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## MANAGING MULTIPLE SCLEROSIS AND MOTHERHOOD: WOMEN'S STORIES

Debbie Payne, Kathryn McPherson and Susan Crerar  
Centre for Midwifery and Women's Health Research  
Faculty of Health and Environmental Sciences  
Auckland University of Technology

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The Commission can be contacted at:  
Public Trust Building  
Level 6, 117-125 Lambton Quay  
PO Box 2839  
Wellington

Telephone: 04 917 7040  
Email: [enquiries@nzfamilies.org.nz](mailto:enquiries@nzfamilies.org.nz)  
[www.nzfamilies.org.nz](http://www.nzfamilies.org.nz)

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# EXECUTIVE SUMMARY

Multiple sclerosis (MS) is a disease of the central nervous system with wide-ranging effects. It is a condition that most commonly affects women of childbearing age. Until recently, women with MS were discouraged from becoming mothers but studies have found that pregnancy and birth do not negatively affect the course of MS.

There is a lack of research about MS in the New Zealand context and, in particular, about women who have MS and their experiences of becoming mothers. This research project explored the nature of pregnancy, birth and mothering young children for women with MS, and marked an important beginning to research about disabled women's experiences of motherhood in New Zealand.

Nine women with MS, who had become mothers in the past five years, were interviewed individually about their experiences of pregnancy, birth and mothering children up to the age of five years. Interpretive analysis of the interviews identified seven themes:

1. The variability of MS
2. Thinking of oneself as a 'normal' mother – putting MS in the background
3. Having a baby – a public private experience
4. Medications – keeping the baby safe
5. Support – anticipating and preventing relapses, and dealing with MS
6. Conserving energy
7. Being the 'ideal' mother.

## Implications of findings

Given the preliminary nature of this research, implications were considered cautiously. We suggest three clear areas with relevance for enhancing the experience of motherhood for women with MS:

1. The importance of 'listening' to women's stories prior to making assumptions about their attributions, aspirations and support needs in relation to motherhood. Clearly this has particular relevance for health and social professionals but is also relevant for members of the public, colleagues at work and family members.
2. The relative place of impairment in women's lives is variable and likely to require ongoing consideration rather than one-off static assessment or action. Ongoing considerations should include the women's life context as well as their pregnancy and impairment.
3. Knowledge and understanding in the area of motherhood for women with MS remains limited, particularly in New Zealand. It is vital that research focuses on how best to ensure appropriate health and disability policy is developed and quality health and social services/support is available for women with an impairment wishing to become mothers.

# 1. INTRODUCTION

Multiple sclerosis (MS) is a common disabling condition that is typically first diagnosed in people aged between 20 and 50 years. Approximately twice as many women are affected as men. As mothers play a key role in the care of young children it was important to find out what the experiences of women with MS were in relation to pregnancy, birth and early childhood.

The aim of this study was to gain a better understanding from the mothers' perspectives of their experience of becoming mothers and to identify:

- a. any areas of concern
- b. the strategies that help families manage when the mother lives with MS.

Remarkably little information is available for women with MS on how to manage pregnancy, birth and motherhood taking into account their MS. With the rise in awareness of human rights and changing attitudes towards chronic illnesses, increasing numbers of women living with MS and other chronic conditions are choosing to become mothers.

The findings of this interpretive descriptive study draw on individual interviews with nine women. Eight of the women had been diagnosed with relapse remitting MS (RRMS) and one with secondary progressive MS (SPMS). These women had experienced childbirth while having MS and the study offered an initial insight into the women's experiences and how they managed MS and motherhood.

The research took place in the greater Auckland area during the latter part of 2006.

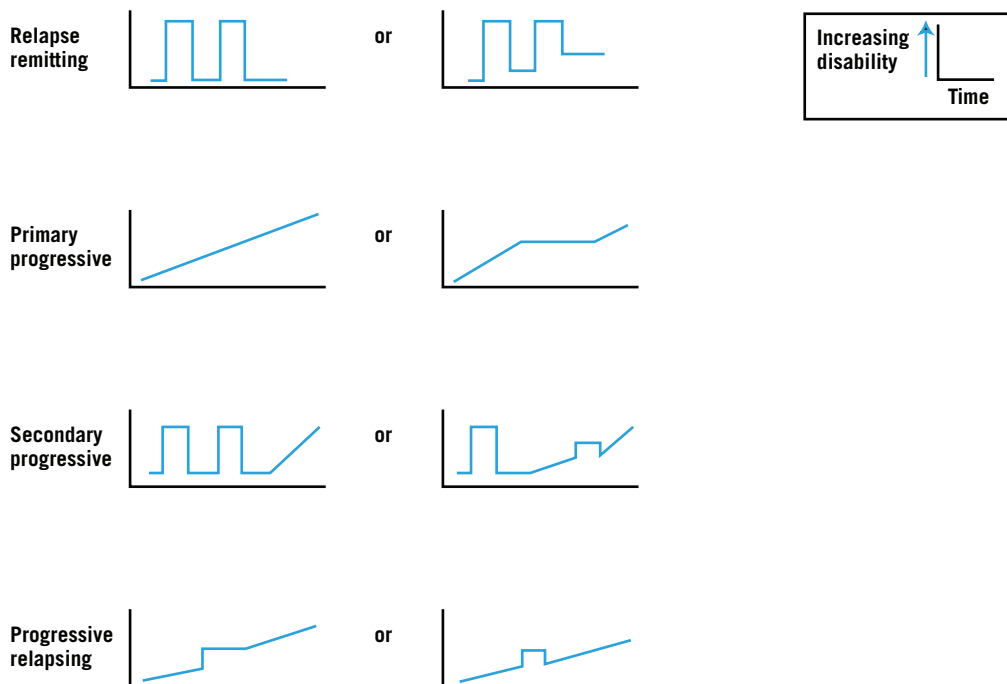
The report begins with a review of the literature in relation to MS and pregnancy, birth and mothering young children. This is followed by an outline of the research method and the key findings of the study. The report concludes with a discussion and recommendations for further study.

## 2. BACKGROUND

Multiple sclerosis (MS) is a disease of the central nervous system which affects the brain and spinal cord. According to the MS Society of Auckland website, more than 4,000 people in New Zealand have MS and about 200 people are diagnosed with MS every year. MS occurs most frequently in young adults and more frequently in women than in men (Geisser, 2003). It is more common in women of childbearing age (National MS Society, 2006).

Some of the symptoms that people with MS may experience are loss of sensation, muscle weakness, altered vision, lack of co-ordination, pain and fatigue (Leary, Porter and Thompson, 2005). Depending on where you look, there are varying classifications of MS. For the purpose of this paper we draw on Leary et al's identification of four types of MS: relapse remitting (RRMS), primary progressive (or chronic progressive) (PPMS), secondary progressive (SPMS) and progressive relapsing (PRMS). According to Leary et al, the first – relapse remitting – is the most common with 85 percent of people having this type. As shown in the diagram below, there are episodes of relapse when the MS becomes active, followed by episodes of remission when there is a complete or partial recovery.

### Types of multiple sclerosis



Source: [www.multiplesclerosis.com/admin/templates/whatisms.aspx?articleid=7&zoneid=35](http://www.multiplesclerosis.com/admin/templates/whatisms.aspx?articleid=7&zoneid=35)

Historically, women with MS were advised against becoming pregnant and to terminate the pregnancy should it occur (Geisser, 2001 cited by Smeltzer, 2002). It is only since the 1950s that pregnancy has been recognised as not being detrimental to women with MS. Blackford, Richardson and Grieve (2000) note that more women with chronic illnesses and disabilities are now becoming mothers. They suggest that this is a consequence of improvements in medical treatments and increased awareness of human rights. Influential too is the view that the option of motherhood is a fundamental part of being a woman. For a disabled woman becoming a mother has been likened to granting her a degree of being a 'normal woman' (McKeever, Angus, Lee-Miller and Reid, 2003).

As Gulick (2003) points out, adjustment to parenthood often involves stress, and for women living with a chronic condition such as MS, this stress is compounded. There exists an interrelationship between



MS and pregnancy in that the physiological changes accompanying pregnancy impact on MS. In turn, MS influences the woman's physical, psychological and social experience of pregnancy and beyond. While there has been study into the physiological aspect of pregnancy and MS, there is a relative paucity of research into the emotional, psychological and social experiences of women who have MS, in relation to pregnancy, birth and motherhood.

One issue is the potential for some MS medications such as disease-modifying agents to have detrimental effects on the unborn child (Geisser, 2003; Lorenzi and Ford, 2002). Evident in the literature is the recommendation that women on such medications plan their pregnancies. The main reason for this practice is that a planned pregnancy allows a woman who is taking known teratogenics (medication that is known to be harmful to an unborn child) to take known safer alternatives. In this context of planned pregnancies, unplanned pregnancies may have implications for a woman with MS and her baby.

One view of pregnancy and birth is that it is a potentially 'risky business' for any woman and her baby (Payne, 2002) but particularly so for women with disabilities (Thomas and Curtis, 1997). Women may be worried about how to maintain their own and their baby's health (Carty, 1998; Smeltzer, 2002). Smeltzer found in her study into the decision-making regarding childbirth by women with MS that there were two major concerns: the effect of pregnancy on MS and the unpredictability of MS.

A Canadian qualitative study interviewed eight mothers with chronic illnesses such as MS about their maternity experiences (Blackford et al). The researchers found that the women reported not receiving enough relevant information from the prenatal education nurses, particularly about their illness and pregnancy. The women felt anxious and tense during pregnancy, and in antenatal classes the nurse educators seemed more focused on the healthy women. When the women did voice their concerns about managing fatigue after the birth of the baby, they were silenced by the nurse educators. The researchers also suggested that some nurses doubted the ability of the women to be decision-makers or responsible 'proper' mothers and in this way perpetuated the disempowerment of women with disabilities. Furthermore, some of the women spoke of not feeling supported by their partners or parents. This may reflect societal prejudices which assume that women with physical disabilities are unable to care for their children (Grue and Laerum, 2002; Prilleltensky, 2004).

The World Health Organisation (WHO) now encourages mothers to breastfeed their baby exclusively for the first six months and to continue breastfeeding for up to two years (2002). An issue that, therefore, confronts mothers who require more aggressive medications is whether or not to continue breastfeeding. Breastfeeding may not be possible if the woman needs to take drugs that could be detrimental to the newborn baby.

While most women living with MS may experience improvement during pregnancy, MS may recur within three to six months following the birth of their babies (Birk, Ford, Smeltzer, Ryan, Miller and Rudick, 1990; Confavreux, Hutchinson, Hours, Cortinovic-Tourniaire and Moreau, 1998). The sporadically occurring symptoms which a woman experiences vary from such things as increased weakness, fatigue, gait disturbance and sensory loss. The degree of effect can impact on a woman's lifestyle hindering everyday tasks, family relationships and social activities. Gulick and Kim (2004) found that first-time mothers needed more information about caring for themselves and their infants. Furthermore, three to six months after the birth, the emotional and physical support that the women were receiving from their partners and family was reducing at the time when the women experienced a heightened vulnerability to MS relapse. Gulick and Kim recommend that assessment and initiation of needed support among mothers living with MS after the birth of their baby is essential to minimise symptoms and promote health.

In relation to parents with rheumatoid arthritis, Barlow, Cullen, Foster, Harrison and Wadw (1999) found a gender difference among their participants: the mothers identified infancy and toddlerhood as the most difficult times, whereas the fathers found that older children presented more difficulties. The tasks associated with caring for young children, for example dressing and undressing the infant, involved fine motor skills and strength that were hard for the mothers to accomplish. This led to feelings of frustration and inadequacy.

As an example, we highlight Crerar's experience that captures the importance of this study and some of the factors that could enhance the provision of appropriate, adequate and well contextualised information and support for family wellbeing when a mother has MS.

#### Susan Crerar's experience

Having been diagnosed with MS after a critical attack and several years later requiring the use of a wheelchair, I still did not doubt my ability to have a child. I did, however, go through some self doubt along the lines of: 'Will I be a good enough Mum?' And of course in the back of my mind: 'What if this or that happens to me?' On my initial diagnosis I was told, 'MS may affect the quality of your life, not the quantity', and so for me one question in thinking about becoming a mother was more particularly: 'Will I be well enough to look after a child?', rather than 'Will I be here long enough?'

I was certainly green regarding child/baby care; however, I did ask my specialist for his thoughts on my having a child. He said, 'In general, pregnancy is not a problem; however, later exacerbation may occur.' Now to some extent MS affects people in a myriad of ways, but for me this statement was totally correct. I sailed through pregnancy and childbirth, but I could never have coped with a baby without a supportive husband who worked from home, and an equally supportive mother who came over regularly. Having my mother and father willing and able to help me along the way, has made full-time mothering possible for me. Being in a wheelchair and having weaker trunk muscles and less energy than the average mother posed significant difficulties for me.

In the end, I had two children, so with help along the way, a lot of planning and knowing my physical boundaries, it was indeed possible. Nine years later, my condition has not got significantly worse, barring the two exacerbations I had in the stressful times of the first years of each baby.

Overall, I think that a woman with MS making the decision to have children or not, has a few extra issues to consider, such as, 'Do I have significant help available to help in my current situation, especially in times of a bad patch/worsening health? How can I reduce stress in managing/caring for a child? Could I manage caring for another over and above coping with whatever MS may throw at me?'

In many ways I feel it has been good for me psychologically not to focus on myself too much, but perhaps I could have done a little more physically without children to focus on – I'm not sure. They certainly bring me a step back towards feeling 'normality'!

Susan Crerar, personal communication, 12 February 2007

While books such as Graham's *Multiple Sclerosis and Having a Baby* (1999) and pamphlets from the Multiple Sclerosis Society of New Zealand exist, there is little available about the experiences of New Zealand women. Our study set out to explore the range of issues that might occur for mothers with MS and, importantly, to focus on the strategies they set in place to manage mothering and their MS.

## **3. METHODS**

### **3.1 Participant recruitment**

Initial contact was made with the women by either the MS nurse specialist or an MS Society Auckland field officer who had identified from their records women meeting the study criteria. The selection criteria for the study were that the women had to have been diagnosed with MS by a neurologist and have given birth within the last five years.

The MS nurse specialist or the MS Society Auckland field officer then sent an information sheet to these women, informing them about the study and inviting them to participate. Within two weeks of receiving the information, the women were contacted by the nurse specialist or the field officer to determine their interest in participating. When a woman agreed to take part, her details were passed on to the lead researcher who then made an appointment at a time and place that was convenient to the woman. In all cases this was the woman's home. Prior to the interview commencing each woman was asked to sign a consent form.

Twelve women were initially informed about the study. Two chose not to participate and one was unable to be interviewed within the timeframe of the study. All those who expressed interest were included in the study.

Seven women were recruited either through the Auckland City Hospital MS nurse specialist or through the MS Society Auckland. Two other women read about the study in a local newspaper and initiated contact with the principal researcher.

### **3.2 Data collection**

Data collection occurred through one-on-one interviews with the women. The interviews were free-flowing with the interviewer following an interview guide. The aim was to ensure the women had a sense of control over the interview and were able to highlight aspects of their experiences that were important to them. The use of an interview guide ensured that the key areas were addressed during the interview.

Each interview lasted from 60 to 90 minutes. One participant requested a second interview as she considered that not all areas had been addressed in the first interview. With the women's permission interviews were audio-taped and later transcribed by a typist who had signed a confidentiality agreement. A copy of the transcription was given to each woman to read through and verify, and to make any corrections or deletions of information that might have breached confidentiality. The women also kept a copy of their interview transcript for their records.

Relevant demographic data, such as age, marital status, the number and ages of children born to the MS mother, ethnicity, age at which MS was diagnosed and occupation were gathered. The women were asked to describe their experiences of pregnancy and motherhood and issues arising from these, with particular emphasis on the strategies they used to manage motherhood and their MS. With regard to the antenatal period the women were asked if they were on medication for their MS and, if so, to describe any changes they made to their medication. The interviewer also explored aspects of the postnatal period such as how the women managed their symptoms; how the symptoms affected their ability to care for their growing child; what everyday strategies they employed for mothering tasks; and what supports and resources they drew on and found most helpful.

### **3.3 Data analysis**

The study used the qualitative research method of interpretive description described by Thorne, Reimer Kirkham and MacDonald-Emes (1997) and Thorne, Reimer Kirkham and O'Flynn-Magee (2004). Transcripts were read and re-read looking for accounts of what it is like to have MS and to become and be a mother. Initial analysis of individual transcripts occurred immediately after each interview. Categories and themes (groups of categories) that characterised the experience of managing motherhood and MS were identified. These key themes were developed and further tested in subsequent interviews as data were analysed progressively throughout the study. The final analysis presented themes that appeared to be relevant and important across the group.

The issue of the robustness of data and interpretation in qualitative research is important and similar to the issue of validity in quantitative approaches. A number of steps were taken to ensure the credibility of findings. These included dual analysis by the authors of this report, participant feedback and several of the participants checking the relevance of the analysis. The nature of the study meant findings might be influenced by recall bias. However, by including the recruiting criterion of the youngest child being no older than five years an attempt was made to minimise such bias.

All names have been removed, an arbitrary initial assigned to each woman and some minor details have been altered to protect the confidentiality of participants.

Ethical approval was obtained from the Northern Y Regional Ethics Committee which reviews research proposals for the northern area of the North Island.

## **4. RESEARCH FINDINGS**

### **4.1 Overview of the participants**

Nine women aged between 22 and 45 years were interviewed for this study. Seven of the women were married and lived with their spouses. The two remaining women were separated from their partners. One lived with her mother and siblings and the other with her three children. Except for one woman who identified herself as a European Māori, all the women identified themselves as being European, Pākehā or Kiwi (see Appendix 1).

Reflecting the incidence of types of MS reported by Leary et al (2005), one woman had SPMS and the remaining eight women had RRMS. While several women reported difficulty in walking during their relapses only one had been wheelchair-dependent during a relapse. None required a wheelchair during periods of remission. One woman, P, used an orthotic device to stop the foot drop she experienced.

Four of the women were first-time mothers, and the remaining five mothers had two or three children. The ages of their children ranged from eight months to 17 years. Five of the women were full-time mothers and four had part-time employment. One mother planned to return to work when her baby reached one year of age. Two of the mothers had their children in childcare for three or more days a week, and only one mother drew on home help to assist her in caring for her two children.

All the women breastfed their babies from the time of birth. Three women stopped after three to four months for various reasons including insufficient milk supply or mastitis. The remaining six women breastfed their babies for 12 months or more.

#### **4.1.1 Themes**

In analysing the interview transcripts, seven themes appeared to capture the MS and motherhood experiences of all the women who participated:

1. The variability of MS
2. Thinking of oneself as a 'normal' mother – putting MS in the background
3. Having a baby – a public private experience
4. Medications – keeping the baby safe
5. Support – anticipating and preventing relapses, and dealing with MS
6. Conserving energy
7. Being the 'ideal' mother.

Each theme will be discussed below with direct quotes from interview data as 'evidence'.

### **4.2 The variability of MS**

Variability in the women's experiences of MS was identified as a key theme evident in the interviews. As stated, RRMS and SPMS fluctuate between relapses and times of remissions, and the length of time between relapses can vary from months to years. The extent to which the women were incapacitated during their relapses varied from woman to woman, as did the residual effects following a relapse.

For example, one woman, who at the time of the interview was experiencing a relapse, described its effect:

Well it's quite a variety of things and it's such a personal thing, but everyone is different. But for me this year I've had weaknesses in both legs. My legs go numb and have altered sensations so they are strangely very numb but also very sensitive. And they can be very cold at first but for me it feels a bit like my legs are against snow all the time. And at the moment I've had my arm go numb and they go weak. My arms go weak. I've had a short burst with walking sticks with both legs this year. And I did have an attack that involved my eyes which started to affect my peripheral vision. But at the moment luckily my leg is starting to go a little bit weak and numb. My arms, the strength is starting to come back a little bit, I think, and I get a bit tired. But I really don't know how it's going to affect me and I have no idea how long it's going to last or how it's going to or what shape it's going to take.

L

In comparison, V, a mother of two, whose last relapse occurred over two years ago, recalled:

The last attack I had was actually quite intense. It was the whole left side. Just everything numb. It didn't go to the stage that I couldn't walk anymore but just that the feeling just was numb, the whole torso and everything on the left side – quite weird. And it's got to the point where I can you know use my hand fine but I can feel if I'm typing it's just not as quick as it used to be. I think quicker than my hands can handle and it's just I find motor skills for the left hand – it drags a bit. But it's not as bad that I couldn't cope with it.

V

The different symptoms and severity of both relapses and residual effects give MS a characteristic of significant variability. No one woman is the same as another. Some are grossly affected and others are not.

Furthermore, the frequency of relapses may change over time. R who had been experiencing MS for 18 years noted:

I always fully recover and they [the relapses] are always of the same sort of nature, a bit of tingling, a bit of funny dizzy head or my brain feels loose. Kind of irritating things but it doesn't look like I'm sick. They're not really bad and I never ... sometimes I can't walk very well but you can get over it. But they are closer together. They were usually, probably from [when I was] 16 onwards maybe every four or five years I'd have an attack. Now it's sometimes twice a year.

R

R did not perceive her relapses as severely impairing her everyday experiences. But since the intervals between relapses had shortened she could no longer assume that years would pass before her next relapse. Now, as a mother of a two-year-old child, and pregnant with her second, her MS was changing. Such uncertainty has the potential to undermine a person's ability to take their wellbeing for granted.

The degree to which MS affected the mothers' everyday lives appeared to influence how much MS was dominant or to the fore in how they spoke about their experiences.

### **4.3 Thinking of oneself as a ‘normal’ mother – putting MS in the background**

For the six women who spoke of comparatively minor residual effects and infrequent relapses, their MS was not of significance to them. It was present, but in the background of their everyday activities. For example, one mother, when recalling being diagnosed with MS stated:

And then again it didn't really affect me as I wasn't, after the initial – 'You have MS', I was like, wow, so...

INT: So it was something that was there but wasn't there kind of thing?

Yeah. It was just sort of in the background. It still is in the background. [...] I can do everything myself. It's not, I don't know. I mean it's not something I think about every day.

F

Another said:

It's just keeping positive about it and not focusing on it. Because I think you can turn around and think oh I've got MS, and this is going to be, you know, and go down the track that I've got MS and just focus on the negativity of it. That sort of thing. Whereas you can think oh well I've got MS, I'm just going to carry on. Just carry on with my life as normal and so don't make any changes.

E

Another mother, before the interview began, felt that she may have nothing to contribute to the study as her MS did not affect her greatly. To these women, keeping MS in the background was a means of not allowing their MS to take over and imbue every aspect of their everyday lives.

For these six mothers it was important to them not to be seen as different from other mothers. Their MS did not prevent them from being able to care for their children. Rather they were like non-impaired women adapting to the busy and demanding role of being a mother to a newborn baby and/or young children. MS, while present, remained in the background of their minds and everyday reality.

What was also significant for this group of mothers was the desire to carry on 'as normal', carrying out the full roles and tasks that were associated with being a mother. They appeared to challenge the commonly held representation of MS as a chronic, disabling illness; instead they presented themselves as physically able and capable mothers. For three women with a greater degree of impairment, MS stayed very much in the foreground and appeared to impact on the women's interpretation of mothering.

### **4.4 Having a baby – a public private experience**

The decision to become a mother had several meanings for the women. For P and L it was the desire to have children together with their spouses. For others it was a means of getting on with life and continuing the life course that they had planned prior to being diagnosed with MS. To give up having children signified stopping living – that MS now dominated their lives and thus limited their life choices. But having MS made the decision to pursue motherhood a complex one.

All but two of the women had planned when to have their children. However, all the women had considered the implication of MS on pregnancy, birth and childbearing. With MS a person's future is

called into question. With the variations that are typical of MS we suggest that a woman cannot know how active her MS will be and how rapidly and to what degree it will progress, raising many questions. As Susan Crerar (personal communication, 2007) terms it the “what if?”:

Before they have children, there are many questions women with MS ask: What if my MS gets worse, how am I going to cope? Is it fair on my children that I have MS and may not be able to fully care for them?

Susan Crerar, personal communication, 12 February 2007

I think because we'd been trying so hard for this baby we were both a little bit paranoid that something would go wrong with the pregnancy. And we were a bit worried about what the pregnancy would do for my health, whether it would cause a big flare up. We were worried about, and we know that it's just purely random, that whether my daughter would have MS as well, whether my MS would cause any deformities with her. You know, your mind just runs wild really.<sup>1</sup>

N

Neither was the decision to become a mother made in private between the woman and her partner. For the majority of the women in the study the decision to become pregnant was a public experience in that it involved discussion and consultation with other people, particularly their medical specialists and family members:

Gosh, I went and saw ... the ladies at the MS society, my doctor, and my neurologist [...] So that was the kind of the prep work so to speak, in terms of even deciding yes. Yes we'd like to have a baby. So we did all the kind of homework. Basically the professional people that I went to see just said, 'Fine, just to go ahead.' And if I fall pregnant that's fine. So that's what I did. I also researched it, did lots of homework myself.

INT: Yes I was interested in that use of the word.

Yes, I did a lot of homework myself because I wanted to know, be 100 percent sure that I myself physically and mentally was going to be able to cope with pregnancy, as well as childbirth, as well as raising a little baby. Also I was 40. But even though I was ... I thought I was healthy and that. I just thought, OK let's look into some of the things that might happen and some of the things I've got to watch out for. And so, both my husband and I we looked into it big time actually, researched up the web. There were a small number of books available. So we read those. And after all of that we still came out of it thinking we still want to go ahead with it.

P

While studies show that MS does not complicate a woman's journey through pregnancy and birth and early motherhood (Smeltzer, 2002), it does call into question her own wellbeing and that of her future child. The woman's body and her capacity to give birth without intervention; to journey through pregnancy and birth can no longer be taken for granted. Getting answers to the questions that being a mother with MS generates was part of the preparation for motherhood. The process of gaining information, as shown by P, was wide-ranging and involved circles of people that extended beyond the women's intimate social networks.

Discussing their intentions with general practitioners, neurologists, neurology nurse specialists and other experts on MS helped assure the women that the pursuit of motherhood was feasible and that they were capable of meeting the demands and responsibilities that the role entailed.

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1 N highlights a common concern for mothers with MS (Graham, 1999). It is important to note that MS is not an inherited condition.



Other family members such as parents and siblings were also informed and consulted in the decision to pursue motherhood.

L was pregnant when she was diagnosed as having MS. Her initial experience of MS was debilitating and shocking. Her diagnosis raised two questions: would the baby she was carrying be affected by MS and should she and her husband have children. Her specialist had phoned her to arrange an appointment to discuss the results of the investigations and to tell her that she had been diagnosed with MS:

Obviously we were quite shocked and I was, 'How does this affect the baby?' And he said, 'Look it shouldn't really affect the baby.' I had a year where I was in bed. I was really quite ill. And getting up and having a shower and getting dressed was all I could do for the day. And that obviously changed our lives quite drastically. So that's how I got diagnosed and I think that was about five years ago. We went through a period of time sorting out whether we wanted to still have children, which was as I said a huge issue seeing my illness. And the other factor really was our extended family. If we didn't have our extended family we wouldn't have had children. We just wouldn't have felt we could cope with the responsibility of having children, of bringing children into the world and just having the two of us to care for them. We just wouldn't have felt we'd be able to do it. So we talked to our extended families too about having children because we realised it would involve them.

L

And we let the family know, even before I fell pregnant. I remember saying, 'Hey, we're thinking of having a baby and if it happens it happens, and if it doesn't well that's ok too.' And they were a little bit shocked, especially when we were telling mum and dad. They were shocked, but I just knew that I would have that family support and because of the other situations I've been through in my life.

P

Both P and L had significant physical impairment. L experienced chronic fatigue and muscle weakness and P had muscle weakness that particularly affected her walking and balance. As their excerpts illustrate there was a need for them to establish their family's support before they embarked on mothering with MS. Becoming a mother while having MS had implications for those family members who were closely associated with the woman. There was an expectation that they would provide the physical, social and emotional support that was necessary to bring up children.

While discussing the decision to become a mother with experts and other people may allay and clarify concerns and establish future support, it also has the potential to expose women to disapproval of their decision.

Smeltzer (2002) notes even though it has been shown that pregnancy has no effect on a woman's MS and that MS does not affect a woman's pregnancy, labour and birth, some women may still encounter discouragement from some family members and health professionals. Accounts of discouragement from becoming mothers emerged from two women; the people who urged the women not to have children were primarily health professionals. One woman was diagnosed with MS while living overseas:

I was ... told, 'You shouldn't have kids.' I'm, 'What?', because of the high risks. They seemed very – dramatising the problem over the MS. Yet here [in New Zealand] the neurologist says if you don't have a problem don't bother coming [to the clinic].

INT. Oh really?

Yes. And I think it's just the attitude over there. I mean the way he [the overseas doctor] diagnosed me everything's a really big drama, 'You shouldn't have kids because of that yo-yo effect. It's too much risk.' And then when I came over here the attitude kind of changed, the neurologist said, 'No, if you want to have kids, have kids.' You know, 'Be aware of the risks.' So, yes, I should be fit and healthy and young enough to go through it.

V

V came across quite contradictory views from the two doctors. One encouraged, the other discouraged her from becoming pregnant. The second doctor's opinion coincided with her experiencing less frequent relapses and no longer requiring medications.

N also encountered discouragement. One day she was visited by a colleague who confronted N with her views about MS and motherhood:

I was quite shocked ... I just said, 'Look, you obviously don't know me at all if you think that's going to stop me. You really don't know me or what I'm about at all.' I just could not believe that someone would... I mean some people are not children people. People do not want to have kids, and whether she's one of those people, I'm not sure. But it would not take much to sway her to thinking, 'Oh no. Too hard.' Or, 'The risk's too hard.' If it was a reverse role, if she was in my situation that she would say, 'Oh no it's too risky.'

N

N's colleague had looked into literature regarding MS and motherhood. She had formed the opinion that the risk of a relapse during the postnatal period was highly probable and would aggravate N's MS. As N comments, the significance of benefits and risks is quite personally determined. For N the benefit of becoming a mother outweighed the risk of having a relapse. For her colleague it was quite the reverse.

## 4.5 Medications – keeping the baby safe

The safety of the baby in relation to taking medications when becoming pregnant, during pregnancy and while breastfeeding, was one of the issues voiced by the women. Only one woman was on medication for her MS prior to becoming pregnant. As she explains, she had sought advice about the safety of the medication with her specialists:

Only once I fell pregnant that's when I came off the Interferon.<sup>2</sup> [... ]

INT: Right, so there was no sort of fear that that would harm your baby in any way?

I did remember asking them about that, whether or not that was going to be a problem with me still taking Interferon as well as trying to fall pregnant and conceive. There wasn't a lot of ... they couldn't answer a lot of questions on that and they said, 'But as soon as you fall pregnant that's when you must come off' and so the day I fell pregnant that was that, stopped the Interferon. And so they couldn't answer ... I remember they couldn't answer any questions on whether or not the Interferon would harm my unborn child so I just said that I would take it up until the time that I fell pregnant. Yeah, it was just a little bit tricky but that's what we did.

P

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2 This should not be taken to mean literally the time of conception but when the woman became aware of pregnancy.

When a woman is planning to become pregnant she may need to stop taking some medications before she becomes pregnant as they may interfere with conception and the early development of the foetus and cause abnormalities. Having ascertained that she could continue to take the drug prenatally P stopped as soon as she recognised she was pregnant. P's experience highlights the sometimes uncertain knowledge that exists about the effects of medications on the unborn baby.

G had experienced seizures as a consequence of her MS and had been recommended to take Tegretol, to reduce the likelihood of these re-occurring:

The doctor was going to put me on Tegretol but because I wanted to get pregnant I didn't want to because of the risks. There was a 5 percent risk of cardiac defect. [...] It's all very well saying only a 95 percent chance of not, but if your baby did have cardiac defects then it would be pretty awful, so I didn't. But it [MS] did resolve over time.

G

G was faced with weighing up the potential risks and benefits for her baby. Even though the probability of her baby being born with heart problems was statistically small, for G heart defects were serious risks. But the potential to have a grand seizure was seen to be risky for both G and her baby. When she was three months pregnant, on her doctor's advice, she did start on a low dose of Tegretol. However, in the later stages of her pregnancy, her baby was diagnosed as 'failing to thrive'. At 38 weeks G was induced and her baby was born early. She now wonders if this was a result of taking the Tegretol.

Being either pregnant or breastfeeding precluded two of the women, L and B, from being prescribed medications for their MS. Both women were committed to breastfeeding and breastfed their children for two years. For B and another woman, E, utilising complementary medicines such as evening primrose oil, fish oil or homeopathy were more preferable treatments. For these women medications, such as steroids, were not an option. Being able to breastfeed their baby was seen to be more important than taking medications that would reduce the effects of MS.

## **4.6 Support – anticipating and preventing relapses, and dealing with MS**

All but two of the mothers spoke of the possibility of a relapse occurring during the postnatal period. As a means of both reducing the likelihood of a relapse and being prepared for its occurrence, the mothers had organised help at this time. In addition, the requirement of rest and restricted activity either as a consequence of MS or as a means of managing their MS, brought about the need for each mother to have some form of support. The extent and timing of the support was determined by the severity and occurrence of the mother's MS. The source of the mother's support depended on who in her immediate social circle was close to hand and ranged from immediate family members to community and organisational support.

### **4.6.1 Anticipating relapses**

While MS does not hinder women's ability to journey through pregnancy and birth and routinely require intervention, studies have found that there is an increased rate of relapse for mothers with MS in the first seven weeks to three months postpartum (Birk et al, 1990; Confavreux et al, 1998; Vukusic, Hutchinson, Hours, Moreau, Cortinovic-Tournaire, Adeleine and Confavreux, 2004). The majority of mothers had been informed of this possibility and expected to experience a relapse during this period.<sup>3</sup> After being informed of this possibility they had organised someone to provide support. Husbands and family members, especially mothers, were most frequently cited as the source of support at this time:

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3 It is interesting to note that only one of the women in this study reported a relapse during the first three months following childbirth, and another woman at five months.

We read research to say it's more common than not that you'll have quite a sizeable attack after the baby is born, when you're tired. So we put a strategy into place where my husband took a month off when my daughter was new and then my mum came and stayed for a couple of weeks when he went back to work. So I had someone home with me for six weeks. My baby started sleeping through at six weeks, so it was really, really good timing. When I was pretty much on my own she was sleeping through the night and I was able to get a lot more rest, so yeah that's what we did.

N

My mother said that she heard that it's quite likely that you are going to have a relapse after you have had a child so to be aware then and keep them in mind for help and assistance.

R

V's mother came from overseas following the birth of her first child:

I must say after the first birth my mum came out for a good eight weeks. She did help a lot with taking baby, so that I could have a sleep through the day. And I think that helped a lot. Because with a first baby you have no one, and you do get stressed, and just to keep that stress level down, she came over. And there's a very realistic possibility of relapse. Now we are fine.

V

It was not uncommon for the husbands to take at least a week or more off from their work following the birth of the new baby. The mothers of three women (or in E's case her sister) travelled from out of Auckland to spend at least a week with their daughters. The husband's and mother's presence was seen as a strategy to ensure the wellbeing of both the mother and her baby. The woman was able to get sufficient rest and sleep, while her baby's needs were met.

#### **4.6.2 Preventing a relapse**

A second supportive role that emerged in some of the women's interviews was that of the husband, who may take on the monitoring of their partner's condition:

When I'm too tired it [her hand] becomes very achy and I don't realise I'm doing it but I just stand there and kind of shake it like it's really sore. And I try and shake it off. And I actually don't even realise I'm doing it. My husband will pick me up and say, 'Oh do you realise you're doing this?' or 'Is your side playing up?' He can kind of pick things without me actually saying, which is quite lovely.

N

But my husband, it's probably a good thing but he tries to make me do less and things. [...] He'll say, 'Oh I don't want you to get too tired.' So I have to try and take it the right way. Yes. But fair enough because he has got an interest in worrying about our baby, but he's worried that I'll do too much or I'll overdo it and in a way he's quite protective. But I think he knows what could be in store for me if I got really sick. He's aware of that, that if I'm overdoing stuff you're more likely to make yourself susceptible for relapse and stuff and then that you could just deteriorate.

G

As illustrated in the women's excerpts some husbands may watch their partners quite closely and comment when they perceive their wife to be manifesting signs of MS. In this way the husband may

play a beneficial role in drawing the woman's state to her attention, thus encouraging her to rest and possibly avoid a relapse.

Mothers were also identified as taking an active interest in their daughter's wellbeing:

I think my mother had said to me, cause mum's really good. She gets everything she can possibly find on MS and is constantly telling me about this new research and this thing and that thing about it.

R

Well my mother – sometimes she picks up on things before I do. Like dropping things. I'm really good at dropping things. If she sees me drop stuff quite regularly, she'll tell me and I'll be like, 'What, oh that's right oh ok.' So I just take it easy after that. Yeah or she will ask me how I am.

F

R's mother shows her concern by seeking out and keeping her daughter current with new information and research findings. In this way she presents her daughter with possible novel treatments that may (or may not) enhance R's future.

F went to live with her mother a year after her baby was born. This day-to-day proximity has allowed F's mother to become familiar with the behaviours that have come to signify an increase in MS activity, signs that F may not be so conscious of.

Not only do some husbands and mothers possibly play a supportive role in preventing relapses, they and other people provide support to women who are affected by MS either during a relapse or long term by its residual effects.

#### **4.6.3 Dealing with MS**

The unpredictable relapses of MS have implications for a mother and her family. If she is severely incapacitated a mother has to establish support for her children and for herself. The emotional, physical and social impact of a relapse was most clearly articulated by L:

It usually sort of takes a week to kind of adjust to the, OK this is what's happening. OK I need to come out of denial that this is actually an attack now, and what do I need to do about it to look after everybody involved, really. So that's what happens to me.

INT: Tell me about when you just said – what do I do to look after everybody else – so what do you do?

Well, first I face up to the fact that something is happening, which is quite a scary thing, as you can imagine. Because you don't know what's going to happen, how seriously it's going to affect you, and how seriously it's going to affect everybody. So what I do first is I come out of denial as quickly as I can. That usually takes me a couple of days to realise – now hang on my hands, yeah, it's definitely going numb. Or yeah, I'm losing some strength in it, or something like that. And then I usually tell my husband. After a couple of days I start owning up and tell him. Then after that I think, ok, so really what do I need to have happen? And that can involve usually ringing an MS field officer [ ... ] Then usually after that I'll tell the home help that this is what's happening, if she hasn't noticed already. Because this is what

potentially might happen, and start her thinking about what might change in our household, because obviously she is going to be affected.

L

Becoming conscious that her body is weakening and noticing that the physical changes are not abating, signals a relapse of MS. L is uncertain how much and for how long the relapse will affect her and these signs are, therefore, frightening for her. Their presence requires L to inform those who will be most affected by her diminished capacity, in her case her husband and home helper, as they will have to increase their level of support.

Husbands also provide support for the women in the study who are not so incapacitated by their MS:

My husband gets a lot of time off work, so he's able to take over on his days off, and give a lot of baby care which is great.

INT: That would be quite important I think, to him.

Yeah, I mean, like any young mum, I mean I'm not saying I get more tired than others but at the end of the day I am stuffed, really, really tired and it's good to hand over to him in the evenings and stuff.

N

So far, touch wood, I've managed to be able to look after her when I've been having a relapse. But my husband's good too, like he'll just take some time off work if he has to.

R

At the end of the day the husbands, recognising their wives' fatigue, pick up and carry on the parenting role. While some mothers may be able to perform the household and mothering tasks, there may be some activities that for several reasons are designated the husband's. As exemplified by P – while she was capable of bathing her daughter, the ritual of the evening bath was pragmatically identified as an activity that her husband could do:

In terms of bathing my daughter ... the fact that we had to bath her in a baby bath initially to start off with. For me physically, I could do it, but it was a lot easier if my husband could do it. And so right from the start – that was his job. He took it on and it was great. And it was also a very, very special time for him and her, that he would bath her every night. Physically I could do it. But it was a lot easier for him to do, because it was the bending over the baby bath and the holding on and ... I just felt safer that he did it, in terms that he did right from the beginning.

P

P's lack of strength makes bathing and carrying her daughter difficult. As well as ensuring her daughter's safety, having her husband bath the baby allows him to spend time together with his daughter.

For L, the support that she requires from her husband is much more substantial:

As soon as he walks in that door and during the weekend he's it. Yes that's right. And I'll work along side him. I don't often, well having said that, usually when he arrives home I have a period of time until dinner time where I go and lie on my bed. Because at that point of the day I'm just so tired. I can't participate in anything in any kind of positive manner. So I need to just disappear. And he does dinner and

looks after the children. The home help has prepared the dinner to a point where he can do it fairly easily. She's done the preparation for it. So that it's just the cooking part or the re-heating part that he does. But he looks after the children at the same time. And about 6 o'clock, when it's dinner time, he calls me for dinner. I come out, and there's the dinner ready for me. The kids are sitting up ready. Then I'll just work alongside him until they are in bed and asleep. Then I'll rest again. He might do work or he might rest, depending on whether there's any work to do. But then he'll get up, tidy the kitchen and do other things that need to be done as well, because, again, that's a situation where I can't participate. If there're things the family needs done then he needs to do it. In the weekends I work alongside him. But he's the one who changes the nappies, gets them [the children] up in their chairs, washes their hands and faces, puts their clothes on. Does all that physical stuff, sitting them in their car seats. He does all that kind of stuff and I help alongside. But I don't take responsibility for that, he does.

L

Before embarking on becoming parents, L and her husband had not expected her MS to affect her so quickly and so severely. They expected that she would have been more able to actively participate in the lives of her children. Her excerpt reveals the laborious and constant nature of parenting and household work. Supportive partners, who are willing and able to perform the mundane but vital stuff that comprises the everyday, help to fill in the gaps, creating a seamlessness of practical and emotional caring.

In dealing with MS, support was also provided by other family members who lived close by.

#### **4.6.4 Extended family**

Three of the women identified extended family members such as siblings, cousins and aunts, who had the potential to provide support should it be necessary:

I've got two aunties just around the corner and cousins and stuff, and they all just jump in, or friends and others will lend a hand. Yeah, I've got quite a good support network really.

N

My mum and dad, and I have one sister and her husband and her family, and I have one brother and his wife and his family, who have been a major part in my life. As well as my first husband's family. They've been wonderful and still are – we are very, very close to them. And so, probably because of my situation that I've been in, my extended family are just part and parcel of my life. They really are.

P

L's extended family had supported her in many ways that decreased the amount of work that she and her husband had had to do. She identified how helpful she had found their ongoing concern, the prepared meals and family functions organised in such a way to reduce her workload. But in the last year her circumstances had changed so that L had to approach her extended family to increase their support:

So, I did the difficult thing of going round, asking them if they could possibly have the children for a morning or an afternoon in the weekends once a month, so that my husband could have time off during the weekend. Because the amount he had to do has just increased. And I started to have a rest as soon as he came home from work. Well I just had to rest more, so he actually had to be the sole kind of

parent more, if you know what I mean. So the amount of time and energy he had went down and also his work load's gone up at work. So I realised we needed more help and I thought the way to do it was just ask my family. And I realised my illness is going to progress. I am going to get sicker and I'm going to need more help in the future. [...] I need also our family to participate a lot in our children's lives and I might need them just that more over my lifetime. I'm guessing I am going to as the amount of energy I can give my children and the time I can give them decreases I'm going to need that to be replaced. And while it's nice to have these people who come in – my home help's great, she's been here nearly a year now so the children have got to know her really well and you know all that's worked out really well, I realise that she's not going to be here for all their life and so I need people who are going to be here all their lives to participate.

L

Not all the women who took part in the study required extended family support or had family close by, but for those who did their family members stepped in at critical times providing support. As highlighted in L's excerpt, her extended family provided not only physical respite for her husband but also continuity for her children in terms of close relationships. Her extended family filled the physical and social gaps left by her inability to provide such support to her children in their day-to-day lives. She foresaw aspects of mothering that she would have lessening capacity for and reluctantly was prompted to ask for support.

#### 4.6.5 Other supports

Other sources of support such as friends, childcare and their church community were identified as being important, especially for those women who did not have family support. While the family may play a significant role in providing physical and social support to mothers with MS and their families, social networks also give necessary assistance especially when families are not present or able to do so. Also it must be noted that the support of husbands or partners cannot always be assumed. One woman found that her husband did not understand her condition and had worked against some of the coping strategies that she had put into place:

Because it wasn't helpful having a husband at the time, but I'd take, because my memory was getting quite bad I'd forget things real easy, and so I'd take to writing a list or putting things in particular places that would get moved [laughs] you know, so it would really disrupt my process.

B

B's strategy for compensating for her memory loss was hindered by her husband. She found he did not understand her lack of energy and the difficulty she had in keeping the house as tidy as he expected.

Other women who spoke of family support said:

My mum and dad, they live out of Auckland, so they are only a couple of hours away and they are always on hand. And I just have to ... a lot of my friends know and so there's a lot of people that can come and help me and do things with her if I can't do things. But as I said, I'm not ... I think I'm lucky I don't get those bad an attacks, that usually I can function, I can do most things.

R

It's all in your mind. If you tell yourself oh this is hard, it's difficult. Well then it will be difficult. And sometimes I have days where I think oh god what have I done, I



can't handle it, it's too much. And I sit down and go: no it's not. Then I look at people who have four kids and I go, if they can do it, I can do it. And if I am tired then I try to arrange ... one day actually just after his birth, my friend came round and she sat here in my living room playing with her kids and I went and slept for two hours. Now she's pregnant and I will do the same for her, you know?

V

We had lots of support, like my church, and everyone brought things [ie meals], I know a lot of women out there that wouldn't necessarily have those things, so I feel grateful for those, so that made things a lot better.

G

With the birth of her second child, V did not have the support of her mother. Similarly with R, G and B, their families were not close by. Two of the women's children attended childcare centres. B used this time to focus on her youngest child, deal with household work and also to rest. For L, childcare provided an important opportunity for her to rest, especially when she experienced relapses.

#### **4.6.6 Plunket**

Five of the women spoke of either being visited by or visiting the Plunket nurse in their area. Three of the women found that their Plunket nurses provided information and support, particularly for breastfeeding issues. For example, E's Plunket nurse reassured her about her breast milk supply and her ability to breastfeed her baby. Two women identified visits to the Plunket clinic as an issue:

They only came to visit me, not many times actually, and then I had to go and make the trip into the Plunket rooms. For me doing that by myself with a newborn baby, not a newborn but a young baby, that was a hard one. It was a bit hard for me. But I did it and I did it well. But it was just, and I don't know if I was being selfish, but I just didn't think that they gave me enough home visits so to speak. They expected me, ok we've seen you, I don't how many visits it was at home, but it wasn't many. Maybe it was two or three and then after that I was expected to go into the Plunket rooms and that. And that for me that was just a little bit scary.

P

For P the home visits stopped too soon for a woman with a new baby. For B, who had three children under the age of five, the effort of getting to the clinic was physically difficult and stressful. Planning ahead was an important strategy for B and had important implications when it came to keeping up to date with her Plunket visits. Her Plunket nurse had on at least one occasion telephoned her to arrange a visit to the clinic that same day. At that time B and her husband shared a car. To keep the clinic appointment she would have had to catch a bus with her three preschool children. As well as the expectation to attend the clinic, she had found, with having three children, the number of the health checks throughout the year was an added stress for her. Consequently she was unable to keep up to date with the scheduled visits.

#### **4.6.7 Government assistance**

The final kind of assistance that three of the women spoke about receiving was government assistance in terms of financial assistance for home help, carers, childcare and physical aids. The process for obtaining physical and funded assistance, however, was a process that the women found both positive and negative. Since being formally diagnosed with MS, and now separated from her husband, B had become eligible to be a sickness beneficiary. P spoke about how means testing limited the amount of support she could claim. Because of problems with balance she needed to have handrails installed. The Government would only fund one set of handrails and she had to choose which of the two bathrooms the rails went into.

L described her experiences of getting home help when she had relapses and was unable to care for herself. She was required to negotiate with two organisations, one that assessed her needs and governed the funding of carers, and a second that organised the carers. For her the process of negotiating with the two agencies was time-consuming and energy-sapping. At one stage during a relapse she did not know from day to day if a carer would turn up to shower her. She describes the support she requires:

In the family the home help comes in and she does housework. She does cooking for us, she looks after the girls, she lifts the girls in and out of the car seats. She does a lot of manual stuff that I couldn't do. Like putting sunscreen on every day, which seems a little thing, I know, to everyone else, but the sort of thing that is very tiring for me. All those kind of things. She makes sure everything's ready for us in the morning, unloads the dishwasher, ensures the washing's out, and brings it back in. She remembers things, because it's [MS] affected my memory. So she helps remember that we have to have certain things to take to kindy and crèche, and comes with me so that she can mind one of the children in the car.

L

In approaching the assessment agency for support during a relapse she had the following response:

Because it [the assessment] has to be written in such a way that it's my personal care, rather than including the children. What that's meant is that the last talking with [the agency] I've had is that they are threatening to put me into a rest home. Because the number of hours that I have is so high that a rest home would be a cheaper way for them to provide that care, you see. Of course [the agency] fully knows that I have two young children and everything. So I said, well I can't really see how me being in a rest home is going to work for my children. And is there a rest home that would have the facilities for two small children to live there? I doubt it, you know. They implied that maybe I would have to go to a rest home and my children and husband would live in a house somewhere else, which obviously is not the situation that I will accept.

L

Access to help was dependent on meeting formal requirements, such as a medical diagnosis and certain income levels. A shared theme in the three women's narratives was the bureaucratic processes that they each had to contend with in order to gain government funding. The level of support that L required threatened her ability to stay with her family. Her needs exceeded what she was allocated and the agency's resources. What is quite clear is that a rest home does not allow the mother to continue mothering and that a resource threshold exists where it becomes too costly for the mother to remain in the community. In this way some disabled mothers may be separated from their children.

## 4.7 Conserving energy

For all the women their energy is seen as a finite resource that is to be used judiciously. This economising strategy is both an outcome of the fatigue caused by MS as well as a means of managing the possibility of a relapse that may be triggered by fatigue and stress. Becoming a mother and being a mother were the two areas which the women spoke about.

### 4.7.1 Becoming a mother

Seven of the women regarded themselves as capable of giving birth naturally and six of these women were under the care of midwives. L, N and P were under the care of obstetricians. All the women gave birth in hospitals. Five of the women gave birth without intervention. P had a normal birth but required

the use of ventouse suction.<sup>4</sup> R and C required emergency caesareans and L had an elective caesarean.

When the time came for the women to give birth, having the energy that labour and childbirth required was raised as being important to some. For L, from the outset it was evident to her and her doctor that she did not have the ability to give birth without intervention. She was told by her doctor:

She said to me, 'Look, the worse thing for you, L, would be to go through a natural labour and then a caesarean, because your body will come out the most tired and worn out and everything at the end of those two things.' [...] And she said to me, 'Look, L, that's what you need to weigh up. The worse case scenario would be for you to send your body through those two situations. Then the recovery from that would be huge. And given your risk of relapse after the baby's born, we want your body to be in the best possible shape you can have it in after that baby is born.'

L

Developing MS had precluded L from the natural birth she had envisaged. She saw herself as being quite different from the other women in her antenatal class and the content of the classes focused on natural childbirth. The fatigue that she had experienced during pregnancy completely incapacitated her. She spent most of the day in bed building up energy, for example, to attend the antenatal classes, some of which she had had to attend in a wheelchair. Having a caesarean was seen as inevitable as her body did not have the energy required to give birth by her own means.

P had been seen by an obstetrician during her pregnancy but, given her previous history of natural childbirth prior to being diagnosed with MS, had felt that a birth without intervention was possible. Fatigue though became a concern after she had been induced:

And that's when it all started to happen. I then had a very rapid delivery and because ... I was going through labour, really it was very fast and intense. But the baby got stuck in the S bend, so to speak, and her head was there. She was crowning. But I just couldn't get her out. And I think I was really tired. The fatigue was really setting in and I just said to the hospital midwife that was with me, 'I'm just really, really tired and I cannot push her out.' So they gave me an epidural and they took me into the delivery suite ready for a caesarean and they said, 'We'll just try once on the ventouse.' Is it ventouse? [Background voice: The plunger!] J: The plunger (much laughter), and honestly she was out within seconds.

P

For the other women there were varying experiences regarding maternity practitioners' knowledge of MS and their use of strategies to prevent the women from becoming fatigued during childbirth. N found that she encountered contradictory views regarding the use of epidurals during labour. In an antenatal visit she had been told by one medical practitioner that, because of her MS, an epidural was not an option. But during labour the attending anaesthetist reassured her that an epidural would not aggravate her MS and so she was able to have it as an analgesic. B's midwife recommended the use of a birthing pool to minimise her energy expenditure. In contrast, E's midwife, who had been recommended as a midwife experienced in caring for women with MS, used interventions, for example, rupturing membranes, to 'speed up' and shorten E's labour. While overall the women felt satisfied with their care, two women suggested that they would prefer to have midwives who specialised in caring for women with MS.

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<sup>4</sup> Ventouse suction is an intervention used to assist the birth of the baby whereby a cap held onto the skin by suction is placed on the baby's head and used to pull the baby from the birth canal.

#### 4.7.2 Being a mother

The mothers see energy as a resource that needs to be monitored, regulated and renewed. It is necessary to ensure that they do not exhaust its supply as this has the potential to precipitate a relapse. All the mothers spoke about managing their energy in relation to their mothering. Most mothers found that their energy fluctuated from day to day and that their level of energy determined how much they could do. But what was significant was how their energy fluctuated from day to day and in this way affected how much they could do.

#### 4.7.3 Monitoring

I see a homeopath, and he sends me different medications. If I feel like I've got a relapse coming on I give him a call, and he tells me to take this and that. He's really good actually and I ring him in a few days and he asks how I am and yeah if I feel a lot better or I change them to one...

INT: holds them at bay kind of thing

Yeah.

INT: Oh. OK and that recognising what comes on is that numbness when as you said earlier you feel that sensitivity you start to get those and then?

Yeah, And I usually find I've noticed a bit of a pattern at the start that if I then had a relapse I got this soreness at the back of my head. Like a real dull pain that just wouldn't go away with taking Pamol or Panadol or Neurofen or anything like that, just a dull ache. So yeah I listen to what my body's telling me.

E

Several of the women spoke about how, like E, they recognised subtle symptoms that signified their MS. When they perceived signs such as tingling, or numbness that signified a potential relapse they then set in place various preventative strategies.

#### 4.7.4 Regulating

All the women organised their days, placing limits on how frequently and how long they would go out for and how much housework they would do each day:

Yeah I do think about – like the night before, I'll think what I have to do in that day and whether it's for my daughter and I'm with her. By the time I have a day off and I've got to walk to the shops or something I'll do one trip and that's it for the day, because if I do more than that then I'll get really tired, really weak. I always think about the next day, I know I always have. I don't know if that's, I suppose that is MS-related really. I don't know it's all normal to me, it's really strange.

F

So if you go out try just one outing. Try to pack the kids up into the car, go somewhere once a day and not try to have a morning one and afternoon one because she sleeps over lunch obviously. And if I have to pick up something for my husband or go grocery shopping or something then if it doesn't get done, it gets done the next time.

V

I'll do the vacuum cleaning usually on like a Wednesday or something and have that break in between. So I'll do one half of the house on Wednesday and the other half

you know not the next day, the day after things like that, yeah so I've just had to stagger things.

B

As well as being organised and ensuring they did not overburden themselves with activities inside and outside the home, two of the women spoke about how they recognised the relationship between becoming stressed and relapsing:

I know that with stress I get, because of studying that's definitely what brought on the episodes, and so I just try to, you know, relax and just make changes in my life so that I don't get stressed.

INT: So would you mind telling me about those, about what changes you've made to minimise stress?

I don't know, it's really hard to say ... I guess, giving up work while I was still studying was probably one of the big things. And being organised with my study when I was studying, because I was in my third year last year. Just to make sure that I was really organised because I did a big project and just make sure that I was organised.

E

To me I would say when I'm going to have a relapse it's usually emotional stress, emotional pressure. Like when my daughter accidentally hit me, I got hit in the head that's the first, the only time I can think of that it was the physical hurt that made me, that started the relapse. For me it's always – for example, I'd broken up with a boyfriend and it was stressful, or something emotional had happened and I'm really stressed and anxious inside myself and that's when it all starts to happen usually.

INT: Right and so it's understanding that those kind of events that might trigger it off?

Yeah, and don't go there and just try and deal with it, deal with things as they come up so that they don't – like don't bottle them up and let small things grow into big things. You know actually work stuff out as you go along in life.

R

The women not only organised themselves in relation to their MS, they also organised others. For example, B highlighted her friends' understanding of her MS and her need to schedule her outings:

But my friends – also it means they tell me a bit more in advance instead of just making spur of the moment decisions. Such as if they wanted me to go shopping with them or something, then they'll give me a couple of days notice, so I can stagger everything else that I was going to be doing that day.

B

P had developed a strategy for making her young daughter aware of her limitations and in a sense regulating her daughter's requests:

I always remember I was just heading off into the shower and we were at hospital and she started to wake and give a few little cries and that, and I always remember telling her quite frankly – like she was only like a day old, I said, 'Mummy's going to have a shower and you are just going to have to wait and I will be back soon', and I

went off. Didn't get panicked or rushed about that. I thought, I need to have a shower and I will be back and I will tend to her when I get back. And so I did that and it was just like I had to say those type of things to her and to myself to think that, you are all right. You're going to be OK in this situation. [...] And still to this day when we go out although she's so independent now at four and a half. But other things, like she holds daddy's hand. She doesn't hold my hand. And she knows. And I always remember like we used to drive home, this is another time and she'd be asleep in the car in the car seat and she would wake up and cry and be all tired and that and I said, 'I cannot carry you inside but I can hold your hand', and she would be OK with that. I said, 'Mummy can't carry you inside but I can hold your hand until we get up to the lounge and then we'll have cuddles.' That type of thing. And explaining to a two- and three-year-old that it's amazing how they accept that.

INT: And you've done that virtually from the time she was born.

Exactly, and that's how it has been with her. I've had to explain, 'Mummy can't do this but mummy will do this, I will walk with you and I will hold your hand and we will have cuddles.' And you know it's all about talking to her and explaining to her and it's amazing how their little minds can cope with that.

P

P has found that by consistently explaining to her four and a half-year-old daughter what her physical limitations are that she has become familiar with them. Her daughter has developed a knowledge and understanding of P's MS. What P makes evident is that she does not deny her daughter's needs. Rather, she provides other ways of meeting her daughter's needs that she is more capable of doing.

As well as regulating their use of physical and emotional energy, the women also set in place a strategy for renewing it.

#### **4.7.5 Renewing**

For all of the women regular rest periods and sleep were critical in managing their MS:

Everyone's tired but I, sometimes I get into bed and sometimes I just think I don't think I could be any more tired, especially you know at the end of the day looking after her, I'm just stuffed and um, yeah so managing the tiredness is a big thing because if I'm too tired things flare up and I know that from past experiences.

N

With having my baby, just every day for about half an hour to an hour I'd sit down with my feet up and just read a book, you know, just do that not to give myself um give myself not so much to do. Because I'm one of those, the sort of person that who likes to, you know, make a mental list of and just do them, and do them, and do them. Whereas I just kind of relax a lot more. I don't offer my services as much as I used to. Take time out for me. Yes, and make sure that I get plenty of sleep. That's the big one as well.

INT: So having a rest then is really important for you?

Yes, when I need it. I mean there are quite a few days where I can go without it and get on with things but there are also some days where I'm just too tired. I go from waking up in the morning to thinking about my nap [laughs] how soon can I get to have it [laughs], you know?

B

The opportunity to rest is sought after by the mothers. As N highlights, excessive tiredness may cause relapses and subsequently rest is a routine and important prophylactic measure. The mothers usually rested while the children were having their rests thus ensuring that they were able to provide continuous care.

## 4.8 Being the 'ideal' mother

Depending on the severity of their MS, some of the women perceived that MS compromised their capacity to carry out some of the activities associated with being an 'ideal' mother:

INT: So what sort of strategies have you set in place so it's been relaxed about your time management and getting things done?

Well I mean especially with two kids. They always manage to do everything at the same time. They both want food at the same time, both cry at the same time. Just if he cries, well he'll have to just cry for five minutes till I've sorted her out. Because she's going to cry louder than he will, and she's going to get more annoyed than he will. So instead of getting stressed and going 'what to do?' I'm, well, he can cry for five minutes that's fine, it's not going to kill you. Just that mind set that it is all right if I take a bit longer to get done.

INT: And so giving yourself that...

And trying not to feel like a bad mother.

V

I still do all the other things that a normal mother would do in terms of the physical stuff in bringing her up. I'm just trying to think, but I pretty much do everything else, like cooking and feeding her and playing with her. Sure there were some things that I physically couldn't do in terms of playing with her and that, but again it's just all about a matter of thinking, 'OK what can I do with her', you know? I can sit down on the floor with her and read books and drawings and things. But I can't maybe run around the field with her, or things like that. But that's what other members of the family can do.

P

While the issue of being an ideal mother was not raised by many women, it seemed a strong perception warranting explicit consideration to encompass the range of experiences. Underlying V and P's evaluations of themselves as mothers are criteria of what constitutes a 'good' or 'normal' mother. These include being able to meet the multiple needs and demands of their young, dependent children, and, as highlighted by V, within a certain time. Mothering is associated with activities such as preparing food, feeding children, amusing them in appropriate ways, avoiding prolonged or excessive displays of distress and maintaining a clean, tidy environment. There is the potential for the mothers, if they are unable to meet these criteria, to be judged a 'bad' or 'abnormal' mother. V resists categorising herself as a 'bad' mother, knowing that this may be detrimental to her wellbeing. She knows that she can meet her children's demands. In this way the women accept the limitations that MS imposes on their physical capacity and find other ways of caring for and being with their children.

In summary, the strategies that became evident in the analysis were as follows:

<b>Timeframe</b>	<b>Theme</b>	<b>Specific strategy</b>
Pregnancy	Backgrounding of MS	Positioning oneself as a normal mother capable of journeying through pregnancy, birth and motherhood without being affected by one's MS.
	A public private experience	Seeking information from multiple sources: GPs, neurological specialist doctors and nurses, MS Society, literature and internet. Discussing the decision to have children with family members.
	Medication – keeping the baby safe	Seeking information about the effects of MS medications on the unborn child. Finding alternative complementary medicines.
	Support	Identifying and enlisting support from husbands, family and others.
Birth	Conserving energy	May depend on each woman, the degree to which she is affected by MS, her perspective of birth and the knowledge of her maternity practitioner.
Early parenthood	Support	Drawing on the support that one has available, for example, husband, parents, siblings and friends. Accessing formal support, for example, MS Society, Plunket.
	Conserving energy	Taking time to rest. Planning and limiting outside activities. Minimising emotional and physical stress.
	Notions of being the ideal mother	Re-evaluating the criteria of being a 'good' mother and determining one's own standards. Accepting limitations and finding other ways of being with and caring for one's children.
	Medication – keeping the baby safe	Finding complementary medicines as alternatives. May prioritise the baby's access to breast milk over taking medications.



## 5. DISCUSSION

The aim of this study was to provide a better understanding from mothers' perspectives of issues of concern and the strategies that help mothers manage when they live with MS. One of the key concerns was the ability to access accurate and up-to-date information about MS in relation to pregnancy, birth and motherhood from a wide variety of sources.

In analysing the interviews, variability both in the course of the MS and its effects on the individual women was a key underpinning theme. Barker-Collo, Cartwright and Read (2006) found in their study of 16 people who had RRMS and PPMS that there was a marked difference between the two groups in relation to the impact of MS in their lives. For the former group they noted that the unpredictable fluctuations associated with this type of MS created variability and uncertainty for their participants. Smeltzer (2002) noted that the uncertainty of MS had both positive and negative aspects for women's decision-making regarding MS and motherhood. One of the positive aspects was that because the course of MS was unknown they were reluctant to give up on becoming a mother.

While this study aimed to explore how tasks which involved fine motor skills and strength were affected, these were not identified as concerns by the majority of the women, except for P and L, the two women whose physical strength was most affected. As described, they dealt with the issue by delegating physically demanding tasks to their family members or home help.

Among the nine women interviewed for the study there was variation in their experiences of MS. At the time of interview some had not experienced relapses for several years, while one woman was in the midst of a relapse. Most of the women reported that their MS did not significantly impact on their lives and hence affect their ability to care for their children. In contrast to the two women who were incapacitated during a relapse, relapses caused only minor changes to their everyday lives or they experienced residual effects that limited their ability to mother. It is possible that the intermittent nature of RRMS, while it may create an uncertainty about the future, can offer women periods of relative normality when they do perceive themselves as capable of carrying out the work associated with being mothers. Practitioners providing services to mothers with MS and their children need to be aware of the unpredictable and variable nature of MS. Assessment should be ongoing and take into consideration the possibility of changing needs. Services, too, need to cater to changing needs.

Similarly, their experiences of relapses and residual effects may well have contributed to most of the women putting MS in the background of their everyday lives. MS was there, but not there. Becoming a mother appeared to allow these women an opportunity to perceive themselves as 'normal' women.

In contrast for three of the women, MS was to the fore of their everyday lives. Their MS, manifested by problems with balance or fatigue and muscle weakness, affected aspects of mothering and needed to be accommodated by family, friends, health professionals and government organisations.

These contradictory perspectives have implications for health professionals and others interacting with mothers with MS. Each woman's experience needs to be seen as unique and particularly in the initial meeting the practitioner should be sensitive and open to how the woman perceives herself and her MS. There needs to be a degree of flexibility in determining how the woman's needs may be met. L's experience reflects how a 'one size fits all' approach to accessing home support has the potential to separate a mother from her child. Using a model that is more appropriate for older adults may deny the place of the family and the mother from being with her children. Prilleltensky, a North American author, makes the point that the presence or absence of financial and practical supports is determined by government priorities. "Ultimately, what mothers with disabilities receive in the way of funded assistance is directly related to the importance politicians ascribe to the well-being of this population" (2003, p. 44). Therefore, one interpretation that could be made of L's experience is that

disabled mothers are seen in New Zealand society as a marginalised group and so funding to enable them to remain at home may be insufficient.

A stereotypical view of a competent or 'good' mother is one who can perform the care-taking tasks traditionally associated with mothering (Lloyd, 2001). This expectation then places pressure on women with disabilities such as MS to show that they can measure up to the role of mothering. Grue and Laerum (2002) found that the disabled women in their study were fearful that if they did not live up to other people's expectation of managing motherhood their children would be taken away from them. In L's case, if she was found not being able to manage herself, her children would have been taken away from her.

Before embarking on motherhood, the women in this study accessed many sources of information such as their family, general practitioners, neurologists and the local MS Society. Seeking advice from expert sources assured the women that motherhood was a possibility and that pregnancy did not aggravate the course of MS. This finding is confirmed by Smeltzer (2002) whose participants similarly drew on multiple sources. In contrast to Smeltzer who found conflicting and inconclusive advice from health professionals, all the women except one in this study received the same advice regarding the effects of pregnancy and motherhood on MS. One main reason for the consistency of information, we suggest, may have been that the women all came from the same geographical location and attended the same neurology clinic and team of neurologists and nurses. As mentioned in the body of this study two women did encounter contradictory views regarding the use of epidurals in childbirth. Two were told that as women with MS it was not an option. Yet one of them was advised to have one during labour.

In going beyond the private relationship between woman and partner, the mothers, ironically while gaining assurance, make themselves vulnerable to the beliefs and values of others. Grue and Laerum (2002) identify one perspective of disability that constructs disabled women as "passive receivers of help and social services, and not as women themselves capable of caring" (p. 673), and, therefore, not capable of becoming mothers. L's experience in this study also highlighted the perspective that for a woman who is severely affected by her MS, especially with fatigue, normal childbirth may appear to be too exhausting. Practitioners then ought to be aware of their own and other such attitudes that women with MS (and indeed other disabilities) may encounter in the process of decision-making, and ensure that women are given the opportunity to explore their own values and beliefs regarding MS and motherhood.

One of the assurances sought by some of the women before embarking on motherhood was the provision of support. The study has identified the vital role of husbands, mothers and extended family in providing support that facilitates mothers with MS to be able to mother, and which also works to provide a physical and social wholeness that draws on kinship links in the care of the children.

The time when all of the mothers had organised support was during the immediate postnatal period which the literature and their health professionals indicated is the most common time in which a relapse is most likely to occur (Birk et al, 1990; Confavreux et al, 1998). In New Zealand unpaid parental leave is available to spouses and partners for up to two weeks. It is interesting to note that while the women were supported by their husbands taking time off work, and/or by their mothers staying during this time, such intensive support did not extend to the full three months.

The amount of support given by the husbands in this study was determined by the women's conditions but overall the husbands provided important day-to-day support. Similar to this study, Fleming Courts, Newton and McNeal (2005) found in their study of husbands and wives living with MS that husbands often assumed the role of protector, safeguarding their wives' environment and activities and protecting them from using excessive energy. In our study some mothers of the women also assumed the role of protector.

Only three of the women received assistance from the Government. These funds and services are determined according to the person's level of physical needs and income, by agencies such as Work and Income Support, Needs Assessment Services Co-ordination and health professionals such as occupational therapists and physiotherapists. Three women had sought advice on assistance from their regional MS Society and one woman had made contact with another mother who had MS. The Plunket Society was also identified as a source of advice for some of the mothers in relation to managing their own wellbeing and that of their child.

The chronic, unpredictable and fluctuating nature of RRMS has implications for employed husbands or partners who wish to support their partners. RRMS places inconstant degrees of demand on the partner and, therefore, the ability to take time off work, work flexible hours or take work home without being penalised is required. Flexibility is called for regardless of whether or not this is inherent in the husband's specific occupation. L's description of her husband's support highlights the demands that may be placed on a working father with young children and a wife with a disability. In order to facilitate husbands' support employers should be made aware of different types of MS and their courses. This may be achieved, should the husband or partner request, through measures such as the MS Society providing pamphlets to the workplace, or supporting the employee in approaching employers.

Acknowledging the role of husbands and other family members raises the question of support for single mothers with disability – mothers who either do not have family close by or family who are able to support them. Graham (1999) notes that some husbands do not understand their wives' fatigue and inability to care for a baby as well as perform the household work often associated with being a woman (p. 120). Some relationships may break up following a diagnosis of MS (p. 60). Therefore, supports beyond the family are important and need to be recognised.

Stressful events have been associated with the worsening of MS symptoms or the development of new symptoms (Buljevac, Hop, Reedeker, Janssens, Van der Meche, van Doorn and Hintzen, 2003). The view of one's physical and emotional energy as a limited resource that requires judicious use and regular renewal is an important finding of this study. The women know their bodies, they recognise the subtle symptoms that signal MS activity and have learnt the link with energy use. In managing their MS by regulating their days and limiting their activities they accommodate their MS as part of their everyday living. It is interesting to note that four of the mothers worked part-time; however, the issue of exploring the implications of managing one's energy and time in relation to part-time work, is beyond the scope of this study but warrants further research.

Understanding the need for a mother with MS to plan her days and limit her activities has implications for health professionals, such as Plunket nurses and community midwives. Appointments for clinics need to be made ahead so that the mother can organise transport and other commitments. Consideration needs to be given to visiting these mothers at home rather than expecting them to make clinic visits.

This study has highlighted information that challenges some apparent attitudes, beliefs and actions of health and social professionals and indeed the general public, that may be 'disabling' to women with MS. The recommendations highlight actions that could be taken to encourage and educate for a non-disabling society for women and their families as called for in the *New Zealand Disability Strategy* (Ministry of Health, 2001). The study has further identified ways to address other aspects of the strategy by highlighting ways to support lifestyle choices, recreation and culture for disabled people; promote participation of disabled women in order to improve their quality of life; and value families, whānau and people providing ongoing support.

## 5.1 Future study

Only two of the women participating in the study experienced a relapse during the six-month postnatal period. A New Zealand study into relapse rates during pregnancy, birth and the postnatal period would add to the international body of knowledge especially in relation to the geographical location of the women.

This study showed the importance of the support of husbands and family members. Further studies could investigate how partners and the family cope with having a wife or daughter with MS. Furthermore, in relation to the work setting, exploration of the impact on both the woman and her partner's opportunity for advancement is warranted and could be raised as a future research question.

While this study did not seek to elicit information on support strategies that midwives and others employed during labour, two women reported contrasting practices used to reduce their energy expenditure during labour. Maternity practitioners specialising in caring for women with MS may provide useful information.

A further area for study could be examining the physical and emotional effects on MS of having children compared with not having children.

As noted in the conclusion, broadening the focus on MS to mothering with other areas of impairment would be valuable.

## 6. LIMITATIONS OF THE RESEARCH

As noted in the methods set out in Chapter 3, a number of limitations to this research exist. Clearly specific findings are not generalisable in the same way as epidemiological or population-based research. However, such generalisability is not an intention in qualitative research studies. It is reasonable to assume that the themes and relationship between themes has relevance beyond the group of women who took part and such theoretical generalisability warrants prospective testing.

The sample size may be considered small (n=9); however, it is not uncommon for smaller samples to be used in qualitative research, for example some studies propose that for a homogeneous population, n=5 will suffice. We expanded to nine for a number of reasons. We wished to avoid any assumption that the experience for women would be similar even though there are a number of similarities in the way MS presents. We also wanted to test out some of the emerging themes in women with similar or different experiences in an attempt to reach saturation of the data – to proceed until no further themes emerged. However, in future work it would be useful and important to expand recruitment to include women who chose to avoid pregnancy or motherhood and also include fathers and other family members as they undoubtedly have a perspective that would enrich our understanding of the impact of MS on motherhood.

All interviews were carried out by one of the three researchers meaning that her approach to interviewing will have influenced the data. To that end, it is important for readers to be aware of her perspective. This researcher is an experienced nurse, lecturer and researcher with an interest in women's health, particularly from a feminist perspective. Her approach to the data was complemented by the involvement of the second researcher, a nurse, midwife and rehabilitation researcher, and the third researcher, a mother with MS who has two children. These three approaches to the research facilitated a fulsome exploration of the data and testing of interpretation.

The study findings cannot be generalised to all mothers with MS for several reasons. We only recruited nine women into the study and there may have been other women who are not known to the two organisations which we used for recruitment. Importantly, our participants did not include women who have primary progressive MS or who were significantly impaired by their MS. It may be that their experiences would be different from the women in our study. Women with primary progressive MS, which has a prognosis of gradual deterioration, may make different decisions about pursuing motherhood and may be discouraged from becoming pregnant by family members and health professionals. Except for one woman who identified herself as a European Māori, all our participants identified themselves as European/Pākehā. The women were not asked to identify their partner's ethnicity.

Future studies could actively recruit women of childbearing age who have been diagnosed with primary progressive MS or women with MS who have chosen not to pursue motherhood, or they could recruit women to compare and contrast their decisions and experiences of motherhood. Other studies, employing a culturally appropriate study design, could include a more ethnically diverse population of mothers with MS and also explore how their partners' cultural beliefs and values influence their experiences of motherhood.

## 7. IMPLICATIONS

Given the nature and size of the study, policy and practice implications are proposed with caution. Nevertheless, we would suggest there are some fundamental shifts to be made in how services and supports are provided to women with MS and, potentially, other impairments. There are three main areas for consideration, each of which has many potential facets for action. We have listed just a few:

1. The importance of 'listening' to women's stories prior to making assumptions about their attributions and aspirations and support needs in relation to motherhood and family life. Clearly this has particular relevance for health and social professionals but is also relevant for general members of the public, work colleagues and family members.

Possible actions:

- a. Further education about the different types of MS at both a societal and health professional level
  - b. Workplace support and flexibility for husbands and other family members
  - c. Recognition of the support given by partners and other family members
  - d. Changes to policies on funding home supports where the person is also a mother/parent
  - e. Extension of parental leave for families where there is a disabled family member.
2. The relative place of impairment in women's lives is variable and likely to require ongoing consideration rather than one-off static assessment or action. Ongoing considerations should include the women's life context as well as their pregnancy and impairment.

Possible actions:

- a. Sensitivity on the part of health professionals and others caring for and working with women with MS. Health professionals need to be sensitive to how a mother with MS considers it will impact on pregnancy, birth and motherhood. This can be achieved through careful assessment, ongoing watchfulness and openness to renegotiation
  - b. Flexible arrangements for mothers who have MS, such as an extended number of home visits from Plunket nurses and set appointment times
  - c. Education for midwives and easy access to existing and emerging information about impairment and motherhood.
3. Knowledge and understanding in the area of motherhood for women with MS remains limited, particularly in New Zealand. It is vital that research focuses on how best to ensure appropriate health and disability policy is developed and quality health and social services/support is available for women with an impairment wishing to become mothers.

## 8. CONCLUSION

This study provides insights into the situation of women of childbearing age who have a particular form of MS that fluctuates in its effects, offering these women periods of relative normality. MS and motherhood are both complex situations. Most women interviewed felt their MS added to that complexity but did not overwhelm it. The experience of becoming and being a mother was considered a vital and important part of life.

Two particular issues were noted as marking the experience to be different: support in both the immediate and subsequent postnatal period has special significance for mothers with MS; and the need for mothers to conserve their energy through various means. Being able to access support and to conserve their energy gives women the potential to maintain a level of wellbeing so they can continue to mother.

We are grateful to the Blue Skies fund for funding this research which has achieved two key aims:

- a. Although understanding about the nature of motherhood, parenting and disability has been strengthened over recent years, particularly by the work of Grue and Laerum (2002), Prilleltensky (2003, 2004), Thomas (2001) and Thomas and Curtis (1997), this study, by exploring the perspective of New Zealand women with MS, has further strengthened knowledge that can be used by New Zealanders.
- b. In addition to the innate value of the enhanced understanding stimulated by our participants' stories, the work has also underpinned an application to the Health Research Council (pending a funding decision but well reviewed) to explore the adequacy and appropriateness of health and social services for women with a range of impairments.

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## APPENDIX 1: AN OUTLINE OF PARTICIPANTS

<b>Pseudonym</b>	<b>Age group (yrs) and ethnicity</b>	<b>Type of MS</b>	<b>Number of children</b>
V Full-time mother Married	25–30 European	Relapse remitting	2
L Full-time mother Married	30–35 Pākehā	Relapse remitting	2
R Part-time work Married	30–35 Pākehā	Relapse remitting	1
P Part-time work Married	40–45 European Māori	Secondary progressive	3
G Part-time work Married	30–35 European	Relapse remitting	2
F Part-time work Single mother	20–25 Kiwi	Relapse remitting	1
B Full-time mother Single	30–35 European	Relapse remitting	3
N Full-time mother Married	30–35 European	Relapse remitting	1
E Full-time mother Married	30–35 European	Relapse remitting	1

## **APPENDIX 2: GLOSSARY OF TYPES OF MS**

### **Relapse remitting MS**

MS follows different patterns in different people. The relapse remitting form of MS follows a course of relapses where there is an increased level of symptoms, followed by remissions in which there are fewer, or no evident symptoms. The periods of acute attack occur when a patch of inflammation damages nerve fibres so that messages do not pass clearly from the brain to other parts of the body. The frequency and severity of relapses varies. Some people with relapse remitting MS go on to develop secondary progressive MS.

### **Primary progressive MS**

A form of chronic progressive MS, in which there is gradual deterioration from the onset of MS, without sudden relapses. About 10 percent of MS cases are primary progressive.

### **Secondary progressive MS**

A form of chronic progressive MS, in which some people who begin with relapse remitting MS find that over time their symptoms gradually worsen without relapses. Some people continue to experience occasional relapses in this phase.

### **Chronic progressive MS**

Most people with MS experience a relapse remitting form of the disease. In chronic progressive MS, however, there is a gradual deterioration in neurological function. The degree of progression, and the time over which it takes place, vary from one person to another. Chronic progressive MS may be primary or secondary in type.

Source: <http://www.msakl.org.nz/glossary.htm>







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Families Commission

PO Box 2839

Wellington

Telephone: 04 917 7040

Email: [enquiries@nzfamilies.org.nz](mailto:enquiries@nzfamilies.org.nz)

**Wellington office**

Public Trust Building, Level 6  
117-125 Lambton Quay  
PO Box 2839, Wellington  
Phone 04 917 7040  
Fax 04 917 7059

**Email**

[enquiries@nzfamilies.org.nz](mailto:enquiries@nzfamilies.org.nz)

**Website**

[www.nzfamilies.org.nz](http://www.nzfamilies.org.nz)

**Auckland office**

Level 5, AMI House  
63 Albert Street, Auckland  
Phone 09 970 1700