 1998; Byng et al, 2000, Mackay, 2003; Hagstrom, 2004; Moss et al, 2004; Parr 2004), the development of more functional approaches to communication therapy (Davidson et al, 2003), the ICF classification inclusion of participation and contextual factors as components in the World Health Organisation's (2001) framework of health, and an interest on quality of life issues for people living with aphasia (Hilari et al, 2003; Cruice et al, 2005).



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This proposed, and developing, model of relational practice in aphasiology is specific to considering issues of self and identity and reconceptualises practice as a relational process. This model is informed by the theoretical framework of the project with a focus on a relational and storied self, the experience of being involved in the research process with people with aphasia, the analysis of the interviews and the ongoing engagement with the literature<sup>47</sup> as part of the formation of a deeper understanding of what was happening. A model of relational practice addressing self and identity in aphasia draws the project's findings together with current research and practice in aphasiology, clinical psychology, counselling, and nursing.

## Relational practice

### *What constitutes relational practice in aphasiology?*

There is the danger of trying to reduce relational practice to a list of skills to be acquired or to be checked off. Emergent from this project is the premise that a relational way of doing therapy is not about acquiring a set of skills or techniques. Relational practice is, instead, a way of "being" in therapy, not a behaviourally learned way of "doing". It is about moving beyond the concept of an individual and separate self in therapy contexts to an understanding of the relational dynamics of therapy and the influences that this has on identity construction (Hartling, Rosen, Walker & Jordan, 2004). This approach to practice draws on the concept of engagement advanced by Hewitt & Byng (2003). They give a specific example of people with aphasia gaining a feeling of engagement through participation in a project group which was not actually a therapy group but that provided an opportunity for people to be and feel valued. An unexpected spin off was that the communication of these people was often better both during and after these experiences. They describe engagement as an opportunity to connect with life in a meaningful way, to confront real life challenges, and to be involved and identify with others in a respectful way. Relational practice underlies this process of engagement and while it is about the tasks being real and meaningful, I believe it is firstly about the communication practices and the relational nature of those practices occurring between people: both people with aphasia and those who do not have aphasia. So what are some skills that can enhance relational practice?

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<sup>47</sup> In Chapter Six (p. 155), the concept of "enfolding literature" was introduced as a critical feature to explain the ongoing comparison of emergent concepts, theory and hypotheses with the existing literature (Eisenhardt, 1989, p.544)

### Awareness of our values, beliefs and assumptions

Being able to identify and articulate the values, beliefs and assumptions that underpin our work is important to who we are and what we do when we are working together with people with aphasia. Just as identifying our ontological, epistemological and theoretical foundations allows us to “do” research in an ethical way, being clear about the values, beliefs and assumptions that support our practice is a responsibility we have when we intervene in people’s lives (Stam, 2000). While our behaviours are observable, the values that support what we think, do and say are not but they greatly influence the type of interactions and the type of therapy tasks. Parr (2004) in her research into what happens to people with severe aphasia identified the need not only for training to support communication but to enable “the expression of acknowledgment and respect” (p. 50). Those values are important as a location from which our communication behaviours develop. A focus on the values, beliefs and assumptions that all participants bring to a situation is of prime importance if meaningful dialogue is to take place (Nolan, Davies, Brown, Keady & Nolan, 2004).

### Focus on relationship

As already discussed throughout the project, the notion of “joint action” focuses on language as a joint, dialogical or relational phenomena (Shotter, 1997). Language is not considered to be something within a person’s mind or in the world around them. Rather it is in people’s dialogue and in their social activities. This calls for a shift in our understanding of the therapist’s role as expert when we accept communication as constructed between people in relationship. It also calls for the recognition of relationships as meaningful and reciprocal (Nolan et al, 2004). It is not just about a way to practice; it is about valuing the role of relationship and it means achieving a respectful, compassionate and authentic way of being with others (Hartrick Doane, 2002).

### Focusing on competency and agency

Associated with a focus on relationship is fostering competency and agency. This is the desire to build and maintain a relationship in partnership with the other rather than the goal being the achievement of accuracy of linguistic performance. The concept of “looking beyond” aphasia aims to maintain a relationship by acknowledging the competency of the person with aphasia. Simmons-Mackie and Kagan (1999) found that “good” communication partners of people with aphasia would

“save face” and sacrifice transactional goals in order to support a positive sense of identity and competency in the person with aphasia (p. 818). Negotiating meaning and attending to client preferences support competency and agency.

### Mutual empathy

Empathy requires not only the therapist having empathy with the experiences of the person with aphasia and their family. It also requires that the therapist identifies and empathizes with his or her own feelings of disempowerment and threatened identity that can arise from encounters with others (Hartling et al, 2004).

### Reflexivity

Reflexivity has been explored through the project but it is also an integral part of relational practice requiring self-observation, critical scrutiny of practice and conscious participation in therapy processes (Hartwick Doane & Varcoe, 2004). Because identity is socially constructed, reflection on our clinical role allows us to examine how our position influences the other and also how we are influenced by the other. The “listening” within the VCRM provide a format for guiding reflexive practice.

### Listening, learning and responding

The focus of the thesis has been knowledge as a subjective relational enterprise created between people which involves the ability to listen and to respond to the other. Listening to our clients is also about listening to ourselves. Listening to and learning from the social process of therapy is not only a client’s role but also a therapist’s.

### Language

How we talk (and write) to or about one another has an impact on our sense of who we are and also on how others might regard us. Language is a powerful tool in influencing self-perception and in

how communication disability is constructed. Consider the labels used to describe people with aphasia and how they position people: “aphasic”, “stroke victim”, “stroke survivor” or “stroke sufferer”. Relational language is language that creates a sense of mutuality and authenticity. It is inclusive and creates and reinforces positive identity.

### Narrative practice

While I have included this last, narrative practice is intimately connected with the discussion of relational practice and self and identity in aphasia. We spend a great deal of time either telling or listening to stories and it is always a relational and dialogical process. How might we incorporate narrative practices into our work with people with aphasia? While the discussion about psychosocial issues has included debate about the potential requirement for therapists to have more counselling skills, the implications of this project and relational practice are not for therapists to be skilled “narrative therapists”. Rather therapists need to be “narrative informed” with a willingness to learn from and apply narrative theory and research (Angus & McLeod, 2004, p. ix).

As discussed, people come to the process not as passive but as active agents with their own theories. Narrative is a tool that allows us to better understand those theories, assumptions and values that people bring to the clinical setting. It is also an important aspect of people ascribing meaning and order to the events that occur in their lives. A narrative informed practice allows us to gain an understanding about how people approach the changes in their lives, the resources that they have called upon to negotiate past events that may well influence our therapy journey, and how they see the future. The stories people share with us also tell us about how they see the world and the people that share that world. We can understand better the implications of those narratives to the clinical world.

Being narratively informed reminds us to be aware of our own stories and how they may influence our practice. Our narratives or “therapeutic theories” are the assumptions we bring with us that establish how we position ourselves in therapy with people with aphasia (Gergen & Kaye, 1992, p. 169). Most importantly, the clinical encounter is recognised also as a site of narrative self construction and whether we identify that we are “working” on identity or not, the social practices of the therapy encounter impact, positively or negatively, on the ongoing construction of self and identity for all people within the clinical relationship.

One of the tasks of therapy therefore, should be the restoration, development and maintenance of narrative agency for people with aphasia. "Narrative agency" is reduced by aphasia but also by people and practices (Manzo, Blonder & Burns, 1995, p. 232). This means that we need to provide the props such as those presented in the research to facilitate this narrative agency. The implication of this is working not just with the person with aphasia but with all partners in communication including our selves and examining practices that may reduce agency which impacts on the sense of self and identity. The life story method outlined in the project has potential for using as a clinical tool to gather information for assessment and diagnosis as well as to monitor change over time. Narrative based practices have been described in detail in Pound et al. (2000) where personal narratives are a key to identity work. They allow the person with aphasia to demonstrate expertise and involve the therapist in the role of listener, supporter and co-constructor. Life story narratives and other narratives of personal experience will appear in a clinical domain if we are open to listening and provide opportunities for people to do the telling. They are as valuable as any tool we may have in our clinical battery and they have ecological validity as an activity that we naturally engage in. They ask us to change the way we listen and acknowledge that we cannot remain unchanged ourselves in clinical practice.

### *The task or the intent?*

While some of these skills and their collocation are not new to practice with people, they are given a different meaning when they are applied to working together with people with aphasia and their families and when they are grounded in relational and narrative theory and research. None of the skills outlined describes a specific therapy activity that is designed to be "relational". It is the process that is relational and it is possible to engage in any therapy task in a relational way. I suspect that some tasks may come to feel less appropriate to relational practice but by applying the skills that contribute to being relational, those tasks may become a place for negotiating what people with aphasia feel is appropriate to their lives and what activities validate positive identity. Further research into relational practice in aphasiology for practitioners and for clients would extend this project and advance practice recommendations. While the discussion has focused on relational practice in aphasiology, all clinical practice with communication disability is about identity and therefore research into what constitutes relational practice in other areas of speech-language therapy would be valuable.

### Implications for my practice

Throughout the process of the project I was still engaged in a limited amount of clinical practice with people with aphasia and other communication disabilities. I have therefore had the benefit of understanding and also living some of the synergy between research and practice. As I have worked together with people, I have considered changes that have taken place in the way I am as a therapist with others. While this is probably not discernable to those who know and work with me, I am much more curious about how it is to “be” with the “other”: clients and their families, other health professionals and even how I am in my personal relationships. I listen to myself working towards acknowledging the relational connection with people; incorporating a more reflexive aspect to my practice, examining my assumptions and judgements, understanding more about my biases and, where I identify it, attempting to reduce the power of the professional role. I wish to value not just the competence of people with aphasia but their expertise. I am aware though that my work takes place in a context which is still strongly influenced by a positivistic approach as in a medical model of practice. Current funders of services for people with communication disability require monitoring of functional outcomes and the evaluation of the effectiveness of relational practice presents challenges in the context of evidence-based practice.

As the result of this apprenticeship in research, I see the strong influence new knowledge and understanding can have on the world of practice. Once again I am reminded of the influence of John Shotter’s work and an earlier quote in Chapter Three which holds a greater sense of meaning at this latter point in this project: “It is not a matter of putting theories into practice, but of inserting or intertwining new reflective and critical practices into our already existing daily practice” (Shotter, 2003, Paragraph 4).

### Limitations and suggestions for further research

A limitation of such a project is concerned with the generalisability of the research findings. Attention was given to this in the discussion of the use of a multiple case study approach. As this is an applied research project, judgment about the generalisability of this approach and the findings rest with whether the reader identifies that the “lessons” learned can be applied to other similar contexts specifically another case that is similar to the population described and also whether it contributes valuable knowledge about aphasia.

One further limitation of the project was the number of participants was relatively small. Those who took part in an interview were people who actively wanted to and were comfortable talking with me about their lives. There is also much to be understood by considering those people who declined involvement. They were younger, were closer to the time of the stroke, and one person resided in residential care. There is an assumption that they have less biographical resources to draw on. Further research across a range of ages would contribute greater understanding of the concepts of biographical disruption, continuity and flow. This may mean engaging people who may initially perceive research as invasive. There may be different methodologies including focus groups where this barrier could be addressed. There is also awareness that the personal narratives of individual participants may not necessarily have been able to capture the impact of the stroke and aphasia for their partners and families.

Narrative inquiry is well suited to exploration of issues of self and subjectivity. Issues of researcher subjectivity are present in interpretive research and while a reflexive stance towards the research process has been taken, there is still the potential for interpretations to be influenced by the researcher's subjectivity. Throughout the thesis, there is an awareness of the fine balance between providing a reflexive account and balancing the voice of the participants.

The VCRM was not developed for people with communication disability. The adaptations to the method that I made did however enable the analysis of more standard text as well as analysis of communication in severe aphasia but they may well have underplayed the more critical use of this method.

A further limitation of the project was the time involved in developing more inclusive approaches and this meant that the final stages of the project were less inclusive than desired. There was a considerable time gap between the interviews and returning the interpretive narrative to people. When the final narrative interpretations were returned to participants for their feedback, there was some communication about the overall project and changes to the narratives, but there was no time or process to meet with participants again and to develop a more relational approach to the final product. From this project, further research could be more focused on involvement of participants in the latter part of the analysis and writing up, and consideration of how this collaboration could be achieved. Further research could also consider developing more inclusive approaches by working with people with aphasia to identify their research agenda and moving towards a more participative

approach. This would involve people with aphasia identifying research priorities and considering how to involve people in both the processes of final analysis and presentation of research results.

There still remains potential for the foregrounding of an individualistic perspective. While telling an autobiographical narrative is an opportunity to actively structure and redirect that life through a coherent story it can be problematic if a modernist orientation considers the narrative as fixed and representative of reality (Gergen & Kaye, 1992; Wortham, 1999). However, while the project does not consider that reality is out there to be represented or that it is purely in the mind, what people say does have some significance to them and does have some relationship to their psychological and social realities and they are communicating something about their lives (Mauthner, 1999; Crossley, 2000b; Hollway & Jefferson, 2000). For participants, facts as reality were important. Feedback from participants was not about the interpretive nature of the final narratives. Rather, it was mainly concerned with issues of content: errors in, or omission of, supporting details. A relational approach and an awareness of personal narratives as relational acts work to resist the research process from returning to an individualized notion of self or disability while respecting the understandings of participants.

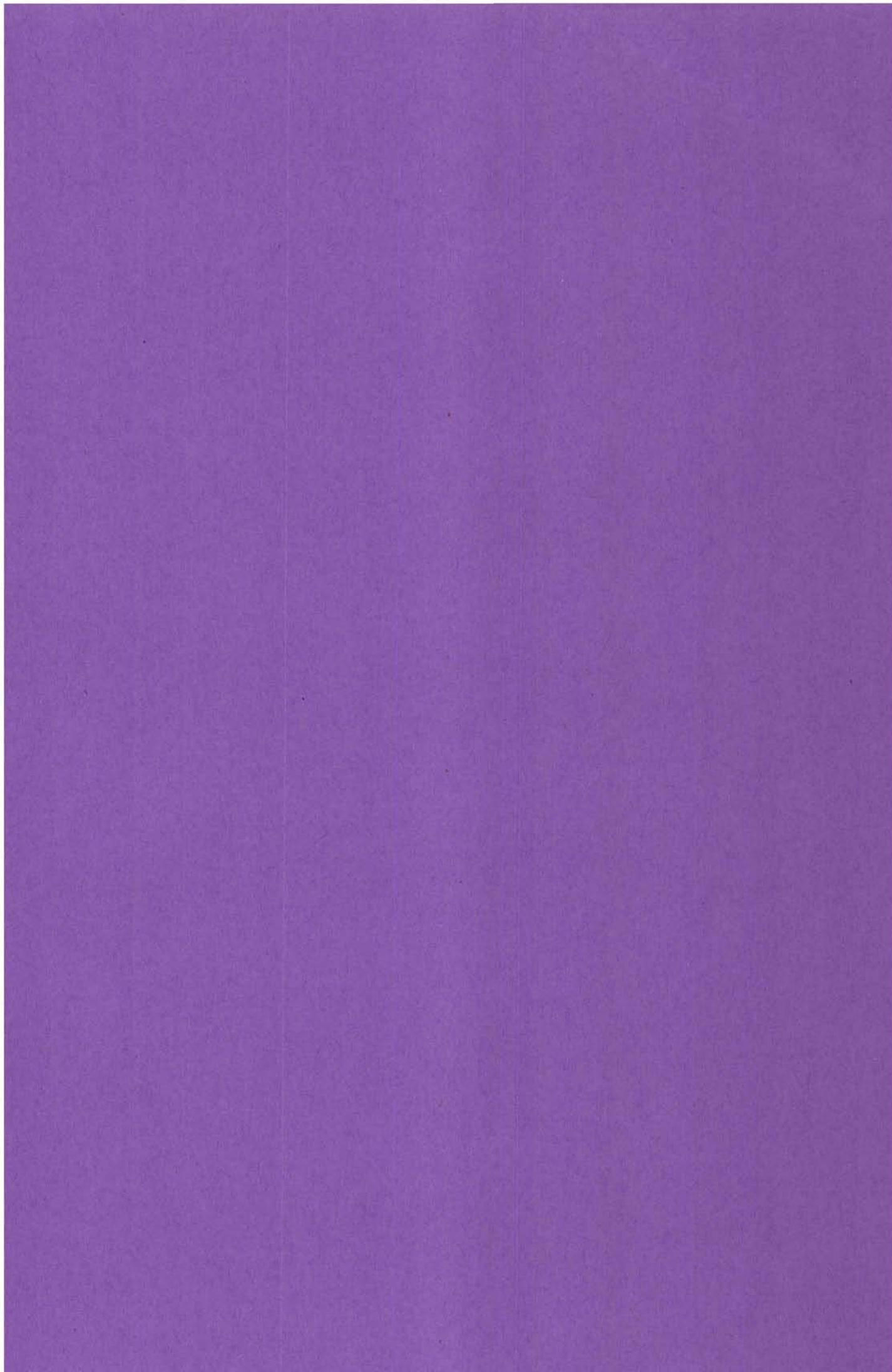
It is recognised that a limitation of interpretive research is that it is less critically oriented and, in this project, the focus on relationship may have muted a more critical approach. However, the aim of the research was to provide a vehicle for people with aphasia to tell about the impact on self and identity of aphasia. Therefore if people read the narratives and gain new understanding of what it is to live with aphasia, if it highlights for the reader the competency and expertise of people with aphasia, if it enables the reader to explore the notion that communication disability lies between them and the person with aphasia rather than at the level of the individual, then that is about social change. Within these stories are narratives about the social practice and provision of speech-language assessment and intervention which have critical value. These were not fully developed within the research but could be through a more critical utilisation of the voice centred relational method. Research into the narratives and discourses surrounding communication disability would contribute to understanding further the social construction of communication disability and some of the barriers that are present that impact on people with communication disabilities' ability to develop positive identities. A starting point would be the identification of narratives and discourses at work within those settings where people with communication disability access services



The interpretive accounts are authored by the researcher and with aphasia there is already the initial process of interpretation occurring in the interviews and in their transcriptions. The second level is the act of interpretation taking place in analysing the material and this is heavily shaped by the researcher. The detailed documenting of the “developing and doing” in Chapter Six and the details of the theoretical decision making in Chapter Three are ways of laying out how the interpretive narratives were developed, the assumptions underlying them and making transparent the researcher bias or selectivity.

### Summary

What started as a clinical interest in self and identity in aphasia was advanced by an interest in narrative inquiry. The process, however, has enabled me to consider more deeply the relational nature of self and identity and ultimately how that applies to a clinical world. This chapter has gathered together the participants’ stories in a way to inform research and practice. It considered the strengths and limitations of the methodology of the project and it developed implications for researching and working with people with aphasia. While the project has a sense of completion, the process is ongoing. I have been fortunate to have had the opportunity to develop a rationale for a relational way of working together with people with aphasia and it has changed, not just my assumptions about the nature of self and identity, but also my practice.



## Chapter 9

### Epilogue

**epilogue** (noun)

**1.concluding speech** (theatre)

a short speech, usually in verse, that an actor addresses directly to the audience at the end of a play

**2.short section at the end of a book** (literature)

a short chapter or section at the end of a literary work, sometimes detailing the fate of its characters

*As narrative inquirers, we recognize that any piece of autobiographical writing is a particular reconstruction of an individual's narrative, and there could be other reconstructions.*

Jean Clandinin and Michael Connelly, 2000, p. 101

In the first week in May 2000 when I was busy pursuing supervisory support for the doctoral programme in psychology, Marcus, my nephew, took his own life. He was twenty-nine years old. I recall posting my Honours project to a potential supervisor from the ferry terminal on our way to his funeral. There will never be an adequate phrase that captures his death and I have come to choose my words to suit the context. I quickly assess my listener's needs while juggling what I say to lessen any distress but also to protect myself and Marcus from the assumptions that are carried with suicide. I tearfully explained to a friend in the early days of my grieving that Marcus hung himself. I am grateful for her sensitivity and her knowledge of my pride in what I consider to be my competence with language and her gentle correction that, in fact, he "hanged" himself. As I was to repeat this many times, I remain appreciative of her timely grammatical correction. However, regardless of the grammatical accuracy, Marcus truly took himself away from us; he separated from life and from our family in a traumatic and devastating manner.

So where does this fit in this thesis? Very early on in my reading, I explored autoethnography and I wondered whether this experience had a place in my academic world as it certainly pervaded my everyday living influencing greatly my life and my own life story. I have since tempered my desire to use this personal experience. However, in looking back over the project and the years between, I have to say that some of what I have engrossed myself in, the world of narrative and qualitative research, has been enormously healing. It has also influenced who and how I have been in this project.

It has also made me very aware that I have continued to dialogue with Marcus, both in inner conversations and within my writing. Looking back over my journaling and poetry writing, a means of making sense of such devastation, I realize that while I was grappling with narrative, the postmodern self, constructionism and my own location, I have always continued to talk to Marcus. My initial acceptance of the notion of individualism stemmed from a humanistic perspective. However, the realization that I have continued to be in dialogue with Marcus in his absence has influenced my conceptualization of the self. Reading back over my endless commitments to paper, I realised that I have never written about Marcus in the third person. He has always remained in relationship with me. In the language of a life story this might be described as an epiphany. I became aware that self is in dialogue and relationship with the other. This has changed my understanding of meaning as a construction not with or through, but in the space between the voices of the self and the voices of the other. I have to acknowledge this has influenced my assumptions and this project. As I have explored and felt a resonance with a relational psychology, I have thought about its influence in adjusting to loss and bereavement. While I have continued to examine my own assumptions, I have also thought about the way in which Marcus's care was managed in the last years of his life. What were the assumptions, theories and discourses surrounding the available support, services and treatment?

So the relevance of this personal disclosure? It has to do with my subjectivity. It has to do with how this work is read, how my assumptions are identified and how my voice and the voices of the people connected with project are heard and understood. I am not separate or absent. I bring my history, culture and context as these are an inescapable part of my self construction. They influence how I have spoken, what I have written and not written in my interpretations. They influence how I have listened to and been with people. Perhaps, too, they influence how I been affected by these stories that are now part of my own.

It is now almost five years since Marcus died and since I started the journey of doctoral study. Both my grieving and my study have shared an enormous place in my life. Now, as the anniversary of his death approaches, there is something about the weather and light that reminds me so much of when he died and of his absence. As I sit and write in the late afternoon, the angle of the sun shining through the window and its changed intensity tell me the time. Sitting outside today, the slight sensation of a now cooler breeze against my face reminds me again of autumns past.

However, I continue to treasure Marcus and his significant role in my life and a thesis is complete.

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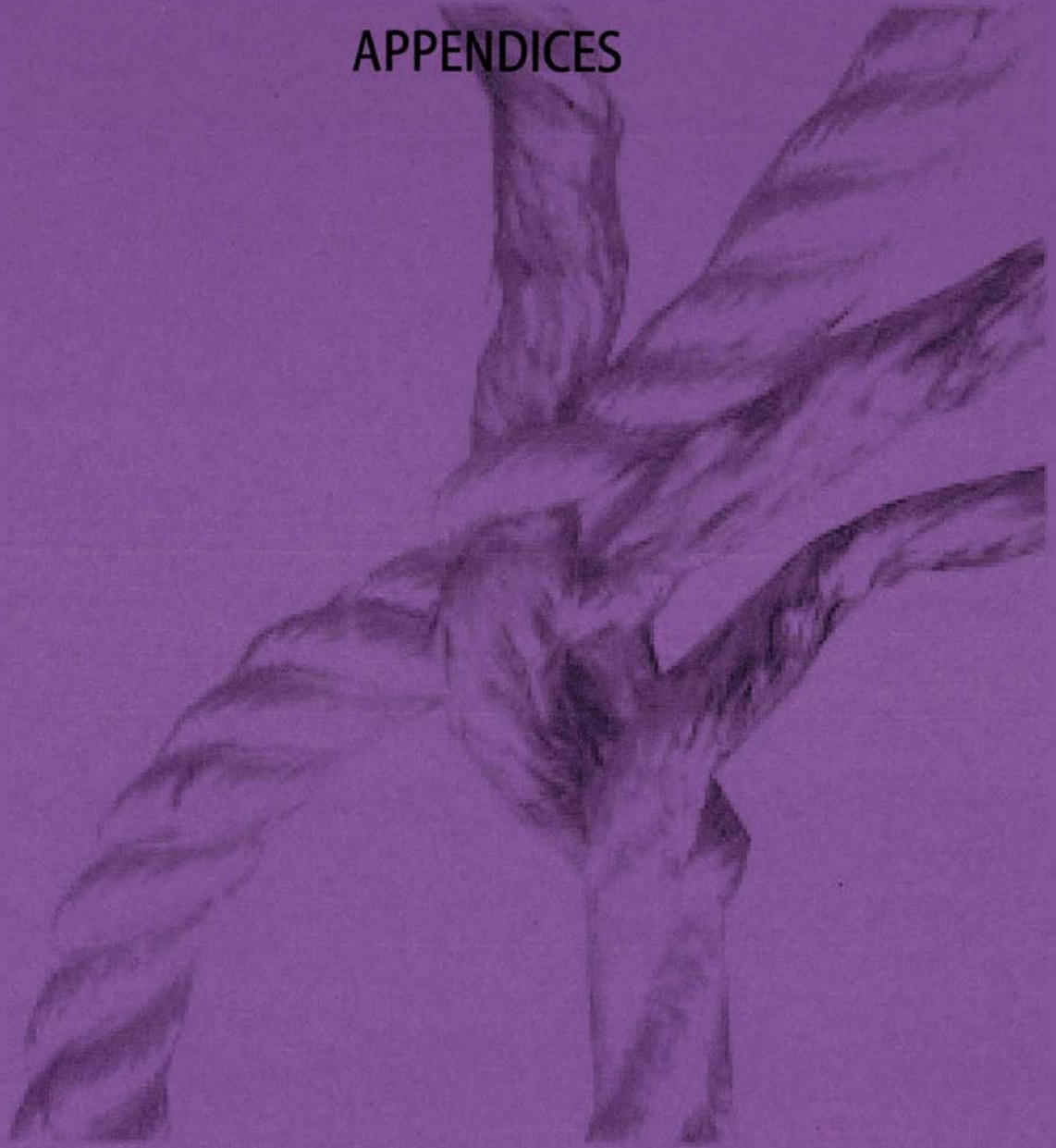
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## APPENDICES



## Appendix A: Transcription key

Notation	Explanation	Example
Number in margin	Line number of transcript	30. Maxine: I went home.
Name	Identification of speaker	30. Maxine: I went home.
-	Hesitation	I went – home.
xxxxx	Emphasised word	I <b>went</b> home.
x:	Prolonged sound	I w:ent home.
(?)	Word not understood	I (?) home.
/xxxxx/	Possible hearings/paraphasia	I /sent/ home.
(xxxxx)	Narrative information	(He smiles and turns away) (Long pause)
Fillers	Orthographic	Mmm Ah Oh
[	Overlapping talk	Maxine: I went home. Joe: [I went home.

(Linde, 1993; Balandin & Iacono, 1999; Hindmarsh & Hindmarsh, 2002; Poland, 2003)

## Appendix B: Aphasia-friendly communication

### Acknowledging and Revealing Competence in Aphasia

- Think about any words or behaviours that could make your conversation partner seem incompetent and avoid them:
  - Correcting someone*
  - Always having the last say*
  - Going too fast*
- Focus on the person's strengths
- Give direct, accurate and adult feedback about communication
- Ensure topic and manner are adult
- Avoid patronising language and tone of voice
- Be as natural as possible
- Share responsibility for:
  - Breakdown in conversation or understanding*
  - Getting it right*
  - Keeping the conversation flowing*
- Be aware of what might make you stop listening
- Offer suggestions so that person can accept or reject them
- Acknowledge the person's:
  - Communication strengths*
  - Expertise*
  - Knowledge of what they want to say*
  - Frustrations*
- Use humour and laugh together
- Use "face saving" ways of maintaining a conversation
- Give the person time
- Don't be afraid of silence

Adapted from Connect (2002)

## Appendix C: Standard information form



School of Psychology  
Private Bag 11 222,  
Palmerston North,  
New Zealand  
Telephone: 64 6 356 9099  
Facsimile: 64 6 350 5673

## **INFORMATION SHEET**

### **APHASIA AND SELF**

#### **Who is involved in this project?**

My name is Maxine Bevin. I am a student in the School of Psychology at Massey University and I am studying towards a PhD. I am also a Speech-Language Therapist with an interest in understanding the experiences of people who have aphasia (the talking difficulty following a stroke).

Although I am a Speech-Language Therapist, I will not be giving advice about your communication or your stroke during this project. However, I can give you information about to whom you can refer if you want advice or support.

#### **What is this project about?**

This project focuses on the experience of people who have aphasia. Having aphasia can affect a person's sense of self and identity. This project explores the changes in self and identity that can occur as the result of aphasia. It looks at how language is used in maintaining a sense of self in aphasia.

#### **Why carry out this project?**

I believe that understanding your experiences will enable people, including health professionals, to improve their communication with and support of people who have aphasia and their families.

#### **What you would agree to do**

You have this information because you have expressed an interest through your local Stroke Foundation contact in participating in this project. If you are willing to take part, all you need to do is complete an interview with me. You will be one of a small number of people with aphasia to whom I will be talking. In the interview we will talk about your life, your experience of having aphasia and what sort of an influence it has had on your life. I will be asking some questions about your life, aphasia and any other issues that you feel are relevant and important. The interview will be like a conversation and will take us approximately two hours to complete.

#### **Protecting your confidentiality**

In order to analyse and review the material we will be talking about, I need to videotape our interview so it is necessary for you to agree to that happening before you participate. If you do not want it to be videotaped, we can tape record the interview instead. I will then write down the recorded interview. The recorded interview may also be seen/heard or the written transcript read by my supervisors, Chris Stephens, Senior Lecturer, School of Psychology, Massey University, Mandy Morgan Senior Lecturer, School of Psychology, Massey University and Sally Byng, City University, London. They will be bound by a statement of confidentiality and like me, will not be able to disclose what you have said to anyone else.

Te Kōwhiri ki Pūrehuāoa

Inception to Infinity: Massey University's commitment to learning as a life-long journey

The tapes will be securely stored and will be destroyed at the end of the research. If you would like to have the tape for your own keeping, it can be given to you. The tapes and written records for the research will be identified by the use of a pseudonym and it will not be possible to identify you by name in any reports that are prepared about the study.

### **Your rights as a participant in this research**

If you agree to take part in this study, you have the right to:

- decline to participate
- decline to answer any particular question
- withdraw from the study at any time
- ask any questions about the study at any time during participation
- provide information on the understanding that your name will not be used unless you give permission to me
- be given access to a summary of the project findings when it is concluded
- to ask for the audio/video tape to be turned off at any time during the interview

### **How to contact me**

You are very welcome to contact my lead supervisor, Chris Stephens, or myself at any time during the project if you want further information or would like to clarify any questions you may have about the project.

I can be contacted:

- By mail                    P.O. Box 202, Napier
- By telephone:        (06) 8366 361
- By fax:                    (06) 8366 361
- By cell phone:        025 231 5291

Chris Stephens can be contacted:

- By mail                    School of Psychology, Massey University, Palmerston North
- By telephone:        (06) 350 5799, ext. 2071
- By fax:                    (06) 350 5673

### **Committee Approval Statement**

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol NO/NO (insert protocol number). If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email [S.V.Rumball@massey.ac.nz](mailto:S.V.Rumball@massey.ac.nz).



## Appendix D: Standard consent form



School of Psychology  
Private Bag 11 222,  
Palmerston North,  
New Zealand  
Telephone: 64 6 356 9099  
Facsimile: 64 6 350 5673

**CONSENT FORM**  
**APHASIA AND SELF**

**THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF FIVE (5) YEARS**

I have read the Information Sheet and have had the details of the project explained to me.

My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being video taped

I agree/do not agree to the interview being audio taped

I agree to participate in this study under the conditions set out in the Information Sheet.

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Full Name - printed** \_\_\_\_\_

Te Kunenga ki Pūrehuroa

Inception to Infinity: Massey University's commitment to learning as a life-long journey

## Appendix E: Aphasia-friendly information form

## Aphasia and Self Information Sheet

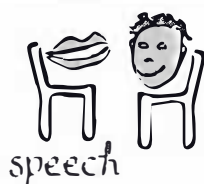
### Who?



My name is **Maxine Bevin**.

I am a student in the School of Psychology,  
Massey University.

I am studying towards a Doctor of Philosophy degree.



I am also a **Speech-Language Therapist**.



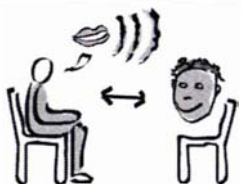
I will **not** be working as a Speech-Language Therapist  
in this project.

I can tell you about **another** Speech-Language  
Therapist or Therapist.

### What?



This project is about '**Aphasia**'.  
(**Talking difficulty** after a stroke)



I would like to talk to you about '**Aphasia**':

- **your life**
- **your experiences** of 'Aphasia'.

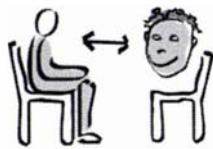
## Why?



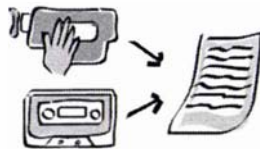
I think your experience will help others:

- **understand**
- **work better** together with people with aphasia and their families.

## How?



It is an **interview**, but more like a **conversation**.



The interview will be **tape recorded** or **filmed**.  
I will then write it down.



The interview may take about **two hours**.



All information will be kept **secure**  
and **confidential**.



Your **name will not** be used.

My supervisors may hear or read our interview and will keep information confidential:

Dr Chris Stephens  
Dr Mandy Morgan  
Dr Sally Byng

## Aphasia and Self Your Rights



You do **not** have to take part in the project.

You can **leave** the project at **any time**.



You do **not** have to answer any particular question.



You can ask **any question** at any time.



Your information or anything we talk about is **confidential**.



You and I will talk about the project when it is **finished**.



You can have the video or tape recorder **turned off** at any time.

Appendix F: Aphasia-friendly consent form

# Aphasia and Self Consent Form



I have **read** the information sheet.

Maxine has explained to me what it is about.



I **understand** what it is about.



My **questions** have been answered.



I can ask **further questions** at any time.



I **agree** to the interview being videotaped.



I **do not agree** to the interview being videotaped.



I **agree** to the interview being audiotaped.



I **do not agree** to the interview being audiotaped.

I **agree** to take part in this project as set out in the Information Sheet

Signed: \_\_\_\_\_

Name: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix G: Life story questions

**LIFE STORY QUESTIONS****General**

- Tell me about your life. Begin where you like and include whatever you like.
- If you had the opportunity to write the story of your life, what would the chapters be about? Chapter 1? Chapter 2 .....?

**Details**

- Tell me about a turning point in your life, wherein you underwent a significant change in understanding yourself
- Tell me about a high point in your life
- What about a low point, the worst moment in your life?
- What is your earliest memory?
- An important childhood memory?
- An important adolescent memory?
- An important adult memory?
- Who have been the most important in your life?
- What does your life look like from where you are at now?
- If you could have your life over, what would you do differently?
- How do you explain what's happened to you over your life?
- Tell me about your plans and dreams for the future

**Self**

- How would you describe yourself when you were younger?
- How would you describe yourself now?
- How much have you changed over your life?
- How?
- What is your philosophy on life?
- Looking back over your life story (with chapters and characters) can you pick out a major theme or message of your life?

Adapted from Atkinson (1998); Gubrium (1993); McAdams (1993)

## Appendix H: Life story prompt book

Life Story  
Prompt Book

Tell me about **your** life.

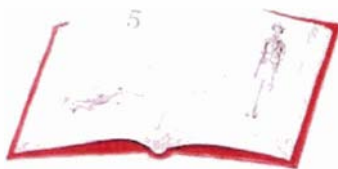
Begin where you like.

**STORY  
OF YOUR  
LIFE**



A **book** about your **life**?

What would the **chapters** be about?



Chapter 1?

Chapter 2?

Chapter 3?

**Earliest** memory in your life?



Earliest memory in your life?



An important childhood memory?



An important teenage memory?



An important teenage memory?





An important adult memory?



An important adult memory?



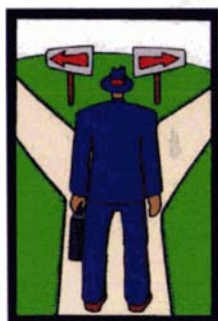
A high point in your life?



A low point in your life?



A turning point in your life?



Who have been the most important people in your life?




Describe yourself when you were younger



Describe yourself now




How much have you changed over your life?




The illustration shows four stages of a woman's life from left to right: a baby in a pink blanket, a toddler in a pink dress, a young girl in a red coat and hat, and an adult woman in a white dress with a pink sash.

How much have you changed over your life?



The illustration shows four stages of a man's life from left to right: a baby in a blue blanket, a toddler in a green shirt, a young boy in a blue shirt, and an adult man in a blue suit.


What does your life look like from where you are now?



A silhouette of a person is shown from the side, looking through a telescope. A dashed line extends from the telescope's lens to the left, representing the past.

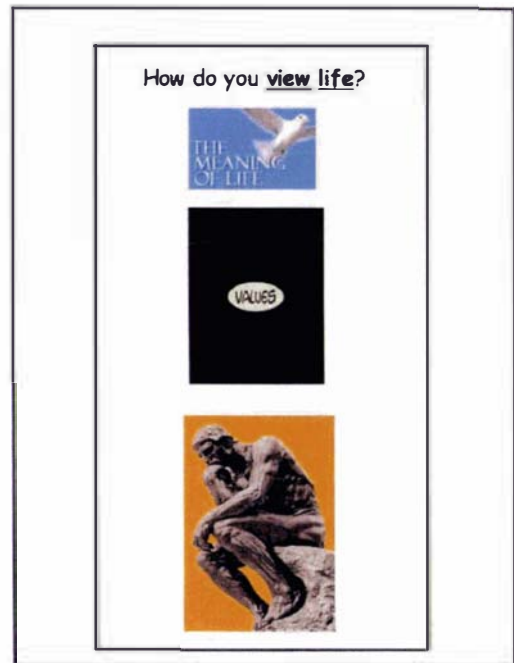
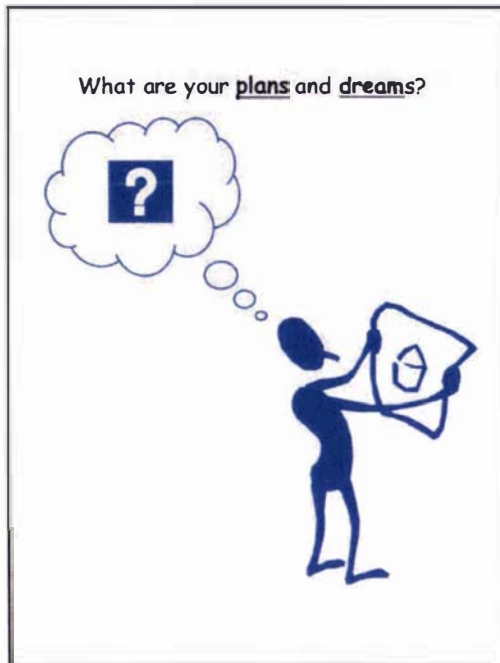
YOUR LIFE

Would you do anything different?



A silhouette of a person is shown from the side, looking through a telescope. A dashed line extends from the telescope's lens to the left, where a construction site is depicted with a person holding up a blueprint.

ANY CHANGES?



**LIFE STORY QUESTIONS**

**General**

- Tell me about your life. Begin where you like and include whatever you like.
- If you had the opportunity to write the story of your life, what would the chapters be about? Chapter 1? Chapter 2 .....?

**Details**

- Tell me about a turning point in your life, wherein you underwent a significant change in understanding yourself
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- If you could have your life over, what would you do differently?
- How do you explain what's happened to you over your life?
- Tell me about your plans and dreams for the future

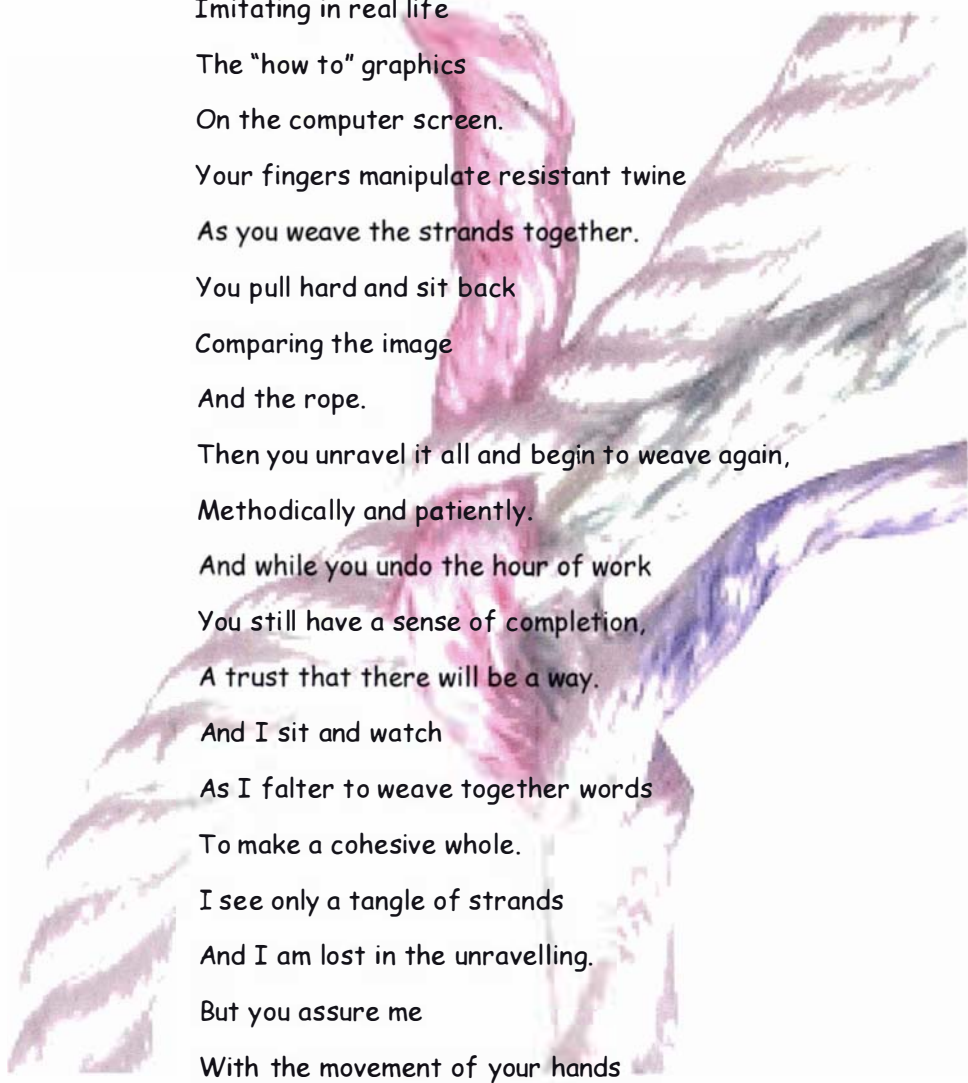
**Self**

- How would you describe yourself when you were younger?
- How would you describe yourself now?
- How much have you changed over your life?
- How?
- What is your philosophy on life?
- Looking back over your life story (with chapters and characters) can you pick out a major theme or message of your life?

Adapted from Atkinson (1996), Gubrium (1993), McAdams (1993)

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### Appendix I: The act (and art) of splicing



I sit and watch you while you study  
And practice  
The art of splicing rope.  
Three strands in your hand  
Marked by brightly coloured tape,  
Imitating in real life  
The "how to" graphics  
On the computer screen.  
Your fingers manipulate resistant twine  
As you weave the strands together.  
You pull hard and sit back  
Comparing the image  
And the rope.  
Then you unravel it all and begin to weave again,  
Methodically and patiently.  
And while you undo the hour of work  
You still have a sense of completion,  
A trust that there will be a way.  
And I sit and watch  
As I falter to weave together words  
To make a cohesive whole.  
I see only a tangle of strands  
And I am lost in the unravelling.  
But you assure me  
With the movement of your hands  
And the set of your face  
That there is completion,  
That it will be done.  
And I'm somehow grateful  
As I lose my way in it all,  
That you remind me  
About the shining of the sun.