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**DOUBLE VISION =**

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**THE EXPERIENCE OF**

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**MULTIPLE SCLEROSIS**

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**THROUGH THE EYES OF WOMEN**

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**DOUBLE VISION:  
THE EXPERIENCE OF MULTIPLE  
SCLEROSIS  
THROUGH THE EYES OF WOMEN**

**A thesis presented in partial fulfilment of the  
requirements for the degree of Master of Social  
Work at Massey University**

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## ABSTRACT

Double vision is a common symptom of Multiple Sclerosis (MS). This thesis is also about double vision in other ways. It is concerned with the perceptions of women with MS of the double discrimination, which they experience, both as women and as disabled people. It is also about the disjuncture between medical views of MS and the lived experiences of women with MS.

Seven women with MS were interviewed in depth for this research. Despite considerable diversity in MS experiences, a number of main themes emerged from these interviews. These included years of uncertainty and stress prior to receiving a definite diagnosis of MS, poor communication on the part of health professionals, high financial costs and difficulties associated with MS and the toll on family life, including 'caregiver burnout' and divorce.

Many of the difficulties experienced by these women could have been eased considerably with more information and practical and financial support. The aim of the thesis is to highlight these themes in order to inform people newly diagnosed with MS, their caregivers and families, health and social work professionals and policy makers about some of the main issues and needs experienced by women with MS.

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### DEDICATION

To my three sons, Duncan, Hamish and Andrew who as my primary caregivers sacrificed an enormous amount of love, time and effort towards helping my academic aspirations to become a reality.

To Laurie, who loved me in spite of my thesis?

And to my late father Allan Hight and mother Paddy Hight, who did not live to see the end result but always believed in what I was doing.

## CHAPTER ONE: DOUBLE VISION

### INTRODUCTION

Double vision was one of the initial symptoms to indicate that I might have multiple sclerosis (MS). As the poem below indicates, Dee (1989) who was born with cerebral palsy and developed MS as an adult, is expressing her fragility as she nears the end of her life:

“I lie as if asleep  
day by half existent day  
in this room  
womb of growing multiple sclerosis  
tomb of my old strength  
life flickering in the darkness”

(Dee, 1989)

Between these two extremes is the way most people experience MS.

The purpose of this exploratory qualitative research was to consider the autobiographical stories of seven women who have experienced MS for at least five years. There are three pressing needs for these stories to be documented. First, few studies have been done which focus on the experience of MS from the perspective of women. Second, the stories the women tell can assist in their own empowerment and self-determination. The third reason is that the issues raised by the women in this study and by other women with disabilities can assist professionals in meeting their needs.

This first chapter describes how I conceived the research questions and what the primary aims were. I will then introduce the six women participants and explain my dual role as both the researcher and a participant. This will be followed by a brief introduction to some of the main themes emerging from the women's stories and how their experiences of MS reflect the experiences of women with disabilities generally. Finally, this chapter concludes with a presentation of the way the remaining chapters have been organised.

The research focus was governed by my desire to make the stories of the seven women with MS visible. This was because I believe that in the eyes of the public there are many mis-guided stereotypes about the nature of MS. I wanted to link these experiences of MS to the lives of other women with MS and for women with different disabilities as well. The primary aim of this feminist research was to find answers for four areas of interest.

The first concern was to provide a description of what MS actually is. Two perspectives are presented in this debate. One is from the scientific community and the other from the perspective of people with MS. Arising out of the realities of the daily experience of MS I wanted to discover what were the most significant issues that the women were prepared to discuss. Because there is no cure for MS at present, the third aim was to try and identify those issues that could be actioned now in order to enhance the quality of life for the women. Finally, I wondered whether it would be possible to create an MS practice model based on feminist principles for women to use as a strategy for survival and self-development in tandem with people who support women with MS.

## THE WOMEN WHO PARTICIPATED IN THIS RESEARCH

Jo, Sue, Ann, Liz, Ali, Jill, (pseudonyms) and myself (Pamela) were the seven women participants in this research. We had all experienced MS for at least five years and my decision for inviting women with this degree of experience was twofold. First, it meant that the women had more or less acclimatized themselves to their varying disabilities and had accepted these. Second, in the telling of their stories their particular expertise had the added potential to be useful for those women who may have only recently been diagnosed and, were struggling to come to a better understanding of how to cope with their experience of MS.

Geographically, the women came from as far north as the Hawkes Bay and as far south as Nelson. Their age range was 34 to 55 years. Five of the women were solo parents. In total they had been the primary caregivers to fifteen children. However, none had the responsibility of small children at the time the interviews took place.

Managing life financially after discovering that they had MS was a major source of concern for the women. Five of the women were in receipt of State benefits and the guilt and stigmatisation they felt by having to plead for these, was reinforced on an annual basis. The women also resented the fact that the people working in these government agencies seemed to have little understanding about, or little appreciation for, the additional costs incurred by having a disability.

Examples of these items include medical visits, prescriptions, assistive devices, significant transport costs, clothing, and home help. The women were permanently short of money, some were in debt and regularly

existed from week to week with food and heating heading the list of priorities. In this regard their experiences reflect the difficulties many disabled people encounter as they go about their daily lives. The fact that many of us are denied the opportunity to buy anything but the basic necessities, limits our choices in life and adds considerable stress which in turn affects our family members and caregivers. Economic insecurity can also create ongoing tension that can affect the whole family especially if the person with MS feels they can no longer contribute as much as they had in the past.

The importance of having real choices in our lives and therefore more personal control over what we can or cannot do, is stated in the work of Briar (1992), when she states:

“It is important for women to have genuine choices in their lives: to choose whether to form or remain in relationships with men; to make meaningful choices about their sexuality; to decide whether and when to have children; and whether to care full-time for their children or other relatives. The economic dependence of women is still a major factor in denying women those choices.”

(Briar, 1992:49)

Denying the women in this study the right to ‘genuine choices’ would perhaps be the most significant theme in this thesis. The other issues raised by Briar (1992) that is, the ability to enter into meaningful relationships with other people; choices about our sexuality; contemplating children and; the caregiving roles that women assume because of their gender are very important. (ibid). For all of the women, when our experiences of MS began to both erode and encroach on our

life options, it appeared that at times we became easy prey as a result of our vulnerability. This clearly illustrates how we were manipulated by those people we perceived to have more authority and control than we did. (Foucault, 1982).

From an empowerment perspective the barriers to having a real choice in our lives is an integral component of understanding our experiences of MS. Without losing sight of the uniqueness of our experiences which must always be respected, there were also many similarities and patterns to our respective disabilities. Identical experiences did not always occur in the manifestation of the disease MS, but sadly our experiences within the society of which we are a part, were chillingly identical. Our experiences relating to these issues are documented in chapters four and five.

#### MY DUAL ROLE AS A PARTICIPANT AND THE RESEARCHER

Because I was both a participant and the researcher in this thesis, drawing clear distinctions between the two roles was imperative. As a participant, my experiences as a woman had been subjected to the same subordination as the other women in the study. In fact we all shared a similar world view and we were able to make the connections between our struggles to cope with our respective experiences of MS as we went about our daily lives. Through being a participant, my autobiographical reflections provided me with a deeper understanding of the forces that have shaped my own experiences and how I had allowed these experiences to be distorted by the influences of ideology to the extent that they were.

Advocates of feminist research claim that it is necessary to always “start from the experience of the researcher, who must be prepared to make herself as vulnerable as those being researched”(Smith and Noble-Spruell, 1986:141). And indeed one of the more difficult tasks from the personal perspective was that as the researcher, it was necessary to make my own

stance explicit (Stanley and Wise, 1983). As a valued feminist principle, I coupled this explicitness with the notion that as far as possible I would endeavour to provide equality in my relationships with the other women.

To carry out these two aspects, an associate conducted my own interview before I began to interview the women. This was an attempt to reduce researcher bias on the one hand and to also experience the same vulnerability the women may have felt when I interviewed them. On completion of the individual interviews I gave each of the women an edited copy of my own transcript and this inclusion provides an opportunity to see the type of information which helped constitute the data (Appendix A).

Given the above, some aspects of this research are a result of my own subjectivity. However, I am hopeful that this will be viewed as an advantage simply because I was in such close 'proximity' with the other women participants (Stanley, 1990). The MS practice model that I created is thoroughly based on a detailed analysis of the views of all of the women participants. It is common for women doing feminist research, to choose projects derived from their own subjective experience. I found that my own understanding of MS allowed me to fully appreciate what the other women shared with me. The personal significance of this research was validated when the other women told me their stories.

I began working on an individual basis with the women and, by discussing our experiences together we could explore the contradictions we had to deal with in coming to terms with, and understanding these. We respected our differences and our own limitations. We were able to learn about the importance of working together with women for our own survival and the survival of other women who may feel oppressed by the reaction of other

people to their MS. Once I had worked out how the model from our experiences could be presented, each participant gave me the necessary feed-back and their ideas were actioned.

In order to have a fuller appreciation of the way the women in this research are positioned within our society, it is important that I describe some of the forces which have shaped the women's views concerning their experiences of MS. The issues discussed by the women are complex social, political and economic concerns which means that only specific aspects of the MS experience can be discussed.

### THE EXPERIENCE OF MS

Women far out-number men statistically. Out of an estimated three million people in the world who have been diagnosed with MS, two thirds are female (Stenager et al. 1990; Reingold, 1994; McCabe et al. 1996; Aronson et al. 1996; Thompson, 1996). Because of the gap between the discovery of a cause and possible cure for MS, it is important that we assist the 'experts' to aim for providing a language which people with MS and their supporters can easily understand and relate to.

MS is a chronic illness but differs from other chronic illnesses such as asthma, epilepsy, and arthritis. MS is ill defined and defies the medical model of disability in that many of the symptoms can not be alleviated or explained by the medical profession. The mean age of onset is about thirty years of age for both men and women and comes at a time when important decisions need to be made. Some of these decisions are: forming life-long partnerships; employment, whether to have children or not and the constant worry about how the disease might progress in the future. While I agree everyone has to make these decisions, the impact for the person with MS, their families and friends is significant. Not so much for the

impact of the disease but more from the social barriers and structural environment in which we find ourselves. These issues include: access to public buildings and transport, the fear of possible dependency on others and whether or not there will be any quality of life in the future. These issues are expanded on in this thesis, but it needs to be remembered that no two people experience MS the same way. The remaining chapters have been organised in the following way.

In chapter two I describe my reasons for using stories as research (Ballard, 1994). I also used the case study approach advocated by Yin (1994). The sample size of this study, the individuality of the MS experience and the case-management approach that Yin (1994) advocates enabled me to apply feminist principles within this framework without having to compromise my aims. These factors seemed to justify incorporating his work into this thesis.

Chapter three explores the subject of multiple sclerosis. I have tried to grasp the main aetiological aspects of this chronic illness and to present these in a way which is neither alarmist nor sensational. I have tried to include as broad a scenario as possible so that the reader can further explore any of the issues under discussion. To provide continuity I have deliberately situated quotations from the experience of MS alongside the scientific research findings which clearly illustrates the gap between the experience of MS and the way some professionals view the disease of MS.

Chapter four answers the first of the two questions that I asked the women to contemplate. The findings from the question: "Would you like to share some of your experiences of MS with me?" revealed that even though this question was so open-ended, the women were consistent with their responses. As a result of this I was able to expose the issues in a way

that allowed for a thematic analysis which in turn created the opportunity to develop a practice model out of the collective experiences.

Chapter five answers the second research question which invited the women to consider how their quality of life could be enhanced. This chapter began by looking at a definition of quality of life. It was demonstrated that women who had experienced MS for at least five years were still finding that communication with their respective health professionals was a continuing site of struggle. The fact that the women are still lacking resources which could enhance the quality of their lives is indicative that our oppression stems from the existing social, political and economic structures in our society. People with disabilities are consistently left on the periphery of a system designed to exclude us.

Chapter six amalgamates the two previous chapters and situates the experiences of MS within an MS practice model that is based on five feminist principles. How I have analysed the experiences of the women is explained. It is hoped that the sum total of our combined experiences and suggested modes of intervention and/or actions can be used to better inform other women and men with MS.

I draw my conclusions in the final chapter, and as a research outcome I suggest that there appears to be enough evidence to suggest that other disabled people may wish to adapt the practice model which is based on our collective experiences of MS to suit their own particular experience of disability.

To the best of my knowledge this is the first time a study has been carried out in New Zealand where the researcher who has MS has also been one of the participants. It is hoped that by canvassing the views of other women experiencing MS it would be possible to make a valid contribution

towards research in this area. While there are some significant improvements in the way MS can be diagnosed and managed, the experiences of women have yet to make an impact on the research literature. However, it needs to be remembered that what is offered in this study is but a brief glimpse into the way we experience our daily lives.

## CHAPTER TWO: RESEARCH DESIGN AND METHODOLOGY

The purpose of this thesis was to document the experiences of seven women with MS. I am a researcher who has experienced MS for twenty years. In that time few studies have been done which focus on the MS experience as it impacts on women (Graham, 1990; Kerstan and McLellan 1995; Hutler and Lundberg 1995; McCabe et al. 1996; Mairs, 1997). Disabled people and their supporters are currently telling their stories and sharing their experiences of disability as a daily lived reality in New Zealand. Boyles (1994) believes that this has been made possible because:

“In the disability context particularly, the concept of partnership is crucial in that reciprocity involves sharing skills, energy and varying abilities. An additional factor is the importance of biography and the use of story telling. By relating their stories in the way that they wish, the daily-lived experience of disabled people becomes visible and the process of telling the story is in itself validating on a personal level”

(Boyles,1994:40)

The stories that the women share in this research are but a brief glimpse into the way we experience our daily lives. While this research has the focus on women experiencing MS, there appears to be enough evidence to suggest that other people with disabilities in our society may wish to adapt the MS practice model presented to suit their own particular experiences. This chapter describes how I conducted this research in a collaborative venture with six other women.

### THE RESEARCH DESIGN:

Crucial to the research design was my belief that as a feminist with a disability, this explorative qualitative research would have as its underlying philosophy a nucleus of core fundamental feminist principles and values. Five of the women saw themselves as active feminists and all of the participants agreed that by sharing their experiences with me there was the possibility that this would be of benefit to other women experiencing MS. They each said that the reason they had agreed to participate was because I had MS and because I was a female researcher. Together, we were to become women working with women in the interests of other women. Women working with women is embedded in the works of Hanmer and Statham (1988) who insist that “women must become valued in and for themselves” (Hanmer and Statham, 1988:3).

With this in mind, one of the first objectives was to find a theoretical framework which would have the potential to explore the experiences of the women participants. Feminist researchers argue that the best way to find out about peoples lives is to let them tell you about it themselves in their own way (Browne, et al. 1985; Hannaford, 1985; Fine, & Asch, 1988; Lather, 1988; Mies, 1990; Reinhartz, 1992).

Thus, one of the aims of feminist research is to value and respect the validity of women’s experience. By providing a forum where the women could recollect their past, unresolved issues were able to come to the fore so that the reality of the present could be better understood. However feminist research goes further than this:

“Feminist research is also about challenging some of the frameworks that are currently used for explaining women’s experience. In the process of seeking better ways of interpreting and writing about women’s experiences, feminist research attempts to find mechanisms for bringing about the necessary changes in women’s reality”.

(Munford, 1994b, op.cit:268)

Providing the mechanisms of how the women could reassess their experiences and in light of these begin to bring about changes in their lives, meant that the stories the women told had to be paramount in this research. By telling our stories the women in this research are making their experiences visible to others. Ballard (1994) believes that the:

“telling of stories is a traditional means of sharing experiences and imparting complex, culturally valued knowledge. Where a person tells their own story, this can be particularly compelling, engaging the reader directly in another’s life and another’s ideas”

(Ballard 1994: 24).

Ballard also suggests that by allowing disabled people to tell their stories in their own way, the researcher has to explore the issues that are of most relevance to the story teller. Any pre-determined ideas a researcher may hold about what is important to include in the research is tempered (ibid). This is an interesting point Ballard raises. As I am both the researcher and a participant the task of balancing how much of my own story should be included in the research always took second place to the stories of the other women. I chose to do this because the opportunities to present my own story are far greater than the other women in this research. For this reason I can understand Ballard when he answers the criticism that using

research as stories can be subjective, biased and unrepresentative (ibid:298). Further:-

“I reject the idea of objectivity, arguing that all social research reflects the values, culture and perceptions of the researcher”  
(Ballard 1994: 298).

And if researchers critically appraise their work and present their findings the:-

“stories increase the range of interpretations, the range of knowledge, and the range of experiences available to the person who would use research to inform action. This person may be a professional or a lay person, because a feature of research as stories is that these accounts are accessible to the general reader”  
(Ballard 1994: 302).

The relevance of these words as far as the women in this research are concerned is striking. This research is openly subjective. The seven women involved believe they have been manipulated by people more powerful than themselves. The stories told by these women are not necessarily representative for all women experiencing MS but the patterns and outcomes of our combined experience of oppression can be compared with the experiences of other minority groups in our society.

Graham (1984) found that stories provide a vehicle through which individuals can build up and communicate the complexity of their lives” (Graham,1984:119). Because the experience of MS is so complex I was always aware:-

“that without the women’s stories, there would have been no research and that the women had the power to involve the researcher and may have been empowered through the reconstruction of these stories”  
(Mason, 1997:23).

Massat and Lundy (1997) advocate for the reconstruction of the stories of women because:

“The research also gives the participants another opportunity to talk about and thus process the traumatic experience. Telling one’s story has value if it is perceived as a form of taking action.”  
(Massat and Lundy 1997:41).

The women in this research knew from the outset that an MS practice model based on our collective experiences would be made available to inform the people we come in contact with on a daily basis. Our stories express the inequality of our existence and describes the double discrimination of both our gender and disability. To organise the stories the women told me and thinking about one to one encounters I decided to adopt the case study approach advocated by Yin (1994).

#### THE CASE STUDY APPROACH

"A case study is an empirical enquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident and when multiple sources of evidence are used"  
(Yin 1994: 13).

For over a decade this definition of a case study by Yin (1994) has remained constant (Yin 1984, 1989, 1993, 1994:13). The four criteria

outlined above seemed to best describe what I was trying to do in my own research. I wanted to 'investigate' a phenomenon (multiple sclerosis); within its real life context (the daily lived experience of MS); when the boundaries between phenomenon and context are not clearly evident and to do this effectively I would use supporting evidence taken from a number of sources. In addition there were other factors which influenced my decision to use the case study approach.

The case study approach can also be seen:

"to satisfy the three tenets of the qualitative method, that is, describing, understanding and explaining"

(Tellis,1997).

Yin also claimed that case studies were useful for confirming or denying a particular theory and that they could be used in 'unique' or 'extreme' circumstances (ibid). The final reason for this choice was because I was asking the participants to respond to two open-ended questions that suited Yin's case study approach.

There were several reasons for using the case study approach in this research from the perspective of the MS experience. Frequently women are diagnosed as having MS in a hospital setting, and a social worker becomes the first point of contact and 'case manager'. Because no two people share the same experience in exactly the same way some common underlying patterns to the experience of MS can be identified. This satisfies 'the unique' aspect of the case study. Retaining this aspect means an holistic image of the women participants is also continued. The case

study approach lends itself well to in-depth interviews that were to be the main source of data.

#### THE UNIT OF ANALYSIS:

The “unit of analysis is a critical factor in the case study”(Tellis, 1997). Usually only a few questions are posed in order to ensure that the in-depth interview has as its impact those issues of most importance and relevance to the participants. In this research, the women were invited to answer two questions. The first question was open-ended and asked: “Would you like to share some of your experiences of MS with me?” The second question that was a little more specific was: “How could your quality of life be improved now?” These two questions were considered the most appropriate because in the first instance, the information shared was how the participants perceived their experiences and what they felt were the most significant factors, as opposed to direct questioning from myself. The second question was directed at how the participants’ lives could be improved by taking action over what they felt was lacking in their lives at present.

#### THE PARTICIPANTS:

The seven women had all experienced MS for at least five years. I selected the five-year criterion so that the women would be more comfortable in the interview situation. This decision was made in the knowledge that women who are newly diagnosed can often take some years before they can come to terms with all they have to grapple with. The age range was from thirty-five years to fifty-four years. Two of the women were involved in various MS support networks and were known to me personally. The remaining four women were not known to me prior to the research process. Two of the women were married. Five of the women were solo parents two of whom still had family members living with them. The

geographic distributions of the women were as far north as Hawkes Bay and as far south as Nelson. I have used pseudonyms and colour-coded the statements made by the women.

#### THE COLLABORATION:

Crucial to the outcome of this research was the collaboration between the other women and myself. When the women were first approached to find out whether they would be willing to become involved in this research, I found out that four of the women had taken part in research projects in the past. Three of the women felt quite disgruntled about the way the research had been carried out. They clearly felt that some researchers had come to do an interview *on* them, got what they wanted and left. I too had experienced this 'let down' feeling but because these sentiments had been expressed to me before the interviews took place, the influence of this knowledge was significant. I was particularly careful to make sure that that this prior experience with researchers did not get repeated.

“By establishing collaborative relationships with participants, researchers can learn about the experiences and coping mechanisms of those who have given their time and have willingly told their stories.”

(Massat and Lundy,1997:44).

The question of how to fully involve the women in all aspects of the research process needed lengthy consideration. While I believe we achieved total collaboration on the MS practice model, only I had an interest in feminist social work practice. The dilemma of working out just how much collaboration there should be was resolved by my providing the women with 'updates' on the progress of the research. This means that only partial collaboration was achieved.

### DATA COLLECTION:

The case study approach is also “known as a triangulated research strategy.” (Yin, 1984). Multiple sources of data can satisfy the need to validate the research process. These sources can also verify ‘construct validity’, by using multiple sources of evidence; ‘internal validity’ by testing theories as they develop through the analysis of the data collection; ‘external validity’ through the differing theoretical relationships and by using the research findings via the formalities of the case study approach one can confirm “the ‘reliability’ that is required of all research” (Yin, 1994:20).

The six features described by Yin that could be included in the data collection process were: ‘interviews, documentation, both direct and participant observation; physical artefacts and archival records’ (ibid.) By using multiple sources of evidence in this way the triangulation of data would verify and enhance the reliability of the study. I used all of these sources in this research.

### THE INTERVIEWS:

The interviews provided the main source of data in this research and are discussed in detail in the interview process below. I used both direct and participant observation in five of the interviews. I wrote down my impressions and reactions to what had happened during the interview in a personal research diary immediately after an interview. While I listened to the tapes I would refer back to this. These observations allowed me to give balance to and improve on the validity of my findings from other sources. It also meant that the individual was always ‘whole’, as I was conscious that because only segments of the respective experiences would be included in this research, it was necessary not to lose sight of the women as

included in this research, it was necessary not to lose sight of the women as real people leading real lives. I also visualised myself back in the interview situation which helped me to understand how the participants experienced their daily lives. For example I noticed, books, photographs, paintings and personal collections. It was a conscious attempt to promote an holistic approach, without being judgemental.

Another feature of the data collection was that I deliberately set out to use the writings of feminist researchers and practitioners in our country as much as possible. Feminist research has much to offer women with disabilities and this research highlights a relatively new phenomenon namely, the academic contributions of people with disabilities and those people who work and/or advocate alongside people with disabilities, in both the research and practice arena. This is not unlike the work begun by feminist social workers in the late 1980's. It is both exciting and challenging to celebrate the works of women who are prepared to bring other women with disabilities and their caregivers out of the margins of exclusion and many of these works proved to be an inspiration when my own reserves were stretched. (Munford, 1994a, op.cit; Boyles, 1995; Georgeson, 1995; Perkins, 1995; Kerr, 1995).

#### DATA ANALYSIS:

In the analysis of the data I systematically categorised the evidence and aligned this with both the theoretical propositions of the research questions and analysed the themes which revolved around the feminist principles outlined above. I also made sure that I included the concerns of the women in the literature review so that there would be additional sources of information for women experiencing MS if they so wished. Data analysis also included explanations of the experiences of MS and the way in which the women described these.

### THE INTERVIEW PROCESS:

I interviewed the women during the winter months of 1997. All of the audio-tape-recorded interviews began in the same way. The willingness of the women to take part in the research was confirmed again and the women were reminded that at any stage during the interview they could stop the recording and withdraw from the study if they so wished.

From the outset the women knew that the interviewing process would only be for about one hour. This time-frame was flexible as initially I had envisaged that because of the varying disabilities associated with MS, such as fatigue or other personal discomfort, it might be necessary to have more than one interview. The women were invited to select the most appropriate time for the interview to be carried out and five of them had their interviews before midday. Two chose to be interviewed in the evening. However, in reality the interviews took between one and one and a half hours to complete with five of the women. A university student carried out my own interview. I needed to have three interviews, each of twenty minutes duration.

The decision to interview the seventh participant by telephone was based on the knowledge that her experience of MS, her current life-style and the fact that she was gainfully employed suggested that this form of interviewing would be the least intrusive. The women were invited to talk freely about some of their experiences of MS for approximately forty-five minutes when I then introduced the second question: "How could your quality of life be enhanced?" By adopting this mode of enquiry it was hoped that my role as the researcher would be viewed more as a facilitator. This was my attempt to lessen any power imbalance between

the other women and myself. I promised that only I would have access to the tapes.

On completion of the individual interviews I gave them a copy of my transcript. This was considered necessary if the research was to be truly reciprocal. Interestingly, when I returned the women's transcripts all but one of the women felt that they had something to add now that they had read my transcript. I returned the transcribed interviews to the women in order to confirm validity. I contacted the women by phone to ensure that no one was upset by what they had told me. All of the women confirmed that their transcripts were an accurate reflection of their experiences of MS.

Five of the women commented that it had been useful and therapeutic to talk about their experiences. All of us agreed that we hoped the sharing of our experiences would benefit other women experiencing MS, social work practitioners and educators and the medical fraternity, so that they could have a better understanding of the problems experienced when living with this particular disability.

During the interview process and throughout the research I was acutely aware that my dual role as a researcher and a participant, would increase the potential for bias to arise. In trying to seek "unmitigated truth," I constantly positioned my own experiences vis-a-vis the participants. (Yin, 1994:20). It would be ignorant to declare the total impartiality in this research, but equally, I feel that the added dimension of the researcher as a participant more than compensates for this. If the women's views concurred with mine of course I got elated. It removed me, and I suggest many others who do research in the disability area, from the isolation of our respective experiences.

## THE TRANSCRIPTS

All of the interviews were transcribed in their entirety. Originally I was going to employ an outside professional to do this task. However when I transcribed my own interview some of the information volunteered encroached beyond the boundaries of personal safety. Fortunately, this oversight on my part was pointed out to me and I accepted the wisdom of my two supervisors and retracted some potentially unsafe revelations. But my mistake was a learning curve in so far as the decision I took to transcribe all of the interviews myself. And yes, three of the women had revealed personal aspects that could not be included in this research. Given this, I thought quite a lot about the degree of personal vulnerability that the sharing our experiences of MS might pose.

Listening and learning from the shared experiences and then trying to find what strategies might bring about change, meant that I constantly held these women's experiences in my head. I re-lived the experiences articulated to make sure that in the writing I could recapture a particular mood, feeling, hesitation, personal grief or happiness. The women broadened my own outlook on life by sharing their experiences of MS with me and this taught me a great deal. I now feel that my own perspectives on the experience of MS have been broadened considerably.

## THE ANALYSIS OF THE TRANSCRIPTS:

After I had transcribed the interviews in their entirety it was time to decide how I was going to analyse these. This was more complex than I had first imagined it would be, simply because of the number of times particular issues were raised by the women. To begin with a general thematic analysis took place. I grouped and categorised the issues to see what aspects of the experience of MS the women felt was the most important issues on an individual basis. I then counted how many times

an individual repeated certain aspects of their lives. I then put these issues in the wider frame of collective issues in the analysis of the transcripts the themes identified were grouped together and the underlying common patterns were disclosed. In order of priority, the most significant themes which emerged and the total number of times referred to were: the doctor/patient relationship, 158 times; the onset of symptoms, 108 times; the relationships between the participants family and/or caregivers, 93 times; the problems associated with the diagnosis of MS, 63 times; the sense of physical and emotional loss, 46 times, the impact on self-esteem, 34 times; the difficulties associated with both cognitive and sexual dysfunction 27 times; and the coping strategies the women used were mentioned 23 times.

I then separated the themes into two groups placing the themes to go into either the chapter on the experience of MS or in the chapter devoted to the enhancement of quality of life. When I began to analyse how all of these issues impacted on the lives of the seven women I decided to create an MS practice model based on these experiences. The model created on the daily-lived experience of MS features in chapter six. I selected the five feminist principles: analysis, integration, affirmation, empowerment and action and reflection within which to nestle the MS experiences. By doing this, it would provide feminist social workers with an additional resource to inform their own practice if they so wished. How the two practice models can be linked is suggested in Appendix 11.

### CHAPTER THREE: THE ENIGMA: WHAT IS MULTIPLE SCLEROSIS?

#### THE MEDICAL RESEARCH:

“Even though we are unable to give a complete answer to this question, basic research has provided us with many important insights into MS leading to improved diagnosis and new therapies. Basic research into MS will continue with the genuine belief that one day we will understand this perplexing disease and provide more effective treatments and possibly a cure”.

(Johns and Bernard, 1994:45)

#### THE EXPERIENCE:

“How much research is about evaluating the needs of people who have MS and their families? How much is geared towards assessing what will make a difference to us and improve our lives, and the lives of those that live with us, care for us and share our predicament?”

(Burnfield, 1995:48)

### INTRODUCTION

The two perspectives above are indicative of the gap between the way scientists view the disease of MS and how people actually experience MS. Out of an estimated ‘three million’ people in the world Aotearoa/New Zealand has one of the highest incidence of MS. Although the French physician Jean Cruveilhier described the first case in 1835, it was the

neurologist Jean Charcot who documented the basic pathological findings about MS. What is even more remarkable is that almost 100 years on from this discovery, attempting to answer the question “What is MS?” is equally elusive today. Why?

Part of the problem stems from the myriad of definitions used in the prevailing theories as to the cause of MS, the type of MS an individual may experience and the ongoing research to find a cure. Because each individual experiences MS differently, it needs to be acknowledged that simplicity is difficult in a discussion about MS. This means that at times the tendency to lean towards broad generalisations cannot be avoided. With this inherent pitfall in mind, the chapter will be divided into three parts.

Part one will work towards a definition of MS. Some of the main debates concerning the possible cause and prevalence of MS, as well as the possible influential factors of the environment, viral, genetic and immunological implications, will be examined. Part two outlines the socio-demographic characteristics, the gender imbalance, age of onset and the type of MS a person may experience. Part three begins to work towards an understanding about the symptoms, particularly those of fatigue and cognitive dysfunction, diagnosis, treatment, and life expectancy. In conclusion, tentative findings will be offered. To facilitate continuity rhetorical questions will be asked throughout.

### **PART ONE:TOWARDS A DEFINITION OF MS:**

Multiple (meaning many) and Sclerosis (meaning plaques) is a neurological disease of the central nervous system involving both the brain and the spinal cord. These plaques of scar tissue are a result of

inflammation that destroys the myelin sheath covering nerve fibres. This breakdown of myelin interferes with an individual's autoimmunity. As Reingold (1996) succinctly claims the:

“most important aspect of immunoregulation is the ability to discriminate between self/non-self. Failure of the immune system to maintain self-tolerance results in autoimmunity. MS is considered an autoimmune disease where the immune system recognises components of myelin as non-self thus leading to the damage characteristic of the disease”

(Reingold, 1996:5)

Once this happens, multiple lesions form within the central nervous system and in so doing, disrupt nerve conduction and give rise to the multiple symptoms that some people experience with MS. Essentially, what this means is that the human body literally attacks itself. The sites of these attacks, known as exacerbations, are unique to the individual. Because of this, predicting the course of the disease is also elusive. An unknown cause, an unknown course and an unknown cure gives rise to much speculation. Some of these debates are worth exploring, to see what the scientific community can offer people who experience MS.

### WHAT CAUSES MS?

The debates about what causes MS demonstrate that the aetiology of MS is unknown. It is speculated that a combination of environmental, viral, genetic and immunological factors cause the disease. The involvement of these factors is still unclear particularly when their relative contribution to its geographical distribution in white populations is less certain. An explanation about what is meant by the terms ‘environmental, viral, genetic, and immunological factors’, may be helpful.

Support for the theory that environmental factors may play a part in the initiating of MS is strong (McDonald, E. 1992; Johns and Bernard, 1994; Shapiro, 1994; Reingold, 1996; Sheridan, 1996). The geographic distribution of MS indicates that it is more prevalent in Northern Europe, Northern United States, Canada, Italy, the former USSR, the United Kingdom, Southern Australia and New Zealand. The highest density occurs in those people who live furthest from the equator, that is, in temperate zones. MS is rare in tropical and sub-tropical areas.

In both Australia and New Zealand there is a marked variation of prevalence with latitude. It has long been known that MS is seven times more common in southern New Zealand than in tropical Queensland. Reingold (1996) believes that in both countries researchers have contributed much to the study of environmental factors but, "it is still not clear if there is a single major factor such as an unidentified virus or several factors acting together" (Reingold, 1996:10). This writer also made the observation that the complexity of the inflammation process during an exacerbation, had been extensively studied, to see whether the interaction between a patient's genetic make-up and the type of immunological reaction produced in the nervous system, was connected. The conclusion reached was that both environmental and genetic factors were involved, the most important of which had yet to be identified (ibid).

In an overview on the role of viruses in MS, Bernard and Johns (1996) found that it has been difficult to demonstrate a viral contribution to MS. However, confirmation that a relapse in MS is well documented following some viral infections was achieved. The most likely way for this to happen would be either via molecular mimicry or immune modification. The writers could only surmise that while remote an unidentified virus could not be ruled out, but that viral influences in MS are more subtle" and consequently that much harder to prove (Bernard and Johns, 1996:37).

Whether or not a common virus is implicated in the development of MS, there seems to be agreement that MS is immune-mediated, that is, the person's own immune system attacks the central nervous system. For some reason there is an increase in the number of immune cells in the body of a person with MS. This may be indicative that there may be some form of immune reaction that sets off an exacerbation.

While it seems that no one gene is responsible, it also seems that a genetic predisposition increases the risk of a tendency for MS. Endorsing this view, the most recent studies undertaken on MS susceptibility genes confirmed:

“that susceptibility to multiple sclerosis results from the actions of a number of genes, no one of which has an overwhelming effect”

(Reingold, 1996)

Results to pinpoint exactly what genes are responsible and their involvement with other factors, could take several years before the outcome is known. Estimates vary about the incidence in some family groups but there appears to be evidence that there is an inherited component to the acquisition of MS and about 10% of people with MS also have a near relative with the condition.

## PART TWO

### WHO GETS MS?

One of the prime reasons for undertaking this study is because out of an estimated three million people who experience MS, the women considerably outweigh men numerically: "Women are more likely to contract MS, with two thirds of people with MS being female" (McCabe et al,1996:38). And there is no explanation why women experience MS in such high numbers. This higher prevalence among females reflects the imbalance throughout the world. Aronson et al. (1996) in a comprehensive study on the socio-demographic characteristics and health status of people with MS and their caregivers, had findings which revealed a sex ratio of 2.3:1 which was nearly at the mid-point of the range of 1.2:1 and 3.3:1 cited in other studies. (Aronson et.al, 1996:12). Enteen (1994) did a study that involved a survey response of 73% being female. (Enteen, 1994:op.cit). Even if the figure cited by McCabe et.al. (1996) and Enteen above, are not as conservative as those provided by Aronson et.al, one has to question the lack of research into the gender differences in MS which are so apparent.

Estimates of the number of individuals with multiple sclerosis in the United States are now set at 300,000, and estimates of prevalence rates have tripled in some communities. 95% of the people who experience MS are Caucasian. (Enteen,1994:19). In scanning the literature it seems that these percentages are fairly typical in most of the high-risk areas. In the UK an estimated population of 85,000 experience MS (Hatch, 1996:40). In these areas the prevalence is approximately 100 per 100,000 population (ibid).

In New Zealand, because the disease becomes more common the further one moves from the equator, the prevalence of MS could be expected to be higher in the South Island than the North Island. And indeed, in 1988, evidence from hospital admissions and deaths found that the prevalence of MS in Southland was over twice that in the Waikato (Skegg et al.1988). The study revealed that the incidence of MS in both the Maori and Polynesian population was 'extremely low' (ibid). Nationally there are 2,394 people who identify as having MS. The reason I use the word identify is because there are a number of people who belong to the MS Society but will not allow their names to be recorded. They are frightened that this public acknowledgement might compromise their future employment opportunities because of employer discrimination. Of the total MS population 1,864 are women and 530 are men (Multiple Sclerosis Society of New Zealand, 1998).

Internationally, MS is one of the major causes of disability in adults under the age of 65 and in it is the "commonest neurological disease of young Australians"(McDonald, 1992:1421). In a recent Canadian study researchers reported a "mean age of Ms onset at between 29 and 33 years, with actual diagnosis several years after the first occurrence of symptoms."(Aronson et al, 1996:6). However, MS can begin in childhood and in older adults. Enteen, (1994) in another study on demographic characteristics found that 11% of people with MS were under 35; 75% were aged between 35 and 64; and 14% were aged 64 or more.

Reflecting on the above, all of the following factors appear to influence the development of MS in some way:

“MS is an autoimmune disease which mostly affects women in their early 30's. The cause is unknown, but it is possible that the environment, an unidentified virus and/or a genetic predisposition may also be contributing factors”  
(Hight, 1999)

#### WHAT TYPE OF MS DO I HAVE ?

Researchers have also argued about the naming of the various categories of MS an individual may experience. Sheridan (1996), has highlighted the inconsistency in the terms used which he suggests is an unfortunate mix of classification. (Sheridan, 1996:4). I believe the categories are extremely important to the person experiencing MS and because most of the literature about MS uses the terms interchangeably I will explain the concerns of Sheridan in greater detail.

In the past, there were four major categories of MS - benign, relapsing-remitting, primary progressive and secondary progressive. The term 'benign' MS means that an individual may experience the odd exacerbation but there will be no ongoing disability. However, Sheridan questions this because using this term as a classification in its own right is fairly pointless (ibid). As this type of MS can only be identified after a period of approximately 'twenty years from the time of

the initial onset of symptoms, would it not be better suggests Sheridan, to link this type as a subset of the term relapsing-remitting? Relapsing-remitting MS means that the beginning of an exacerbation and the subsequent decreasing of symptoms may or may not cause permanent disability. Sheridan criticised this because the next level (progressive) has the potential to be viewed in two ways. Does it represent a fundamental change in the disease process or secondly, is there a transition in severity due to long-term incremental damage? (ibid:7). Once again, because of the great variation between the individual experiences of MS, the outcome will depend largely on the severity of the exacerbation.

‘Primary progressive’ MS, formerly known as chronic progressive MS means that when periods of remission become less this could also involve different implications for prognosis, therapy and management. Once again, it needs to be remembered that the length of time it takes for the MS to develop to this stage (which may not happen), also varies between individuals.

Finally, secondary progressive MS that is, symptoms that remain after an exacerbation, is problematic for Sheridan for the same reasons outlined in the third category. The value of the points raised by Sheridan is that maybe it is more useful to see the development of MS as a continuum of manifestations of the disease.

Reinforcing Sheridan’s concerns Reingold (1996) reported on a survey, which asked 215, physicians who were familiar with the MS experience, what they understood by the terms used in classifying the different types of MS. The replies showed agreement on some terms but wide confusion on others.

These days the term 'benign' MS is no longer used and is now part of the relapsing-remitting type of MS. Primary progressive and secondary progressive are retained and progressive-relapsing that is, a "pattern of clear-cut relapses that are progressive over time with continued worsening", has been introduced (ibid:4). Reingold is optimistic that this new terminology should create the situation where individuals with MS will have a better sense of their disease and more confidence that their physicians are all speaking the same language. It would be nice to be able to share this optimism. After some deliberation the different terminology used by Sheridan remains in situ, for the simple reason that even if a universal nomenclature has been established, that knowledge will take considerable time to filter down to a general practitioner and to those experiencing MS.

It may well be that some people will be diagnosed with the now defunct types of MS. The argument presented here is that if professionals in the medical, scientific and research field cannot agree on a universal nomenclature, people experiencing MS and are searching for information will instead be confronted by a language which is not only almost impossible to understand but also at variance with the terminology used.

It can be seen by looking at the above categories of MS that symptoms play a seminal role in the MS experience. It is therefore appropriate to examine some of the more significant symptoms that directly relate to the women's experience of MS. In this next section emphasis is placed on the symptoms of fatigue and cognitive dysfunction, the problems associated with diagnosis and treatment of MS, life expectancy and tentative findings from the medical research.

### PART THREE: TOWARDS AN UNDERSTANDING OF MS

#### THE SYMPTOMS:

##### THE MEDICAL RESEARCH:

“The disease is intermittent in most cases, the initial symptoms are usually transient and may last only several hours or a few days. They generally disappear after the first attack, leaving the person symptom-free often for many years. The symptoms then usually recur and disappear again, fully or partly. This waxing and waning of symptoms, which may vary from relapse to relapse, may occur over many years, leaving few after effects at first but eventually producing permanent disabilities”.

(Vorhaus, 1996:5)

##### THE EXPERIENCE:

“Many conscientious physicians have been stumped by the array of symptoms exhibited by the MS patient. I hear from so many of you about the odd difference between MRI results and clinically observed anecdotal symptoms displayed or expressed by an individual. It is hard to make anyone, including doctors, understand and in some cases, even believe, what we are telling them. We know what we are experiencing is real.”

(Tofteland, 1996:3)

Symptoms vary according to the sites of the lesions in the nervous system. The most common neurological symptoms experienced by people with MS include visual problems, balance problems, slurring of speech, heat and/or cold intolerance, numbness in the hands and/or feet, (often described as pins and needles), weakness in the arms or legs, spasticity, bladder and bowel problems, pain, neuralgia, depression, fatigue and cognitive dysfunction. With such a vast array of symptoms, it needs to be remembered that the number of symptoms experienced at any one time will depend on the severity of the exacerbation. The two symptoms I have selected for closer scrutiny are fatigue and cognitive dysfunction. All of the women in this research felt that these invisible symptoms caused them the most concern. While fatigue is probably one of the most common symptoms experienced, cognitive dysfunction has only recently attracted the attention of the scientific research community.

### FATIGUE

#### THE MEDICAL RESEARCH :

“Lassitude is the most common fatigue in MS and can occur without depression. It presents as an overwhelming sleepiness that may be quite disabling. Management is with stimulating antidepressants, cerebral stimulants and amantidine”

(Shapiro,1996:30)

### THE EXPERIENCE:

“Aah, fatigue...That most destructive of all the MS thieves that rob us of our pre-illness lives. Fatigue is also one of the hardest MS symptoms to combat, though it can be managed to some degree”  
(Tofteland, 1995:3)

In almost every discussion about MS, the symptom of fatigue is raised. While the cause of MS fatigue, is not fully understood, it differs from the fatigue experienced by those without MS in two ways. Most people experience and describe fatigue as a result of tiredness after a long day at the office or, on completion of a strenuous working out at the fitness centre. This type of fatigue can be related to muscle tiredness whereas, MS fatigue can often be caused by the very slow “transmission of nerve impulses along demyelinated nerves” (Burnfield,1989). In a recent study based on the health status of 697 persons with MS, 88% of the respondents claimed that fatigue headed the list as the most disabling symptom experienced (Aronson et al. 1996:12).

This is not to say that people experiencing fatigue do not have the ‘normal’ sort of fatigue that others have. For those people who have the primary or secondary type of MS, Shapiro (1996) believes that it is necessary to ascertain what type of fatigue is being experienced. As well as the nerve fatigue described by Burnfield above, Shapiro states that it is important to be aware of the type of fatigue which can be caused by depression. Suggesting that this type of fatigue ‘may not be recognized by the MS person’, the solution offered is that it “must be managed by appropriate medications and counselling” (Shapiro, 1996:30).

Conversely, a study (Krupp et al., 1989), based on structured interviews with individuals with MS, was carried out specifically to find out whether MS fatigue could be linked to depression. Their findings revealed that “fatigue and depression are primarily separate entities in individuals with chronic illnesses, such as multiple sclerosis”(Krupp et al., 1989:7). A fatigue severity scale has been developed which has been found to be reliable and highly sensitive to clinical changes (RRTC, 1996). It is hoped that “this tool will prove a useful adjunct in the evaluation and treatment of this prominent and disabling symptom”(ibid).

### COGNITIVE DYSFUNCTION:

#### THE MEDICAL RESEARCH:

“For longer than one can remember it was felt that MS did not affect the mind. The books told us that MS was not accompanied by cognitive problems. That clearly was not correct as we now know that 50% of people with MS have cognitive problems” (Shapiro, 1996:31)

#### THE EXPERIENCE:

“You’re sitting in your cubicle at work, sorting out a tough statistical problem in your research and somebody looks in the door and tells you that it is raining outside...just what you needed to know, right? Normally, you’d just ignore it and go on with your work. But often with MS, that interruption will interrupt your entire train of thought, making it necessary to go back and start over, losing 30 or 40 minutes worth of productive work” (Britell, 1996:1)

For people who experience the progressive type of MS, cognitive dysfunction can cause considerable stress. Britell (1996), has isolated six ways that cognitive dysfunction is affected by MS. Attention/concentration and short-term memory head the list. When these problems exist, Britell says that they can be dealt with systematically. For example, giving the person involved a private room and an answer phone can rectify the experience cited above. Any incoming calls can be returned once a task has been completed. The other suggestion made by Britell, is to set an alarm which has a note attached as a reminder that there is an appointment or task which needs to be done when the alarm goes off.

Information processing can be problematic sometimes. An example of this is the length of time it may take to digest new material. Basically it really relates to the speed required to respond to a question that is asked or, having to provide a reason for a particular course of action. The answer to this problem according to Britell, is to allow more preparation time and to “avoid situations where quick processing is imperative” (Britell, 1996:2).

The third problem which can arise with cognitive dysfunction is referred to as ‘executive functions’. For the few people who may experience difficulty with:

“organizing and prioritizing thoughts controlling expression of emotions, and changing topics of thought. This can be rectified through the re-training of those areas where this ‘normally’ takes place automatically”

(ibid:2).

Perception is the fourth aspect that can be disruptive. Britell offers no remedy, but it concerns the inability to make sense out of what

one sees. From personal experience, two ways to reduce this, is to make lists and to be extremely tidy. Problems with speech can also be attributed to cognitive dysfunction. Britell differentiates between word retrieval which is rare in MS, and the difficulty associated with “not being able to form words quickly in a coordinated fashion” (ibid:6). No solution is offered, but for the women in this study the problem can be lessened by informing the person you are speaking with, so that if the right words cannot be found the listener is able to prompt the train of thought, making retrieval of the lost information much more likely for the person with MS.

Finally, the sixth way cognitive dysfunction may affect those who have MS is intellectual function which includes the “abilities to reason, learn and make conclusions and judgements” (ibid.3). Fatigue, depression and stress can aggravate all six aspects of possible cognitive dysfunction so Britell believes it is important to seek professional help under these circumstances.

In the past professional help for cognitive dysfunction has been difficult to obtain for some people experiencing MS. Shapiro (op.cit:31), correctly points out that it has taken some members of the profession a long time to admit that cognitive dysfunction is a reality for many. Critical of fellow neurologists for “largely ignoring the memory problems many with MS encounter”, Cohen (1996) suggested that the role of a neurologist is to “firstly listen to patients and make them feel they have a legitimate problem” (Real Living, 1996:13). Recognition of this is reaffirmed by Langdon and Thompson (1996), who believe that:

“for those people with MS who experience the cognitive aspects, acknowledgement and understanding can be crucial elements of their social support system”

(Langdon and Thompson, 1996:6).

Three reasons for information about cognitive dysfunction and why it should be made accessible to patient’s carers and professionals are given.

The first is to ensure:

“as complete an understanding as possible, so that all areas of function likely to be vulnerable to MS are considered and monitored”.

(ibid:6).

The second reason is:

“to increase awareness of the impact of cognitive dysfunction on all aspects of daily life, including physical activity”  
(ibid:6).

and the third reason given is:

“to facilitate the dissemination of management strategies and treatment options relating to cognitive dysfunction”

(ibid:6).

## HOW IS MS DIAGNOSED?

### THE MEDICAL RESEARCH:

“One of the more recent scientific discoveries which has made the diagnosis more meaningful for the individual involved, has been the use of magnetic resonance imaging (MRI). This medical diagnostic technique creates images of diseases of the brain and central nervous system”.

(Reingold, 1996:7)

### THE EXPERIENCE:

“Diagnosis of a disease of such unpredictable potential to affect every area of a person’s life is devastating to most people. Incredible though it may seem, the time of diagnosis is a relief to some. It may often follow a long time of uncertainty about the nature of the symptoms and many people have been labelled neurotic or feel that they are going mad during the time prior to diagnosis”

(Burnfield, 1995:19)

The greatest improvement as far as the individual with MS is concerned is as Reingold (1995)states, the introduction of the Magnetic Resonance

Imaging (MRI) which can show lesions in the central nervous system (Miller D,1995:36). This discovery has a second benefit other than revealing any increase in lesions in so far as an MRI can also be used to see if further lesions during or following an exacerbation can be seen. The capability of this machine means that for newly diagnosed people with MS, the years of uncertainty as to whether or not MS was the underlying disease, which was experienced by all of the women participants, have been significantly reduced with this technology.

It needs to be pointed out that an MRI scan can only detect “95 per cent of clinically definite cases” and Miller D, (1995) and Miller A, (1996) both believe that MRI scans should also be supported by other ways to diagnose MS. Two other tests carried out to assist in the diagnosis are by a lumbar puncture (spinal tap) which allows cerebrospinal fluid to be examined and what is known as visually evoked potential tests which can have abnormal characteristics indicative of MS.

### CAN MS BE TREATED?

Efficacy of treatment is also controversial. Even though there is:

“no way that choices among different MS treatment options will be easily made, for there are simply too many variables”

(Reingold, 1995:34).

It would probably be fair to say that symptom management has improved markedly, and that new drugs are being tested and offered. The treatments offered fall into one of three groups. Those designed to manage specific symptoms, for example, anti-spasm medication; those that are used during an exacerbation, for example, intravenous steroids; and those that employ “new medications, which modify disease activity,” for example, Betaseron, which was approved for MS treatment in 1993. (ibid). Recovery from

acute relapses may be hastened by treatment with corticosteroids and the frequency of attacks in intermittent cases can be reduced by long –term treatment with interferons. Some people find it beneficial to have physiotherapy and /or occupational therapy for symptomatic relief. But perhaps the most positive and exciting research which may lead towards an effective treatment will develop out of what is known as “The Myelin Project”. The international scientists involved in this project have been able to find out that remyelination within the brain and spinal cord might be possible. As yet, how this process actually takes place is not absolutely certain, but it does represent something to look forward to.

#### WHAT IS THE LIFE EXPECTANCY AFTER THE ONSET OF MS?

The life expectancy for people who have MS differs with the degree of the severity of the disability experienced. It appears from the literature that for those people who have minimal disability, the lifespan “is approximately the same as that for an unaffected person of the same age, sex and health risk factors”(Hansell, 1995:19). On the other hand, Colville (1994), collected data on mortality statistics from a self-acknowledged limited sample, which suggested that when “MS causes a significant persistent disability, the prognosis for life is not easy to predict but the life expectancy from onset is approximately halved”(Colville, 1994:18). Further, the writer believed that sex and age at onset had “little effect on that prognosis, but data regarding younger and older age onset is inadequate” (ibid). Much like AIDS, when there is early death the cause is usually related to other complications such as upper respiratory infections.

#### TENTATIVE FINDINGS

This chapter began with the question “What is Multiple Sclerosis?” and although it has been possible to work towards a definition of MS and

explore some of the current debates from the medical perspective, providing an answer to the question remains somewhat unsatisfactory. It appears that the environment, genetics, viral and a person's immunity all play a part in the initiating of MS. But, to what degree? The terminology used in the type of MS experienced is important for people who have MS. In the meantime, it could well be beneficial to heed the words of Sheridan when he said that maybe it is more useful to see the development of MS as a continuum of manifestations of the disease. Improvements in symptomatic treatment and diagnosis are welcomed. Yet, it is also problematic.

It is accepted that there is an increasing awareness of the enormous gap separating the scientific endorsements and the reality of the experience of MS. However, there is still a sad lack of recognition that the person experiencing MS can have symptoms that are outside the research understanding. A classic example of this is demonstrated in the area of cognitive dysfunction.

Until the last few years, researchers believed that this symptom was not a 'significant problem'. Now there is a veritable cognitive dysfunction 'bandwagon' as researchers rush to study this phenomenon. People, including all of the women in this research, have consistently complained about memory problems, retention and recall, loss of concentration, reasoning abilities, tiredness and lassitude, which fell on silent ears until scientifically proven. Equally damning is the fact that the imbalance of the prevalence between women and men experiencing MS is not being addressed.

With these reservations in mind, and in sharing the belief expressed by Johns and Bernard (1994) at the beginning of this chapter, it is hoped that ongoing research will change the way MS is experienced today. Until that happens, making sense of our MS is imperative and the documentation of our realities becomes all the more critical. While the enigma of MS still

dominates, it is now time to move away from the medically-orientated research and focus on the stories that the women in this research tell about their experiences of MS.

## CHAPTER FOUR:

### INSIGHTS INTO THE EXPERIENCE OF MULTIPLE SCLEROSIS:

ANN: "Multiple sclerosis is like living in the crater of a volcano. There are a few rumbles and then it subsides. But you know it can explode at any time. It never leaves you – it just seems to lie in wait. It drives me crazy. Do you know it took me ten years of denial? And even now I am not sure that I do really accept my MS."

The previous chapter examined the medicalised approach to MS. But for the women in this research, while we eagerly await the elusive cure we still have to try and make sense out of the way we experience MS on a daily basis. The aim of this chapter is to bring the experience of women with MS nearer to the people with whom they come in contact and thereby enable them to better understand the issues that are important to us. The four themes to be described in this chapter are: the onset of symptoms; cognitive and sexual dysfunction; body image and loss of self-esteem, delays in diagnosis and the experience of loss and grief. Some of the coping strategies the women have used conclude this chapter.

The women participants began sharing their experiences with me by describing how an array of symptoms started to encroach on their lives. While most women experiencing MS will easily identify with these descriptions, it would be fair to say that the years of doubt prior to diagnosis and, the associated psychological trauma for us as participants in this research, has in fact been diminished. New technology, such as the MRI which can monitor an increase in the lesions of the brain, mean that the delay the women were subjected to in having a diagnosis are not so

common now. However, delays still happen and the feelings expressed by the women when their symptoms flared, remain a timeless factor. And once again it needs to be remembered that no two people experience MS the same way.

### THE ONSET OF SYMPTOMS

The initial symptoms associated with MS may well go undetected for some time by some women. They often coincide with major life decisions women are considering at this time such as career options, forming partnerships with other people, deciding whether or not to have children and generally being active. Under these circumstances ongoing fatigue, tingling, numbness, visual or other transient symptoms with eyesight and/or the occasional sensory disturbances that many people with MS experience, are often ignored and/or dismissed because of the frenetic pace at which we conduct our lives at about this time.

And there are many women whose experience of MS is just that, a few transient symptoms which go no further. For some unexplained reason experiences of remission, when there are no or few symptoms over a long period of time, are quite common. (Sheridan, 1995 op.cit; Shapiro, 1996; Burnfield, 1996, op.cit). But for many of us, including the women in this research, these transient symptoms persist and we need to find out and understand what it is we are experiencing.

The women in this research endorse the view of Tofteland, (1995) who states that the period leading up to diagnosis often follows a long time of uncertainty about the nature of the symptoms and many people have been labelled neurotic or feel they are:-

“going mad during the time prior to diagnosis. This is particularly true if they have symptoms that cannot be confirmed on physical examination and this is not uncommon with some sensory symptoms”

(Tofteland, 1995:3)

Confusion about what was happening to our bodies before MS was diagnosed was in many respects very destructive. There was a great deal of self-flagellation by all seven women. As we tried to make better sense of our symptoms our inner feelings at this time were expressed in terms of a sense of loneliness and the constant fear that we might be imagining our symptoms:

JO: “I felt so lonely when I was experiencing some of my symptoms- it got to the point that I was too scared to tell anyone”.

JILL: “My symptoms were so bizarre, nothing seemed to make sense”.

SUE: “Well there is one thing about symptoms, they sneak up on you”.

ANN: “I was afraid to say anything- you know what it is like when people raise their eyebrows. Why don't they just come out and say it?”.

LIZ: “There is nothing wrong with you, that is such a cruel thing to say”.

ALI: “When you have to deal with the disbelief of some members of the family you get to the point that you know longer feel safe about saying anything”.

PAMELA: “It doesn't take long before you start to think that the views of everyone else might be right. I think my worst fear was that I really was insane”.

I know that when I felt there was no one to turn to I realised that my MS was a gender issue. If this was happening to me within a marriage and I had the bonus of being able to articulate how I felt, how on earth did other women live through similar experiences? Once again Tofteland (1995) supports this statement:

“...it’s hard to make anyone, including doctors, understand and in some cases even believe what we’re telling them. We know what we’re experiencing is real, what anyone else may think is his or her problem. That’s the key to dealing with many things that come with chronic illness. Learning to accept what is and being strong enough to separate yourself from worrying about what other people think are two of the most difficult but important lessons we must master. It’s imperative for us to stand firm”

(Tofteland, 1995:3)

One of the symptoms now being recognised by researchers is cognitive dysfunction. Four of the women said they had cognitive problems. Two of us found this most evident while studying at university. Both of us were very upset that our concentration span had decreased and that reduced retention levels meant that storage of new information took a number of readings.

Fortunately at the most difficult times, we were able to support each other. Although we had mentioned the problems associated with cognitive problems in the past to our respective neurologist and general practitioner, we were told that cognitive dysfunction was not a symptom of MS. However:

“For longer than one can remember it was felt that MS did not affect the mind. The books told us that MS was not accompanied by cognitive problems. That clearly was not correct as we now know that 50% of people with MS do have cognitive dysfunction”

(Shapiro, 1996:31)

Sue’s experience in the university setting was expressed as:

SUE: “My university results do not reflect the hours that I spend doing my assignments and I think it takes longer every year. Whether it is cognitive dysfunction or just my age, my brain leaves a lot to be desired”.

My own experience is perhaps the most depressing symptom I have:

Pamela: “If you have lived a lifestyle where you have had to make instant responses, dealing with cognitive dysfunction can disturb both emotional and social well-being. If your brain loses the capacity to logically think a problem through to possible solutions then you probably deal with it by avoiding contact with other people. I think one of the hardest aspects of cognitive dysfunction is that you have to admit to that. To give an example, yesterday, I spent seven hours altering the text of one page. One year ago this task would have taken me ten minutes”.

We all agreed that everything we do seems to take longer than the time before. We joked about forgetting to remember things, including appointments, outings with friends and birthdays, but inside we felt devastated. For people who love us, they understand, but it is more

being lazy or downright rude. Some of these difficulties can be overcome by using diaries and writing things down, but if you also forget to look at the lists there really is very little you can do. These are the times when we desperately need emotional support but the fear existing alongside the admission of not being able to cope is often far worse than the problem. Besides it all gets exposed in the end, particularly when the guests have turned up for dinner and you have already eaten! It really does help to have a sense of humour.

The next symptomatic concern, which seemed to have caused a great deal of trauma for six of the women was sexual dysfunction. I wondered whether this was a direct result of the length of time that we had experienced MS for, but then I realised that given our age range, the difficulties expressed had remained latent more as the result of the subject being 'taboo' and not one that was easily raised by our generation. Fortunately, these days sexuality has 'come out' into the open and for younger women with MS, the raising of these issues with other women and perhaps their general practitioner, does not carry with it the stigma that had silenced the women in this research.

The practical solutions to some of our problems were not as readily available as they are now. There is a great deal of recent literature which focuses on sexual dysfunction in men experiencing MS and it appears this is one symptom where men experience more difficulties statistically than women, manifesting itself in impotence and/or premature ejaculation. Assistive devices have been developed for men which appear to have beneficial effects, but alas for women, our anatomy in combination with our symptoms does not overcome many of our residual problems. To better understand some of the difficulties people with MS are confronted with, it is helpful to look at some examples in the relevant literature.

Lublin et.al (1996), carried out one of the few surveys in the literature which specifically “assessed the effect of MS on sexuality and interpersonal relationships”(Lublin et.al. 1996). These writers developed a questionnaire to determine the influence of the level of disability and time since the onset of the illness on sexual functioning, social and family relationships, and quality of life of people experiencing MS and their partners. In their study, 37 males and 74 females took part and the findings suggested that having MS impacts on both ‘sexual activity and sexual dysfunction’ (Ibid: 17).

For both men and women experiencing MS sexual problems are largely the result of the plaques existing on the nerves closest to the sexual organs. A second survey found that out of the 300 participants:

“91% of the men and 77% of the women reported a change in their sexual activities. Symptoms that are frequently reported are: loss of sensation in the genital area, loss of libido, inability to achieve or maintain an erection, and loss of orgasmic capacity”

(MS Matters, 1997)

The women in this research also talked about their problems with both bowel and urinary incontinence and pain which interfered with their sexual pleasure. The ways the women coped with their varying sexual dysfunctions, had quite a lot to do with the fact that four of the women believed that they could not talk about what most worried them with their husband in case their respective husbands would be repulsed and want to leave the marriage. Some of the problems experienced were:

LIZ: "He blamed our divorce on lack of sex. That was not the reason, he just couldn't handle my MS".

ANN: "My intermittent lack of sensation from the waist down has meant that sex cannot be enjoyed. But because I do not want to let my partner down I make all the right noises and feign pleasure".

PAMELA: "Prior to my divorce, I had such low self-esteem which did little to improve our relationship and once he started to have affairs that was it. Fortunately I now have a new partner who is able to satisfy all of my needs".

SUE: "...Since we have been using a condom, the pain I always felt has been reduced. Early on in our marriage it was always me with the libido, and then I reached the point where for me, lovemaking was looked upon with dread".

JO: "Things are much better now as there are plenty of devices that can be used. Just ask any chemist".

ALI: "I always have a sleep prior to sex, that works".

JILL: I ask my doctor (a female) to see what she can suggest".

Further findings revealed that the complexities of the psychological impact of these problems meant that changes in 'body image' could cause 'loss of self-esteem, depression, anxiety, and anger' and generally add to 'the stress of coping with a chronic illness' (ibid). And indeed, these were some

of the issues most heartfelt by the women in this study and I believe for many women who have a chronic illness.

### BODY IMAGE AND LOSS OF SELF-ESTEEM

Five of the women cited changing body image and loss of self-esteem as one of the contributing reasons for the breakdown in their marital and/or partnership relationships. As young women it was a struggle for us to be daughters, wives, mothers and lovers while we tried to make better sense out of what was happening to us. Not only did we have to cope with an unknown quantity as far as the MS was concerned and, try and adapt to our new situation as best we could, but we also had to cope with our family and friends' reaction to what was happening to us. It seemed as though we had to be everything to everyone.

The success of the way five husbands adjusted to the diagnosis of MS can be measured by the fact that five of the women were left to bring up children on their own. We had the responsibility of looking after their respective children, who in turn were then caught up in not only the emotions of a divorce but also the ongoing emotions of the MS experience.

We all believed that many of our problems stemmed from the myriad of ways our bodies were invaded by the medical profession that did not abate even after diagnosis. This loss of ownership of our bodies is discussed in the next chapter in more depth, but the culmination of these invasions seems to have penetrated into every aspect of our MS experiences.

It seemed that every time our bodies changed, our loss of self-esteem became heightened. Self-perception as to how you feel about yourself makes an enormous difference to your whole outlook on life. Our changing body images and our lack of self-esteem were expressed as:

LIZ: "The impact on my self-esteem was unbelievable. There was no way I could enter into a relationship when my bladder could not be depended upon, however once that got sorted out I gained more confidence and was able to enjoy other company more".

PAMELA: "Each time I looked in a mirror I was reminded about the ballerina that I used to be. I don't know why I kept looking at my reflection -all it was doing was torturing me".

ANN: "It is awful when you remember what your body used to look like. Who wants to look 60 when they are 40?".

Jill: "When your body is falling apart and you realise that some of your dreams will fly out the window, it is easy to let yourself go".

JO: "Sometimes I get jealous seeing someone doing something that I can no longer do. As if it's my fault I have MS!".

ALI: "It was bad enough for me to not be able to do the things that I would have liked to and I worried so much about the fact that I was letting my husband down I ate. And of course I got fat which made me all the more depressed".

Six of us felt really devalued as women and because we did not realise the impact that symptoms such as fatigue, bladder incontinence, ataxia and cognitive dysfunction had on us, we accepted our disabilities as personal failings. This did little to enhance either our body image or our self-esteem. So when we did eventually get an official diagnosis, did it bring

Three of the women in this research had made their own diagnosis of MS before they were officially told by a health professional. All of the women had waited years for the diagnosis to be confirmed. During that period we had to assume that whatever was wrong with us could be fixed by just applying mind over matter. All seven of us were firmly entrenched in the medical model of disability.

The medical model of disability has been vigorously debated over the years. (Sobsey, et.al. 1990; Munford,et.al.1994c; Finkelstein, 1991, Morris 1989, 1991 and; Oliver, 1992; 1996). Oliver (1996) states:

“for me, there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component”

(Oliver, 1996:31)

Oliver’s explanation of the individual model, also known as the personal tragedy theory of disability, locates the problem of the disability as being the fault of the individual. The problems arise because of the functional limitations or psychological losses residing within the individual. The antithesis of this model, is the social model of disability which:

“is all the things that impose restrictions on disabled people: ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on”

(ibid:33).

However, for the women in this research, the experience of MS is more akin to the definition provided by Sullivan (1996):-

“For many disabled people their impairment has medical implications which compels them to adopt certain regimes of care without which the organism may deteriorate and die. These regimes might, in turn, require them to organise their lives around the care of their bodies. From this perspective, disability is not only the consequence of attitudes and the built environment, but also the subjective and practical experience of living an impaired body.”

(cited in Sullivan and Munford 1998:184)

All of the women in this research were living an impaired body and while the diagnosis brought relief for most of us the underlying problem still remained. The doctor diagnosed, but could do very little towards alleviating our symptoms or enhancing our quality of life. The women experienced a range of reactions to the diagnosis:-

ANN: “I was diagnosed fifteen years ago but my MS has been in remission for the last five years- I may never have another relapse which would be great”.

PAMELA: “I had waited seven years for this diagnosis. With a real diagnosis, I could feel a real person again. The fact that I had MS was irrelevant in my eyes. Inwardly I had always known that. What mattered most to me was that no-one could take my sons away from me because I wasn’t insane”.

JILL: “I always knew I had MS, the diagnosis meant nothing”.

LIZ: “On the one hand I was relieved about the diagnosis, but the waiting period meant that I had seen a psychiatrist and I was so depressed and I had lost all my self-confidence and it was years before I recovered”.

ALI: "It was such a relief when I was diagnosed six years ago. I honestly think if it had gone on much longer without a diagnosis I might have either gone mad or something much worse. I thought suicide was the answer at one point, and then I thought what would happen to the kids".

JO: "By the time I was diagnosed, it was too late to take back the awful things that had been said about me – my husband had already decided that I would end up in a wheel –chair. The year I was diagnosed we separated".

Six of the women had been given a diagnosis of MS but there was still an inconclusive diagnosis for Sue at the time of the interview. The issue for Sue was:

SUE: "Because I don't have a diagnosis I am always compromised when something goes wrong. They look at my notes and do very little and get away with it because they say "You have had this before"- it makes me feel like a fraud".

We could all relate to each other when we spoke about the agony of not having a diagnosis when our integrity was stretched to the limit and our faith in the ability of anyone being able to understand what we were experiencing. All of us avidly read any information about MS that we

could find, but most of the available information was from medical books and were couched in terms that were difficult to understand.

My own excitement was short-lived, but confirmation was a vote of confidence for me as I tried to cope with the other happenings in my life.

Pamela: "When I knew that I had MS, it amazed me how many people asked me whether I knew Jacqueline du Pres, who had been diagnosed with MS some years previously. They did a double take when I said "yes and do you know that her husband left her because of her MS? It's ironic that mine left me but unfortunately this is often the case. Research has shown that if the male gets MS, the wife usually stays with him to take care of him. That says a lot about the female nurturing instinct."

### THE EXPERIENCE OF LOSS AND GRIEF

For all of us, the years of not knowing or understanding what was happening as we experienced the onslaught of MS, in some ways was harder to contend with than the neurological symptoms themselves. The inner turmoil we experience is akin to the grief disabled people and their families are subjected to and more often than not, this arises from the way in which disability is perceived and the notions held about disabled people who are normally assigned to in the so-called egalitarian society of ours. The degree of uncertainty about what will happen if the MS progresses are coupled with the stigma we feel.

Some writers argue that while we have to contend with our own disabilities as they arise and how these complexities are dealt with by our families and friends, the reality is that our status as fully functional and participating women is negated by attitudes held by non-disabled

members of our society (Georgeson, 1994 op.cit; Munford, 1992, op.cit; Gordon, 1994; Ballard, 1994). These writers talk about the way people with disabilities are forced into ascribed roles not of their own making.

The difficulties experienced by the women in this research clearly demonstrate that even the reactions from some of our own families are shaped by the way they themselves perceive disability. The mere fact that five of the women got divorced and none of the women initiated the proceedings themselves suggests that these women have paid a high price for their disabilities. But the sense of loss and grief goes further than this.

It is evidenced by the fact that as participants experiencing MS, we have been 'labelled'; we have accepted that anything that is said about us must be true; we have been denied access to the needs of humankind; we have been prodded like slabs of meat; we have been forgotten following diagnosis and we have been abandoned by a society which doesn't care. And during all of this time, for the few morsels that come our way mean we have to be forever grateful. I think we really understand about grief and loss. We confront it every day. So how can things be different for us?

Although we have shared some of our MS experiences, the usefulness of these lies in the way the seven of us have worked towards our own empowerment. We have employed various coping strategies, which have made our daily lived experiences that much easier to deal with.

Mairs (1997) who has MS, highlighted the problem of being 'different' when she wrote an article called: 'Why I'm a cripple' (Mairs, 1986) which sent shock waves through disability groups worldwide. Mairs deliberately enraged people so that people would focus on the fact that the experience

of disability were the issue and not a particular disease someone might have. Her overnight fame is also discussed in her autobiography called “Waist-High in the World” which explores the nature of MS and her coping strategies. (Mairs, 1997). These are not unlike some of the coping strategies the women in this research have used.

### COPING STRATEGIES

Some of the coping strategies the women in this study employ indicate that it is still possible to lead productive and worthwhile lives on a daily basis. Together we identified two key positive approaches. The first approach is to accept the fact that a diagnosis of MS does not necessarily equate with the stereotypical impression that our lives are over. All of the women in this research felt that they wasted what excess energy they may have had, by allowing their symptoms to dominate their thoughts and actions. We used various excuses for this, but at the end of the day we were able to recognise that we mostly blamed ourselves for the inadequacies of other people: -

JO: “My family tried to do everything for me, I guess to protect me, but this resulted in my being stifled by them”.

Taking ownership of our MS experiences was the second approach adopted. By doing this we could take control over the symptoms that arose. There are now significant medical advances, which mean that most of the symptoms described above can be treated relatively easily. For example fatigue, perhaps the most infuriating of symptoms, can become

less so by:

JO: "having to pace yourself. I used to just keep going but then everyone suffered. These days I listen to my body and stop when I get tired".

Cognitive problems cannot be overcome quite so easily, but some of the suggested coping mechanisms are:

SUE: "A personal diary helps".

ANN: "Copy appointment dates and times and put them by your bed, by your phone and on your fridge".

ALI: "Always have a pen and paper next to the phone".

JO: "Ask other members of the household to remind you of important happenings, whether there were phone calls or mail".

PAMELA: "Be careful when using the iron and cooking. With reduced sensation it is easy to burn yourself- this applies to most household items".

JILL: "Have a friend who also knows where you should be!".

Women are socially defined in terms of their sexuality and are deemed “to be asexual; women with disabilities are further disenfranchised by the medical profession”(Hannaford, 1985:77). Be this as it may, there are now some devices that can deal with both urinary and bowel problems and referral to a urologist can be useful and in some cases ‘fix’ the area of concern. However, for the women in this research it was the psychological barriers that were of most concern. We decided that our embarrassment affected how we coped in differing situations.

The two women who were married believed their open communication with their husbands had held their marriages together. Four of the women had gone to marriage counselling prior to their divorce. We all felt that sharing such personal problems was probably easier today than it had been some years ago. Three of the women said they would not hesitate to go as an advocate and/or support person for younger women experiencing similar difficulties. Our various coping strategies were expressed as:

**JO:**“ I used to worry: do I smell? Incontinence is very embarrassing and it does put people off. But then I started using discreet catheters and now I can relax”.

**JILL:**“My solution was a supra-pubic catheter, which drains fluid from my stomach. This leaves me totally in control”.

**PAMELA:**“I just say what I like best in bed now. While I was married I felt too inhibited to say anything”.

**ANN:** “There are some great inventions to heighten my pleasure and experimenting is fun”.

We can also take responsibility for our relationships with others. Self-empowerment encourages us to be more assertive about what our needs are and how some of our expectations in life can be realised. And sometimes these achievements can be as simple as finding out from other women experiencing MS, just how they manage their lives on a daily basis. By sharing our ideas, hours of frustration can be saved. And collectively, we can reinforce and articulate what we think as a group so that our voices become all the more powerful. I believe this is the only way to bring about real changes in our lives.

This chapter has documented those issues that as far as the women are concerned were some of the most central to their experiences of MS. We all had an acute awareness of how important it was to remember the difficulties we faced as we struggled to make better sense of our lives. We have painfully shared these aspects of our experiences, in the hope that other women experiencing MS now would benefit from this knowledge.

We have opted to include those issues that we felt were quite misunderstood by the people we love or, where we saw the current gaps in information about MS. The coping strategies offered are just some of those that have helped us to go about our daily lives. We hope that these suggestions may be useful to other disabled women as well. The next task is to explore how the quality of our lives can most be enhanced.

## CHAPTER FIVE:

### DEMANDING QUALITY OF LIFE

#### THE EXPERIENCE:

“It is essential to promote research that reveals the restrictions that the disease, attitudes and environment place on those of us with MS, together with the research that evaluates ways of overcoming these restrictions. Whether or not medication proves beneficial to people with MS in the future, there are those of us who have the disease now who also want improvements. We do not necessarily expect our MS to be instantly ‘cured’ but we would like whatever can be done to improve the quality of our lives done and as soon as possible”.

(Burnfield, 1995, op.cit:47)

In chapter three, the gap between the experience of MS and the way the professionals viewed the disease of MS, demonstrated that perhaps as Burnfield suggests above, the medically-orientated research is not actually meeting the needs of people experiencing MS now. This chapter explores the second research question which invited the women to consider how their quality of lives could be enhanced. First, the concept of ‘quality of life’ will be broached. Second, the subject of ‘power and control’ and the way this impinges on all of our relationships with other people will be addressed. Third, the relationships between the women and some members of the medical fraternity will be exposed. Fourth, the relationship between the women and their family and/or caregivers will be articulated. The chapter ends with a brief discussion of other issues raised by the women in their quest for an enhanced quality of life.

Given the number of people experiencing MS, it is amazing that so little research has been devoted to ways of looking at what would enhance the quality of life for people experiencing MS. Part of the problem could stem from the fact that even in scientific publications, 85% of the investigators do not give a definition of quality of life (Gill & Einstein 1994). The matter is further compounded by the fact that other terms such as: 'health status, functional status, health-related quality of life and general well-being,' are often used in an equivalent manner to the term 'quality of life'. What researchers do agree on however is that quality of life is a multidimensional concept. In an ongoing study Ritvo et al.(1996) define quality of life as:

“the subjective evaluation of a person on three important life domains: the physical, psychological and social functioning”

(Ritvo, 1996)

In this chapter I use this definition to structure the exploration of data. Physical functioning refers to the disabilities as perceived by the women themselves and includes the impact of symptomatic relief. Psychological functioning includes anxiety, depression and fear of what may lie ahead, given the unpredictable nature of MS (Spilker, 1990). Social functioning as understood by the women includes the social supports of health providers, family members, caregivers and friends, and how the women perceive their changing roles as providers, mothers and partners.

The sense of personal 'loss' over the ravages of time, as a direct result of our experiences of MS never abates. Uncertainty about 'if' and 'when' the next MS exacerbation might occur, makes all of the women feel vulnerable. Daily we need to contend with our emotions because just like

our MS these fluctuate accordingly. This makes it difficult to contemplate just how we can enhance our lives while some of our more basic requirements remain absent.

We all agreed that we needed to find more satisfying and desirable ways to lead our lives. The seven women had an enormous range of requirements that reflected their differing personal, family and financial situations. Primary health care, the support for family and caregivers, economic sustenance, adequate residential care, attendant care services, respite care, home help, and accessible transport all featured. In identifying these the women once again illustrated the wide diversity of the ways MS is experienced. To give some examples:-

JO: "I would like to be able to go where I want to when I want to- not just when it suits others".

ANN: "On reflection things would be a great deal easier if I did not feel obliged to try and live up to the expectations of other people. My quality of life would improve dramatically if I could refrain from becoming frustrated".

LIZ: "I use a lot of taxis to get around. And taxis are not cheap. It doesn't seem fair that people who do not have a disability take everything they do have for granted. The problem with MS is that people think you look OK when in fact you are so tired you do not know what to do with yourself. A bit more energy would make my life easier".

ALI: "Life would be much easier if other people did not keep reminding me of the past. As if I could forget about all of the things I used to do".

The women identified both the tangible and intangible costs of having the disease MS. The tangible costs were the requirements needed on a daily basis:-

JILL: "Just having enough food in the cupboard would be nice. There must be more to life than existing day to day".

SUE: "I would like to have a car of my own one day, but when we save money most of it goes on my medical bills".

Whetten-Goldstein et.al. (1996) conducted a two-part study, which examined the cost to people with MS and their families (Whetten-Goldstein et.al. (1996). Part one examined the costs attributable to the disease such as:

"health care expenses, renovations to houses, vehicles, equipment purchased and lost income all due to MS"

(Whetten-Goldstein et.al.1996)

Part two examined the losses to "the intangible aspects of MS such as fatigue, numbness and paralysis" (ibid:35). These American writers claim that that MS is very costly and the average total loss for individuals with chronic progressive MS is close to US\$ 50,000. The intangible losses due to MS did not have a monetary value and by not attempting to value such losses "we are implicitly putting a value of \$0 on the losses"(ibid).

In Britain, Holmes et al.(1995) used a sample of 672 members of the MS Society to find out what the economic burden was. Their findings were:

“a significant economic burden is also borne by non-professional carers, whose lost earnings account for 26.3% of the total of cost of the 395 million pounds per annum lost earnings resulting from MS”

(Holmes,et.al.1995).

To be eligible for an Invalid Benefit in New Zealand a person needs to present a certificate from a doctor, stating that the person has a 90% disability rating. If a person does not get this certificate from their own doctor, they can re-apply for the benefit by going to a different doctor who is designated by the funding agency. The absurdity of this arrangement is someone who has no prior knowledge about the applicant assesses the life-state of the person seeking a certificate.

As an advocate for women with MS I often accompany women applying for this benefit. I have a list of disability friendly doctors. The doctor knows that I have discussed all the sensitive issues with the person involved. What the department doesn't know is that the personal things which prevent the women from being employed such as bladder and bowel incontinence, fatigue or cognitive problems, symptoms which totally humiliate and degrade women do not get put on the certificate. The doctor uses the language on the form to match the criteria of the agency, so that the information supplied does not make the woman more vulnerable than she already is.

While the women identified the material things that were lacking in their lives, this seemed to be coupled with a sense of abject powerlessness to be able to change their respective situations. This powerlessness is well-recognised for women with disabilities and their

caregivers (Hannaford, 1985; Deegan, 1985; Savage and Georgeson, 1989; Opie, 1992; Munford, 1994a,b,c,d,op.cit).

#### THE QUESTION OF POWER AND CONTROL

The question of power and control throughout this research would perhaps have been the most salient. It permeates most of our experiences of MS. From my own perspective in my relationship with the participants I was very conscious of the fact that it was essential to form a partnership with all of the women. In our collaboration my own understanding of the experience of MS in some respects had to take a back seat so that the themes would reflect the voices which do not normally get listened to and therefore remain unheard.

To better understand the oppression felt by the women participants in their relationships with other people, it is useful to first examine the philosophy underlying the writings of Michel Foucault. (Foucault, 1982). In many of the discourses about disability the writings of Foucault are cited because of his appreciation of what is known in the literature as 'body criticism' and the way people can be controlled by others, which is exemplified in the medical model of disability. (Zola, 1982; Fine and Asch, 1988; Morris, 1991; Munford, 1994a,b,c,d,op.cit; Sullivan, 1995). Foucault described the exercise of power as:

“ in itself the exercise of power is not violence; nor is it a consent which implicitly is not renewable. It is a total structure of actions brought to bear upon possible actions; it incites, it induces, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects ”.

(Foucault, 1982:789).

The relevance of these words for all women with disabilities lies in our respective experiences of having to expose our various body parts to the whims of some professionals who depend on our lack of knowledge and control over treatment decisions, to do as they wish. The women in this research felt that their experiences with the medical profession had kept them in subordinated positions while our bodies were allocated to differing specialities as we frantically tried to keep ourselves physically and emotionally intact. Indicative of the far-reaching impact of this constant authoritarian approach by the profession in my case was:

PAMELA: "It took me years to come to the realisation that knowledge means power. As far as doctors are concerned equally, this same knowledge could also mean the abuse of power. I had been stripped of my self-esteem and confidence, denuded of my identity and victimised by a society who found that my determination to take control over my MS unwise".

For some women with disabilities and for all of the women in this research the influence of people in positions of authority had been devastating. At the time of an exacerbation they were unable to be in control of their bodies particularly when there was a need for medical reassurance. The women felt that their subordination was increased by the way their bodies were being invaded. This contributed to their sense of humiliation and loss of dignity. We all found it was the doctor/patient relationships that threatened us most.

## THE DOCTOR/PATIENT RELATIONSHIP

The most distressing aspect for me in this research was that all of the women shared the feeling of estrangement from the two health professionals with whom they had the most contact namely, their neurologist and/or general practitioner. While these two professionals headed the list, nurses, social workers, MS field officers, physiotherapists and occupational therapists were also criticised. The methods of intervention by some of these professionals have the potential to not only either empower or disempower the women, but can also make a considerable difference towards enhancing their daily lives.

The total number of times the women passionately mentioned these relationships was 158. In stark contrast to this was the researcher who had resolved these dilemmas over ten years ago. But because this was such an ongoing issue for the six other participants and before the women speak for themselves, I reviewed the literature regarding this phenomenon to find out whether other people who were experiencing MS elsewhere, had a similar view.

The Multiple Sclerosis Research Center (MSRC) carried out one of the more revealing surveys in 1997 in Britain that involved 900 people with MS and 136 consultant neurologists around the country. (MSRC, 1997). I believe that the most significant and alarming finding was:

**“Multiple sclerosis patients may not be getting the treatments and help they feel they need because of a wide doctor/patient communication gap”**  
(Ibid:2).

The experiences of the patients were identified and while 60% said that they wanted to be able to decide what their treatment would be, less than one third believed that this happened in practice. Interestingly, the “neurologists perceptions differed markedly, with 72% saying they involved their patients in treatment decisions”(ibid:3). These patients also revealed that the information about possible new treatments in the management of MS had been provided by MS support groups, not via their neurologist. Further findings from the survey showed that:

“74% of patients who responded to the survey were female; 37% of patients surveyed did not know what type of MS they have; 64% of patients did not understand all that their neurologist was telling them; 44 % of patients said they had come away from a consultation with a neurologist feeling their point of view had not been taken into account; 42% of patients said that their neurologist paid them little or no attention.”

(ibid).

Researchers who have carried out similar studies confirm these findings. (Sprangers and Aaronson, 1994; Slevin, Plant and Lynch, 1988; Patrick and Deyo, 1989). Most disturbing about the figures quoted above is that it is usually a neurologist who transmits the diagnosis and is the one person who has the information many of us crave. This is how the women articulated their own experiences with doctors and it can be seen that their concerns are not unlike those outlined above:-

ANN: "Because of improved diagnostic capabilities things are different now. It took years for the doctors to confirm my MS. By the time they decided I did have MS my life was in total chaos. I was separated and I was poor. If the so-called professionals had expressed things a little better maybe all this would not have happened. At one stage I thought the doctors must be right about there being nothing wrong with me. I had been brought up to never challenge what older people said".

The points raised by Ann reflect the views held by women generally in this period. The medical experts were very rarely challenged. It was not the polite thing to do. Sue's experience typifies the medical model of disability described in the previous chapter:

SUE: "They (doctors) cannot find a cure for MS so any problems are individualised. After an appointment, you go away knowing that you have left unsaid most of what the current problems are. This is because of the fear of being labelled a hypochondriac. My doctor sacked me. He said that I was too difficult a patient. He blamed his inadequacies on me. What really happened was that he had not read the recommendation from a specialist. That recommendation could have made a huge difference to me and my family".

Liz felt that since she was given a diagnosis there was an obvious attitudinal change in the way her doctor treated her as a patient: -

LIZ: "I know that my doctor thinks I'm neurotic but I don't care. After my MRI that proved my MS was real, his attitude towards me has changed. It is almost as if he respects my MS. I think he feels a bit awkward not believing that I had MS".

Ali's comment was interesting in that she totally rejects the patronising way her doctor talks to her:-

ALI: "I hate it when the people who should know what is wrong with you like doctors say: "I feel sorry for you." I feel sorry for him!".

My anger over the way I had been treated in the past was expressed as:

PAMELA:"I had allowed the option of choice and control over what happened to my body to be taken away. After all, who was I to question the wisdom of the doctors? This went on for years and in fact it took a divorce before I could gain any self-esteem and begin to reclaim my sense of personal control and power. By taking control I then took on the medical profession and I was staggered by the positive responses. I can now ask for what I need without fear of rejection. This achievement allowed me to recognise that other women were and probably are, feeling equally powerless. My affirmation of self also meant that I could begin to affirm the experiences of other women".

While the concern about the respective relationships with the medical profession were deemed to be the most urgent by the women, there was also a great deal of concern for the interpersonal relationships the women had with their families and/or caregivers. For the women experiencing MS in this research they were adamant that it was necessary to highlight another dimension which should always be taken into account in any discussion about MS, that is, the impact MS has on the immediate family, relatives and friends.

One of the doyens in the articulation of the roles and relationships involved in the caregiving process in Aotearoa/New Zealand, is Munford (1989; 1992; 1994a; 1994b; 1994c; 1994d). Munford employs Foucault's "productive aspect of power" in order to demonstrate how the "caregiving process is revealed to be one that social organisations would prefer to ignore "as it undermines the caregiving relationship"(Munford,1992:19). This of course directly links the personal to the political. The voluntary sector in our society are the main caregivers for people with disabilities and it suits the government of the day to foster the notion of caregiving because the economic contribution these caregivers make is nothing other than cheap labour. This is a direct result of there not being enough alternative community support and resources both emotionally and financially, which would assist the social wellbeing of all those involved in the MS experience. This in turn challenges both the traditional and often marginalised relationships between caregivers and the wider socio-political and economic environment in which they find themselves.

The importance of this is clearly identified through the current process of deinstitutionalisation when people with disabilities generally are "moving from the private realm of the long-stay institution into the public realm of the community"(ibid). The unmasking of the realities of the needs and

daily lived experiences of oppression faced by those in the social services their clients and families is imperative. The women expressed their concerns about the caregiving relationship in various ways. For Liz, Sue and Ali it was the level of dependency they felt:

LIZ: "What really bugs me is the level of dependence on others that I feel. (Spouse) works so hard and never complains".

SUE: "(Spouse) is so good. It seems that every time we manage to save money, it gets spent on my medical bills".

ALI: "I think about the fact that he (partner) too is getting older. Physically, the time will come when I will become too big a burden for him".

For Jill and Ann it was the caregiving roles being provided by family members:

Jill: "Goodness knows what I would do if anything happened to my sister. I feel she does so much for me. I think she feels guilty that it is me with MS and not her".

I know that the significant input from my own children was:

PAMELA: "The one thing I most resented about MS in the past has been the responsibility that my kids have had to assume. Now that they have all left home it has been possible to live a lifestyle that suits my fatigue levels etc".

The women had a combined total of fifteen children. While four of the women initially felt that their children coped well with the stress of MS in their lives, three of the women changed their minds after reading their own transcripts. The women acknowledged that perhaps their children did experience more coping difficulties than they had realised at the time. On reflection, the women felt that in the early stages of MS there was a considerable lack of knowledge and that perhaps if their families had been able to receive as much as the information about MS that there were now, their children would have coped better.

The interpersonal relationships between the women and their families and/or caregivers and the balancing of quality of life, also needs to be understood in terms of the subjective realities of both the woman experiencing MS and the impact on the daily lives of other members of the household. A substantial proportion are carers providing large amounts of unpaid help to family and friends and, they are major contributors financially. Two of the women saw their spouses as the primary caregiver. For Ann, the input from her spouse was so physically demanding that it appeared the spouse was experiencing caregiver burnout:-

**ANN: My family are my caregivers. They never get a break. In fact we could all do with a holiday”.**

In order of priority, other significant quality of life enhancing issues that the women raised included fatigue, depression, assistance in the home, decreasing mobility and decreasing social interaction.

### FATIGUE

The women agreed that fatigue was one of the symptoms that caused them the most discomfort. All felt that family members, caregivers, friends and members of the medical profession did not fully understand the difference between 'normal' fatigue and MS fatigue. This was consistent with the findings of Frohner et al. (1995) and Langdon (1995) who found that fatigue, mobility, housework, lack of social interaction and depression were all mentioned and that "fatigue underlay the other five dimensions"(Langdon, 1995:51). Petajan (1997) is currently analysing contributing factors of MS fatigue in order to find out why this experience results in excessive tiredness particularly:

"while performing day-to-day activities, especially those that require repeated muscle contractions (and why) coordination problems often accompany this fatigue".  
(Petajan, 1997:21)

Petajan believes that a better understanding of these factors might "lead to strategies to combat it to improve the quality of life for people with the disease" (ibid).

### DEPRESSION

All of the women had experienced or were experiencing differing levels of depression. Two of the husbands had also experienced severe depression. Four of the women stated that they believed they lived with low-grade

depression on a daily basis. When three of the participants consulted their doctors they were told that anyone with a chronic illness experienced depression and that 'they would get over it'.

### HOME HELP

Six of the women had home help. In our country housework and the care of families continues to be some culturally assigned domain of women, whose labours remain undervalued. For some women with disabilities this means that gaining assistance for this work from support services is extremely difficult to negotiate. It is not easy to admit at a relatively young age that you physically cannot manage to maintain a home in the way you would like to. Pamela and Ann suffered guilt over this situation because they felt it made them 'less of a woman'.

### DECREASING MOBILITY

The women expressed two extremes of decreasing mobility. For two of the women decreasing mobility was couched in terms of not 'wanting to end up in a wheelchair'. Four of the women could still drive a car but Sue preferred to use a wheel-chair van rather than drive at night. Sue used taxis regularly and had always been impressed by the courtesy of the drivers involved and felt by using this mode of transport greater independence was achieved.

### DECREASING SOCIAL INTERACTION

Six of the women found that their social interaction outside of the home had diminished considerably in the face of increased disability. One of the women declared she was a 'social isolate by choice'. Three of the women felt that their diminishing source of friends was a direct result of their not

being able to handle the experiences of MS. Sue said that this was one of the things she could not understand:

SUE: "They (friends) seem to have forgotten that I am the same person inside. I have lost a number of friends because of not being well. It's sad really".

### CONCERNS FOR THE FUTURE

The concerns the women had about their future seemed to hinge on their perceived increasing social isolation should their disabilities increase. Two of the women felt they needed to accept that full-time care was an option in the future. Four of the women felt that it was difficult to plan anything given the unpredictable nature of the course of MS. If these concerns are added to the issues outlined above, it appears that the perceptions of the women regarding how their quality of life could be enhanced have particular implications.

Future research constructs could be developed regarding these quality of life experiences which could be given an equal status alongside the more medically-favoured research agendas. It would then place the individual experiences at the centre of the research map. Professionals, while also looking for a cure, could reflect on ways that might enhance our abilities rather than the situation many of us now experience, that is, being 'managed' by others who fail to deliver effective services. Services which could actually make a real difference to the way we lead our lives. But it would need to be in an accessible language easily understood by people experiencing MS, their families, caregivers and friends. We need to demand an acceptable quality of life. One based on our perceived requirements and opinions. I believe that the following statements echo the concerns of many women with disabilities:

ALI:“ I worry about what will happen if my MS gets worse. I am currently in the longest period of remission I have ever had but every night I go to bed wondering whether I will wake up and find out that I have come out of remission. Not so much the remission really, but more the end result of another attack”.

JO:“So long as I never have to use a wheelchair I think I will be OK. It means other people don't know I have MS. I can keep my MS invisible. . I had to use a wheelchair once and I hated it. Everyone stared at me it was just awful. So as long as that doesn't happen I will be happy”.

PAMELA:“I would like to have more choice and control over my life even though my body can no longer do what it used to. I still want to feel as if my opinion matters. Public attitudes are changing but there is still a lot that can be done to encourage other people to think differently about people with disabilities”.

SUE: "All I want to be able to do is to go to a doctor, explain what is wrong with me and for him to believe me and act accordingly".

ANN: "It would be really nice to meet someone of either gender, who really understands my MS. And I mean really understands".

JILL: "Of course I want a cure to be found for MS, but in the meantime what will be of most benefit consists of having my basic needs met. Like food in the cupboards etc."

LIZ: "You can cope with anything if you keep your sense of humour. I wish my doctor had a sense of humour, that would make a difference".

This chapter began by looking at a definition of quality of life. It was demonstrated that six of the women, who had experienced MS for at least five years, were still finding that communication with their respective health professionals a constant site of struggle. The issue of power and control, or in the case of the women in this research lack of power and control dominate many of our interpersonal relationships. Equally, there is an obvious toll on family, caregivers and friends as they attempt to maximise our full potential in life. The fact that the women yearn for an

enhanced quality of life illustrates that our oppression stems from the existing social, political and economic structures that mean we are left on the periphery of a system designed to exclude us.

To combat this, frameworks that promote feelings of inclusion need to be used in an empowering way so that real social action and reflection can evolve and then be promulgated. My contribution to this cause is suggested in the next chapter. The framework guiding this chapter is derived from the experiences of the women in this research.

## CHAPTER SIX:

### A VISION REALISED

Chapters four and five described some of the experiences of MS through the eyes of the seven women in this research. In light of these findings, this chapter will begin with the MS practice model I have created out of our collective experiences. This will be followed by linking the issues that have been raised by the women to the issues that many disabled people confront in their everyday lives. The chapter will conclude with a brief appraisal of the importance of insisting that our concerns be placed on political policy agendas.

Whether our differences are gender specific, cultural, physical, intellectual or those arising out of a different sexual orientation, it is our very differences which determine the positions that society accords us. It is this positioning which provides the impetus for working alongside each other. In the construction of a practice model for women with MS to use which would also be inclusive for the people who work with women with MS I decided to base the model on five feminist principles.

These five principles are: analysis, integration, affirmation and action and reflection (Nash and Munford, 1994). A full explanation of the principles and how they might be used to inform generic social workers can be found in Appendix 11. I saw the principles as a way to link some of the experiences of MS within a feminist perspective that could in turn be useful for other disabled women if they so wished. The principles are not static and therefore some women with MS will experience these aspects in their lives depending on their circumstances:

## A DAILY-LIVED EXPERIENCE OF MULTIPLE SCLEROSIS

<u>ANALYSIS</u>	THE EXPERIENCE IS DEFINED BY THE WOMAN WITH MS. UP-DATED INFORMATION AND RESEARCH ON MS MAY BE REQUESTED	AT THIS STAGE A WOMAN MAY FEEL VERY POWERLESS AND SCARED BY THEIR EXPERIENCE.
<u>INTEGRATION</u>	THE EXPERIENCE OF MS NEEDS TO BE SEEN WITHIN THE CONTEXT OF FAMILY MEMBERS/CARERS. IT IS A WHOLISTIC APPROACH TO MS SO THAT ALL INVOLVED KNOW WHAT IS HAPPENING	THIS IS A TIME WHEN THERE MAY BE A NUMBER OF FEELINGS AND ADJUSTMENTS TAKING PLACE. ALL PERSPECTIVES ARE VALID. ACCEPTANCE OF A DISABILITY CAN OCCUR AT THE STAGE OF INTEGRATION.
<u>AFFIRMATION</u>	THE VALIDATION OF AN EXPERIENCE. IT IS OK TO HAVE A DISABILITY. SEEKING NEW GOALS WHICH ARE REALISTIC. THE FOCUS CAN NOW BE ON HOW THE COPING STRATEGIES ARE A STRENGTH. THIS SHIFTS THE DISABILITY TO A DIFFERENT LEVEL. A SENSE OF ACHIEVEMENT AND GROWING SELF-CONFIDENCE REAFFIRMS ONE'S POSITION IN SOCIETY.	ANY ACHIEVEMENT, NO MATTER HOW SMALL, IS SOMETHING TO CELEBRATE. IT IS A TIME OF CONSTANT ENCOURAGEMENT. IT IS THE BEGINNING OF 'TAKING CONTROL'. THIS SHOULD BE ALLOWED TO HAPPEN. SELF-ASSERTIVENESS IS A STRENGTH.
<u>EMPOWERMENT</u>	THIS HAPPENS WHEN THE POWERLESSNESS EXPERIENCED AT THE OUTSET HAS DIMINISHED. WITH EMPOWERMENT, THE SENSE OF FREEDOM BY DOING SOMETHING FOR ONE'S OWN BENEFIT IS OF GREAT VALUE.	EMPOWERMENT IS THE RESULT OF ALL THE EFFORTS MADE TO GET THIS FAR. 'GUESS WHAT I ACHIEVED TODAY?' BECOMES THE REALITY. THE STRUCTURAL BARRIERS RESTRICT ME NOT THE DISABILITY.
<u>ACTION/ REFLECTION</u>	SURVIVAL SKILLS THAT REFLECT THE STRATEGIES OR ACTIONS TAKEN CAN NOW BE SHARED.	THE WOMAN WITH THE DISABILITY IS THE EXPERT. OUR DIVERSITY IS CELEBRATED

In linking the experiences of MS to the issues confronting disabled people, I have used the writings of Munford, Georgeson and Gordon (1994) who provide an in-depth analysis of the key areas involved when working with disabled people (Munford, Georgeson and Gordon, 1994). In social work with people with disabilities and their families, these writers describe social work from the perspective of people with disabilities (Munford et al.1994). Seven key themes pertaining to the experience of disability are explained: the importance of the definition of disability; an explanation of the meaning of difference; 'changing aspirations; the experience of grief; assertiveness skills; being able to make decisions; the importance of positive experiences. I will now discuss these seven themes in more detail.

#### THE IMPORTANCE OF THE DEFINITION OF DISABILITY

According to these three writers, a clear definition of disability has to be understood by social workers when they work with people with disabilities. They believe that who defines and, in what context disability is defined, can have implications for the way disabled people are treated and positioned in our society. Both historically and currently the medical definition of disability is perceived by society to be a result of personal blame or deficit. This theme was expanded on in chapter five and all of the women experiencing MS in this research had the same problem. We viewed our MS as something we needed to take the blame for. And by allowing this to happen, other people defined how we should feel, what we should do and if these things could not be achieved it was our own fault.

There is no doubt in my mind that for a number of years I was the perfect candidate for the medical model of disability. Morris (1991) describes how a woman with MS expressed her difficulties prior to diagnosis:-

“This sense of blame was something Clare Robson experienced in respect of other people’s attitudes towards her physical condition. She had multiple sclerosis for years before she received confirmation of it. During that time, there were all sorts of pressures on her to deny her illness and what was happening to her body. Nobody wants to be ill or to have a body that doesn’t work properly. We all find it difficult to confront another’s pain and physical difficulties. After she received final confirmation that she had multiple sclerosis, Clare realised that many of her friends had assumed that her physical symptoms had been psychologically motivated”

(Morris, 1991:181).

Munford, Georgeson and Gordon feel that social workers should understand how important it is to reinforce the social model of disability that is, ‘the structural constraints of disability’. By structural constraints the writers refer to poverty in this instance but, you could also add most of the issues raised by the women in this research that could enhance the way they live on a daily basis. For example, lack of money, lack of transport, lack of resources and lack of access to services and provisions. This in no way denies someone’s experience of disability but highlights the need to locate the barriers we confront as a direct result of the ways in which the structured social environment responds to the requirements of people with disabilities. Once this is acknowledged the meaning of difference can be explored.

### THE MEANING OF DIFFERENCE

The understanding of the word 'difference' is closely connected to the structural environment. If the lives of people with disabilities are portrayed as seemingly useless and have no value ascribed to them by the society in which they find themselves, their difference can be used by other people as a weapon to keep people with disabilities in a position of powerlessness. An example from the literature is provided by Oliver (1996) who thinks that people with disabilities should collectively demand:

“that difference not be merely tolerated and accepted but that it is positively valued and celebrated. Further, in making these demands, it is not just a matter of providing a legal framework but backing that framework with moral fervour and political will to ensure its enforcement”

(Oliver 1996:89)

Stone (1995) examines the social construct of disability and in the myth of bodily perfection she argues that when people with disabilities look different they are often defined by people without disabilities as 'other'. Whether we are labelled 'different' or 'other' our experiences as disabled people are a constant reminder that society perceives us to be defective and they deny us the reality of our daily lives. This attitude adds to the oppression of people with disabilities.

### CHANGING ASPIRATIONS

If people with disabilities are kept in a state of powerlessness then irrespective of what their notion of having hopes, needs and expectations

may be, their choices and options are sometimes restricted. These restrictions manifest themselves because of the way other people decide what disabled people can or cannot do. Browne, Connors and Stern, (1985) in their anthology of personal accounts of women with disabilities, challenge all women to acknowledge and reflect on the women who have allowed the stories of their lives to be opened to public scrutiny (Browne, Connors and Stern, 1985). The claims of discrimination, medicalisation, isolation and even damnation, in this book are very similar to the ones the women experiencing MS have identified.

Fine and Asch (1988) are probably the most well-known authors who have collected the personal stories of women with disabilities. Over the last decade they have encouraged feminists without disabilities to justify why women with disabilities have been left off the feminist agenda. Their anthology of women with disabilities is a classic exploration of the changing aspirations of women with disabilities.

Similar works which have made an impact on the literature about women with disabilities and their changing aspirations include: Finger 1985; Hannaford, 1985; Deegan, 1985; Savage and Georgeson, 1989; Opie, 1992; Keith, 1992, 1994.

### EXPERIENCING GRIEF

When Munford, Georgeson and Gordon, talk about experiencing grief they are referring to the difficulties faced by people with disabilities and their families when they have to:

“fight for the rights of your child and coping with the rejection they may experience. It is also about having to feel grateful for the services you and your child do receive”

(Munford, Georgeson and Gordon, 1994:271)

This is exactly how I felt when the psychiatrist told me that he thought I had MS. I was overwhelmed with gratitude. Here was a professional affirming what I already knew. But because of my experiences prior to this, the fact that in this instance I was not put in a position of rejection yet again, heightened my sense of gratitude. I am quite sure now, because of my own rejection of the medical model of disability, my assertiveness skills would temper my gratitude for services rendered. In this respect I fitted into the category of a 'stereotype' that endorses what Browne, Connors and Stern(1985) have to say about women with disabilities who describe:

“two stereotypes which are frequently projected onto disabled women. One is the happy, humble women who has “accepted her handicap” and is endlessly grateful for the help of others. Her counterpart is embittered, blames everyone else for her situation, and continually lashes out. Society approves of our complacency and discounts our anger. Either way, we are made invisible” (Browne, Connors and Stern 1985:77)

### BECOMING ASSERTIVE

In highlighting professional intervention for people with disabilities and their families, Munford, Georgeson and Gordon raise the importance of the need to acquire assertiveness skills (Munford, Georgeson and Gordon, 1994, op.cit). For anyone to question and challenge someone who is paid to be authoritative is extremely difficult. People with disabilities are often forced to reveal aspects of their lives that are humiliating, hurtful and embarrassing. Assertiveness skills help ease this pain. For women with

disabilities, past experiences may mean that it is too difficult to think about assertiveness skills in which case the social worker may need to use her own assertive and advocacy skills.

### MAKING DECISIONS

Making decisions is a crucial aspect in the lives of people with disabilities when they try to work out what resources are available to them. It is important to enlist the help of social workers who can:

“play a significant part in ensuring that families and people with disabilities have adequate information for making informed choices. They also have a key role in listening to the experiences of families and people with disabilities in order to participate in the development, implementation and evaluation of new models of service provision”

(Munford, Georgeson and Gordon, 1994:273)

The last of the seven themes that Munford, Georgeson and Gordon advocate, is something that many of us forget in struggling with our experiences of disability. These are the positive experiences we encounter.

### POSITIVE EXPERIENCES

People with disabilities and their families have become so used to the negative way we are portrayed by society that our achievements are not celebrated as often as they should be. The diversity with which we

experience disability accentuates:-

“our reciprocal relationships (with non-disabled people) which we can and do have.....and the ways in which people with disabilities do carve out meaningful lives, despite the social and environmental barriers which may be put in their way”

(Munford, Georgeson and Gordon, 1994:275)

The seven themes outlined above explore an understanding of disability from the perspective of women who have worked alongside other women with disabilities, have a disability themselves or have a disabled child. The writers locate this understanding within the social, political and economic context of what it means to have a disability in our country. The examples given reflect the issues raised by the women participants in their respective experiences of MS. Given these themes, how can disabled people challenge the oppression inflicted by other people?

By endorsing the social model of disability it becomes apparent that if we are to achieve equality with non-disabled members in our society, it is necessary to fight for our inclusion and for the inclusion of our disability into mainstream society. The experience of disabled people in our country means that our standard of living reflects the political ideology of the government of the day. The way we go about our daily lives depends on our dollar value, If there is a nil dollar value put on our lives then it means that our lives are worth nothing and not worth living. Every aspect of our lives is determined by the way we can access and participate in all things that non-disabled people accept as their given right as productive citizens. Disabled people are denied the right to access the basic essentials of daily living.

This restriction has come about as “a result of disabled people as the ‘other’ has been restructured” (Sullivan and Munford, 1998:185). These two writers reflect on the ways that disabled people do not have a voice and have no real choice or control over what social services they can or cannot receive (ibid:186). The patriarchal nature of our society means that basic rights are diminishing which of course impinge on the freedoms associated with social justice and an ethic of care. The position of most disabled people rests on the false premise that our disabilities do not warrant consideration.

The MS experience is unique to the individual and even by virtue of our birth, we are viewed by some people as a ‘drain’ on society sapping the economy, education and health budgets and what little service provision there is. Most disabled people I know realise that non-disabled people view us in this way. However, over the last five years or so, disabled people have demonstrated at both the national and local level there have been “initiatives aimed at resisting and transforming disability policy throughout Aotearoa New Zealand” (Sullivan and Munford, 1998:195). Two examples of the way this has happened will now be discussed.

The first example of the way disabled people have made a difference by challenging the status quo was to insist that disabled people be included in the Human Rights Act. Disabled people applied intense political pressure to gain parity with the status of non-disabled people in our multicultural society. We began this quest by presenting a nineteen thousand and ninety-six signed petition to the Minister of the day, sixth months prior to the human right’s enactment. This signaled the seriousness of our aims to become equal in the eyes of the law. We believed that our inclusion in this Act would stem our history of oppression. There was an air of buoyancy from those people who had managed to achieve what we first felt was

impossible. We believed that we had finally opened the door to our eventual emancipation.

In retrospect, our history of oppression, should have alerted us to expect that even though provision had been made for our inclusion in the Act, the institutional practices and barriers to our inclusion were still powerful enough to maintain our subordinate position. This leads into the second example of how we challenged yet another oppressive structure and is linked to the Human Rights Act (1994).

It was one thing to be included in the Act, but would the Act work? There was only one way to find out. Under section 52 of the Act we asked the Human Rights Commissioner that if we as disabled people had parity with non-disabled people, why was it that disabled people who use wheel-chairs for their mobility could not access public transport. We wanted the right to choose what form of transport we would use. We began the accessible bus campaign by insisting that wheelchair access on buses would also benefit the elderly and young mothers with babies and small children because there would be no steps.

Whether we were entitled to access public transport in this way, all hinged on section 52 of the Act, which said that, a provider of public services must make 'reasonable accommodation' in the provision of their services. It was our responsibility to prove that in the case of public transport disabled people were significantly disadvantaged in not being able to use a public bus. The physical and emotional toll that three years of campaigning for this right of access, was great. The information that we had to provide to prove our case even went as far as having to find out how many bolts there should be to ensure that a wheelchair (not to mention a person) would need to be used on the grounds of safety when the bus was moving! Our celebration after winning the right to ride on a bus was dampened by

knowing that for all of the structural barriers disabled people confront, the same amount of time and energy would need to be applied for each issue.

The mere fact that both of the examples above were successful, says a great deal about the passion and determination of a few people who refused to buckle under blatant oppression in their quest for parity. I believe disabled people have the qualities to resist their respective oppressions. The reason for this is quite simple. Our daily lived realities of being disabled, equip us well to find our own solutions in partnership with the people who believe in us.

This chapter began with a practice model for some women with MS to use as an aid towards empowerment. I then made some links between the women in this research and disabled people in our society generally. The chapter concluded with a brief appraisal of the importance of insisting that our concerns be placed on political social policy agendas. As disabled people our full inclusion in society would be a vision realised.

## CONCLUSION:

### DOUBLE VISION IN OTHER WAYS

This thesis began with the premise that it is in the analysis of a women's position in society that we can better understand our multiple realities. Women in Aotearoa/New Zealand, have had to fight for their rights and status in all areas. As this research unfolded, the reality of the possible alliance between seven women experiencing MS and disabled people became less of a possibility and more a realistic approach towards building relationships that could strengthen our respective positions in our society.

Our growing resistance to the structural inequalities existing within our society is enabling disabled people to have their views respected and actinide. We have been able to do this by adopting a number of strategies and alternative courses of action.

But we cannot do this alone. Social workers are ideally placed to help us recognize, achieve and maximize our abilities to their fullest potential and because of the diversity of our experiences we too, have much to offer social workers. In formulating a process that will enhance the way we as women can validate not only our similar shared experiences, but also our differences so that our very autonomy can then become the reality. Our gender, our history, our knowledge and our passion, are all features that need to be considered (Ings, 1988:99). These then need to be linked to some of the specific disability related issues in this thesis.

It is essential for us to search beyond many of the formal structures in which we operate while trying to validate the experiences of the women we

work with. By adopting this wider vision, we must not lose the momentum engendered by these experiences. Reflective action has at its core the strength to match the daily needs of the living, not the needs of the societal structures.

The diversity that exists among women increases our understanding of other women and in terms of the MS experiences of the women in this study, is that it is our very differences that give cause for celebration. I believe that the recognition of the diversity of the lives of the women in our society is the key ingredient if we are really serious about changing the positions of women and supporting each other to break-out of positions of subordination.

In this thesis I have interpreted feminist research by the way it upholds feminist principles and values. A practice model for women with MS to use but may also be useful for other people who work with women with MS. The six women shared their personal daily experiences with me at a very deep level with a passion and understanding not only of themselves but also of their families and carers. The meanings the women themselves attributed to their experiences are the very same meanings that these women would bring to the social work setting. This research provided the women with the opportunity to say what they felt needed to be expressed and I wanted to be the conduit for that expression. And indeed, what the women shared indicated the need for further research to be carried out.

Once we understand how our positioning as women that is, how we are perceived by society and, how we would like to be perceived, our collective identities can begin to work towards social change. We must articulate our experiences and form alliances with other vulnerable groups. I have tried to do this.

In chapter one of this thesis I began with the formulation of an idea to find out whether it might be possible to construct a practice model based on some of the daily lived experiences of MS. This practice model could also then be made available to social workers as a guide to create a better understanding of what those experience may mean. In chapter two I described the research methodology and the importance of documenting the stories told by women with disabilities. Chapter three, discussed multiple sclerosis from the scientific perspective. Chapters four and five discussed the experience of MS and the way seven women felt that their quality of life could be enhanced. Chapter six presented a MS practice model that could be made available to other people with MS or other disabled people to use as a tool for self-empowerment if they so wished. The importance of social policies for disabled people was addressed.

There also seems to be a pressing need to consider further ways that we can bring disabled women and men out of the margins of exclusion in our society and demonstrate that these experiences are a distinct part of the way we lead our lives. All of the women had internalised their experiences and all of the women had been subjected to and subordinated by, people whose authority was 'legitimised' by the way our society operates and I believe still is, structured. We had all received the same sort of degradation. As women we had allowed ourselves to be treated without protest and without question.

Our collective multiple realities suffered from the differing relations of power imposed upon us that made our lives hell. And yet somehow the seven of us survived. This says a great deal about the shifting identities women simultaneously hold. Any oppression, individual, group or organisational has the potential to be exposed. If as women together we break our silences and demonstrate that we are determined to no longer

tolerate our collective bodies being controlled by others, through sheer tenacity and strength of numbers we can form alliances with other like-minded women who also belong to vulnerable groups.

Institutional barriers that are literally man-made currently trap women with disabilities and their caregivers. Many of them remain unchallenged and are causing people severe distress. Every day social workers have to deal with this distress. We must attempt to reclaim our gender and therefore it is vital that we form as many partnerships as we can now.

As a result of this research there are some specific recommendations which would improve the lives of women with MS, their families and caregivers. The full costs of having a disability are not recognised by the amount paid out by the government in the invalid benefit. Greater financial and practical support would relieve the pressure imposed by not having to weigh the cost of food against other essentials such as transport, clothing, heating, medical costs and social activities.

Our families and caregivers also need practical financial and emotional support. The support given to us mainly reflects the invisible work of women in their voluntary and un/underpaid experiences of caregivers. Additional support would ease the 'caregiver burnout' that has been blamed for the divorce of three of the women in this research. More courses aimed at training appropriate assistance for disabled people would ease this burden.

Lessons can also be drawn from what the women have to say about the medical profession and to a lesser extent other allied health professionals. To achieve our maximum potential and an enhanced quality of life we need to be able to take control over our MS management and we can only

do this in partnership with those people who have the knowledge and skills to enable us to do this.

If as women together we break our silences and demonstrate that we no longer will tolerate our collective bodies being controlled by others, through sheer tenacity and strength of numbers we can form alliances with other like-minded women and men who also belong to vulnerable groups. For people with MS in Aotearoa/New Zealand, it is important that we force a particular pharmaceutical company to reduce the cost of a drug that may be beneficial for some people to use to combat MS. The expense of the drug is also a factor taken into account by a general practitioner prior to referral to a consultant. There are three ways that action could be forced. Complain to the local Member of Parliament, complain to the Minister of Health or, complain to the Human Rights Commission. There are many people in our country that are denied similar expensive drugs who could assist in a campaign to reduce these costs.

The inner strengths that the women in this research displayed, their raw honesty and their determination to share their MS experiences for the benefit of other women who may be experiencing MS now, is accompanied by their willingness to form alliances with other women. By providing the information so that I could construct a practice model based on our combined MS experiences, which can sit alongside a (suggested) model for feminist social workers to use (if they so wish), the women have in fact gifted their knowledge to the social work profession.

By working together as women we can celebrate a shared power and a shared vision. As we lick the salt off our lips, the wounds of our history will become the foundations for our future. Our tears will be of joy rather than of the pain that we are experiencing today.

### 'An Afterword'

For the women in this study it seems as though they have been creating their own waves of resistance to the way things used to be. How the women in this research have chosen to actively seek ways to further empower themselves since the time of the interviews is worth recording.

Liz has moved from the Hawkes Bay to Tauranga.

Ali is doing extramural study at Massey University and loves it.

Ann. is in a new and stable relationship. Ann works on a part-time basis and goes to a monthly MS support group.

Jill is working with a woman who has recently been diagnosed as having MS and she also goes to monthly support group meetings.

Jo has moved from Nelson and lives on the West Coast. A new partner has made her very happy.

Ali, Sue and Pamela are currently enrolled extramurally at Massey University and have targeted those courses where they can put their experiences to good use. For example, Social Work; Gender and Health; Disability Studies and The Sociology of Disability. These women are studying extramurally which means they can study at their own pace; Ali, Sue and Pamela use the internet and have found that their concerns over feeling isolated are not as pressing. They can now directly link into the "World of MS" (WOMS) an excellent web-site for gleaning new information about MS. The immediate benefits of this access means that

the women can present their general practitioner with documentation that could influence their ongoing treatment.

For Sue, who did not have a definite diagnosis, the outcome has been both illuminating and heart-breaking. Not long after I interviewed her, at her own expense (\$1,500.30), she had an MRI and now has a definite diagnosis of Arachnoiditis. This disability can be caused by medical misadventure, neck surgery and can also be present in people who have experienced MS for some years. It is the result of the dye myodil being injected into the spine as a diagnostic aid to determine any abnormalities, which then show up on the myelogram or x-ray. Unfortunately at the end of the procedure, if the myodil was not totally removed from the spinal column it could enter the brain stem causing similar symptoms to those found in MS.

It is only in recent years that claims against the medical profession regarding the use of myodil have been lodged. Alas, for people who had this test done prior to the Accident Compensation Act taking effect, which includes Sue, they do not qualify for any type of claim. The implications for Sue and her family have been devastating. Had the general practitioner read the recommendation made by the specialist some two years earlier, the personal cost could have been avoided and a further two years of doubt and uncertainty could have also been prevented. Not only does Sue have to contend with the arachnoiditis but, there is also an element of doubt as to whether or not she has MS. Sue now belongs to an arachnoiditis support group. And myodil is no longer in use.

APPENDIX 1:

EDITED TRANSCRIPT OF THE INTERVIEW WITH THE RESEARCHER

**QUESTION ONE: WOULD YOU LIKE TO SHARE SOME OF YOUR EXPERIENCES OF MS?**

“My pre-marital career had been as a ballet dancer so loss of balance was probably the first symptom to cause me concern. This was in 1976 and I was overseas. In retrospect, there had been some transient symptoms prior to this that I had simply dismissed, for example, abnormal fatigue. With two children under the age of four I assumed that this was the cause of the fatigue. Visual problems, no, specifically double vision, soon followed and after three weeks in hospital, a lumbar puncture and plenty of steroids, the medical profession declared I had a brain tumour. I decided that if I was going to die at the age of twenty-six it would be in New Zealand.

In New Zealand no brain tumour was found and thanks to the steroids, the more obvious symptoms had abated. Unfortunately the first seed of doubt about what was wrong with me had been sown. Relieved that life was worth living, I survived the second of four miscarriages, divorced parents and the death of a brother who committed suicide by jumping off the Auckland Harbour Bridge.

The fourth miscarriage coincided with permanent loss of vision in the right eye. Probable MS was diagnosed in Greenlane Hospital and confirmed in intensive care at Auckland Hospital one week later, following a cardiac arrest. A further exacerbation landed me in Wellington Hospital three months later.

The attending neurologist had told me that the MS diagnosis was not definite at this stage. Apparently, both he and my husband had agreed to say this in case there was any emotional overlay given all I had been through over the previous few years. While they both knew it was probable MS, this was kept from me because we were going to live overseas again. This conspiracy between my husband and the neurologist almost cost me my sanity.

I was hospitalised twice while we were overseas. The second time, I temporarily lost all vision. Aided by my husband, the neurologist wondered whether there could be any 'emotional overlay' attached to my predicament. It was then that I realised my husband did not believe that I had MS. This was a tremendous shock to me. In fact, it was the worst thing that had ever happened to me. Perhaps they were right? Perhaps I had gone completely insane? If this was the case how could I possibly take care of my three sons? There did not seem to be any alternative but to agree to be admitted to a psychiatric hospital. Even now, I marvel at how lucky I was to be at that hospital at that time.

Somehow while drowning in the depths of despair, I had not lost my ability to think. An eminent psychiatrist assessed my 'condition' and told me that tests would start the following day. I said I would agree to this if two conditions were met. The first was a request to ring my father in New Zealand and the second was that no medication was to be given to me prior to the tests the next day. The psychiatrist gave me his promise.

All my life I had been taught that when things get tough you just pick yourself up and carry on. That theory left me when I heard

my father's voice that night. It must have been an equally miserable telephone call for him. For some considerable time I made him repeat "you are not going mad" and sought assurance that he would not let my husband commit me, which he was threatening to do. Some years later, I asked my father whether he had wondered about the state of my mind that night. He responded by saying that for as long as he could remember I had spent my entire life driving other people mad. Now I have digressed, where was I?

Interviewer: The telephone call to your father...

"Oh that's right. Even though this happened more than twelve years ago, every detail is still in technicolour. Once in bed I sobbed and sobbed. In fact I wallowed in self-pity. At least I could still trust my father. But sobbing was not allowed. Without vision, I felt my hands being restrained and an injection in my leg. Before a deeper blackness engulfed me I asked what I had been given. More significantly, I remembered the answer.

The next morning the eminent psychiatrist sat down on the bed and explained what would be happening to me. I listened until the inevitable "have you any questions"? It was obvious that I had left my status in the shower as I hissed at him "you broke your promise, I was given medication last night". "Not to my knowledge" he replied. I then hissed out the name of the drug and while he was gone, I wondered who would tell my father that I was indeed beyond all help. On his return he made what was to become an oft-repeated phrase: "I am so sorry Pamela". Now that my trust had been destroyed yet again, it was agreed that I could be released and that it was the considered opinion of the psychiatrist

that I did in fact have MS. With very little trust in anyone I returned to my home and two weeks later the sight in my left eye gradually returned. The steroids had worked again.”

(Second Interview)

“By now, I had reached the conclusion, that the only person who would treat my body with the respect it deserved was me. I began to listen for signs of fatigue and I tried to make better sense out of other transient symptoms. Unfortunately, when I refused to be wife-ly, I was constantly reminded of the fact that I was ‘mad’ until proven otherwise. It was then that my MS became a gender issue. If this was happening to me within a marriage, and I had the bonus of being able to articulate how I felt, how on earth did other women live through similar experiences? But how could I look beyond my own experience without having a definite diagnosis?

It was important for me to go where I was unknown. I flew to Dunedin and a family friend who was a general practitioner gave me a referral to a neurologist at Dunedin hospital. Two weeks of neurological tests confirmed a definite MS diagnosis. I asked the neurologist to ring my husband so that he would be the first to know. I had waited seven years for this diagnosis.

With a real diagnosis, I could feel a real person again. The fact that I had MS was irrelevant in my eyes. Inwardly I had always known that. Logic goes out the window when you feel vulnerable. What mattered most to me at that time, was that no-one could take my sons away from me because I wasn’t insane.

I went back overseas prepared to work hard at the marriage and look forward to the future. This was short-lived as three weeks

after my return I had contracted a sexually transmitted disease because the husband had slept with multiple partners.

Not long after this I had another exacerbation, and was forced to revisit the neurologist. The neurologist wanted to give me a test on his new machine. When I saw the machine I announced that I had already been tested on a similar one. Without waiting for me to finish I was told that this would have been impossible as this was the only machine in the region. Without argument I said, "well go ahead then." It took him a short time to read the results so I invited him to ring the Dunedin neurologist to confirm his findings. "Pamela, I'm so sorry". Four days later I was paralysed from the neck down.

I think I felt a bit betrayed by my body. We had been through so much together. And then I turned my situation around. Perhaps my body was this way because of all it had been subjected to over the years in the quest for a definite diagnosis. And then I became very angry about the way I had been treated in the past. As far as I was concerned the medical fraternity over the previous five years, had a great deal to answer for.

It was my body and what happened to it was my choice. I reasoned that up until now, the option to choose had been denied me. I reclaimed my body and by so doing I started to reclaim my power. Together the neurologist and I decided to opt for a relatively new treatment for MS by using the drug cyclophosphamide. Because of the rare type of exacerbation I had (and it is still quite rare today), it was necessary for me to give my consent to demonstrate I understood the risks involved. Cyclophosphamide works in much

the same way as chemotherapy does for people experiencing cancer. It has the same side effects.

This treatment gave me three years of remission. Although I was now paralysed from the waist down, minus the waist length hair and a marriage on the rocks, I returned to New Zealand secure in the knowledge that I had reclaimed my gender, and my power, and my reason for living. This had all been possible because a psychiatrist had kept his promise. It seemed as if my quality of life would improve.

If my overseas experiences had taught me anything, it was the realisation that knowledge means power. Equally, this same knowledge could also mean the abuse of power. As a receiver of this abuse, it meant that I had been stripped of my self-esteem and confidence, denuded of my identity and dispossessed by a society who found that my determination to take control over my MS was unwise.

But it did not matter anymore because for the first time in many years I had family and friends to support me. Fight power with power became my next mission. And of course the key to this was to continue my education that had been put on hold while we lived overseas. Living permanently on New Zealand soil was wonderful and a commitment to my continuing education made all the difference in being able to manage as a solo parent. It provided a balance to the more mundane chores of unpaid women's work. But the first degree wasn't enough, as another example will demonstrate.

I had been hospitalised for some weeks, and the two youngest were fighting about whose turn it was to do the dishes. One thing led to another, and the youngest refused to return home with either brother. The hospital was happy to have another guest overnight and in the morning the school was contacted to say that my son would be spending the day with me. An over zealous person believed it to be her duty to inform me that the Department of Social Welfare could take my kids, the implication being that I was unfit to be a mother. That was no different to being told I was mad until proven otherwise. All the insecurities of the past flooded in. Was I an unfit mother? The outcome was that I discharged myself from hospital, against medical advice, so that if the Department of Social Welfare came and pounced on the kids the mother would defend them.

Talking about this now, I find it incredible that I felt cornered enough to take this course of action. I could speak and I had a degree. It was a salutary lesson. I was unable to advocate on my own behalf. The theory of a degree did not equip me to handle the realities of what was being experienced. It also highlights another dimension that should always be taken account of in any discussion about MS. That is, the impact MS has on the immediate family, relatives and friends.

The person experiencing MS can never be seen in isolation. You see if one person in the family has MS the entire family has MS. It is particularly hard on the oldest child and in my case, the oldest child was the father figure for the younger two. It was the one thing above all else that I resent about having MS. And it needs to be remembered that not everyone is as fortunate and as blessed as I am in the abundant support I have received when necessary.

A diploma in teaching people with disabilities was my next target as I was conscious of how easy it would be to become myopic over a particular disability. If I was to become an advocate for other people, it would be necessary to have a much broader outlook and understanding of the diverse ways in which other women experience and cope with disability. And I guess that sums things up.

Survival for me is always based on my own coping mechanisms. Some of the methods I use are really crude. But who gives a damn! Besides, how many physiotherapists, occupational therapists, neuro-surgeons, neurologists, doctors or nurses do you see doing their job from a wheel chair?

My freedom knew no bounds after my divorce. I celebrated it by reverting to my maiden name. This simple step allowed me to relocate myself without carrying any past baggage. All three sons have reached adult status and are making their own decisions about what they want to do in life. And so am I. In continuing my education I am compensating for what is lacking physically, by exploring what is academically possible. If my experiences of MS can contribute towards enhancing the quality of life of someone with a disability, their caregivers, family or friends, then the effort I am making now will be worthwhile.”

## APPENDIX 11:

### **FIVE PRINCIPLES FOR FEMINIST SOCIAL WORK PRACTICE**

When I explored the possibility of using an established model for feminist social work practice in this research, the idea to develop a practice model constructed around some of the experiences of MS, in tandem with this feminist practice model, emerged. The five principles within a feminist framework designed by Nash (1987) were triggered by a response to the work of Wood-Wetzel (1986). More recently the 1987 social work practice model was further expanded upon in partnership with Munford (Nash and Munford, 1994). Throughout this appendix I will oscillate between the 1987 and 1994 practice models as I explain the individual principles and suggested forms of intervention.

What was so exciting about the earlier Nash model (1987), was the way it explicitly demonstrates to social work practitioners and social work students how they can use their own experiences to facilitate a greater understanding of themselves and others within the social work setting. The five principles for feminist practice developed by Nash reflects the authors 'dual interest in feminism and social work education' and was designed so that social work practitioners and their respective students, could strive towards a truly woman-centred practice (Nash, 1987:85). The aim of establishing a woman-centred practice at about this time, was also attracting the attention of many other writers both in our country and internationally (Brook and Davis, 1985; Smith, 1986; Wearing and Marchant, 1986; Craig, 1988; Ings, 1988; Hanmer and Statham, 1988). I make more in-depth references to the works of some of these women throughout the thesis but suffice to say historically, Nash was not alone.

Constructed in a five-step process the feminist principles devised by Nash namely, analysis, integration, affirmation, empowerment and peer supervision, has enjoyed a rebirth in the last few years. The only significant alteration made since 1987 has been the re-naming of the last principle 'peer supervision' which has now entered feminist discourse as 'action and reflection' denoting the language used in the current social work environment. (Nash and Munford, 1994).

Writing from a socialist perspective, Nash states that her analysis is based on "both the biological and the class-based origins of women's exploitation", indicating that her philosophy is entrenched in the reclamation of a 'woman-culture' (Nash, op.cit:3). Emphasis is placed on the avoidance of any imposed stereotypes about women:

"which it can be argued, are now  
 dysfunctional and certainly in discord  
 with our code of ethics"  
 (ibid).

This is a common mandatory factor within feminist debates which looks at the question of whether we as feminists "should focus upon making women's lives visible and contradicting false stereotypes about women" (Briar, 1993b:4). Within our country it appears that the most vulnerable women including women who work in the social services are the most likely to be assigned stereotypical roles. Examples of women writing about disability which explore the ways in which women and children can be devalued by a society who still largely believe that all people with disabilities and, most women, are a drain on society, are numerous (Munford, 1994c:265; Sonntag, 1994:185; Dixon,1994:71; Timutimu-Thorpe,1994:95; Tihi and Gerzon, 1994:145; Boyles, 1995:141; Perkins, 1995:179; Georgeson, 1995:59; Kerr, 1995:111).

In their own way all of these women are writing about gender, exploitation and a history of oppression. While it is cause for celebration that so many women are prepared to make their respective experiences visible, their theoretical frameworks for critical thought illustrates many of the structural inequalities existing within our social institutions. This is directly related to the first principle 'analysis', which will now be discussed.

#### THE FIRST PRINCIPLE: ANALYSIS:

"Analysis is concerned with developing a theoretical framework for critical thought. Feminist analysis provides the guidelines from which strategy evolves".

(Nash, 1987:37)

As indicated here, analysis takes place initially when social workers examine the theoretical and critical appreciation of the structural inequalities existing within social institutions. Disclosure of these inequalities can occur by applying a feminist perspective. This application reveals the ways in which women can be oppressed, exploited and discriminated against. It is a process that can assist the social worker to explore her values and her own identity. It is a crucial first step.

It is crucial because without this process of self-analysis the strengths and weaknesses of the social worker remain latent. The social worker can recognise that her own position as a woman automatically locates her experience from the personal to the political and seeks explanations as to how she might be being disadvantaged because of her gender. The experience of the social worker only becomes meaningful when this theoretical understanding can inform how a plan or strategy for action

might be possible. Combined with this knowledge is the realisation that the understanding of another woman is informed by the acceptance of her particular social, cultural, political, psychological and economic situation. Once this is acknowledged, any semblance of a power imbalance between the social worker and the woman or group she is working with will be diminished.

As a result of this shared relationship a meeting becomes a dialogue. The worker listens to the story being told and attempts to link similarities from her own experiences in order to make better sense out of the many and various oppressions women face in their daily lives. Nash found that feminist social workers wanted to work with women:-

**“to raise women’s level of consciousness and encourage them in getting together to help themselves, and get rid of oppressive living conditions”**

**(Nash, 1989a)**

From the social work perspective analysis looks like this:-

### *ANALYSIS*

#### **MEANING**

**“Feminist theoretical understanding and critical appreciation of social institutions structural inequality; the production and distribution of resources and how these affect groups and individuals in our society”.**  
**(Nash, 1987:98)**

#### **INTERVENTION**

**“Research and theoretical development. In order to be able respond to the changing role of wo in the family and workforce. This activated through submission writ education and discussion”**  
**(ibid)**

## THE SECOND PRINCIPLE: INTEGRATION

Integration as the second principle is “represented by the development of processes that recognise the importance of seeing people holistically” (Nash and Munford, 1994, op.cit:239). The partnership between the social worker and the women with whom she works, explores an holistic approach which is sensitively inclusive of all women. It breaks down and highlights how “class, gender, race and disablement” affect all of us (ibid.) There is solidarity in the knowledge that by women for women and with women, is a powerful way to combat felt oppression and blatant discrimination.

Integration as a concept, has enormous relevance within Aotearoa/New Zealand. For many Maori, Pacific Island and women of different ethnic minorities an holistic approach is already a significant part of their respective cultures. Their emphasis on integration which is realised through a spiritual, physical, individual and community setting, blends in with their life-style. The fact that Maori women identify their position in society in terms of the tangata whenua which comes before their position as a woman, demonstrates a commitment which is truly holistic. (Irwin, 1992; Selby, 1994; Foliaki, 1994; Tulele, 1994).

Integration reinforces the responsibility of the social worker in terms of striving towards an integrated approach to her practice. Whatever the situation that the social worker may be confronted with, until she actually crosses the threshold and:

“stands alongside her clients to experience solidarity with them in mutually experienced oppression”  
(Nash, 1987:38)

the tensions and possible conflict of loyalty between the employing agency and the women she works alongside, will remain largely unresolved.

To prevent this from happening, the motivation for social workers to integrate around a conscious use of self and acknowledge their identity, needs to be strong. Driven by this consciousness, the ability of the social worker to move away from the philosophy of blaming the victim is increased. Integration is part of the search for developing ways to make sure that the individual is removed from a position of marginalisation in society. For example, women with disabilities are then linked to “the political or public systems that affect women”(ibid). Without integration the other principles fall apart because integration stops the fragmentation of the individual or collective experience.

From the social work perspective integration looks like this:

### INTEGRATION

#### MEANING

“Events/people are seen in a holistic context. The personal and the political are linked to allow the social as well as the psychological aspect of the client situation to be explored...Integration links an understanding of power relations at the personal level to those at the political level demanding that the worker has an understanding of the links between theory and practice”  
(Nash and Munford, 1994)

#### INTERVENTION

“Applied analysis. Avoidance of deficit practice models, blaming the victim. Integrated model of social work practice. Women working with women for women”  
(Nash, 1987op.cit:37)

### THE THIRD PRINCIPLE: AFFIRMATION

Embedded in the third principle is the:

“crucial aspect of understanding the diversity of women’s experiences and the differences they bring to the social work relationship”  
(ibid).

For this to be able to happen the historical tradition of women being placed in a subordinate position to men needs to be remembered. Throughout the women’s liberation movement, there was the claim that women could perform as well as men in the labour force. Today, while equal opportunity is espoused, many women in our country still feel the need to strive to be better than men in order to attain equality with their male counterparts, or to get promoted. Feminist social workers should be encouraged to validate their daily-life experiences with each other.

In validating their own experiences, social workers accept that it is critical to reaffirm that women can now enjoy the experience of not always being the object or ‘other’. Once a woman becomes the subject, lack of confidence, low self-esteem and personal negative feelings can be dramatically reduced. These negative feelings will be replaced by feelings of self-worth and respect for self, which can then be nurtured in other women as well.

An important factor pointed out by both Nash and Munford which is extremely relevant today is the endorsement put by Lewis (1992), who asserts a co-requisition for affirmation is:

**“the transfer of power and authority. I’m talking about men, who have had an affirmative action in place for 2,000 years, to understand that what they find difficult in relinquishing, namely power and authority, must be relinquished in order to have a sense of equity in the world”**

**(Lewis, 1992)**

Without this transfer of power and authority the *empowerment* of women which affirmation should bring about, will not take place. In essence this is about women taking control for themselves and by sharing this with other women. For example, if the principle of affirmation, which includes ‘assertiveness skills’ is shared with women with disabilities basic rights can then be fought for. (Munford, Georgeson and Gordon, 1994b:271).

In the work place the social worker will need to use assertiveness skills so that her rights are acknowledged. In eliciting the support of co-workers, the struggle for resources is made more powerful by using a collective approach. It is in fact a recognition that women do not waste their efforts in pitching ‘women against women’ and always support each other. By taking control in this way and by valuing the work of each other, women start taking control for themselves and this domino effect makes life easier for her clients. Affirmation is now added to the first two principles:-

#### **MEANING**

**The personal and the political are linked to allow the social as well as the psychological aspect of the client situation to be explored...Integration links an understanding of power relations at the personal level to those at the political level demanding that the worker has an understanding of the links between theory and practice.”**

**(Nash and Munford, 1994,**

#### **INTERVENTION**

**“Applied analysis. Avoidance of deficit practice models, blaming the victim. Integrated model of social work practice. Women working with women for women.”**  
**(Nash, 1987op.cit:37)**

### THE FOURTH PRINCIPLE: EMPOWERMENT:

In the social work setting if the principles of analysis, integration and affirmation have been attained the principle of empowerment can evolve. It is a natural progression. When Nash articulated the concept of empowerment, it was at a time when this understanding of empowerment remained unadulterated. To retain its historical virginity and to support and reinforce the definition provided by Nash:-

“Empowerment as a feminist principle for action entails the recognition that women are oppressed and that it suits the western patriarchal capitalist system to continue this oppression. ‘Empowerment’ is intended to convey a commitment to lift this oppression from women; to restore our power by increasing our opportunities to participate in the public sphere; and to educate women to understand our individual oppression so we can organise fruitfully against them.”

(Nash,op.cit.9)

which clearly states that empowerment is all about restoring our power. Towards the new millennium and beyond, we need social work practitioners who will fight for social justice on their own behalf and for the women they work with. By taking responsibility to act and be accountable for their actions, oppressive features can be exposed. This is the only way change will come about. Both Nash and Munford support the work of Beddoe (1993), when in a personal communication she claims that some of the basics about an empowering approach should consist of:-

“the idea of helping women to achieve what they want to achieve, setting goals, raising self-esteem, being positive about our lives, taking control, all those things.”

(Beddoe,1993).

Given these basics, it is important to remember that the feminist social worker has to consider her own need to cope and survive while working within her social work setting. Because women have been oppressed for so long many women do not value or indeed recognise that their coping and survival strategies are something to be proud of. Feminist social workers need to consolidate their skills and strengths and fight for what they believe in. Each success is empowering.

It would be naive to suggest that all a feminist social worker needs to do is to fight for what she believes in. This can of course be very difficult at times. However, whatever resource (allocation constraints) a social worker may be operating under, she is viewed by the client as a woman who has considerable power. Which she does. Personality clashes can sometime determine the level of assistance a social worker is prepared to give. Paternalistic platitudes are no longer acceptable to women clients and need to be done away with. And this is why it is so important for the feminist social worker to forge a partnership with those women in whose name she works.

People have different realities. Empowerment is all about sharing power. This principle helps practitioners identify the factors and contexts that empower them and others. From the social work perspective empowerment looks like this:-

#### MEANING

“Recognition of women’s oppression and the importance of giving women the power we should have. Helping women to gain confidence and be independent. Knowledge is the source of power”  
(Nash and Munford, 1994, op.cit:242)

#### INTERVENTION

“Demystification of helping processes, encouraging women’s self-help organisation and the principle of client self-determination. Liberating women from all forms of oppression in our daily lives, as well as structurally. Empowerment means ‘the ability of women who, having come to terms with their lives, go on to demand social justice and change wherever they see the need.’”  
(ibid:242)

### THE FIFTH PRINCIPLE: ACTION AND REFLECTION

The fifth principle for feminist social work was originally called peer supervision but in keeping with current discourse action and reflection became the preferred name. With the dawning of the fifth principle the working relationship between the social worker and the women she works with has now reached maturation. This last principle is argued in terms of how social workers can evaluate a plan of action. It is a time to examine and reflect upon the strategies used in this five-step process. The experience shared with an individual or group and the very nature of that experience will add to the knowledge and skills of the social worker.

Peer supervision and support when enacting this principle is a very important component. Planned strategies can be discussed with co-workers. Feminist social workers who are prepared to share their power and knowledge, in an effort to make life easier for others, should be supported to speak out. And not be afraid to do this.

In the fusion of all five principles the potential outcome can be one of emancipation. In the eyes of the women we work with, action and reflection maintains our credibility. This principle also allows the social worker to take account of and evaluate her performance. It is now possible to believe that a truly woman-centered practice is in operation. In the process of reflection, the social worker can take account of the direction her future actions may take. The evaluation may be directly linked to social policies that are currently in use or, it may lead to new ways of working out solutions which had not been considered previously.

It will be a time of learning and development for the feminist social worker. The strengths and weakness of an integrated approach will

become apparent. Her work will be something to be proud of. By incorporating these principles into her practice, the women she works with will know she is a professional. A professional with compassion.

From the social work perspective action and reflection looks like this:-

### ACTION AND REFLECTION

#### MEANING

“The process of action and reflection takes place both within the client relationship and in social work supervision. It is a strategy for practitioner survival in which like-minded women support each other in their work with women. It enables the social worker to link theory and practice and to link the individual stories of women to those of other women”  
(Nash and Munford, 1994, op.cit:244)

#### INTERVENTION

“Group and peer supervision, where the social worker remains accountable to the principles of feminist social work practice. This allows the ability to continually evaluate our actions in line with our goals and visions”  
(ibid).

Feminist social workers who are prepared to share their power and knowledge in an effort to make life easier for others should be supported to speak out. And not be afraid to do this. In the final analysis how successful a feminist social worker will be, depends on the attitude they bring to the social work setting. From the client perspective I would like to suggest that as each principle is mastered the following self-addressed questions can be explored:-

**ANALYSIS:**

Who is telling the story?

How do my own experiences relate to what I am being told?

If it were I, what would I do in this particular situation?

How do I work so that personal change can come about?

Will this change overcome some of the restrictions imposed on me by the employing agency?

**INTEGRATION:**

Do I understand this woman's experience, if not why not?

How do other people influence the story being told?

What is the political, economic, social and psychological influences governing this woman's experience?

Do I have an integrated approach in my feminist social work practice?

Am I reinforcing the partnership - by women and for women?

**AFFIRMATION:**

What skills do I have to demonstrate that women have shared realities?

Have I looked at my strengths as a feminist social worker?

How do other feminist social workers approach particular situations?

What achievements have I accomplished?

Have I affirmed our code of ethics?

**EMPOWERMENT:**

Have I offered to share all the resources at my disposal?

Have I encouraged confidence and independence in others?

Am I willing to share my power with other women?

Is client self-determination one of my main goals?

Are my client's needs more important than mine are?

**ACTION AND REFLECTION:**

Are my actions in accord with the women I work with?

Do I have the support of my peers and supervisors?

Is this course of action consistent with feminist principles?

On reflection, should I re-evaluate the proposed action?

On reflection, have I been able to act in line with my goals and visions?

There are five questions for each of the five feminist principles. Every social worker will opt to work in a setting that suits their particular skills. This is a matter of choice. However, the women who most need the skills of a social worker very rarely have a choice. The outcome of her partnership with the social worker is something she will have to live with, whereas the social worker does not. Both Nash and Munford believe that:-

“it is in the analysis of women’s position in the societies and cultures we live in that informs the principles and which gives them their distinctive nature”

(Nash and Munford 1994, op.cit:237)

and although this statement was in reference to social workers you will be able to see that this philosophy is just as applicable to the women participants in this research and I will show you the connection in chapter six.

Nash has provided a model for social work practice that reflects feminist principles and values. Analysis defines the situation or problem. The integration brings the problems together. Affirmation creates the courage to challenge the existing status quo. Empowerment is the goal for change. Action and reflection is the celebration we share by looking back to

**remind us how far we have come and how we can improve on what we have already achieved.**

**APPENDIX 111****Application to the Human Ethics Committee****Massey University****NAME: Pamela Highet****STATUS OF APPLICANT: Masterate student****DEPARTMENT: Social Policy and Social Work, Massey University****EMPLOYMENT: Full-time student****PROJECT STATUS: Project to fulfill requirements for Masterate  
in Social Work****FUNDING SOURCE: Student Loan****SUPERVISORS: Mary Nash and Celia Briar****TITLE: Double Vision: The Experience of Multiple  
Sclerosis Through the Eyes of Women****ATTACHMENTS: Information Sheet:****Consent Form:****SIGNATURES: Researcher:****Supervisors:****DATE:**

## **1. Description of the project:**

### **1.1. Justification**

This research will explore some of the experiences of seven women who have Multiple Sclerosis. It is intended that the research will be collaborative and that the information shared will be of value not only to other women experiencing multiple sclerosis, but also for some feminist social work practitioners who believe in the philosophy of client empowerment as a realistic outcome.

It will be argued in this research that it might be possible to create a practice model for some women who have MS to use as a strategy for survival and self-development in tandem with people who are working with them. I will link these experiences to a social work practice model based on five feminist principles.

### **1.2. Objectives:**

There are five main objectives in this research project:

- 1. To develop a theoretical and practical approach to the possible partnership between a feminist social worker and some women who experience MS;**
- 2. To use a social work model based on five practice principles namely, analysis, integration, affirmation, empowerment and action and reflection. (Nash, 1987; Nash and Munford, 1994);**
- 3. I will use these feminist practice principles to create a practice model for some women who have multiple sclerosis to use as a strategy for survival and self-development, in tandem with people who are working with them;**

4. To provide as accurate information as possible about the realities of living with this disability;
5. To document and publish some of the daily lived experiences of women who have MS.

## **2. ETHICAL CONCERNS**

### **2.1 Access to participants:**

Initial approaches have been made to recruit participants from informal monthly meetings that provide ongoing support for people who have multiple sclerosis. Of those people who have expressed an interest in the study, the final selection of participants will be limited to women who have had multiple sclerosis for at least five years.

The researcher has been involved in these networks of support for the last ten years in her role as Vice-President of the Wellington Multiple Sclerosis Society.

### **2.2. Informed Consent:**

Each participant will have the procedures and implications of the research project explained to them. Once the participants confirm their interest and agree to participate, the consent form will be signed in the knowledge that they can withdraw from the project at any time. (The consent form is attached).

### **2.3. Anonymity and Confidentiality:**

Anonymity and confidentiality will be ensured to participants. It is expected that the personal stories shared by the participants will be audio-taped and transcribed by the researcher. Therefore, the researcher will protect the accuracy and privacy of the individual interviews. The participants will use pseudonyms. All participants will receive a

transcript of the information they provide which will allow for the deletion or inclusion of any information given during the interview. Tapes and transcripts will be returned to the participants at the completion of the project. While the researcher is in possession of the tapes these will be kept in a locked cupboard which only the researcher can access.

#### 2.4 Potential Harm To Participants:

Potential harm to each participant will be discussed prior to each interview.

Because each participant will be sharing some of their experiences, it could be expected that there might be the possibility that the recollection of these experiences may be difficult emotionally. Should this happen, the researcher will refer the participant to a counselor who has experience in working with people who have multiple sclerosis.

The second safe-guard for the participants will be the researcher's sensitivity and knowledge about the disease process itself. Two side-effects of multiple sclerosis could dictate the actual interview process. These are fatigue and cognitive dysfunction. It is anticipated that each participant will be interviewed for one hour. However, there is a likelihood that one hour may be too long for some participants. If this seems to be the case, the researcher will end the interview and will return at another time to complete the one hour interview. For example a participant may be more comfortable with three interviews of twenty minutes duration.

The researcher intends to ask the participants if they would like to end the interview, if and when the need arises. Throughout the interview process, opportunities to discuss what has been said will be offered to each participant. Should a participant wish to withdraw I have other women who could be considered as participants.

#### **2.5. Potential Harm To The Researcher:**

As the researcher is also a participant, the same concerns in 2.4. above, can be expected. To ensure that the dual role of researcher and participant remains distinct the first interview will be that of the researcher. The researcher will be interviewed by a university student. Once the data has been transcribed, the researcher will discuss the findings with the supervisors. The researcher has absolute confidence in both supervisors and in this respect, believes that the potential harm to the researcher is minimized.

#### **2.6. Potential Harm To The University:**

There appears to be little risk of potential harm to the University in this research project.

#### **2.7 The Participants' Right To Decline To Take Part:**

The participants' have the right to decline to take part at any stage of the research process. The tape-recorder can be turned off at any time during the interview. No participant needs to provide a reason should they choose to withdraw from the study. Once a participant has had the opportunity to see their own transcript they will be given the opportunity to withdraw or add any information as they see fit.

#### **2.8. Use Of The Information:**

The consent form will request participants to agree to let Pamela Highet use the information gained for the MSW thesis and for other published or unpublished work.

#### **2.9. Conflict of Interest:**

Because the researcher is also a participant in the research project, the first interview will be that of the researcher. The researcher will be

interviewed by a friend who does not have multiple sclerosis. This decision has been made so that the interviewer will receive the information without any pre-conceived notion about the experience of multiple sclerosis. By so doing, the researcher will need to explain the experiences to someone for the first time. This should ensure that the researcher would not assume that there is a shared knowledge about the terms used during the discourses on multiple sclerosis.

In the interests of reciprocity, critical in feminist research, once a participant has been interviewed, they will receive a transcript of the researcher's interview. In this way, the participant will know as much about the researcher as the researcher the participant. It will mean a true sharing of the respective experiences.

#### 2.10. Other Ethical Concerns:

One has to consider the ethical issues involving people with disabilities in a research project such as this. Although I am a woman with a disability, there can be no assumptions made about a participant's disability. That is why the researcher has chosen to be a participant as well. Reciprocity in feminist research implies that a researcher must give something back to the people who assist in this research. Self-reflexivity will be my constant companion in this research and I believe that it is possible to make this research enjoyable for all that participate.

##### 2.10.1.

If the researcher is to do justice to the experiences of the participants, it needs to be made clear from the outset that the participants will be viewed as the 'experts'. The aetiology of multiple sclerosis and the individual and unpredictable nature and experience of people with multiple sclerosis, may not necessarily make sense to other professionals working in this field. For this reason, the researcher will be offering a specific model for

feminist social work, which can be used as a guide for social workers when working beside women with multiple sclerosis.

### **3. Legal Concerns:**

#### **3.1.1. Intellectual Property Legislation:**

The researcher has read, understood and, accepts the Massey University policy on intellectual property legislation effective from 1 January 1996.

#### **COPYRIGHT:**

Copyright of papers produced from the research will rest with Pamela Hight.

#### **3.12. The Privacy Act 1993:**

The information volunteered will be governed by the Privacy Act. Pseudonyms will be used to protect the identity of the informants.

#### **3.2. Other Legal Issues:**

The researcher is not aware of other legal issues.

#### **Cultural Concerns:**

In Aotearoa/New Zealand the incidence of multiple sclerosis for Maori, Polynesian and other ethnic minorities is rare. In the interests of cultural sensitivity and because the researcher is a Pakeha, only Pakeha participants will be selected for the research project.

### **5. Other Ethical Bodies Relevant To This Research:**

None.

#### **5.1. Ethics Committees:**

This research project will not be submitted to any other ethical committee.

#### **5.2. Professional Codes:**

**There are no other professional codes to which this research is subject.**

**6. Other Relevant Issues:**

**I am unaware of any other relevant issues.**

**APPENDIX 1V:****CONSENT FORM****MASSEY UNIVERSITY****DOUBLE VISION: THE EXPERIENCE OF MULTIPLE SCLEROSIS  
THROUGH THE EYES OF WOMEN**

I have read the information sheet for this research project and I have had the details of the research explained to me. The questions about my involvement in this project have been answered so that I understand what my role will be.

I may ask additional questions at any time.

It has also been explained to me that I may withdraw from this project at any time without providing the researcher with a reason for my withdrawal.

I agree to provide information to the researcher Pamela Hight on the understanding that this information is completely confidential.

I understand that copyright to the audio-tapes is held by me.

I wish to participate in this research under the conditions set out on the information sheet.

**SIGNED:**.....

**NAME:**.....

**DATE:**.....

**APPENDIX V:****INFORMATION SHEET****RESEARCH TITLE:**

**DOUBLE VISION: THE EXPERIENCE OF MULTIPLE SCLEROSIS THROUGH THE EYES OF WOMEN**

**THE RESEARCHER**

The researcher is Pamela Highet who is completing a Master of Social Work degree at Massey University. In partnership with you, Pamela would like you to share some of your experiences of multiple sclerosis.

Pamela Highet can be contacted during the day on (06) 3678503

**DESCRIPTION OF THE RESEARCH PROJECT**

By sharing some of your experiences of MS with me it is hoped that particular aspects of living with this disability will emerge so that in some way it will be possible to share your knowledge with others. The information you provide may also be useful for social workers and/or other allied health professionals who work with women who have MS.

As a participant what will you have to do?

The researcher would like to meet with you and audio-tape-record your discussion about your experience of MS. There will be approximately one hour of conversation in total but this can be adjusted according to the comfort of the participant. For example, the session can be divided into three twenty- minute sessions if that would suit you better. I understand that copyright of the audio-tapes belong to me.

**Each participant will be asked two questions:**

**The first question will be:**

- 1. Please will you share some of your experiences of MS with me?**

**The second question will be:**

- 2. How could the quality of your life be enhanced?**

**It is important for you to know that the researcher believes that you are the expert on how you experience multiple sclerosis. After you have shared some of your experiences, the researcher will give you a copy of her own interview. Once your contribution has been typed up you will be given a copy. You will then be given the opportunity to alter or add to the transcript.**

**When the research project is completed, you will be provided with a summary of the research findings and your recorded interview will be returned to you.**

**If you decide to take part in this project you have the right to:**

- 1. Refuse to participate and withdraw from the project;**
- 2. Expect the researcher to answer any questions you may have;**
- 3. Provide information which is portrayed anonymously so that confidentiality is maintained;**
- 4. Have telephone access to the researcher during the day.**

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