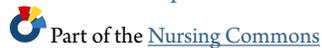

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"Taming the beast": Exploring the lived experience of relapsing remitting multiple sclerosis using a life history approach

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CHAPTER 6 – STUDY FINDINGS: “WALKING THE LOW ROAD”

Following on from the narratives in the previous chapter introducing the study participants with their life stories, this chapter presents the first five of a total of eight themes developed from the study data analysis and findings. The five themes comprising this chapter titled “Walking the Low Road”, reflect the difficulty, struggle, hardship and a redefinition of self following a diagnosis of RRMS. Although this chapter is mostly a story of challenge, there are some key moments of positivity, of finding hope and of moving forward with optimism and with anticipation. Hints of what is yet to come. In the early years after diagnosis these times of positivity seem to be frequently interwoven with times of struggle, especially in the very early days after a diagnosis of RRMS. However, as the story progresses, PwRRMS develop their own set of expert skills in managing RRMS and work towards a better future living with RRMS. There are suggestions of this in Chapter 6, but these skills really came to the fore in the following chapter “Finding the High Road”, as study participants identified key ways in “Taming the Beast”, as they shared their experiences living with RRMS.

This chapter Walking the Low Road, consists of five themes, each possessing its own *central organising concept*, as suggested by Braun and Clarke (2006, 2013) to succinctly outline the inclusions and boundaries of each theme. Themes have been categorised into subthemes and sub-subthemes to further clarify and highlight specific areas and concepts related to the overarching theme. A discussion of each theme will follow, interwoven with what is known from the MS body of knowledge to further introduce, explain or justify the concepts. Quotes from the participant transcripts will demonstrate the grounding of the themes in the study data and provide support to the theme development. The participant quotes are *italicised* and will be documented by the line number the quote commenced in the transcript. If data unrelated to the theme was then discussed within the quote, it will be left out and be represented within the quote by three ellipses (...) in the transcript text. Often participants would discuss a concept, go on to something else and then come back to

the original thought. As the quotes are taken out of context, if any clarifications on exactly what the participant is referring to are needed, they will be placed within brackets in the quote. As per APA guidelines, each developed theme will only be in “quotation marks” until explained. Table 4 demonstrates a summary of the themes, subthemes and sub-subthemes comprising Walking the Low Road.

Table 4. *Summary of themes one to five of the study findings; demonstrating central organising concepts, subthemes and sub-subthemes developed from the study data.*

Theme	Central organising concept summary	Subthemes	Sub-subthemes
1. Piecing Together the Puzzle	Experiencing or dealing with the initial neurological symptoms, seeking help for them, undergoing tests and being told the diagnosis of RRMS	What’s happening? Pieces start to form Tests, tests, tests (the puzzle starts to come together) The puzzle is complete (the day my life changed forever)	<ul style="list-style-type: none"> • Seeking help • “Brushed off” • Exposure to vulnerability –as the pieces form • Vivid recall of the diagnosis • Relief at the diagnosis • Disclosing to others • With-holding disclosure
2. (Re) defining Me Now That I Have RRMS	Making sense of the world with a diagnosis of RRMS, working out how to manage life, family and community, balancing the losses and the gains	Getting acquainted with RRMS Dare to compare Negotiating normalcy, disability and independence Working out work Parenting with RRMS	<ul style="list-style-type: none"> • I think I’m normal, aren’t I? • How others see me • Maintaining independence • To be or not to be (a parent) • Breaking the news to children • Impact of RRMS on parenting • Parental losses • Joys of parenthood

		Balancing losses and gains (my life plan (re)defined)	<ul style="list-style-type: none"> • Battling losses • Accepting gains
3. Battling the Demons	The battle of negative or difficult emotions that can get in the way of life enjoyment, threaten vulnerability and steal away joy	<p>Facing fears</p> <p>Weary with worry and anxiety</p> <p>Depression and despair</p> <p>Struggling with the saboteurs</p>	<ul style="list-style-type: none"> • Fear of symptoms/relapses • Fear of DMTs & side effects • Fear of progression/disability • Fear of the wheelchair • Worry about being a burden to family • Existing with Anxiety • Dealing with depression • Face to face with despair and hopelessness • Coping with uncertainty • I'm never free from RRMS • Social isolation
4. Surplus Suffering	Suffering over and above that imposed by the diagnosis and disease state of RRMS and often inflicted by others	<p>Surplus Suffering inflicted by HCPs in clinical care</p> <p>Surplus Suffering inflicted by "brush-off"</p> <p>Surplus suffering inflicted by HCPs in research care</p> <p>Surplus Suffering inflicted by family, friends and community</p>	
5. High (In)Visibility	The presence of invisible symptoms which cannot be seen by others and cause chaos and misunderstandings, but may also provide a refuge from chronic illness	<p>Striving to make the invisible visible</p> <p>When my RRMS isn't enough- reverse stigma of RRMS</p> <p>Invisibility as a welcome cloak- the downside has an upside</p>	<ul style="list-style-type: none"> • Please see me • Exposing the "secret one" • I'm not enough MS for you, devaluing the impact • A "pretender to the throne"

Theme 1- “Piecing Together the Puzzle”

It's silent, it's dark

I try to sleep but the burning pain stops me

Where is this coming from?

This pain stopping me being able to see

Do I get some help or see what happens?

Risk sounding silly and complaining

Or hope it goes away

It goes away, there it goes, it settles again

I no longer have to worry

Hold on... back it comes

I'll need a day off work again

They will wonder what's wrong with me

The problem is...I don't know

What you say, what is this?

It is MS, of that they now are sure

What does that mean, how will things be?

Regarding that, no-one can tell me

I don't know what to expect

How to act, what to do

What's going to happen, what's true

But I'll keep going, keep getting up

And hopefully I'll get through

TB

The **central organising concept** for the theme “Piecing Together the Puzzle” is the participant’s recall of experiencing initial neurological symptoms, seeking professional help, undergoing multiple tests and finally being told that RRMS is the most likely diagnosis. The theme is anchored by the notion that diagnosing RRMS is essentially about putting together a puzzle piece by piece, as symptoms are initially often vague and remitting in nature. After confirmation of the diagnosis, the theme

then explores dealing with the immediate aftermath and impact of the disease. Often the journey to diagnosis involves exposure to intense vulnerability, and for some, involved long periods of waiting time before an answer was given. Most study participants vividly recalled the day they were diagnosed formally with RRMS, dealing with their own feelings and emotions and also negotiating disclosure of the diagnosis to others. The theme of Piecing Together the Puzzle involves three distinct subthemes as the puzzle starts to materialise and progress: “What’s happening?” (pieces of the puzzle start to form), “Tests, tests, tests” (the puzzle comes together) and “the puzzle is complete” (the day my life changed forever) the first and third subthemes having several sub-subthemes to provide further clarity.

The time prior to a diagnosis of RRMS is often burdened with challenges, with research suggesting that the period from the onset of symptoms, to when diagnosis is delivered is a time where communication challenges between PwMS and HCPs are particularly heightened (Thorne et al., 2004). This was certainly the case in the current study, where almost all participants faced challenges communicating with various HCPs, including family doctors [known in Australia as General Practitioners (GPs)], along their journey to the diagnosis of RRMS. Participants were desperately trying to make sense of strange and frightening symptoms, and often went on to seek the help of a GP, who may or may not have been actively thinking about or aware of the symptoms of, a diagnosis of MS. The diagnosis of MS is always challenging and generally there may be poor awareness of MS by GPs (Hinton & Kirk, 2015).

The vagueness and intermittent nature of symptoms also plays havoc with the diagnostic process, patients seeking help to legitimise their symptoms and the HCP trying to piece together the puzzle, sometimes on very limited evidence. For several of the participants in the current study, the process of being investigated for, and diagnosed with RRMS, was viewed as traumatic and left a lasting impression. During our interview, several participants cried or became distressed as they recalled the time of diagnosis, and some participants were visibly distraught. For some of these participants, the diagnosis was decades prior to the study interview, but they recalled the event in fine detail and with much emotion.

What's happening? Pieces of the puzzle start to form

Recent research from Hinton and Kirk (2017) in the field of paediatric MS found the process of diagnosing MS to be lengthy and frightening, with the involvement of multiple HCPs, each giving conflicting opinions, different labels and expressing professional uncertainty, further intensifying parental anxiety in the possibility of the diagnosis. Uncertainty was a recurring theme, and similar to many participants in the current study, making sense of being ill and experiencing symptoms without a definitive diagnosis was difficult. Interestingly, previous work has also reported that PwMS had trouble differentiating MS symptoms from routine ailments and found it difficult to know exactly when to go to the GP for advice, regardless of the severity of their disease (Moriya & Suzuki, 2011).

Pieces of the puzzle were the little clues that something was amiss, but usually in the beginning never progressing to the thought that this could be a sign of a chronic neurological disease. Usually, but not always, the initial symptoms (the first pieces of the puzzle) were sudden in onset, were vague in nature, stayed around a little while and then disappeared. They were not severe enough to prompt a visit to the doctor or to seek help at that point, but nonetheless they caused some worry for many participants as they described feeling “different”. At times, participants wondered if they were imagining symptoms, self-diagnosing that they were sleep deprived, too busy or too stressed at work. Sometimes symptoms were forgotten about, only to resurface as memories at a later date when HCPs questioned directly about vague and unexplained symptoms in the past. Participants such as Ruby suffered vague symptoms at first, Ruby’s symptoms coming on after a plane trip which led to her reasoning that the sensory leg symptoms she was experiencing were related to flying. Ruby did not to seek medical help for some time after this first event.

*One of my first symptoms...the calves got very tight and tingly and numb...that lasted a couple of years...I thought it was just the flight...because it happened on the flight...then when I got home I could walk fine, it was just uncomfortable...it must have been a year...two years...the first sign that things aren't going quite so well.
Ruby line 288*

Others experienced long periods of remission after the first symptoms disappeared, times of silence and seemingly, no connection between the various symptoms. Paul did not link any symptoms of the “funny” episodes he was experiencing, mainly because they occurred several years apart. The medical staff Paul had consulted along the way did not link the episodes together either.

*I had L’hermitte’s (an electric shock-like sensation along the spine when moving the neck forward)...it only lasted a couple of days...but it was a really funny feeling...a bit odd...it lasted a couple of days and disappeared...a couple of years later I had optic neuritis and it (my vision) just went completely white...I went to the ophthalmologist and he gave me some prednisone...he said it was probably a virus.
Paul line 15*

Susan described initially being a bit concerned with the sudden onset of her first neurological symptoms, but made a self-diagnosis of sleep deprivation as she had been working on night shifts.

I was at work one night and I thought my legs feel funny, it’s a bit numb at the calf...maybe I just need to sleep...it went on for a few days. Susan line 151

For some, the background pieces of the puzzle, the symptoms, became harder to disregard. For others, new symptoms, new puzzle pieces, appeared and could not be ignored due to their intensity and severity. For many participants in the study, this was the time that they decided they had to tell others about the symptoms they were experiencing and to seek help. For many, the GP was the first port of call, and then participants described the response as being “brushed off” by being ignored or the symptoms minimalised, left in a holding pattern with recognition but no plan to investigate further, or referred on to a neurologist.

Seeking help

Most participants were stalled at the start of their MS journey for varying periods of time, but eventually found a HCP who recognised that RRMS might be a possibility and referred them on appropriately. Very few study participants were fortunate to be

referred on early to the appropriate professional and begin the journey to a RRMS diagnosis promptly. After initially seeing her own GP who trivialised her symptoms, Susan sought alternative help for her vague sensory symptoms from an acupuncturist, who gave the help she needed. The acupuncturist (also a GP) realised there something serious was happening, refused to treat her with acupuncture, but referred her on to a neurologist. Piper had been unsuccessfully trying to have her vague symptoms diagnosed for many years with local GPs in her country town, but exasperated after yet another neurological event, sought advice from a HCP girlfriend who immediately recognised what this could be.

(for help with sensory symptoms) I went to this acupuncturist, an old Chinese man...he said I'm not going to touch you, I want you to go and see a specialist...a neurologist...and I said "I've been going to my GP and he's not listening to me, he thinks nothing's wrong with me" ...the acupuncturist was also a doctor and referred me on. Susan line 176

I called my girlfriend, she was a doctor...she straight away said..."it sounds like MS to me...I can't believe nobody has sent you for an MRI" ...(she referred me to a neurologist) and she (neurologist) diagnosed me straight away...I was probably lucky...a lot of people have to wait years and get pushed around from pillar to post. Piper line 556

"Brushed off"

"I was becoming more and more anxious, knowing there was something wrong but people were just brushing me away". Piper line 506

Almost half of the participants in the current study described being “brushed off” in their initial encounters with HCPs, meaning that they presented and described their symptoms, but weren’t taken seriously or investigated any further. The term “brush-off” is more formally defined as rejection or dismissal in which someone is treated as unimportant (Oxford dictionary, 2017). For several participants, this was their first encounter with the hospital/medical system and they simply did not have the health literacy or the awareness to request and insist on investigative tests or a second

opinion. Health literacy is a multidimensional concept referring to a person's ability to acquire, understand and use information about health and health services (Batterham et al., 2016). Health literacy is important as people possessing health literacy often have better health outcomes than people with low health literacy (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011), a skill which could effect the entire life journey living with a chronic illness such as RRMS. Participants in the current study already possessing greater health literacy moved on quickly to other HCPs after initially being brushed off, and were subsequently diagnosed with RRMS not long afterwards. Other participants tried to help themselves when told nothing was wrong by their HCP, by increasing or decreasing exercise, changing work hours, reducing stress, anything to help the strange and unexplained symptoms they were feeling.

Recent studies in adults exploring the diagnostic period and diagnosis delivery in RRMS are lacking, although some recent paediatric studies exploring these themes have shone much needed light on this topic. Hinton & Kirk (2015) explored the life experience of children with MS and found that many early symptoms of MS are misinterpreted, because they are vague and non-specific in nature. Parents began to feel unease as symptoms returned and the realisation struck that something might be wrong with their child. Communicating these concerns to HCPs was met with a variety of responses, some meeting expectations to investigate symptoms further and others not. Parents also expressed difficulty in communicating symptoms that were intangible and without physical evidence (headache, sensory symptoms) and many felt as if they were dismissed by the HCP. These findings present a very similar pattern to some of the adult participants of the current study.

Piper suffered for many years struggling with her unexplained and undiagnosed symptoms, her situation exacerbated by living in a small rural town where there was a constant stream of GPs coming in and out for short periods of time, offering little continuity of care. Piper describes being regularly brushed off by the GPs when she presented with her symptoms and how it made her feel. At times she felt like she was “going crazy” and spent many sleepless nights during a severe relapse just prior to her RRMS diagnosis, worrying about what might be happening to her.

You feel like a hypochondriac because you are always at the doctors and nothing ever found. Piper line 251

The doctor said “there’s nothing wrong...you know, go away”...I went to a few doctors actually...I feel like a fraud because I can feel these things...I’m not dreaming it...I was really struggling to grip and turn...no strength and I was told it’s cold, because this is winter go home and put some gloves on...it actually makes me cranky because I’m not making it up...I know what’s normal. I said” I think there’s something neurologically wrong with me” and she said “no there’s not, there’s nothing wrong with you”...new doctors would come and do a 12 month stint and move on...I feel like a fraud because I can feel these things...I’m not dreaming it. Piper line 407

Susan, a HCP herself, consulted her long time family GP and requested a referral to a neurologist on numerous occasions, but her GP ignored her symptoms and did not provide the referral.

(My GP) he’s not listening to me, he thinks nothing’s wrong with me and I’ve asked him “could you send me to a specialist because I think something’s wrong” but he kept pushing it aside saying “no, you’re fine, you’re fine”. Susan line 184

Margot also felt like she was not listened to when seeking help for continuing vague sensory symptoms in her legs. She had waited a long period of time, firstly for an appointment with the neurologist, and then for an MRI scan. Margot was keen for some answers to explain what was happening.

I saw him (neurologist) and he said “there are a couple of spots on the spine...so I think it’s a virus” ...in hindsight, as if he patted me on the head, well off you go, nothing wrong with you, it’s only a virus. Margot line 309

Joy had experienced a childhood where her mother had taken her to the doctors repeatedly for her many symptoms, but her mother was known in their small town as a “Munchausen’s mother”, so Joy felt the backlash of that label as she tried to piece together the puzzle of the mysterious symptoms plaguing her. She feared nobody

would ever take her seriously and investigate what was happening; in the end she gave up and lived in silent agony for many years.

I was sick...and they just treated Mum like she was a Munchausen's mother...they thought she was crazy, so when I went to the doctor's and said "I'm sick" they just believed that this is the child of the Munchausen's mother, well of course she's going to be a hypochondriac. Joy line 375

The form of brush-off discussed in Piecing Together the Puzzle relates only to the time in the lead up to the RRMS diagnosis. The concept of feeling brushed off will be explored again in a later theme "Surplus Suffering".

Exposure to vulnerability as the pieces form

Previous studies in the adult population of PwMS have supported the theme of vulnerability when dealing with MS, which was also experienced by many of the participants in the current study. Isakkson et al. (2006) used content analysis to investigate the illness experience of PwMS from onset of symptoms to diagnosis, interviewing 61 PwMS (type not specified). Findings from the study revealed that when initially diagnosed, most PwMS perceived disablement and death to be their future with MS. The lack of efficacious MS DMTs available over a decade ago may have strongly influenced this perception. Participants in that particular study also reported that MS was a disease that no-one talked about after the diagnosis. It is possible that the changed perception nowadays to openly discussing the disease is because of current levels of patient education, internet availability of accurate and up-to-date information and social media support. However, participants in Isakkson et al.'s (2006) study did report that the period from symptom onset to diagnosis was stressful, exposing them to immense vulnerability, as most of the participants in the current study also experienced. It appears the concepts of a decreased time between symptom recognition and the introduction of DMTs have not changed these feelings in this population.

For several participants in the current study, the onset of symptoms provided the PwRRMS their first experience in hospital or with specialists, and many were

overwhelmed by this experience and felt intensely vulnerable. Participants felt anger and mistrust when they felt they had not been taken seriously or brushed off with a dismissal or a psychosocial explanation. However, other participants felt confidence in the HCP when they were treated kindly and offered support through the process. An earlier study found that many PwMS were treated for depression and emotional issues prior to their diagnosis, and it was common for PwMS to feel like they were “going crazy”, were hypochondriacs or that they were imagining the symptoms (Russell, White, White, & Parker, 2006). For some participants, just the validation that they weren’t “going crazy” and that something was physiologically wrong, was all the support they needed.

The early days of unexplained and strange symptoms led to intense vulnerability as several study participants struggled with whether to let anyone else into their world and share the load of worry, or whether to just keep pressing on and hope things would settle down. Periods of symptom remission often confused them and made it hard to work out what to do, if anything. Alternatively, for participants such as Piper, earlier visits to the doctor without any resolution had led them to feel that they weren’t coping with life and the fault lay firmly within them.

I got to a point that I remember laying in bed one night...I was becoming more and more anxious with it, knowing there was something wrong...and I said “I really think I’m going crazy...I must be going crazy like the doctor’s think I am”...in the end I gave up almost...they can’t find anything wrong. Piper line 506

Even with intense and dramatic symptoms, some participants reported that they kept things to themselves, worried they would expose their vulnerability, not be believed or not be able to explain their symptoms well enough to be understood. Participants described how the symptoms could be frightening and scary, occur without warning and leave most of them clueless as to what could be causing the symptoms. Trying to pretend nothing was wrong and keep the symptoms secret from her work colleagues failed for Davina, exposing her to intense vulnerability when the symptoms suddenly took hold.

So, a year to the day (after the first relapse) I was at work again and every time I bent my head...I got this strange sensation down my back and in my feet...and I ignored it...and I felt like I had a really tight belt on...it just got...worse...and they had to put me in a wheelchair and take me to emergency. Davina line 410

After initially seeking help, the investigative phase also led to feelings of vulnerability for participants, wondering what it could be, what was happening or what they possibly did to cause the symptoms. Many participants recalled this period in their lives, expressing emotional pain and distress, at being given no immediate answers to quieten their minds. Susan, working as an HCP, intrinsically knew something was wrong whilst she was undergoing nerve tests and feared the symptoms were a result of something she had done, she wasn't told the diagnosis for several weeks after testing.

I got in and they said...well, something's not right here...and they got a doctor to come in...but they would not say anything to me, everything was hush hush and I could tell something wasn't right...and I thought...did I do something when I bunjee jumped?...I was so scared. Susan line 219

Other participants put the symptoms aside as they remitted and forgot about them and moved on with life, not sharing their experience with anyone else. At the age of 18, Will had some initial tests after some neurological symptoms but never went back for follow-up after his first episode resolved and never told anyone else about them. As a teenager with no parents and little close family around him, he felt vulnerable and uncertain without close support of others.

I never went back for results...I forgot all about it...had I followed up back then probably I would have been diagnosed much earlier...but just...young...naïve...there was always something in the back of my mind that something was wrong...in my early teens I could always run but if I stopped, I couldn't run again...I am telling my foot to do one thing but it's not doing what I'm telling it to do...I never told anyone about it. Will line 506

For those lucky few participants (such as Jane) who were sent to an MS Specialist neurologist early on in the journey through the medical system, there was mostly a rapid diagnosis of RRMS made and a treatment plan commenced. For several participants, specifically Rudi and Davina, being transferred to a specialist caused further frustration as they were brushed off yet again, or sent on their way with no real answers or guidance.

(the neurologist told me) “your symptoms sound like it might be MS...but it isn’t conclusive...before we go any further, you’ve just married, have your family and once you have children, come back and we will do the next phase”. Ruby, line 49

He (the neurologist) told me I was a textbook case of optic neuritis and a severe one...he said he knew I would go home and look it up, and that it was a symptom of MS...but I wasn’t to panic because I had no other indications of it. Davina, line 389

Tests, Test, Tests...the puzzle comes together

Although diagnosing MS earlier is advantageous (with efficacious DMT choices to alter the course of the disease), it is more important to be correct in the diagnosis (Giovannoni et al., 2016). Meticulous care should be taken to exclude the many conditions that mimic MS, and this can take time and patience (Aliaga & Barkhof, 2014), which is hard to explain to a patient experiencing symptoms. What is now emerging is that MS has a variable and sometimes long pre-symptomatic phase of years, potentially decades, and this may include a significant amount of cognitive deficit (such as issues with information processing and memory) (Giovannoni, 2016). Possessing cognitive deficits could also hinder PwRRMS in coping emotionally with the long and arduous diagnostic process because of these issues with information processing. However, a frank discussion from the HCP and MS Nurse about the reasons for the careful and thorough testing at the beginning of the journey could potentially change the goals of the journey for PwRRMS and significantly lighten their emotional load.

For some participants, the constant stream of tests and more tests was a trial in itself, trying to find the elusive answer to what was happening. Many participants recalled

this time as challenging and difficult as they played a game of test, wait, doctor, another test, more waiting, another test, doctor again and hopefully, but not always, an answer. Evie, Paul and Will describe the ongoing barrage of tests over extended periods of time, which still did not always conclude in a definitive diagnosis.

My GP said...straight to a neurologist...go...then that led to two years worth of tests, which are just the worst...lumbar punctures and electrode tests. Evie line 525

(I took myself off to the hospital to have it checked out) I ended up having an angiogram, I had a colonoscopy, an endoscopy they did everything to find out what's going on...(with no answer), but I went back to the doctor and said "something's not right" ...Paul line 63

I was in hospital for 4 weeks, I wasn't recovering...I was having MRIs, tests...I was diagnosed with sarcoidosis...nothing was happening...then I had test after test...biopsies behind the eye...it was just so hard...I had a breakdown...I hid it from everybody...I was released from hospital without a diagnosis. Will line 683

Piper describes having numerous tests done but they were not appropriate tests to determine a diagnosis of MS. She had test upon test, but never once a simple neurological examination, even though the majority of her symptoms were sensory in nature.

I had all the tests under the sun. Piper 131

I've had everything and they can't find anything wrong. Piper line 259

Because she (diagnosing GP) did a lot of the neurological things that the neurologist would do...nobody had done any of that to me, nobody had checked for sensitivity. Piper line 573

Other study participants suffered the opposite experience, with no investigations what-so-ever. Joy pleaded for most of her life to be investigated, when she developed new symptoms and when she experienced blindness and deafness, but to no avail.

Finally, there was one participant, Rudi who had testing completed but the results were either ignored or misunderstood by her HCP. Rudi recalls reading her MRI report herself and noting the comment that it was likely demyelination given her age and sex, and yet was diagnosed with migraines and sent away, only to be diagnosed with RRMS years later after a relapse so severe she was admitted to intensive care.

They couldn't work out what caused it (blindness) they didn't really do a barrage of tests, they couldn't understand, again, they didn't believe me. (and later on) they weren't really interested, they didn't believe me...I was a fruit loop, they thought I was crazy. Joy line 130

Even though the MRI report indicated that I had lesions, demyelination, consistent with my age and female...the report was saying...he (neurologist) treated me for focal migraines and I slowly got new symptoms. Rudi line 92

The puzzle is complete- the day my life changed forever

It was only about 30 years ago that it was discussed in the medical literature the merits of even telling a patient that they had MS. In some cases it was advised that this was not always a good idea, potentially causing unnecessary upset and stress in a disease with no cure (Sencer, 1988). Two decades later, research into receiving a diagnosis of MS reported that PwMS often felt intense feelings of abandonment and isolation from their neurologist following their diagnosis of MS. Most often this was likely because they were sent away with no plans for follow-up or treatment (Johnson, 2003). This was not replicated in the current study, possibly because there were no, or limited, treatments for RRMS in the years prior to the earlier study reports and no need to be reviewed again by the neurologist, with family doctors and community care taking over care in many cases. However, this has changed greatly in recent years and now close follow-up care after diagnosis and commencement of a DMT is expected by the Neurologist and MS Nurse, and crucial to ongoing management (Giovannoni et al., 2016). Imparting a diagnosis of MS is the start of a transition between HCP/MS team and the PwMS, which needs to provide information, offer advice and continue support in an ongoing manner (Johnson, 2003).

Vivid recall of the diagnosis

For several participants in the current study, recalling the day they formally received their diagnosis of RRMS was fraught with emotional distress; for some it was the method in which the diagnosis was delivered and for others it was recalling the lack of support or information received afterwards. It has been reported that the day of MS diagnosis can be recalled by PwMS vividly and with a great deal of emotion and detail (Isaksson et al., 2006; Solari et al., 2007; Malcomson et al., 2008; Solari et al., 2014). This highlights the importance of the conversation and the amount of effort the HCP needs to invest in the consultation. As highlighted in previous sections of this theme, sometimes PwMS have been waiting years (and occasionally decades) for a diagnosis and most often the diagnosis will come from a Neurologist. The power of this interaction and the potential impact on the future life of the PwMS cannot be underestimated. PwMS have reported frustration with the vagueness of the diagnosis, lack of commitment, and lasting negative impressions of the HCP (Malcomson et al., 2008), themes strongly supported by several participants in the current study. An honest, frank discussion from the Neurologist/HCP explaining the reasons for the delays of making the diagnosis, the need to be certain of the diagnosis, the difficulties in prognostication, together with the potential for hope and the power of current research, could counteract much of this negativity and set the PwRRMS on a more hopeful and positive path for the future.

All study participants recalled in detail the day (and the way) they were diagnosed and given the news that the symptom cluster and diagnosis of RRMS was confirmed. Participants recalled how they felt as the words “MS” were verbalised, sometimes for the very first time. Some participants were alone when they received the news, others had the support of others, but no matter the circumstance, the day is firmly etched in their memory. Even though it was over 20 years ago, Evie recalled what she believed were the exact words from her neurologist.

I remember the day I was diagnosed (20 years prior)...I remember the exact wording...he said to me “ I think you have a mild case of MS”...and I went “Oh OK”...I knew it wasn't good, it could have been bad...”there is potential for it to be

very bad” ...I wasn’t scared, I wasn’t upset, I wasn’t angry...so OK...what do we do about this? Evie line 567

Rudi recalls how she felt as the diagnosis was being delivered, as sensory symptoms started to ascend in reaction to the stress she was feeling as the words she had feared became reality.

And she (the neurologist) was starting...I knew where she was going and I could feel the numbness coming in my face, I remember that vividly...and then...I had the wheelchair in mind. Rudi line 1616

After months of waiting for a diagnosis, Will begged his neurologist to tell him the diagnosis over the phone, and so he was in his car in a garage on the side of a major freeway when he heard the news that he had RRMS.

(the neurologist rang and he wanted me to come in) I said “can you tell me now because...it’s killing me...I’m waiting for your call” ...so I pulled over to a garage and he said “this is most likely what we’re going to have to...the route that we’ll take” ...I wanted him to tell me...he said “I can’t tell you over the phone...I cannot have that conversation with you”...but I said” if you don’t...I’m not coming in...what are you going to do?”. Will line 755

For many, having solved the puzzle and leading to a diagnosis of RRMS left them deeply wounded by the revelation. They felt the covert message from the HCP was this is your new life, accept it, move on, I’ve done my job now. This was heartbreaking for some, and was the start of a difficult relationship with RRMS and with their HCPs. The manner in which the diagnosis itself was delivered caused utter devastation for both Kate and Davina, who can both clearly recall the encounters over 20 years later.

The first thing he said to me was “you know what, I think you have MS”... I said...”oh what does that mean”? Because I had no idea what MS was ... and he turns around “and you may end up in a wheelchair and you will probably be blind in

five years time” ... I said “I’m only going to be 27 and I’m going to be blind?” ...and I was a mess. Kate line 234

The consultant I wanted to see was away so the one I had (in hospital) stood at the end of my bed and said “it’s 99% definitively MS because you fit the sex, the age, your symptoms are very textbook...so I suggest to you that you think about your future and perhaps if children were something you were looking forward to, it might be something to think about now, because better to be a disabled young mother than a disabled older mother” (starts to cry)...I was distraught. Davina line 467

Other participants felt resentment at the diagnosis and a sense of unfairness, particularly Rudi who felt a sense of anger upon hearing the news.

Even though I read the report...after I was diagnosed I became very angry... (another friend with MS) say’s it’s relief...but I didn’t find that, I wasn’t researching anything...it didn’t come as a complete surprise...later Mum went down and got some pamphlets...”Mum” I said “you can stick these up your arse, I don’t want to know anything about it”, I was at that angry stage...I don’t want to know. Rudi line 777

Griff was grateful to have a diagnosis after many years of trying to find the cause of his symptoms, but didn’t feel as happy as he thought he might in finding an answer. Solving the puzzle was “cold comfort” for what lay ahead.

I feel like death warmed up...then I have a name to it...but it’s a cold comfort... because the name comes along and all of a sudden, now I have “it”. Griff line 1312

Relief at the diagnosis

Although some participants felt devastated at their diagnosis of RRMS, and others felt anger, some participants felt a sense of relief. Making downward comparisons is very common, both in the lead up to diagnosis, and in the immediate period afterwards (Taylor, 1983). Downward comparisons happen when patients compare themselves favourably with the lives of others whom they believe to be worse off

them themselves (Taylor, 1983). This was echoed on multiple occasions in the current study as participants pieced together the puzzle themselves; fear of having a brain tumour, cancer, motor neuron disease (MND) or permanent blindness were common, and felt to be a far worse outcome than MS. Perhaps this was a coping mechanism which assisted participants survive the period from symptom onset to diagnosis, and beyond. For several participants, the day they were diagnosed with RRMS was a day of relief and the puzzle was solved, and in their minds, solved in their favour. The fact it was RRMS brought a lightening of their burden and possibilities for the future. Piper, Margot and especially Joy had all imagined illnesses they considered worse than RRMS and were grateful to have an answer they considered to be less of a burden.

I said (to the neurologist) thank you...I was relieved...I was relieved that I wasn't going mad. Piper line 614

You go through every scenario...what could it be...could it be cancer...and I don't think MS came to mind really...I was thinking motor neuron disease...so I was really quite worried...two to five years of expectancy...it was a relief...thank goodness it wasn't MND. Margot line 385

I said what have I got again?...and he said "MS"...and I said "is it going to kill me?"...and he said "no"...and then I said "you've just given me my life back again...I'm laughing yes, I'm not going to die from this"...I don't have to line up foster care for my son, I can finish raising him myself...I don't have to live in fear anymore. Joy line 1879

Disclosing to others

Piecing together the puzzle and confirming the diagnosis of RRMS was one thing, however telling this story to loved ones was another, and often induced feelings of dread and uncertainty. The journey wasn't over with confirmation of the diagnosis, in many ways it had really only just begun. Many participants struggled with sharing their news, even though they may have been relieved themselves, they were still mindful that they were about to change the lives of their loved ones forever. Telling

someone they loved that they had an incurable neurological disease, of which no-one could tell them where or when the next relapse would strike, how severe it would be, if they would recover and that they would need to take a medication which could make them feel worse, or do serious harm, was a mammoth task. They would often have to put their own feelings aside so they could comfort others, and sometimes this came at a high price for their own mental health.

Most participants were diagnosed between the age of 20 and 40 years and were reluctant to tell their parents of their diagnosis for fear of worrying and upsetting them, particularly if parents were elderly and would base their understanding of MS on that of years ago, when wheelchair scenarios were common. This was especially difficult for Susan, who had to halt her own intense feelings, to deal with the hurt and responsibility her parents felt upon learning her diagnosis.

I think they (Mum and Dad) didn't understand it...they were very emotional and blaming themselves...how could this happen? It was very emotional (and Dad) sobbed like a little boy...I didn't show any emotion, I held it all in because I had to be strong for them...that didn't help me because it delayed my grieving and delayed me dealing with it because I was trying to be strong for Mum and Dad. Susan line 374

This time was also difficult for Davina, whose diagnosis of RRMS caused a family rift. Davina's uncle, who was diagnosed with MS decades prior, had been hidden away at home and denied the diagnosis of MS by his family, associating the disease with shame.

I also had my two families...my father's family and my mother's bickering about whose fault it was genetically...so that was a bit hard to deal with and I was in the middle...and my mother was frightened...because on top of all of this I had an uncle who had MS and was wheelchair bound...so that was a lot for my family...because my grandmother used to tell everybody he had a head injury when he fell off a ladder and he didn't have MS. Davina line 568

With-holding disclosure

Other participants held the diagnosis close and from diagnosis to retelling their story to me, told only the bare minimum number of people they needed to. Paul had still only told his wife, his parents, his brother and his work boss of his diagnosis, not one other friend. Paul says he doesn't need other people worrying about him, he does enough of that himself.

Not many people know...I told my CEO...nobody else knows...I much prefer it that way...no friends know...I just get enough canoodling from Mum, I don't need any more, that's enough you know...I'm reminded enough of it as it is. Paul line 994

What next?

Now that the pieces of the puzzle have completed a picture of RRMS, it was time for the study participants to work out the next step on the journey of living with RRMS. However, just because the puzzle was solved for now didn't mean that it was solved forever. The unpredictable nature of living with RRMS ensured that new pieces of the puzzle were very likely to form, at any given time in the future, and often suddenly. The next theme, (Re)defining me now that I have RRMS, begins the story of how PwRRMS make sense of their new diagnosis and how they move forward in their lives.

Theme 2 :” (Re)defining Me now that I have RRMS”

Who is this new me I find in my old body?

How do I belong? Where do I belong?

Do I belong? Will I belong?

I didn't choose to change, it choose me

Finding my way without warning is difficult

I struggle to be

The road isn't sign posted and I cannot see the lights

Does the old me even exist anymore?

What fate awaits me?

I need to be, I need to see

Let me try and find how to be me

TB

The first weeks, months and years after being diagnosed are critical for the PwRRMS to define, or (re)define their identity now that they are living with RRMS. For some, the confusion and devastation of the diagnosis of RRMS played heavily on their minds and bodies and they struggled greatly, as discussed in the previous theme. Others seemed to take the diagnosis in their stride and march on, eager to find out more about the disease they had acquired and boldly declare that they are ruling it, it's not ruling them. How do PwRRMS make sense of the time after diagnosis and move along on their life path, still the same person, but now different?

After the diagnosis of a chronic illness such as RRMS, people are confronted with new situations that challenge their habitual coping strategies, strategies they may have used in past illnesses or times of hardship, and now they must find new ways of coping (Taylor & Aspinwall, 1996). It has been said that a diagnosis of RRMS opens the door to uncertainty and variability and has specific challenges (Koopman & Schweitzer, 1999) as well as extremely complex ones (Dennison et al., 2010). Additionally, as RRMS occurs in the prime of life, it is likely to leave a strong psychological imprint, with very real changes in values and beliefs in how the PwRRMS views him or herself (Irvine, Davidson, Hoy, & Lowe-Strong, 2009). Defining oneself, or (re)defining oneself, in the face of a newly diagnosed chronic illness is always difficult, but the challenge is amplified in RRMS where the long term prognosis of the illness is not known and the future is highly unpredictable.

The ***central organising concept*** of the theme “(Re)defining Me Now That I Have RRMS” is about how the PwRRMS makes sense of the world with their new diagnosis. This involves discovering more about the disease, working out how to manage feelings relating to work and finances, relationships, parenting and finally balancing the losses and gains of now living with RRMS. It is a mammoth task. Six subthemes presented during the current study, each distinct but sharing the central organising concept of defining a part of self or finding a part of self in their context as a PwRRMS. The subthemes that are grouped under the theme (Re)defining Me

Now That I Have RRMS are: getting acquainted with RRMS, dare share compare, navigating normalcy, disability and independence, working out work, parenting with MS and balancing losses and gains, each with further sub-subthemes to provide more detail and clarity.

Getting acquainted with RRMS

“Diagnoses, especially those that relate to serious illness, mean much more to patients than simply the identification of a particular disease state. Diagnoses are permeated with cultural and personal meaning”

(Toombs 1995, p7)

In the time immediately following a RRMS diagnosis, the majority of study participants were determined to find out as much as possible about their new companion in life, RRMS. Of course, the uncertainty and unpredictability of RRMS in general ensured that many questions remained unanswered. For several participants, this was extremely difficult, as they were provided with minimal information at diagnosis and received little follow-up care.

Prior to the 1990's, the MS neurology consult was sometimes referred to as “diagnose and adios” or “MRI and goodbye”, first coined by Neurologist Labe Scheinberg at an MS meeting in 1986 (Pearce, 2004). Thankfully MS practice has moved on since this time, mostly due to the introduction of DMTs. Now the primary role of the neurologist and MS team is not just to diagnose an untreatable condition and then say farewell, but to continually assess and monitor after the diagnosis for the entire life journey with RRMS; to ensure DMT safety, to detect relapses and to observe for signs of disease progression.

In order to (re)define self, many study participants set out to acquire knowledge of what RRMS was and what was most likely to happen to them in the future. Most PwMS find information on MS empowering (Malcomson et al., 2008), but unfortunately for many, there is a lack of information given at the beginning of the journey (Rintell & Melito, 2013). This reality applied to several participants in this study. Kate, Ruby and Davina recall that they were provided with little information

after diagnosis, no chance to ask questions and no health management plan. A systematic review addressing the information provided to PwMS following diagnosis reported that there is growing evidence that information provision can increase disease related knowledge and may have a positive effect on decision making and quality of life, with no negative effects noted (Kopke et al., 2014). Information for PwMS needs to be given in a way that allows appropriate time, repetition, flexibility and must be individualised according to needs (Krahn, 2014). HCPs also need to be mindful that the information and resources are appropriate for the individual and take into account factors such as education, occupation, financial status and social level. If these factors are not considered, PwMS can be left feeling vulnerable and the information rejected as useless (Sharifi et al., 2016). This was the case for Jane, who literally threw the initial information booklet and resources straight into the rubbish bin. Jane felt that the information provided and the method of delivery did not meet her individual needs at the time.

Lode et al. (2007) revealed that almost half of their study participants (n=86) were dissatisfied or very dissatisfied with the information provided to them at the time of MS diagnosis. As optimising information delivery early in the disease course induces coping styles that provide a better adaptation to living with MS (Lode et al., 2009), MS HCPs and MS Nurses need to manage this important process in a method which is supportive of individual needs. A later study interviewed 61 PwMS at their first MS clinic appointment regarding their on line MS research activity, and discovered that 82% of people in the study gathered medical information on line before their first appointment, yet only 36% discussed what they found with the physician (Hay, Strathmann, Lieber, Wick, & Giesser, 2008). This area needs further investigation so HCPs can stay engaged and aware of information seeking habits of PwMS, to provide guidance on appropriate, relevant and reputable websites and to truly partake in shared decision making, based on the same shared information. Careful and individualised education planning (incorporating written, verbal and electronic methods) is needed in newly diagnosed PwRRMS, and with reassessment as necessary along the disease trajectory.

Nowadays typing the words “Multiple Sclerosis” into a Google search results in almost 29 million “hits” at your fingertips in less than a second. However, there are

unfortunately no systems in place to advise what is factual and trustworthy information, and what is not. For someone newly diagnosed with RRMS, possibly medicated with high dose steroids and dealing with the suddenness and havoc of the new diagnosis, trying to negotiate 29 million websites and work out what is helpful must be almost impossible. Many study participants in the current study commented that there was “a lot of junk” out there and that the sheer volume of information was overwhelming. Other participants tended to wade through the minefield of information and narrow down the websites that seemed to make sense to them. A recent Australian study explored online information seeking in PwMS (n=51, type not specified) using focus groups (Synnot et al., 2014). The study revealed that all participants had used the internet for information at some stage of living with MS and mostly indiscriminately soon after diagnosis. Many participants in this study also described the dichotomy that exists for MS information; in that they felt there was too much information in general, but too little information on what they really needed (Synnot et al., 2014). Worry about parents or children obtaining information on the internet about a family member with RRMS, particularly if there was a focus on wheelchairs in MS, also concerned several study participants. This phenomenon has not been supported by recent literature, however is worthy of further exploration.

There was a great deal of difference between participants in the current study regarding how they acquired knowledge, depending on the decade they were diagnosed. Participants such as Davina and Evie, who were diagnosed over 20 years ago, had to rely on books, pamphlets and phone calls to receive information, others diagnosed more recently such as Piper and Paul, were able to embrace the internet immediately. Most participants were somewhere in between, relying on help from the MSA for initial information, finding others with MS in their local community to ask questions of, or receiving information from their MS Neurologist, MS Nurse and local MS clinic, where these were functioning. However, information gathering is not static, initial information at the start of the journey was sought, but in MS, information needs are continual and all participants relied on the internet and websites for their current updates and new information. Some participants such as Kate, Paul and Will preferred highly scientific websites for their knowledge, but others such as Ruby and Piper favoured more low-key blogs and real-life stories.

I just have this...overwhelming...overwhelming thirst for trying to understand reality I think...I mean there's a lot of trash out there, but there's a lot of good stuff as well...I register with on line scientific journals...at night I don't have very good sleep...I get on my phone or my ipad and just read about all this stuff...for hours at night, every night. Paul line 647

Absolutely yes (I go to the internet)...some of the stuff, I take with a grain of salt...I'm registered with a couple of scientific journals, I get a bit from there as well. I hate the MS Australia stuff because it's all wheelchair shit you know...it's all worst case stuff. Paul line 693

Margot also realised that not everything on the internet was factual and helpful; and was grateful because her elderly parents didn't have a computer and wouldn't be exposed to that information to cause them further worry.

The good thing with elderly parents was that they didn't have a computer and they couldn't look things up on the internet...but everything on the internet, just because it's on the internet doesn't mean that its true...so I've kept that in my head... so you don't trail for all sorts of quick fixes and horrible stories. Margot line 532

Seminars and webinars seemed to be an effective way for PwRRMS to gain the information they needed and also garner support to educate their family and friends. Positives for some participants included the fact that the information was freely available at a time when it was convenient for them, and in the case of webinars, that they could do this in the privacy of their own home or office. Susan found MSA helpful in her quest to learn more about many aspects of her new illness.

I always thought knowledge is power. I joined MS Society because I asked them what to do, what do I need to do, where do I get my information...I used to go to a few talks...whatever drug I was on at the time...how to live with MS...anything to help me. Susan line 448

However, not all participants valued the sources of information in the same way. Rather than turning towards the information available to them, some participants

turned away. Not all study participants were ready to take on the wealth of information in RRMS at the beginning of the journey. Rudi had definite views that they would acquire information in their own time, when they were ready to do so. This highlights the importance of gathering and providing information appropriate to the individual at suitable times in their RRMS journey.

My Mum went down to the MS Society here and got pamphlets...I was sitting there rolling my eyes and I said "Mum, you can shove these...I don't want to know anything about it...I've got MS, don't talk to me about it, I don't want to know. Rudi line 797

Jane wished to keep a positive mindset from the beginning and didn't want information focusing on negative aspects of RRMS around her.

(after diagnosis) Mum gave me the book about MS...and you end up in a wheelchair and incontinent...all the horrible things with this...it was a really old book...and I just binned it. Jane line 105

Following diagnosis, many participants had some sort of contact with the MSA, whether in person, by phone or internet. However, no participants mentioned any contact *during* the diagnostic process. Ruby, Piper and Susan all gained value from the help of MSA as a professional organisation in the early days of acquiring knowledge, and Susan also took family and friends along to educate them directly.

The MS Society is brilliant...I used to love the blogs but I can't handle negative...(there is also) a facebook page that was a really good site to be on (for a particular DMT)...I think on line there's a fair bit but I use it quite discerningly and I try not to look at too many blogs...there's a few on there that whinge too much and I can't stand that, I know there's a lot to whinge about, but when you're feeling low anyway, it doesn't really help. Ruby line 995

I went and saw (our local MS Society representative) when I was first diagnosed to find out whatever information she had. Piper 1793

I've done a few webinars, I love those...just to be updated with anything that's new...there's that much junk out there. Piper 1921

I took a couple of girlfriends and my Mum with me (to the MSA) just so they could understand what was going on because...they see me as...as I'm OK, they don't know what's going on inside...I wanted them to understand what MS is about. Susan line 498

Dare to Compare

Another source of information to acquire knowledge to help (re)define self involved daring to compare oneself to others also living with MS. For some study participants, there was struggle in deciding whether to engage with the world of MS, or whether to avoid the world of MS. This was reported by participants in Dennison et al.'s (2010) study as whether to engage or avoid "the cripple club". Engaging with other PwMS and witnessing disability can potentially have three effects: helpful interactions (support and advice, sharing tips), to be shown the spectre of what may happen (dare to see) or to not relate at all (compare and not fit in) (Dennison et al., 2010). Moreover, being with other PwMS can lead to empowerment in the peer community and to shared resources, a mutual recognition of ability, social relations and an environment that displays no "stereotyping shame" (Skar, Folkestad, Smedal, & Grytten, 2014).

Following diagnosis, many study participants described how they needed to see what RRMS looked like in others, but the participants differed greatly in their reasons for doing so. Most initially knew very little about what RRMS meant, the little they did know was through MS read-a-thons conducted in primary schools in Australia many years previously. If they dared to compare they sought out MSA meetings where they could meet others dealing with the same disease, or what they thought was the same disease. Other participants tread more carefully and sought out individuals they knew through others to gain access to the MS world. This subtheme is concerned with several aspects: daring to see what was out there in the MS world and seeing what they may become as a PwMS, comparing themselves on the MS severity scale and also hopefully learning more about RRMS in the process.

Whatever their motivation, attending MSA meetings was a common event for participants to dare to compare in their journey. Some participants went to MSA meetings solely to make downward comparisons, to prove to themselves that their MS was less severe and that they compared more favourably than others. For Paul, this marked an important line in the sand to make sure that he could cope with the diagnosis. Paul harboured guilt, daring to compare himself against others with MS, but mostly in the progressive state and not the RRMS type he was diagnosed with. Paul did this early in his RRMS journey when he was relatively unaffected by disability. He attended a meeting, knowing the meeting would attract people living with progressive MS, and in a worse situation than himself. He felt as if he needed to see the worst the disease could do, and found comfort in doing so. It was part of daring to see what could happen and comparing himself more favourably against that outcome. He utilised the information to actively do every thing he could possibly do to stave off the same future, he (re)defined himself as someone with MS but not *that* type of MS.

I don't know if this is a little bit morbid...(MSA were running seminars)...and this is the morbid bit...I wanted to see what other people with the condition were like...I think people that have been more severely affected were probably more interested in being there...I hope that was the case because it was pretty depressing actually...and I don't know if I was going there to be depressed...I was thinking...with everything I'm reading, maybe this isn't a very big deal...so I wanted to go and see... this sounds really terrible, but it was a comfort thing...well, I'm alright. Paul line 1310

Jane also went to a meeting with people with progressive MS, but her experience was very different, suffering reverse stigma about her own RRMS. Jane's "dare to compare" didn't go as planned.

I did go to a few MS meetings...the first meeting I went to was really depressing and these young kids who have the other type of MS...we were all just sitting there crying and I thought...I don't want to go back to this because this is just too depressing...and it was like I was the lucky one in the room...it's almost as though...well, you're lucky, it makes them feel even worse. Jane line 202

Susan also went along to a group meeting, but what started out as an uneducated glance at her possible future, ended with Susan acquiring new knowledge about RRMS, which she used to empower herself and move forward. Margot sat back and watched the reactions of others in her physiotherapy group, as a severely disabled PwMS began therapy, and felt that everyone in the room was glad it wasn't them. The comparisons for them were favourable.

There were a few people in wheelchairs...really bad ones...that scared me...confronting...I thought...that's going to be me...that's how I felt...but then, doing more reading and research...that's the worst of the worst...it doesn't always have to be like that...everyone's different. Susan line 506

(on seeing patients in a wheelchair today) I feel OK because I know that I'm not going to be like that...I'm better...I'm different because there's all different MS's. Susan line 1239

(in my physio group) there's people there a lot more disabled...they get driven by community transport and they're in wheelchairs...there's a woman...and she has to be wheeled in...I don't think she can do much herself at all...there were a few people with MS around...I just glanced at them...everybody was looking...I could imagine in their mind, thinking "oh gosh, she's worse than me, it could be worse"...they're probably all thinking "at least that's not me, I'm better than her at this stage". Margot line 2204

Signing up for the nearest MSA meeting straight away was not for everyone and some participants chose a more measured approach to joining the MS world. Will avoided others with MS as much as possible, not wanting to compare with them. When Will attended the day admission centre at the hospital for his monthly DMT treatment, he carefully avoided PwRRMS, preferring the company of "cancer patients" also attending the same centre for treatment, who he felt had a better and happier disposition.

I stay away from other people with MS ...because I don't want to hear bad stories and I don't want to know how other people cope with it, because I believe the way I cope with it...works for me...I would purposively sit with the cancer patients because you could have fun with them. Will line 289

Other participants such as Margot and Griff enjoyed their time receiving their medication in the infusion centre at the hospital surrounded by others with RRMS. They both expressed their sadness at the loss of their readymade social RRMS network when their DMT infusions were stopped and they were switched to different DMTs, demonstrating the experience as a helpful interaction.

Although the majority of study participants sought to dare and compare against others with RRMS, several participants sought comparing with others who had difficult life circumstances but were non-RRMS, in an effort to (re)define themselves. Susan enrolled in a course to help with making positive life plans, attended by people with mental health issues, loss of family members and other sad events. Davina was directed to a church group by her Church Minister to help her come to terms with her own diagnosis by appreciating and sharing the hardships of others who had been in war zones and lost children. Both Susan and Davina were able to spend time with people they considered to be worse off than themselves, helping them to build positivity and to have hope in their own futures.

In that group course, I met lots of beautiful people who had lots of sad stories who came there to learn, also how to be strong and cope with difficulties in life...people had lost children or partners or also dealt with illnesses...it gave me a lot of strength...also people didn't understand what they were going through, weren't listening to them...it's similar, it's similar. Susan line 731

(as I struggled after my diagnosis, a Minister) got me in contact with women in the church where they had been in some really bad situations overseas, where they had lost children to diseases...older women... it made me stronger. Davina line 1178

Daring to compare for the PwRRMS is an important part of (re)defining self after their diagnosis. PwMS organising their own network can function as a coping

system, assisting with stigma and introducing role models who have accepted MS into their lives and adjusted (Grytten & Maeside, 2006). However, as demonstrated by participants in the current study, this needs to be the right group for the right person, there is definitely no “one size fits all” approach. Mixing PwMS of different types and stages can be disastrous to self-identity and image, as Jane discovered at her first MSA meeting with progressive PwMS and no people living with RRMS. Jane recalled how many in the group cried as they heard sad and demoralising stories and how it left her feeling depressed afterwards. However, when Jane connected with a group of people living only with RRMS, the situation was vastly different and she gained much more out of the meeting and left feeling positive. It is important that MS Nurses are able to assist, advise and educate PwRRMS on how to engage in meaningful and appropriate social relationships with others living with MS, and how to negotiate social contexts and comparisons of MS in a fair and realistic way. Referrals to appropriate sources of support in this regard have the potential to be life changing.

Negotiating Normalcy, Disability and Independence: what's what and who's who

Trying to (re)define self as a PwRRMS led to numerous participants struggling with the idea of what being “normal” actually meant, against their existing perceptions of disability. I feel normal, am I normal? What is normal? Am I disabled if I just have numbness in my little finger? Do I need to be immobile to be disabled? Do you have to see disability for it to be real?

One way to manage chronic illness is to construct and live a story of “life as normal”, for people to think of themselves as living a normal life, just with a few problems (Robinson, 1993). At the beginning of the RRMS journey this can be particularly difficult, but is possible once the disease is under control, less active and the PwRRMS has had time to process the changes and acquire knowledge about living with the disease. Normalisation is a chiefly positive response to illness acquisition and involves actively adapting to changes wrought by the illness, allowing resumption of previous roles and responsibilities (Joachim & Acorn, 2000). Returning to work, or usual daily activities, and minimising disruptions as soon as possible after a relapse also provided opportunity to assume to live “a normal life”

(Dennison et al., 2010). Kate demonstrated this repeatedly, suffering a relapse, going to hospital for treatment, straight to work and home again without telling her family, much preferring to keep things as normal as possible.

I think I'm normal, aren't I?

The body of work by Charmaz (1983, 1987, 1990, 1999, 2006) in chronic illness explains how living with a chronic illness implies feelings of living a restricted life with loss of the former self image (Charmaz, 1983), sufferers striving to include the illness in their daily lives and their identity (Charmaz, 2006). Several of the study participants either still viewed themselves as normal, or tried to give the illusion of being normal, either to themselves, or to others (or in most cases, both). Some participants queried what normal was, particularly in terms of vague symptoms such as fatigue and tiredness. To most study participants, looking and behaving normally meant not looking disabled to others. Susan took a pragmatic view to negotiate her symptoms and for Ruby and Kate, the appearance of normal was very important.

*I get tired... but I work four days...they're tough days...and I look after a house, my husband, a little one who is full of beans...that's normal...I'm just like a normal everyday mother doing all the normal things a mother does...and she gets tired.
Susan line 1144*

Just normal, I want a normal lifestyle, I want to be able to teach my kids to give...I want them to be happy...I just don't want to be in bed...or on the sofa...I want to be moving. Ruby line 1575

I do make an effort every morning to have my shower, get dressed, put some make up on...to get my nails done...so I can be a normal person. Kate line 1930

For Davina, the quest for normalcy was so central to her sense of self that it led her to overachieve, to work harder to be accepted as normal. In contrast, just maintaining the function of mobility constituted normal for Piper, and is her goal living with RRMS.

I would say that since I was diagnosed I have tried harder in everything to be normal...I have not worked on a normal level, I've worked above target...now I am exhausted because I've tried so hard to do that to make myself look normal. Davina line 978

Being diagnosed has...now I can hopefully control it...I feel more confident...I do envisage myself...hopefully...never being with a walking aid...so that's what I'm hoping for...I think you can live a normal life. Piper line 2017

How others see me - not being defined by my diagnosis

Even if the PwRRMS view themselves as normal and not disabled, ill or sick; if others look at them differently or treat them as different, frustration and anger can develop as PwRRMS are judged against their disease instead of themselves. In essence, others judge them as a person with MS based on what they know about the disease. Both Rudi and Ruby felt that RRMS had hindered them from appearing normal to others.

I notice still to this day, that people treat me differently since my diagnosis...I'm fine, just treat me like I'm normal! So I found that a bit condescending...they look at me as a person with a disease now, which is a bit frustrating. Rudi line 1435

The hard thing is...when people look at you like a basket case and you lose your identity...Oh...that's MS. Ruby line 707

Not wanting to be seen as disabled, Will did not disclose his diagnosis to his extended family for some time and only wanted to see them in person when he was at his best and not as someone who appeared disabled.

I only went to see them (extended family) for the first time, two years ago...and I think I know what it is...being seen, I don't want to be seen as having a disability...I think that's the first time I've used that word today...I think that's the first time I have used it, ever. I want to be seen as Will, everyone knows Will as the big, strong guy. Will line 1235

Dealing with episodic disability presents further challenges for PwRRMS in negotiating normalcy, possibly being disabled one week with a relapse and not the next, and can prove a difficult concept to deal with. Most people with episodic disability inhabit the space between illness and wellness, a space that is fluid, dynamic and open to change at any time between sick and well, normal and disabled (Vick, 2013). Thus, they can be living under the appearance of, and genuinely feeling, normalcy for long periods of time. Additionally, invisibility of symptoms encourages the belief that the PwRRMS is normal, especially if they look normal to others and function well most for the time, challenging the notion of what it is to be disabled (Vick, 2013). For those with episodic disability holding onto the appearance of normalcy and being reluctant to disclose their diagnosis, stress and worry about others uncovering their secret was ever-present. Several participants were determined to present the persona of normalcy and not disclose their diagnosis (to be discussed further in the next section), hiding their episodic disability and thereby proving to themselves and to others, that they were functioning as normal. Success in this was essentially proven if others around them did not notice any issues.

Maintaining independence

Maintaining some degree of independence was extremely important to many study participants. If they could possibly manage to do a task, they certainly wanted to try. Asking for help was simply not something that came easily to them. This may be a reflection of wanting to appear normal to others or reinforcing normalcy to themselves.

I have plenty of family, everybody's here...so I'm lucky in that regard I don't like to ask people to do anything...I do it myself thanks if I can...I'll do it myself...it's only when I'm really down and out with fatigue and I can't do much...then I'll ask for help...but I will push on if I can. Piper line 1300

It's hard to ask for assistance...it was hard to ask for help...I didn't want to seem needy, I guess. Margot line 1188

(when I needed steroids) I would do things myself, I don't really depend on anybody...you can't be seen as you're moaning and groaning all the time...and half the time (my husband) didn't even know I'd just had steroids...I did things myself.
Kate line 946

It's really tough when you go through a relapse and you've got to give up your independence...the simplest thing...that was a big struggle...having to ask for help for simple things like giving kids lifts and things...I know it's no hassle because I do it all the time for people...to do that and ask yourself was a big hill to climb. Rudy line 1743

Working out Work

Part of (re)defining self for many participants involved negotiating employment and what their work future might look like with their new diagnosis of RRMS. For some study participants this was a positive experience, and for others a more negative experience. This proved to be an issue at many times during the life trajectory (not just in the post diagnostic period) and could be an issue for a different reason at a different time. For example, a relapse could suddenly bring a new symptom (such as loss of sensation in the hands) which impacted on work performance. Making the decision to disclose a diagnosis of RRMS at work was a significant decision for many participants. For a few participants, secrecy and non-disclosure ensured that they could maintain control over who knew the diagnosis and allow them to try and maintain normalcy at work. For others, disclosure meant they were able to secure the help they needed at work to allow them to keep working and performing in their position, albeit with some adjustments.

Most participants in the study were still working, part time or full time, only Kate and Griff (not by choice) and Margot (by choice) were not currently employed. The situation in regards to MS and employment in Australia appears to be improving, with a recent longitudinal study of 1260 participants suggesting that employment rates for PwMS (type of MS not specified) increased over the study time period 2010 - 2013 compared to the general population and was thought to be related to positive organisational responses to work adjustments and work roles for PwMS (van Dijk,

Kirk-Brown, Taylor, & van der Mei, 2016). However, the news was not as good for men living with MS, as the data showed that male unemployment rates in MS remain significantly lower than the general population (van Dijk et al., 2016).

Rudi needed over 2 years off work to recover from a severe MS relapse and recalls her feelings from this time and how she turned it around into a positive (re)definition of self.

When I lost my job I thought...I can be down and think that I'm unemployable, I can't work...or the path I chose to take was well, work's always going to be forever, the kids are going to grow up and I need to look at this as I'm lucky because I get to spend this time with my children...whilst it was tough financially, we adapted. Rudi line 944

It has been reported that fatigue, cognitive difficulties and mood disorders may have an enormous impact on work ability for PwMS (Sterz et al., 2016). A recent study exploring the meaning of work in the lives of PwRRMS found that becoming familiar with the disease, adjusting expectations, having a supportive, realistic manager and seeing work as meaningful, were all helpful in facilitating employment (van Gorp et al., 2017). For several participants, they took the opportunity to (re)define themselves in terms of work. Ruby enjoys her job, it gives her purpose, and although ambulation is difficult, she can perform her role in education with adaptations and has excellent support from work colleagues. Davina worked harder to prove herself at work, and Susan was given an opportunity to change her work environment to suit her new needs living with MS. For Rudi, whilst the work itself is not interesting, she values that she can choose her days and hours to suit her lifestyle and this is currently more important to her.

I'm really supported, I've got lots of friends there who check on me and I feel very supported. I'm working full time but have asked next year to have part-time so hopefully I will get a day off a week...to do a little gym...and I want a day with (my daughter) at home. Ruby line 790

Workplace was good...I was very close to my boss and on a level of that first line management...the rest of management didn't know, where I worked was such a big organisation that I was protected...I think I showed them that it didn't worry my ability to work. Davina line 946

(after my diagnosis, a manager I knew offered me a role)...so you don't get as tired and without shiftwork so you can stay healthy...I liked where I (already) worked, so I decided to do half in both, two days and two days...they looked after me and they understood, so I was very grateful and very blessed. Susan line 579

I'm now back working 12 hours a week I chose the hours and the days...this just landed in my lap so I was lucky...whilst it's not the most stimulating job, it's a job, this is good for now. Rudi line 955

The decision to disclose or to not disclose an MS diagnosis at work was one of the most important and personal decisions for study participants. Protective disclosing is a tactic used by many PwMS to successfully inform others the diagnosis of MS, in their own words and in a way that is acceptable to them, as a form of information control (Grytten & Maeside, 2006). This enables PwMS to protect themselves and exert some control over who knows the diagnosis and exactly what they know, a concept important in the workplace. Individuals with MS develop strategies and utilise resources, identifying priorities, and planning, part of (re)defining themselves not just as a PwRRMS, but also as an employee/ worker after diagnosis. Some participants in the current study chose to fully disclose their diagnosis at work with good outcomes (Piper, Evie, Ruby, Susan), others partially disclosed (Davina, Paul) practicing information control, and others have never disclosed (Jane, Joy, Will) because they don't feel it is necessary. No study participants in the current study expressed regret at their decision.

Several participants had chosen not to disclose their RRMS diagnosis in their workplace and were committed to keeping the secret, for reasons of privacy, fear of losing employment and/or fear of being stigmatised. Employment discrimination has been reported in MS, primarily through not providing needed accommodations at work, unfair working conditions, denial or delay of promotion and different

standards of performance (Roessler et al., 2011). However, it has also been suggested that early disclosure at work may help maintain employment, if disclosure is followed by appropriate work adjustments (Frndak et al., 2015).

I still haven't told my current workplace that I have MS...I don't want to tell them...I'm only on a year's contract and they might not employ me full-time...better if I don't. Jane line 504

Not many people know...I told my CEO, he's provided support in knowing...I got a major promotion a few months ago...and he knew at that point...very supportive, but nobody else knows, I much prefer to keep it that way. Paul line 994

(when I was being diagnosed) my workplace were being very difficult at the time about the amount of time I took off and they actually put me on performance management...it was really hard to hit my (work) target...and my manager was not supportive, or the company...they didn't give me any help at all. Will line 740

For Joy, who did not disclose her diagnosis at work, in hindsight losing her job gave her the chance to recover fully from a previous relapse and allowed her the time to rest and later to (re)define who she wanted to be and what she wanted to do. Joy changing her area of employment to one which she enjoyed more and gained fulfilment in.

I pushed and pushed and I just deteriorated, it was really hard and I was just trying to hold down a job...I'm so sick and I can't work (and my husband wouldn't let me leave my job)...I was just heartbroken...I lost my job...I wasn't doing my job...but not working gave me the reprieve...I could just sleep and heal. Joy line 853

(and now) I really do love my job, my job is to give other families' hope...I teach what I've learnt. Joy line 1851

Evie experienced an interesting situation at work, where a work colleague newly diagnosed with RRMS became aware that Evie also had RRMS and started asking her questions during work time. Eager to help in the beginning, Evie was soon

overrun with questions and conversations from this person, which started to impact her own work role in both time spent talking about RRMS (and therefore not working) and in how others viewed her (always talking about RRMS). She had previously disclosed discreetly at work to a selected few but Evie had not openly told all of her colleagues, who were now aware of her diagnosis. Evie had preferred to have a division in her life between RRMS and work, but that was now dissolved.

(the colleague with MS would constantly ask questions and advice at work) so, my MS had now infiltrated my personal life and my work space...so I was forced to think about that whilst I was at work too...I couldn't get away from it. Evie line 1089

Re-establishing a new identity after the loss of the role as a worker has been identified as often leaving a void in the life of the PwMS (Hunt, Nikopoulou-Smyrni, & Reynolds, 2014). Griff has felt this most keenly as he has struggled with financial dependence on his wife and maintaining any sort of social circle since leaving employment due to his MS. For years he was reliant on attending his monthly treatment infusions to provide social stimulation, and with a change in therapy and no longer a need to attend the centre, he has struggled to maintain any social interaction. Leaving the workforce has been reported as shrinking the social and geographical worlds of PwMS, as lives are now hidden from view, particularly as disease progression occurs (Dyck, 1995). For Griff, losing social contact was a major casualty of not working.

No income, that's a bit hard...all of a sudden I'm a dependent, financially dependent and that's never sat comfortable with me. Griff line 837

After working for 22 years...reality slaps me in the face...social contact is what you're trying to establish so people have a community to operate in...all those links have gone...I don't have those links anymore. Griff line 504

It has been reported that mourning the loss of a meaningful occupation is a real threat for PwMS (Matuska & Erikson, 2008). In the current study, this was experienced profoundly by Kate, who suffered greatly with the loss of her identity along with her

employment, a world where she felt accepted and valued, moving to her new reality of unemployment and struggling to make a meaningful contribution.

(losing my job last year) it was a bit of a nightmare at work...they wanted to shut down my department...it didn't make sense...I fought really hard, to the point where I got sick...and I thought...I can't do this...I've done everything for them, and this is the way they treat me...there was a lot of anger as well...I can't cope with it, I'm a real mess...there are times when...I'm lost...I'd rather work...I loved my job. Kate line 1899

If new roles, identities and interests could be established, participants spoke of how losses could be turned into gains with new hobbies and new opportunities. For both Griff and Kate, they have still not recovered from the loss of the work role in their lives, whilst others such as Piper, Margot and Rudi, have made the most of their enforced time off work and have found new ways to enjoy their time, travelling, exercising, maintaining wellness and expanding social circles.

The MS Nurse has an important role to play with support, education and guidance on aspects of work and employment in living with RRMS. Early referrals for advice from MS organisations to assist with work disclosure decisions and allied health professionals such as occupational therapists for practical work management solutions (Yu & Mathiowetz, 2014) can significantly impact the journey. (Re)defining self in regards to employment is an important part of the life journey with RRMS.

Parenting with RRMS

One of the most surprising revelations when analysing the current study findings was realising what an enormous impact the role of parenting had on PwRRMS. As a parent myself, I was always cognisant of the fact that the parental role was important in chronic illness, yet I was completely unprepared for just how important this role is to PwRRMS. It may be due to the unpredictability, which threatens to change the parental role, or being at the mercy of a disease which could render disability at any given time. It may be the heightened sense of value placed on parenthood living with

a chronic illness. All but two of the participants in the current study were parents and they all became visibly physically changed during the interviews when talking about their children, their faces and voices softening, becoming animated and happily discussing the positive aspects, and becoming sad and upset when discussing the challenges of parenting as a PwRRMS.

To be or not to be (a parent)

Historically, women with MS were advised not to have children, and if pregnant, to terminate the pregnancy (Smeltzer, 2002). This is currently not the case with pregnancy reported to have some protective effects on the course of RRMS and on disability progression (Pozzilli & Pugliatti, 2015). The impact of MS on family planning was an issue for several participants in the study. Plans for more children in families were curtailed as a direct result of the impact of RRMS, and also as a result of unknown effects of some of the RRMS treatments. Ruby wanted a third child, but understood that the bulk of the childcare would probably fall to her husband as she was gaining disability and so elected not to contemplate further pregnancies. For Kate, there were simply too many unknowns to consider a second pregnancy, and coming from a science and medical background, she felt very strongly that this was the right parenting decision for her and how she wanted to (re)define herself with RRMS.

(with two kids) we were blessed...and now that my body is so worn...there is no way that I can put that pressure (another baby) on him (my husband)...I would if I was physically able to take care of the child...I think we're very blessed to have the two that we have, I can't be too greedy. Ruby line 1320

And the decision not to have any more children...it was related to MS...I was scared, thinking, what if I have another child, I get sicker, how am I going to bring up two children? And I've got no idea what these drugs are doing to me and what they're going to do to a baby...I did make the right choice, I know that. Kate line 1377

Breaking the news to children

Breaking the news of an MS diagnosis to children could be a daunting process. The impact of MS on children has been shown to be a concern for parents with MS, supported by research reporting that MS can have a negative effect on children (Bogosian, Moss-Morris, & Hadwin, 2010) with most children having a poor understanding of MS (Bostrom & Nilsagard, 2016). A recent study identified that children may also worry that their parent with MS would die, highlighting the importance of support and communication to strengthen the child's ability to cope (Bostrom & Nilsagard, 2016). Rudi needed professional help for her daughter, who experienced emotional trauma after witnessing Rudi suffering a severe relapse.

I had to get my 12 year old into therapy because she didn't cope, she became quite anxious and she thought I was going to die every time I got carted away by the ambulance. Rudi line 600

At the time of diagnosis, more than half of the participants were already parents. Rudi (four children under 12) and Paul (three children under the age of eight) described how they set out to explain RRMS to their children.

You know what it's like as a mother...you just get on with it, as hard as it is...I got them (four kids) all together and explained as best I could to a child...they knew I was sick, no hiding that...the youngest took off halfway through the conversation to go play on the swing...it was hard...it was hard work. It's been distressing, especially my two young girls...I find that tougher than the physical side of things sometimes. Rudi line 568

I really haven't gone into too much...I have explained with...Dr Seuss's book "Inside Outside" and he (son aged seven) always goes "they're yucky white blood cells...you've got yucky ones"...and sometimes he asks me "how's your brain today, Dad?". Paul line 980

The impact of MS on parenting

Recent studies have shed light on the impact of MS on parenting, although most of this literature has concentrated on mothers and MS; with a paucity of literature exploring the experience of fathers and MS. An Italian study interviewed 16 female PwMS, of varying types and stages, aiming to uncover the value of motherhood in PwMS (Willson, Tetley, Lloyd, Messmer-Uccelli, & MacKian, 2017). The researchers described how the participants strove to maintain control of their MS, how they compared themselves to other mothers and how they frequently felt different to other mothers (Willson et al., 2017). Several participants in the current study echoed these concepts. Rudi, a mother of four, reported that she felt different to other mothers because of what she could not do related to her RRMS.

My girls look at that (what I can't do) and see that I'm not like other Mums and that's hard for them when I say "I just can't go because I'm too sick"...and that, that's hard on them. Rudi 685

A study exploring the lived experience of mothers with MS (type not specified) has reported that PwMS who are mothers of young children describe the experience as physically challenging, yet highly rewarding (Plumb-Parlevliet, 2015). Mothers with MS recognised that energy is limited, and this is often challenged by children, causing the mother to regulate and limit activity (Payne & McPherson, 2010). Many mothers have support networks in place to help them cope with MS and this includes partners, family and friends (Payne & McPherson, 2010; Pakenham, Tilling, & Cretchley, 2012). In the current study, Piper, Margot, Kate, Rudi, Davina and Ruby all reported the importance and value of a close network to assist them in their motherhood challenges with partners and family being particularly supportive.

My mother-in-law...if I tell her I'm crook she'll be around in a heartbeat, so that's good. Piper line 1329

When we moved here, Mum and Dad bought around the corner, they knew that that there was a potential diagnosis...I'm pretty close to my family, and my sister lives close by...this has brought us closer together for sure. Ruby line 1122

Parental losses

It has been reported that mothers also experience loss related to their ability to fully engage/participate in their children's lives due to MS (Willson et al., 2017). In the current study this was expressed by a father, Griff, who struggles greatly with the impact MS has made on him as a parent, his sons observing their father exhausted with fatigue instead of playing with them and taking them to the park.

My kids have grown up with someone who struggles...when I should have been going to the park, when I could have been kicking a ball... their primary role model was probably somebody who fell asleep at 3 o'clock in the afternoon. Griff line 1323

As Ruby experienced a severe relapse shortly after delivery, she missed out on crucial time with her first baby, those memories still haunting Ruby seven years later.

(my new baby) it was hard not being able to take care of my baby...I couldn't pick him up, I just had no strength, I couldn't get up to him, I couldn't change him...(cries)...it was so...hard...the kids have seen a lot...it's hard on them as well because it limits us from what we can do. Ruby line 430

The joys of parenthood

In the current study, all mothers and fathers valued their parenting role and several participants felt that parenting with RRMS left them feeling empowered and bringing out their best qualities. Being a mother may bring some beneficial psychosocial effects to the life journey with MS, enriching lives and providing purpose (Plumb-Parlevliet, 2015) which may be important given the high rates of depression reported in MS (Feinstein, 2011). Possible rewards from parenthood cannot be underestimated, it has been reported that PwMS who are mothers have higher quality of life and more social activities compared to childless women with MS (Twork et al., 2007). Davina gained a sense of empowerment from motherhood and Will uses his love of fatherhood to give himself hope for a future where he is active with his children.

I was desperate to have a third child...I was good...at least I was really good at something...I really enjoyed being a mother and I felt I was quite successful at it...it gave me a sense of empowerment. Davina line 675

I want to be able to play sport with my son and daughter...we are the best of friends...we play netball and we play golf...I want to play football with my son and I want to take him on the golf course! Will line 1488

The immense value of the role of a mother remains evident, regardless of the degree of disability or whether the MS diagnosis or motherhood came first in the equation (Willson et al., 2017). The fathers in the current study also expressed happiness and delight in fatherhood, although it wasn't always easy to keep up with the children. Balancing both the challenges and the joys of parenthood takes skill, patience and time. The MS Nurse has a vital role to provide guidance, education and support on parenting issues at all stages of the life journey with RRMS.

Balancing losses and gains – my life plan (re)defined

Chronic illness has been described as a disorder that persists for an extended period, affecting a person's ability to function normally (de Ridder, Geenan, Kuijer, & van Middendorp, 2008) and profoundly impacting day to day lives (Moss-Morris, 2013). The presence of chronic illness has the potential to induce intense changes in a person's life and can result in negative effects on both their wellbeing and quality of life (Sprangers, Hanneke, & Haes, 2000). However, chronic illness can also provide the potential for individuals to find advantage in the situation and a positive effect on lives, known as benefit finding (Pakenham 2005a, 2005b). Findings from the current study to be discussed in this section demonstrated examples of both scenarios, and sometimes both scenarios in the same person, at different times. Balancing these losses and gains was an important part of (re)defining self and setting a new life plan with RRMS.

It should also be noted that the onset of MS doesn't necessarily bring into question a person's sense of self, rather it is the degrees to which symptoms impact on a

person's ability to fulfil roles important to their pre-MS self, that appear to have the greatest re-defining impact (Mozo-Dutton, Simpson, & Boot, 2012). MS symptoms, which have the power to threaten the PwMS's perception of self, may also contribute to emotional issues such as depression and anxiety (Mozo-Dutton et al., 2012). For several participants in the current study, this was certainly the case. Kate's burgeoning career in academic study was grossly threatened by sudden blindness, rendering her unable to read intermittently and leading to failure to complete a course for the first time in her life. On treatment, Kate's relapses lessened and she gradually regained some control and resolution of her symptoms. Accepting this particular symptom into her life story was not easy for Kate and involved years of anguish. MS HCPs can apply this knowledge to their dealings with PwRRMS by assessing patients and clients for symptoms which impact the most upon their life; and not just the symptoms that HCP working within the medical model, believe to be the most important.

Battling losses

Feelings of loss dominated the immediate post diagnostic period for several participants and for some, this was repeated again at various times later on in the life journey. The fact that RRMS could occur randomly and cause relapses at almost any time could potentially lead to the loss of important life milestones. Piper believes she lost the opportunity for a memorable wedding and honeymoon due to RRMS symptoms, suffering continuously from severe headaches and facial nerve pain in the weeks prior to and involving her wedding.

*I'd be in tears with those headaches...I had this new bout just before I was married...they don't go away and they just wrap around my face...it's just horrible.
Piper line 384*

(my honeymoon) was a disaster actually...(and the) wedding day was a disaster...I again had really severe, severe headaches...my wedding day was a blur...(and the honeymoon) we actually came home early...and called the doctor. Piper line 361

The onset of a new relapse and/or significant physical disability could induce feelings of loss for the normal body, and loss of independence without warning. Rudi keenly felt the loss of her normal life during a severe relapse and the degradation of not being able to perform activities of daily living. Jane was an avid athlete who was not able to go back to her usual level of competition after her diagnosis and continues to feel this loss of physicality.

(with a severe relapse) it was degrading...have to be wheeled to the toilet...the basics...and that was hard to cope with...things are just taken from you...that's what I find hard with MS, giving up simple things like not being able to go for a walk...because that's my time out and I enjoy doing it...and you don't think it's much to ask. Rudi line 276

My balance and the way I hold a pen isn't good...my balance isn't good...I don't ride a bicycle any more...(MS) has curbed my lifestyle...not that I was ever a risk taker, but I used to do a lot more...things like that are disappointing. Jane line 552

Margot had a difficult time dealing with her gradual loss of mobility. Her husband began looking at wheelchairs as they enjoyed travelling and he felt it would be a safer option, but he was met with stiff opposition from Margot who didn't give in easily.

It's a real mental block...(crying)...it's really hard to do that...it's the elephant in the room...it was a real mental block to sit in that (a wheelchair)...in public. Margot line 1533

Accepting gains

Appreciating the gains that may occur in RRMS will be discussed more deeply in the theme of positivity and hope, but for many participants, finding some benefit in their new life with RRMS was crucial to them finding peace and courage to move on and integrate RRMS into their life. Benefit finding is a specific type of coping strategy whereby, despite adversity, individuals positively evaluate their circumstances and report gains such as personal growth, improved relationships and changes in

priorities and goals (Pakenham 2005a, 2005b). Research has shown that benefit finding has been strongly and directly correlated with positive outcomes in MS (Pakenham 2005a) and practicing benefit finding by valuing life and acknowledging simple pleasures could be beneficial in MS (Irvine et al., 2009).

Benefit finding was a positive and active process for Rudi, who appreciated the personal, family gains she found directly as a result of living with RRMS.

I got really angry (after my MS diagnosis), but by the end of it I actually think of it as a gift because it's made me live my life differently...it's made me start to travel whereas I would have put that off...I was heavily involved with my kids anyway...but I just have a different outlook on life now, I tend to care less about things I don't have time for gossip, I've let all that go...so I view MS as a gift. Rudi line 835

Margot overcame her fear of the wheelchair to gain new awareness and opportunities and find benefit in the things she had learnt.

I think I accept things a lot more...I think you become more patient, you tolerate a lot more and you become...more accepting of people and maybe you develop a thicker hide...overseas people are so good to people in wheelchairs...they were just fantastic...and straight to the front of the queue...it was great...I thought, I can't believe I haven't done this sooner, it was the best thing. Margot line 964

Enrolling in a course to help her cope with her new diagnosis, Susan gained so much more and greatly valued the insights she learnt which improved other areas of her life as well.

I had lots of fun and went on more holidays...I hadn't had any relapses and I felt better about myself and I was doing a course...in that group I met lots of beautiful people...what I've learnt through this has made me a better person. Susan line 731

Balancing the losses and gains after a diagnosis of RRMS often led to constructing a new life plan. Gathering new information, working out what is important to the self, what doesn't matter and what might matter in the future takes time and effort. How

participants managed this, and how long this took, was highly individual, but always involved a personal decision to move on and to embrace a new life, with changed attitude and values. The majority of study participants had moments where they made a decision to embrace the new self and move forward with purpose. It was as if they reached a cross-road and actively chose to embrace their life living with RRMS.

I said, from that point, nothing's going to stop me I'm sick of being...that guy that just goes home...I never used to go out (following diagnosis)...I used to go home from work, go to sleep...I just said I'm not going to go home and sulk on my own...go to work and live in circles...so I joined a basketball team, I joined a football team...I'd go and play poker with my friends...I just lived this active life. Will line 1151

I thought well, I've got to try harder...to try and meet someone or do other things...so I started up doing other hobbies and taking up different interests to try and meet people...and also to learn other things to make myself feel better. Susan line 697

So I got really angry and obviously went through the stages of grief, but by the end of it I actually think of it as a gift because it's made me live my life differently...it's made me start to travel whereas I would have put that off. Rudi line 835

I take each day as it happens, one day at a time. I don't plan for the future, if things happen, they happen...you've got to put things in little pigeon holes...with my studies and my work I did not put too much emphasis (on relapses)...it was an inconvenience...but it was not my biggest problem...you're (RRMS) not going to beat me. Kate line 2419

(I had an experience) where I said "fuck you body, you will do what I tell you to do" ...so I got my two walking sticks out and went for a six kilometre walk...and I pushed hard and the more it hurt...you are not doing this anymore and I took back...took back control of my own life...yes, the disease doesn't control me, I control my own body. Joy line 1090

It is true that although MS does present complex challenges and signals a difficult period of adjustment, the majority of PwMS do adjust successfully (Eeltink & Duffy, 2004), and we as HCPs can openly discuss this with PwRRMS early in the journey. Pakenham (1999) has also shown that adjustment to MS improves as the time since the onset of symptoms lengthens, meaning that for many PwRRMS, that time will often be their friend. Time will heal emotional pain and time will help (re)define who they are and where they fit in, not just within the MS world, but within their own world and what is important to them as an individual. Adjusting to RRMS, like many chronic illnesses, is a process that continues throughout the course of the life lived with MS, and responds to changes in the illness status over that time (Sharpe & Curran, 2006). In RRMS, these changes are likely to present many times and particularly around times of relapse, new symptom onset, pregnancy, medication change, and disease progression. A PwRRMS is likely to require many redefinitions of self throughout their lifetime.

Participants described their losses, different for everyone depending on their individual beliefs and values. As previously discussed, loss of employment was a major concern for several participants, and for Griff and Kate, this continues to be a major issue in their lives. Other losses, affecting the participants in the current study, such as loss of independence, physicality and mental health have also been discussed in this chapter (Clair, 2003; Courts et al., 2004). The sense of loss and regret for PwMS who are parents knowing that children are observing the journey and possibly missing out on life (Willson et al., 2017) was replicated in this study (by study participants Rudi, Ruby, Griff and Davina). There is a paucity of recent literature on the experience of being a PwMS and feelings of loss.

There have been several research studies identifying benefit finding in MS acceptance and adjustment (Pakenham, 2005a, 2005b, 2009) and thereby impacting positively on (re)defining self. A study exploring story making and living with MS uncovered that for some, being diagnosed with MS was akin to MS being a saviour, delivered to save them from the person they were becoming (Clair 2003). No study participants in the current study expressed their feelings in this regard, although Rudi discussed how she changed her “attitude to gratitude” after living with MS for a while and recovering from her initial relapse. Most participants in the current study

viewed MS as a partner, finding new ways of working with the disease rather than against it.

Many PwMS change negative reactions (denial, concealment, loss of confidence) into positive changes and outlooks, including an increased appreciation for life and spirituality (Irvine et al., 2009). Most PwMS modified their lifestyle to do the things they wanted to do and needed to do (Matuska & Erikson, 2011). This was also demonstrated by several study participants, most notably Rudi, who described how if she wants to “play hard” and enjoy activities and sports, then she also needs to “rest hard” and nap regularly, even if it means missing out on other things.

Coming to terms with a new life plan may mean consequences to current lifestyle for PwMS. These concepts will be discussed further in the following chapter but it is important to recognise what these changes might be in terms of (re)defining the self with MS. The amended life plan for many study participants meant changes to family life, to relationships, to social lives, a new strategy of planning, changes to workplace and employment, to new methods of stress management and to seeking joy and happiness in their lives. Some looked at the balance scales of life and chose to openly accept the gains (Joy, Evie), some chose to focus on the losses (Paul, Griff, Kate), some participants accepted both (Piper, Rudi, Susan, Will). But, for all study participants, the process was fluid and dynamic, it could change regularly and swiftly, and signalled a new life trajectory. It became the nature of living with the disease for many, part of who they were now, an identity that was constantly open to change and (re)defining. It prepared participants for one of the next important steps in their lives living with RRMS, to Taming the Beast and set up their life in a way that they felt they were in control of RRMS. This will be discussed further in the next chapter. Before this time however, many participants needed to embark on “Battling the Demons” before they could regain some of this much needed control.

Theme 3: “ Battling the Demons”

My Demons

Though quiet

Are never quite silenced

Calm as they may be

They wait patiently

For a reason to wake

Take an overdue breath

And crawl back to my ear

Sarah Boswell

For the purposes of this study, “demons” were conceptualised as negative emotions, sometimes very strong emotions, which can threaten the livelihood of PwRRMS. Demons can be subtle, creeping in every so often on a bad day and upsetting routine and peace of mind, or they can be like a runaway freight train completely annihilating all in its path. The end result is that PwRRMS are mostly never free, even when clinically or physically things are in quiescence, there’s potentially always something beneath the surface, where demons lay. For all participants in the current study, a variety of demons threatened them at different times, and for different reasons.

The *central organising concept* for Battling the Demons in this study encompasses the experiences of confronting and living with the negative emotions that PwRRMS may feel throughout the life course, the things that steal away joy from life. There are many potential trigger points in an RRMS life journey to disrupt emotional equilibrium and quality of life (Dennison et al., 2009), including the time of diagnosis, the presence of new or chronic symptoms, with a relapse, change of DMT, when meeting other PwMS, or with disease progression. MS has been described not just as a journey of feelings, but a journey of feelings that change over time (Lysandropoulos et al., 2015). Adding to the burden is that people with neurological disability may be more likely to resort to ineffective ways of coping with emotions, which adds additional strain (Gedik et al., 2017).

Psychological problems in MS have been recognised for many years. A seminal paper on common psychological problems in MS from Burnfield and Burnfield (1978), described emotional reactions to MS as being inevitable, having serious effects on both the patient and their family, and also recognising at this early stage that they may be responsible for more disability in terms of suffering, than physical effects of MS.

Too often in our busy clinics today, a patient's emotional well being generally takes a back seat to discussions about DMTs, medication side effects and physical symptoms (Minden, Turner, Kalb, & Burke, 2014). Unfortunately, necessitated by the highly efficacious, but also potentially dangerous medication armamentarium of the modern day. The presence of these new, and longed for DMTs and earlier and more rapid diagnosis clearly does not remove the emotional burden in PwRRMS. At times it can be just the opposite, they can be the cause.

The theme of Battling the Demons comprises four intricate sub themes, which all fall under the umbrella of demons, stealing away happiness and causing angst to the PwRRMS. These subthemes are facing fears, weary with worry and anxiety, depression and despair, and struggling with the saboteurs. Each of these subthemes also contains additional sub-subthemes to provide deeper exploration.

Facing Fears

Fear can be best described as an unpleasant emotion caused by the threat of danger, pain or harm (Oxford dictionary, 2017). This threat can be real or perceived, which is an important point in RRMS as so much is unknown, and nothing can be guaranteed. This means that some threats are connected to reality, but some may not be. For the purposes of coding and analysis in this study, and to separate fear from some similar emotions such as worry, stress and anxiety; fear was conceptualised as being frightened to the point of terror, invoking physiological body changes such as body heat, shaking, sweating and crying (Scheff, 2015). Some of these body changes I witnessed when the participants talked about fear and what they were fearful of. This reference to fear being a *distressing* emotion was essential in the initial coding for this category. For example, during Paul's interview, he started to turn red in the face

and loosen his collar when talking about his fear of wheelchairs, he started to perspire and needed to have a short break, his fear was intense and physiological.

It has been reported that for PwMS, the first two to three years after diagnosis can be marred by distress and worry about the future, from being seen as healthy, normal and able-bodied to sick, abnormal and disabled (Mortensen & Rasmussen, 2017). A mixed methods study using both questionnaires and semi-structured interviews of 85 PwMS explored the theme of uncertainty in MS (Boeije & Janssens, 2004). The type of MS was not specified, but many were on DMTs and had a low-moderate disability score, suggesting a high proportion of RRMS participants. Uncertainty about future disease progression was a predominant factor, for those with both low and high perceptions of risk. Wheelchair dependence was perceived as a serious outcome, primarily because of lack of independence and a shrinking social world (Boeije & Janssens, 2004) and provides some understanding for the current study where so many participants were fearful of the possibility of needing a wheelchair and disease progression in the life journey, feeling like a burden to their family and worrying constantly about the future and what might happen. One would have thought the advent of higher efficacy medications to treat RRMS may have had some effect on these emotions, but for many that is not the case, fear continues to be a constant battle. It is a hard task for MS HCPs and MS Nurses today to change the stereotypical representation of PwMS being wheelchair bound and misunderstandings surrounding what RRMS actually is and how the disease course can be significantly altered with modern treatments abound.

Elements of facing fear expressed by the current study participants included the sub-subthemes of fear of medication side effects, fear of symptoms/relapses, fear of disease progression/disability and fear of the wheelchair.

Fear of symptoms/relapses

For PwMS, symptom changes can be overwhelming and almost feel akin to receiving a diagnosis of MS all over again, facing an acutely uncertain future much like an “emotional yo-yo” (Blundell-Jones, Walsh, & Isaac, 2014). Several study participants voiced a fear of symptoms striking at any time and relapses occurring

suddenly, blindness in particular. Rudi had a tendency to relapse rapidly and severely, and as the mother of 4 young children, this induced fear of relapses, and what her children may witness.

I can relapse very quickly...when the paralysis comes...it happens very quickly...they've seen that happen and it's been quite distressing, especially for my two young girls...the other week I fell and lost my balance, I lost my speech. Rudi line 582

For Joy, sudden blindness from optic neuritis (a common presentation of MS involving demyelination of the optic nerve) induced deep fear and a second relapse causing dyslexia left her terrified, again. For Susan, a hospital admission with a severe relapse left her fearful of what may happen in the future and if she would recover.

I was completely blind...for periods of time...terrifying, really terrifying and they couldn't work out what caused it...and it happened again and terrified...absolutely terrified. Joy line 123

So I came into hospital and I stayed the night...I was very scared and I was crying...I couldn't sleep...I said to the nurse "I'm very, very scared, I don't know what's going on". Susan line 280

Fear of DMTs and side effects

The physiological look of fear on some of the faces of PwRRMS during the interviews in relation to some DMT side effects has never left me. Once again, there were strong physiological reactions talking about how dangerous they felt some of the DMTs are, as well as possible unknown effects in the future. This concept will be discussed in greater depth in theme 7, "The DMT Dance", but also belongs as part of the story of fear in this particular theme as well. The most dramatic of these fear reactions were Piper and Joy, who had very strong feelings. After a relapse, Piper's neurologist wished to increase her treatment to a new DMT known to cause PML, but she was adamant she was not having it, nor the new and experimental HSCT

because of perceived high mortality. Joy was also equally adamant she wasn't taking a DMT which had recently been associated with deaths in others living with RRMS.

That PML thing keeps popping up ...what does scare me with that is how do you know it's that or an MS symptom causing it?...I'd rather be in a wheelchair than dead...Piper line 1362

(later when talking about HSCT) I think the risk is too great...I get that these people are in a real state of bother...they're struggling...but I just think I'd rather be, like I said, I'd rather be in a wheelchair than dead, I just think the risk is too great. Piper line 1960

(my neurologist) wanted me to go onto a drug that was about at the time...which had only killed about three people...it had only killed three people! So I said "you've got to be kidding". Joy line 820

Ruby had been offered a stronger DMT after her disease had progressed rapidly, but Ruby declined due to fear about the significant side effects. A couple of years later during our interview, Ruby wished she had taken the opportunity earlier, crying as she recalled her lost opportunity, lost to fear.

I really wish I'd listened to him (neurologist), I was just so scared, he said it could lead to other autoimmune things...and I think it was just pure fear, pure fear...going...I've got two young kids and the risk of cancers...I just didn't know if it was worth the risk...my fear of the PM...? What was it called, PML? That was massive...like every time you have that injection, you just go...(sobbing). Ruby line 511

Fear of progressing/disability

Although this subtheme has similarities with fear of the wheelchair, it is more general and involves disability in all forms, rather than the specific fear of a wheelchair itself. Some study participants met others with more severe disability at clinic visits or at MSA, and many became fearful that this might also be their future.

Being lonely and isolated as a result of disability weighed heavily on their minds and the possibility of a bleak future was ever strong, especially when confronted with the reality of other PwMS.

Margot attended exercise sessions at the local MSA and observed people living with progressive and more serious forms of MS on many occasions. She talked to them and realised many were socially isolated, raising with her a fear deep inside that this may one day happen to her as well.

A lot of them (people with progressive MS) I think are isolated and a lot of them are lonely...it's very isolating...people become very isolated which is a real shame because then it's hard to...how would you make friends if you're isolated at home with disability? who are you going to meet?...I think that would be very hard. Margot line 2517

Griff was a family friend of a celebrity with progressive MS who featured in many MSA fundraising campaigns for MS. As one of only a few people Griff knew with MS at the time, he was fearful for his own future with disability.

(I knew) the picture boy for the MSS for years so I'd been exposed to MS for at least 15-20 years with him...so it was a pretty scary image to measure myself against him...so I did have an understanding at least of how much damage it could do. Griff line 511

Will had personal experience of what severe disability in MS looked like, and he became immediately fearful at diagnosis that this could be his future with disability as well.

A friend of mine's stepfather has MS...he's in a wheelchair and he's flat ninety five per cent of the day...the first thought in my mind when I was diagnosed was what happened to him. Will line 16

Fear of “the wheelchair”

When confronted with a diagnosis of RRMS, many study participants jumped straight to imagining life in a wheelchair, an expectation which is common in the community and based on the natural historical progress of the disease. Before modern day DMTs and treatments, the risk of requiring a walking aid to walk half a block was quoted as 50% at 15 years from MS onset (Weinshenker, 1994). Nowadays the risk of needing assistance to ambulate in the future has not been quantified, the common switching between medications and the heterogeneity of RRMS making predicting future scenarios difficult. This fear of the wheelchair commonly settles with education and guidance from MS trained neurologists and MS Nurses, but for some participants in the current study, abject fear was the resulting emotion, terrifying and paralysing in intensity. Fear of the wheelchair could strike at any time, during relapses or with new symptoms, at the sight of another PwMS, or sometimes, with no specific trigger at all.

Rudi considered her future and the possibility of being in a wheelchair during a severe relapse, where she lost all motor function in her legs as well as the power of speech. The episodic disability of this relapse induced fear that one day the symptoms may be permanent.

The worst case scenario is I will be in a wheelchair...and that will be a very, very black day for me, or a black time if it does happen...afterwards I thought how's this going to affect my life...I might be in a wheelchair next year...and those sorts of thoughts...and that's why I used to get down quite quickly with my relapses because it's almost like a little bit of a taste of what may be reality. Rudi line 856

Paul disliked the MSA education material and resources because he felt that there was an undue focus on wheelchairs in MS, unnecessarily inducing fear in PwRRMS. Paul became emotional as he recalled how he felt reading this information.

I hate the MSL stuff because it's all wheelchair shit you know...it's all worse case stuff...I don't want to be in a wheelchair. Paul line 880

Susan's fear of the wheelchair was directly related to the fact that she felt that level of disability would take away any chance of her finding a partner to share her life with. Susan was tearful as she recalled her feelings at that time.

I'm very, very scared...well if it's MS am I going to be in a wheelchair, or what's going to happen...will I meet someone...who's going to look after me...you know, will I be a burden? Susan line 335

I always thought it (MS) was bad...that people would look...Oh no...I don't want to...to be with her cause she might end up in a wheelchair...I might have to look after her or they'll leave...that's what I thought. Susan line 855

Davina was terrified at her diagnosis, because her uncle's MS had rendered him wheelchair dependant at a young age and was looked upon by the family with shame. The family used to tell people he had a head injury from falling of a ladder, denying MS. The fear of the reality of a wheelchair in MS was personal for Davina.

I felt terrified, absolutely terrified because I had no idea what was happening to me...and my mother was frightened...because on top of all of this, I had an uncle who had MS and who was wheelchair bound . Davina line 360

Post traumatic stress disorder (PTSD) is a disabling condition typically characterised by the re-experiencing of a traumatic event and experiencing intense fear, helplessness or horror (APA 2013, p. 467). The prevalence of PTSD in MS was first postulated as being approximately 15% in a study sample of 58 participants (Chalfant, Bryant, & Fulcher, 2004). However, this finding was not replicated in a larger study of 232 participants where PTSD prevalence was reported as approximately 5% (Ostacoli et al., 2013). Interestingly, there was no relationship found between the presence of this mental health disorder and the severity of the disease. There are some peculiarities in PTSD in MS, as it is not related to a single event in the past but rather to the course of the degenerative condition, and the intrusive PTSD symptoms are typically orientated to the future, such as fear of the wheelchair, relapses and progression (Ostacoli et al., 2013). In the current study, no participants were formally diagnosed with PTSD, however intense physiological

reactions to talking about fear of future disability and wheelchairs figured strongly for Paul, Davina, Will and Susan.

The mere thought of MS can strike fear in people, even without any knowledge of the disease (Lysandropolous et al., 2015). Previous studies have demonstrated fear as an emotion central to the MS journey, but more recent studies on these specific phenomena in RRMS are lacking. A qualitative study, which interviewed ten women with SPMS, described how the women felt fear due to uncertainty about the future, fear intruding as the participants felt they did not know what was happening to their physical bodies (Olsson et al., 2008). A larger study interviewed 27 PwMS and used IPA methodology to reveal that fear of the future was prominent for PwMS, and in particular, fear of mobility loss, becoming a burden to family members and placement in a nursing home (Finlayson, van Denend, & DalMonte, 2005). Although the authors did not specify the type of MS in their inclusion criteria, participants needed to have MS for more than 15 years and be aged over 55 years, suggesting some elements of progressive MS and possibly influencing the fact that nursing home placement figured in fear. This nursing home fear was not evident in the present study, perhaps due to earlier disease stage of the participants or the presence of more effective patient education and DMTs in the modern era.

Fear is often induced by the vagueness of symptoms pre-diagnosis, and the uncertainty of the cause of MS post-diagnosis and the possible disease trajectory (Thorne et al., 2004). A study from Thorne and colleagues (2004) used focus groups/individual interviews and phenomenological methodology with a group of 12 PwMS and introduced the concept of “fear points” in the MS journey. “Fear points” are modifiable moments where patients receive either support or obstruction to their fear (Thorne et al., 2004). If timely, relevant and accurate information and validation of their experience is provided at these vulnerable times, the MS HCP/MS Nurse can modify these experiences significantly for PwMS (Thorne et al., 2004). “Fear points” will be different for each individual, but if carefully looked for and assessed by MS HCPs and MS Nurses, appropriate referrals may prevent future escalation of emotions and improve QOL. For some participants in the current study, fear resolved over time, but for others it never completely resolved. Fear sometimes turned to more chronic worrying, or expressed itself in other ways such as anxiety and

depression. Sometimes it was addressed with counselling and psychological interventions and sometimes it was shelved temporarily only to resurface at a later time. But fear in some form, at some time, featured in almost every participant's life story.

Theoretical foundations from fear studies can also help MS HCPs understand that perhaps some degree of fear may be helpful in clinical care. Looking at a positive aspect to the fear story, the seminal work of the "fear drive model" assumes that the emotional response of fear can function as a drive to mediate belief change and behaviour change (Leventhal, Meyer, & Nerenz, 1980). At times during the RRMS journey, our patients need to change beliefs and to change behaviour in order to adhere to evidence-based MS wellness prescriptions such as smoking cessation, adherence to DMT regimes, adherence to safety monitoring programs and follow-up appointments. A careful assessment by the MS HCP/MS Nurse is crucial in determining the impact of fear on an individual patient and whether referral to appropriate resources is required.

Weary from worry and anxiety

Worry is carrying tomorrow's load with today's strength

Carrying two days at once and moving tomorrow ahead of time

Worry does not empty tomorrow of its sorry

It empties today of its strength

Corrie ten Boom

Worry is negative thinking arising from anxiety; it is a longer-term feeling than fear and has been described as an active anticipation of possible negative outcomes (Vasey, Crnic, & Carter, 1994). For the purposes of coding clearly and consistently for data analysis in this study, worry was conceptualised as different to fear and was defined as both a noun and a verb "being troubled or feeling troubled over actual or potential problems" (Oxford dictionary, 2017). Anxiety disorders are listed in the Diagnostic and Statistical Manual of Mental Health disorders, fifth edition (DSM-V), (APA, 2013) as a diagnosable mental health illness, of which I am not authorised to

diagnose as an registered nurse. However, I do have the skills to assess for the presence of anxiety and to refer to appropriate HCPs for further assessment and advice. For the purposes of this study, anxiety was based on DSM-V descriptions; challenging a person's control, consisting of a mix of symptoms such as fatigue, impaired concentration, irritability, difficulty sleeping and impacting on day to day activities for a prolonged period of time, and conceptualised as excessive worry.

Previous studies have demonstrated high levels of worry in PwMS, and a link between worry and anxiety, separate but unique related psychological constructs (Bruce & Arnett, 2009). A quantitative survey based study of 50 patients (of mixed RRMS and SPMS) demonstrated that 36% of participants experienced worry in the elevated range and also that worry was associated with depression and anxiety (Bruce & Arnett, 2009). The authors report that indeed, the very nature of MS (uncertainty, symptoms, threat of relapse) may create an optimal environment for excessive worry, supporting the findings in the present study where some degree of worry interjected the lives of all participants at some time. The concept of worry in MS as an independent construct certainly requires further exploration and research, particularly as excessive uncontrollable worry can also progress to a more serious generalised anxiety disorders (Bruce & Arnett, 2009) or other anxiety and depressive disorders (Thornton, Tedman, Rigby, Bashorth, & Young, 2006).

In the current study worry took on several forms, and sometimes the participants worried about themselves, but just as often they worried about their loved ones and how RRMS was affecting the family unit as a whole. Almost all participants worried about something directly related to MS at one time or another, with worry about becoming a burden in the future a common worry. The chronic worriers could then go on to feel anxiety, either acutely or more long term, and for this reason (as a linked concept) anxiety has also been included in this sub theme.

In the midst of a severe motor function relapse, Rudi felt at her most vulnerable, feeling anxiety herself, but also feeling that she was the cause of anxiety for her young daughter. Rudi was worried about hurting her children if a relapse came on suddenly whilst she was driving and caused an accident.

I went through a really bad period with anxiety, to the point where I nearly gave up driving...because it happens so quickly (relapse)...so I thought...I'm going to hurt my children or I'm going to hurt someone else...I suppose it's going to be always in the back of your mind...I mean I was to the point where I used to drive with no-one in the car and see how long it would take me to stop by pulling the handbrake on...working on things to keep my children in the safest place possible. Rudi line 702

In the first year after his diagnosis, Paul spent hours at night researching on the internet everything he could about MS, his GP suggesting that he might need some professional help and counselling because the worrying and need for information became excessive.

And you know at night ...and this is why the GP sent me off to the psychologist, I don't have very good sleep at all, I sort of just lay there and I sort of get on the phone or ipad and read all this stuff (on MS) for hours at night, every night...the first year after diagnosis was very hard...I was...you know...anxiety...and you know, no matter how you try, and rationalise it, you can't, you just can't beat the fact that you're a human being and that emotions are part of...you know, being alive. Paul line 477

Davina was learning to cope with her new diagnosis of RRMS and became pregnant shortly afterwards, causing her worry and anxiety over how she was going to balance both the new disease and motherhood.

It was a huge shock and I was such an anxious person to start with, so dealing with a diagnosis and then being a very young mother...I also had a very anxious pregnancy because I didn't know how. Davina line 539

Worry about being a burden to the family

Worry about being a burden, either in the present or in the future, and worrying about what MS was threatening to do to their family unit and loved ones was common to almost all participants at some point of their RRMS journey. This sub-

subtheme also focuses on the participants worrying about family members being worried about their RRMS.

It has been suggested that one of the greatest challenges for children whose parents have MS is balancing caring for the parent with restraint in expressing their own feelings to protect their parent and avoiding burdening them with their own sadness of MS (Moberg, Larsen, & Brodsgaard, 2016). For Rudi, her children witnessing her last severe relapse has been a constant cause of worry for her, sometimes much more than the worry she has for herself physically. Rudi sought psychological counselling for her daughter to help manage the anxiety her daughter feels.

(When my last relapse happened) the children were hysterical...the kids, so they were in tears and so...so...that's really tough...I find that tougher than the physical side of things sometimes...they shouldn't have to go through that at such a young age...(my daughter) she takes too much of it on board. Rudi line 625

After a serious fall and fractures a few years before, Kate's mother worried constantly about Kate falling again and being on her own, sometimes frustrating Kate as she struggled to get to one phone with limited mobility.

If I don't answer the phone then she'll ring the mobile and if I don't get to that in time, she'll ring again and it's whole panic stations, she thinks something's happened to me...I know she worries but it doesn't help. Kate line 2398

Ruby worries for her sister, that her sister feels left out of the family unit as there is so much fussing over Ruby. The situation of Ruby requiring frequent assistance with home and childcare because of her significant MS symptoms also causes stress for her retired parents as well.

MS has changed our family dynamics...I mean Mum and Dad were stressed about me...I think my sister feels a bit left out (Ruby cries)...it would be nice if it wasn't all about me. Ruby line 1147

Worry for PwMS regarding affording MS healthcare and medications has figured prominently in an overseas study (Jones & Amtmann, 2014), however this theme did not present in the current study. This could be due to the fact that the Australian government has subsidised access for residents prescribed DMTs to treat RRMS, providing them at a greatly reduced cost.

Existing with anxiety

As previously discussed in chapter 2, anxiety is more prevalent in the MS population than in the general population (Wood et al., 2013; Feinstein et al., 2014) and has been strongly associated with lower QOL scores across all levels of illness severity, from mild impairment to severe (Ionescu et al., 2012). Anxiety is also more prevalent in females than males in PwMS (Theaudin et al., 2016). Several participants in the current study reported feeling anxious at many stages of their RRMS journey and often felt that they were left to cope with anxiety on their own.

High levels of anxiety have been associated with an emotional preoccupation of MS, and focusing on the emotional consequences of the disease (Roy-Bellina et al., 2010; Tan-Kristanto & Kiriopoulos, 2015) rather than physical symptoms. Susan demonstrated this in the present study when she described a time in her life when she felt being completely mentally overtaken by MS, to the point where she couldn't concentrate anything else in her life, not her family, not her work and not her usual sources of happiness. Paul described spending many nights lying awake, feeling anxious and researching MS on the internet, despite having very little physical disability at the time.

Interestingly, negative life events, problems in family life and social functioning can also be significantly associated with anxiety (Liu et al., 2009). Stress in childhood has been explored as potentially being a risk factor to developing MS in later life (Nielson et al., 2014). Childhood stress was present in the life stories of Joy, Will, Margot, Rudi, Davina, Evie, and Griff, for varying reasons including loss of parents, divorce, alcoholism, moving to foreign countries and childhood illness. A nationwide cohort study from Denmark found that there was an increased risk of MS amongst persons exposed to stressful life events before the age of 18, especially long term

stress (such as parental divorce) rather than acute events of significance (such as the death of a parent or sibling) (Nielsen et al., 2014). Others have also found that exposure to abuse and neglect in childhood increased MS risk (Spitzer et al., 2012). In regards to stress influencing MS activity, there is substantial evidence that disease activity is increased under stress (Saul et al., 2016), but this particular study looked at stressful life events in the 12 months preceding diagnosis, not in earlier childhood.

A systematic review exploring predictors of anxiety found that positive reinterpretation, social emotional support and humour predicted an improvement in anxiety symptoms (Butler et al., 2016). In the current study this was demonstrated repeatedly as study participants recounted stories of anxiety followed by seeking assistance and at times, psychological help. Anxiety is most highly associated with depression, low self efficacy, stress, emotion focused coping, pain, fatigue and QOL, factors that may be amenable to intervention if identified and actioned by MS HCPs (Butler et al., 2016). Furthermore, a prospective study has shown that depression can strongly predict anxiety and anxiety can predict later depression (Brown et al., 2009), continued revisiting of both of these issues by MS HCPs longitudinally could have an immense impact in preventing future problems.

Depression and Despair

Depression...I knew what that felt like...there was nothing...it's nothingness...a feeling of nothingness...I know this sounds strange but it's the only way I can describe the feeling. Evie line 270

Dealing with depression

As already discussed in chapter 2, for people living with MS the lifetime prevalence rate of a depressive disorder has been reported as greater than 50% (Hoang et al., 2016). As with anxiety disorders, depressive disorders are a diagnosable mental health illness under the DSM-V (APA, 2013), following listed criteria including depressed mood, loss of interest and enjoyment in usual activities, reduced energy, reduced self esteem and confidence, ideas of guilt and unworthiness, pessimistic thoughts, disturbed sleep and appetite and ideas of self harm (APA, 2013). For the

purposes of this study, depression was coded if it seemed reasonable in the descriptors the participants used to express their feelings, or if the participants used the term themselves (which occurred in the great majority of cases). “Feeling depressed” is a common phrase people use to describe many emotions, but I only included it in the coding if there was supporting evidence from the study participant that it was more serious than a fleeting emotion (such as a formal diagnosis or a story of prolonged depression with symptoms such as those described above). Despair was defined as a noun, the complete loss or absence of hope; and as a verb, to be without hope (Oxford dictionary, 2017). Both depression and despair have been conceptualised under the same subtheme, as they often paired together in the participant’s narratives. However, the accounts of the participant’s stories for depression and despair will be kept separate.

A British study exploring patient’s feelings when transitioning from RRMS to SPMS, used thematic analysis to interview nine PwMS and seven HCPs. The researcher found that shock and devastation is common in response to being reclassified as SPMS, and is a significant psychological blow (O’Loughlin, 2015). Participants in the study emphasised the importance of being able to debrief with an MS Nurse after discussions on this topic so that they have ample opportunity to ask questions and reconfigure the news in a hopeful manner (O’Loughlin, 2015). In the current study, this experience was shared by Davina who pinpoints the day she was told that she would one day transition to SPMS, as the day her battle with depression began. Davina was reviewed by a psychologist and diagnosed as being moderately depressed, but failed to follow-up or seek further care, she had a fear that she would be medicated and didn’t want that for herself following years of working in the health system herself.

When something does happen it hits me like a steam train and I go down to the depths of depression...like I won’t get back up again...I think I’m consistently just a little bit depressed...I think it after I was told that it could convert to progressive...and then the interferons would make that feeling of desperateness...hopelessness...it would make it a hundred times worse. Davina line 1068

Piper was formally diagnosed with depression at different stages of her life journey, both before and after her RRMS diagnosis. Despite the negative impact depression was having on her life, she was not keen to seek help until her husband demanded it.

I sort of probably had a bit...a bout of depression...I was treated with a counsellor...in hindsight you could see a pattern from younger and it was only that my husband said to me if you don't do something about it...this marriage is over...that it sort of pushed me. Piper line 279

Susan was single for many years, deeply concerned that she would not find a life partner who would accept her RRMS. Living alone with RRMS at times of major life events often triggered symptoms of what Susan termed as depression.

(Buying a house) was another turning point for me because I was again...depressed...thinking I'm doing it on my own and what if something happens again? Susan line 633

After her first MSA meeting, where she met several young people living with significant disability and progressive MS, Jane refused to go to any more meetings and to avoid the feelings of sadness she was experiencing, which Jane referred to in her life history as depression.

We were just sitting there crying and I thought I don't want to go back to this because it's just too depressing...because they don't work, they don't study, they're at home in a wheelchair and they're not going anywhere...and it's just too depressing. Jane line 211

The interferon injections were also a constant source of what Jane refers to as depression, not just the fact she was self injecting, but that she always felt so much worse after the injections. Jane ceased treatment after a couple of years, finding it preferable to be on no treatment and risk relapses rather than feel depressed.

(being on Rebif®) you just had to inject all the time and it's just depressing...I used to hate it...and I thought I might as well just give up and do nothing...and it was just really depressing. Jane line 372

After his neurologist sought special permission for compassionate use of an expensive DMT so he could have it at no cost, Will was tormented about doing the right thing and battling his feelings of depression. His life went into a downward spiral for several months.

It's probably the greatest thing anyone has ever done for me...but then I threw it all back in his face...depression set in pretty bad...I just wasn't feeling any better...I didn't contact them (MS team) so I went unmedicated...I quit my job...I hadn't told my family at this point about my diagnosis. Will line 880

Rudi felt that because she has been through so much in her life, from a troubled childhood living with a single mother diagnosed with bipolar disorder to the stillbirth of her third son, that it was time for life to be fair to her. Rudi often felt the demons of depression and worked hard to fight them.

I do tend to crash and burn emotionally because things are just taken from you...I suppose that's when I get down cause I think it's not fair...I think because I've been through so much in the past that you know how hard I have to fight and you look at it and you feel tired just thinking about it...when you've had to fight all of your life. Rudi line 1690

Face to face with despair and hopelessness

It has been suggested in chronic illness literature that despair and hopelessness actually help move towards hope for patients, as awareness of the future and consequences become clearer (Morse & Penrod, 1999). It has also been suggested that maintaining hope is a balancing act between hope, hopelessness and despair, with patients often passing through despair when moving toward hope or hopelessness in a study of living with another chronic illness, acquired immune deficiency /human immunodeficiency syndrome (Kylma, 2005). Moore (2005) has

placed hopelessness at the centre of despair, with despair occupying the bigger picture and hopelessness one component of it. Threats to hope (and thereby opens to hopelessness and despair) include pain and other uncontrolled symptoms, spiritual distress, fatigue, anxiety, social isolation and loneliness (Fitzgerald Miller, 2007), all potential threats when living with RRMS. Interestingly, perceptions of hopelessness from those seen by the patient as “powerful”, such as HCPs and family, may also threaten hope (Fitzgerald Miller, 2007).

Davina described times of feeling hopelessness and the angst she felt at never ending darkness. For several years after her diagnosis, Susan struggled with managing her feelings around RRMS, often taking two steps forward and one step back and never feeling emotionally in control as life when on around her.

I've had times of hopelessness, people say to me you're not your disease and I'm not...but...sometimes it becomes my focus and I can't think past it because hope to me is looking to my future, that's hope. Davina line 1523.

Hopelessness is dark and it's lonely...and it's never ending darkness and misery...hopelessness feels like it's never going to end, that nothing's ever going to fix it. Davina line 1539

I felt like I'm here but I'm not here...I felt numb...I thought I can't feel like this...I can't think like this. Susan line 481

Joy suffered debilitating bouts of deafness and blindness, the aftermath of coping with sensory loss took her to the depths of despair.

It was horrific...it nearly broke me (tearing up)...and I went into a downhill spiral emotionally...(and later)...I deteriorated from there...so the visual thing would come and go it was just really, really hard and I'm trying to hold down a job and I'm saying to my husband I'm so sick I have to, I have to give up work I'm so sick, I can't work and he was just like 'absolutely not' ...I was heartbroken. Joy line 855

Choosing to keep thoughts of despair and hopelessness to themselves was sometimes the chosen path, no matter how much support was around them at the time. Will discussed his feelings, keeping his friends away from what was happening after the diagnosis of RRMS was made. He made this conscious decision to distance his friends from his diagnosis of MS because of a family friend who was wheelchair bound and severely disabled.

I had a breakdown to be honest...and no-one saw it, not even my best friends, I hid it from everybody...it was just the worst and again, looked back at my friends stepfather...and that's all I could think of. Will line 700

Depression, despair and loss of hope in MS can be serious and life threatening issues. Loss in MS goes beyond loss of ambulation and function and also incorporates the loss of future plans and dreams, pre-morbid roles and significant relationships (Gedik et al., 2017). Thoughts of death and self-harm are prevalent in MS, with data suggesting that over a quarter of PwMS (type not specified) contemplate suicide (Feinstein et al., 2012) and that young males in the first five years of diagnosis are the most at risk (Feinstein, 2011). A recent study of 3,823 MS patients used a systematically collected questionnaire during routine clinic visits to capture the frequency of thoughts of death in patients with epilepsy and MS (Dickstein et al., 2015). A prevalence rate of 15% in the MS cohort was reported (slightly higher than epilepsy), associated factors being depression, male and unmarried, medical comorbidities and poor QOL (Dickstein et al., 2015).

Exploring suicidal thinking in MS, researchers used questionnaires and semi structured interviews to talk to 16 PwMS (type not specified) who all expressed suicide ideation, but not suicidal intent (Gaskill, Foley, Kolzet, & Picone, 2011). Fear of burdening their family was one of the most common reasons participants gave for thinking about suicide as a way of reducing family tension. They also identified issues of feeling a loss of control, loss of femininity/masculinity, hopelessness, feeling lonely and symptoms of MS; all amplified if they were in distress (acute symptoms, pain) exacerbating the feeling of being a burden (Gaskill et al., 2011). Despite most participants in the current study expressing concerns about burdening their families, no participants in the current study spoke directly about

suicidal thoughts. Will discussed having several emotional “breakdowns” during the course of his life journey living with RRMS, during his long diagnostic process and hospitalisation and then again a few months following his diagnosis of RRMS.

Struggling with the saboteurs

A saboteur destroys, damages or obstructs (Oxford dictionary, 2017). Saboteurs are the unwelcome demons that threaten happiness and downplay moments of joy for PwRRMS. These saboteurs were different for each individual, but could have a significant negative impact on living with RRMS. The saboteurs I identified as subthemes were “Coping with uncertainty”, “I’m never free of MS” and “Social isolation”.

Coping with uncertainty

When a person’s actual present and future is characterised by uncertainty, a person’s sense of feeling whole is threatened (Olsson et al., 2008). Uncertainty in chronic illness has been well recognised (Mishel & Braden, 1988; Mishel, 1990) and it is not surprising that the uncertain and ambiguous nature of MS creates the “perfect setting for uncertainty to thrive” (Tams, Prangnell, & Daisley, 2016). Uncertainty can take several forms in MS, including symptom uncertainty, medical uncertainty and daily living uncertainty (Gray & Arnett, 2014). This is further hampered by a lack of pattern manifestation in terms of remission and relapses (McReynolds, Koch, & Rumrill, 1999), so it becomes difficult to control and predict. Eventually being diagnosed with MS and piecing together the puzzle doesn’t do away with the concept of uncertainty, in many ways the uncertainty has only just begun.

Mishel (1990), a nurse researcher and theorist, spent many years studying uncertainty in illness theory. Mishel (1990) defines illness uncertainty as being multifactorial and encompassing doubts and unpredictability’s relating to symptoms, diagnosis, treatments, relationships, prognosis and future planning. All of these components are features in the RRMS journey and impact directly on PwRRMS, sometimes on a daily basis and in multiple ways. Every participant in the current study felt the wrath of unpredictability at some time in their life, with the inability to

plan for a “normal” future, presenting as a constant stumbling block. Coming to terms with uncertainty in MS and the inability for long term planning is problematic for many PwMS (Finlayson et al., 2005) and, as previously explored, can lead to other demons, such as anxiety, fear, despair and depression breaking through the barriers to take control.

Of all the saboteurs, coping and living with the uncertainty of such an unpredictable and incurable disease caused challenges for most of the study participants. They told of stories about the uncertainty of where MS will target next, how bad a relapse might be and how their individual disease may ultimately progress. Many found the concept of being diagnosed with a disease with no definite prognosis difficult to live with and coming to terms with uncertainty was a daily battle for them. Kate was the mother of a two year old child when she was diagnosed and uncertainty caused some challenges in planning life.

RRMS...is unpredictable...and scary...extremely scary because you don't know what's going to happen...Kate line 24

I had a two and a half year old son at the time (of diagnosis)...it was scary...You couldn't plan your life because you were always worried about a relapse...going on a holiday...I was scared and always at the back of my mind was what would happen...what am I going to do? Kate line 1248

Knowing the DMTS could reduce relapses, but not stop them altogether impacted both Jane and Piper, the uncertainty always a factor.

You just think it's a very difficult disease because you never know what's going to happen...you can't judge anything. Jane line 745

I'm still going to relapse at some point really...aren't I...I could relapse more often on one of them (medications)...you don't know. Piper line 1393

I'm never free of RRMS

Caring for chronic illness takes planning, time and motivation by the patient (Katon et al., 2010) and can be hampered by constant intrusion to everyday lives (Larsen, 2016). Integrating illness into daily life includes skills of modifying lifestyle and seeking normalcy through balancing activities and illness needs (Schulman-Green et al., 2012). Some participants discussed how RRMS is always with them, which is one of the realities of living with a chronic illness. This seemed to be most prevalent in the time after diagnosis when thinking about MS took up so much time and energy. Life enjoyment was sabotaged by the continuous preoccupation with RRMS, and this could happen at any stage. For Paul, it was constantly on his mind, and he felt that he didn't need to share that burden with others.

There wasn't a moment that would go by where I wasn't thinking about MS...I've always got it in the back of my mind...don't get too comfortable and think that everything's going to be OK...be prepared. Paul line 852

(on non-disclosure to his close friends) I'm reminded enough of it as it is...I don't need to...other people to...I don't need any more, that's enough, you know...everyday you don't go without thinking about it...it's impacted my life in that way, in a big way. Paul line 1024

Between relapses, Rudi kept a lot of her symptoms to herself and frequently hid how she was feeling, reluctant to let others know that RRMS is always with her, even when she appears well and back to “normal”. Similarly, Will refused to be a burden to his wife, he worried that he wouldn't be seen as the strong man he wanted to be seen as and often hid symptoms from his wife so that she won't have cause for worry. However, sensory loss in his hands and the loss of the feeling of intimacy when holding hands with his wife, are reminders that he is never free of RRMS.

I don't think (my husband) realises that I have something every day...because I don't tell people...oh I had pins and needles today...or I'm a bit tired today...I get sick of talking about MS. Rudi line 1413

I hid it from my family and I do it for the simple fact that...my wife's pretty fragile...we've got responsibilities...I need to be that strong person...I wouldn't want anybody to have to go through how I feel on a daily basis. Will line 64

I hide the aspirin packet so my wife doesn't see it because I don't want her worrying about it...she's got a baby to look after...I know how hard it is to deal with all of this and all of that...My hands are very numb you know, things like having my wedding ring on, I don't know if I've got it on or not, I can't feel it, which is sad...I've never said this to my wife because my wife always wants to hold my hand and I don't know if I'm holding it or not. Will line 100

Social Isolation

Social isolation refers to the absence of social relationships and social networks (Umberson & Montez, 2010) and has been reported to be a risk factor for suicide in MS (Feinstein, 2002; Pompili, 2012). Seminal work in chronic illness suggests there are health risks of social isolation and loneliness (Charmaz, 1983). There is a paucity of literature exploring social isolation and MS, but there have been reports in health policy literature, which suggest that both the quality and quantity of social relationships affect mental health, health behaviours, physical health and mortality risk (Umberson & Montez, 2010). Prospective studies of mortality have shown that individuals with low levels of social relationships were more likely to die than those with greater social relationships (House, Umberson, & Landis, 1988). In adults with medical conditions, social relationships also reduce mortality risk, confirmed in a study of coronary artery disease (Brummett et al., 2001).

The daily grind of social isolation could be a constant saboteur to mental health and how the participants saw themselves. Griff became a stay at home father after losing his job because of his MS symptoms and has never returned to the workforce. Now that his children are older, he finds himself frequently alone and struggling with social isolation.

The social consequences of social isolation...I was never allowed to be completely "in" with the mothers groups, with the playgroups...the kids start high school and

the first thing they tell you is we don't want to see you...my days are spent wastefully...social contact is what you're trying to establish so people have...you know, community to operate in...well I don't have those links anymore...it's not going to be easy for me to return to the workforce...who'd want me anyway? Griff line 707

Recognising the demons to battle

What we know about some of these demons (fear, anxiety, depression, PTSD) and MS is that they can be fatal. Of course, MS and MS treatments can also be fatal, but that situation is far less prevalent than demons such as depression, which can induce suicide (Feinstein et al., 2014). The demons of fear, worry, anxiety, depression, despair and social isolation can be interlinked in many ways, for example depression and anxiety often go hand in hand to sabotage mental health, predictive of each other in MS (Brown et al., 2009). Worry can lead to anxiety, anxiety can lead to panic and depression can lead to despair and hopelessness. These negative emotions can then also interfere with RRMS treatment, with people suffering mood and anxiety disorders in RRMS being five times more likely to non-adhere to their DMT (Bruce et al., 2010). MS Nurses have an important role to play in assessing and monitoring for signs of these demons, as trusted confidantes by PwRRMS, they often can discuss these issues and advocate for PwRRMS to ensure early referral to appropriate services (Porten & Carrucan-Wood, 2017).

The following theme of “Surplus Suffering” explores a novel concept in MS care, which may inadvertently contribute to some of the demons experienced by people living with RRMS. The concept of Surplus Suffering is suffering over and above that experienced by the disease of RRMS itself and represents an area of MS care with no existing specific literature.

Theme 4: “ Surplus Suffering”

Only through the experience of trial and suffering can the soul be strengthened, vision cleared, ambition inspired and success achieved.

The world is full of suffering; it is also full of overcoming it.

Helen Keller (1880-1968)

The **central organising concept** for the theme of “Surplus Suffering” is suffering inflicted by others onto the PwRRMS over and above that imposed by the condition itself.

Eric Cassell, a physician who has explored the concept of patient suffering in medicine for decades, has defined suffering as “the distress that is brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person” (Cassell, 1991, p. 4). Suffering affects the entire person, extending past the physical to emotional, social, spiritual, existential and financial domains and often not fitting neatly into current biomedical paradigms (Epstein & Back, 2015). Many people living with chronic illness suffer as they experience their illness, but it is the broader significance of the suffering beyond physical discomfort which can cause the loss of self for many people with chronic illness (Charmaz, 1983). Indeed, consequences of suffering spread and accumulate through one’s life and can prevent patients moving forward into the present, stealing joy and limiting social worlds (Charmaz, 1999). Suffering is important for MS HCPs to consider because it can lead to some of the demons discussed in the previous chapter, especially isolation, hopelessness and vulnerability (Reed, 2003) and involve a loss of dignity and alienation (Coulehan, 2011).

It has been argued by Cassell and others that little attention or discussion has been given to the problem of suffering and patient emotions in medical education, research or practice despite the relief of suffering being considered one of the primary ends of medicine by both patients and the general public (Cassell, 2004; Kenny et al., 1997; Shapiro, 2011). Furthermore, suffering is ultimately highly personal, the presence and degree of the suffering can only be known to the sufferer

(Cassell, 2004). If suffering is not relieved, there is a threat to the person's integrity and a loss of part of that person as their suffering continues (Cassell, 2004). This degree of suffering and loss to self was evident during the current study. Several participants whose physical, mental and emotional suffering continued with them for many years after the precipitating event, felt an intense impact on their present sense of self and their life living with RRMS. This will be highlighted throughout the remainder of this theme with the use of participant comments, crystallising their experience of Surplus Suffering.

Medical models of suffering tend to concentrate on fixing, curing and eliminating illness compared to the nursing perspective which tends to look at the broader paradigm of the quality of a life lived (Ferrell & Coyle, 2008). As nurses play a fundamental role in the caring of those who suffer, and are present for people as they struggle through illness, the relief of suffering is at the core of nurse's work (Ferrell & Coyle, 2008). Suffering is a universal human experience and nurses commonly encounter pain and suffering at all levels when caring for their patients (Davitz & Pendleton, 1969; Reed et al., 2003). Nurse researcher Morse (2001) has identified two stages of suffering: *enduring suffering* which occurs when the sufferer brackets their emotions so that they continue on in everyday life, not expressing the negative emotions and *emotional suffering* which is a distressing state where emotions are unconstrained. Individuals can move between the two types of suffering depending on their circumstances and context (Deal, 2011). Participants of the current study reported experiences of both enduring and emotional suffering.

Surplus Suffering as a concept was first described by James and Clarke (2001) as they explored the experience of Portuguese immigrant women adjusting to life in a new country and the extra suffering inflicted on them as a result of seeking healing in a western health care system where disagreement arose between their old culture and the new health care system (James & Clarke, 2001). In that particular study, Surplus Suffering was conceptualised as the women suffering over and above the signs and symptoms that brought them to medical care in the first place (James & Clarke, 2001). Further work in Surplus Suffering by Clarke and Fletcher (2005) explored experiences of parents when their child was living with cancer, interviewing 29 parents and discovering that "problems in the system" and carelessness, unkindness

and mistakes led to increased suffering for children and their families. In this work, the authors conceptualised Surplus Suffering as the extra, unnecessary suffering that can result from the HCPs and the health care system, in addition to the inherent physical suffering already resulting from cancer and its treatment (Clarke & Fletcher, 2005). Clarke went on to explore further themes of “Surplus Suffering” as a key component in studies of people living with Asperger’s syndrome (Clarke & van Amerom, 2007), parenting a child with mental health issues (Clarke, 2012) and childhood mental health issues (Clarke, 2013).

Whilst listening to the stories of many of the participants I interviewed in the current study, at times I was struck by the realisation that the medical/health system had let these PwRRMS down in some way and induced additional distress on top of the burden of living with RRMS. By this I mean suffering in addition to that caused by disease onset, disease symptoms and disease related disability and in addition to the considerable mental health and emotional burdens discussed in the previous theme, *Battling the Demons*. Very sadly, the stories of additional distress experienced by the participants in the current study sometimes involved compromised care from their HCPs, neurologists and nurses, exacerbating the disease-related suffering these PwRRMS were already experiencing. For other study participants, it was the additional emotional pain inflicted by those they loved or trusted, such as family or friends or sometimes by strangers. During the study interviews I was struggling to find a way to describe some of the similar feelings and experiences I was hearing from the participants (and later coding and analysing) that effectively described the concept of what I initially termed “added distress” or “compromised care”. When I unexpectedly came across the work of Clarke at a qualitative research conference in May 2017, the concept of Surplus Suffering fit the data exceptionally well and truly captured the essence of the stories I had been told. Unfortunately, I realised at that moment that Surplus Suffering was alive and happening in the field of RRMS.

Surplus Suffering reminded me of the seminal work by Charmaz (1999, P.365) of suffering and chronic illness:

“When in agony suffering is immediate and relentless. Suffering can also be insidious. It steals in and it spreads out. It is of the self and it is social. As suffering

spreads out it shapes social relations and limits social worlds. Such suffering means work - for chronically ill people, caregivers and co-workers.”

The notion that suffering is dangerous, stealing in and spreading out and affecting many others in its path was highlighted in the stories of study participants. Surplus Suffering presented a risk to the health and livelihood of the affected study participants until it was discussed, assessed and positively managed. The significance of suffering in chronic illness has been well documented by nurse researchers (Morse & Carter, 1996; Charmaz, 1999); suffering shapes stories and meaning and poses existential problems of identity and self as one lives with chronic illness (Charmaz, 1999). Often MS Nurses will hear stories from patients of positive and negative experiences they have had with other HCPs leading up to, and after, their diagnosis of RRMS. Even if Surplus Suffering was not inflicted under their care, the MS Nurse could possibly be dealing with the impact of previous Surplus Suffering on the PwRRMS in current consultations. This could in turn influence learning and education, adherence to medication/lifestyle recommendations, trust, loyalty and likeliness to partner with us as HCPs in future care. It is something MS Nurses need to explore and assess at the beginning of their professional healthcare journey with a PwRRMS. Everyone’s journey is unique, not all PwRRMS will have stories of Surplus Suffering to tell, but many may well.

Towards understanding and a definition of Surplus Suffering in RRMS

From the study participants’ interviews and stories, and from the literature on the phenomena of suffering, I have adapted a definition of Surplus Suffering from the work of James and Clarke (2001), Clarke and Fletcher (2005), Clarke & Amerom (2007) and Clarke (2012, 2013) to fit a conceptual model of living with RRMS:

Surplus Suffering is suffering caused to PwRRMS over and above suffering from the existing physical, emotional and mental burdens of the disease. Surplus Suffering in RRMS is caused by the actions of others; including HCPs, the healthcare system, family, friends or community.

Surplus Suffering inflicted by HCPs in clinical care

The most moving story I listened to during the interviews was the multifaceted story of Surplus Suffering incurred by Joy for most of her childhood and then continuing into her adult life. As a small child Joy endured mysterious burning sensations which interrupted her sleeping patterns and stopped her from enjoying play with other children in her small country town. Joy's Surplus Suffering began when her parents never believed Joy's pain and neither did doctors when her mother eventually took her to be assessed. The Surplus Suffering lay in the emotional pain in this case of being ignored, rather than the physical pain. Additionally, Joy's mother had been labelled as having Munchausen syndrome, a form of factitious disorder listed in the DSM-V (APA, 2013) where people exaggerate or create symptoms to seek medical attention and assume the patient role. Growing up in a small rural community this was a difficult label for Joy to avoid. Her pleas for help were not taken seriously and intense pain and sensory symptoms were not investigated further. Even when Joy suffered a form of sudden dyslexia at age 16 and in just a few months plummeted from an A level student to failing school, she was still not believed; not by parents, not by teachers nor by HCPs. This pattern stayed with Joy into her adult life as she suffered various neurological complaints over the years (such as blindness, deafness, stroke-like symptoms) but was never investigated properly by her HCPs, often refusing her requests for further specialist referrals or investigative testing.

The doctors really weren't interested, they just didn't believe me...they thought I was a fruit loop, they thought I was crazy. Joy line 360

They just thought I was crazy and they weren't remotely interested and it didn't help that my mother...they treated her like she was a Munchausen's mother...they thought she was crazy, so I went to the doctor and said "I'm sick"...they thought...they believed this is the child of the Munchausen's mother, well of course she's going to be a hypochondriac...I didn't even get any tests or anything. Joy line 369

I went deaf and my right leg dropped and right arm...but again he wouldn't send me for tests to see if I'd had a stroke...and I thought you're frigging joking! My right

side had dropped and you're not willing to do any tests on me? I just...despair...it nearly broke me. Joy line 403

Kate, highly educated and with experience in the medical and scientific field, sought neurological medical attention after sudden episodes of blindness could not be explained. Over 25 years prior to our study interview, Kate recalled her first visit with the neurologist when she was told her likely diagnosis was MS. Kate had no knowledge of the disease at that point in time and struggled greatly with the abrupt delivery of the diagnosis, leading to extreme Surplus Suffering in the many years since. There was no follow-up education and no chance to ask more questions at that consultation.

He says "you probably have MS"...he turns around and goes to me "and you may end up in a wheelchair and you will probably be blind in five years time"...I looked at him and thought, five years...I said I'm only going to be twenty seven and I'm going to be blind? And I was a mess...he gave me antidepressants to get over it and I thought...Oh, this can't be happening to me. Kate, line 243

Davina's experience of Surplus Suffering was also the result of the news of her diagnosis when it was revealed to Davina at the foot of her bed in a full hospital room shared by others. The doctor was presumably unaware of her family history. Davina had an uncle who had been hidden away from family and society with his MS, his physical disability instead explained to others as being the result of an accident and head injury. Davina was left devastated with no offer of follow-up care at that point and cried during the interview as she recalled this experience.

He stood at the end of the bed and said it's probably 99 percent definitively MS because you fit the age, your sex and your symptoms are very textbook...so I suggest to you that you think of your future and perhaps if children was something you were looking forward to, it might be something you think about now, because better to be a disabled younger mother than a disabled older mother...I was distraught...there was no-one to go to really. Davina line 471

In the area of power, dominance and medical interaction, the doctor-patient relationship has traditionally been viewed as an area where doctors exercise power over patients (Pilnick & Dingwall, 2011). In recent years this has been addressed in medical training programs, but research on whether there is a positive impact on a more patient centred approach having a positive impact on health outcomes has not been established (Jaen et al., 2010; Lee & Lin, 2010). One extreme model of the doctor-patient relationship is paternalism, where the doctor makes all the decisions without patient input (Goodyear-Smith & Buetow, 2001). In some ways, recent advances in medicine (such as the introduction of the more efficacious RRMS DMTs in the last decade) discards the whole person and concentrates on a list of scan results and blood tests (Aitini et al., 2014). This feels especially true of RRMS where the new DMTs dictate careful and prolonged scan and results monitoring, perhaps at the expense of a closer doctor-patient relationship. MS HCPs must be mindful to maintain a balanced, individualised and holistic approach. Relationships between doctors and patients with MS are particularly complex (Burnfield, 1984).

However, more recently it has been suggested that proper disclosure with effective communication requires discernment, tact, timing, flexibility, responsibility and sustained attention to the particular needs of the patient as a person in their own, unique context (Krahn, 2014). Studies have also shown that getting clear information can help reduce patient anxiety and distress with suspected MS, at all stages of the process (Heesen et al., 2004; Kopke et al., 2012). This means that the consultation where a diagnosis of MS is revealed should be planned thoughtfully with adequate time for preparation, a discussion of the likely diagnosis and planned treatment options, sources of support for afterwards, time for questions from the patient and a planned date for a follow-up appointment.

The paternalistic delivery of diagnosis and prognosis experienced by both Kate and Davina affected them negatively for many years. Kate immediately decided not to consult further with that particular neurologist and was fortunate to find a new specialist she was able to talk to about her concerns, listen to her questions and consider her feelings. However, she still felt anger and resentment for many years after her encounter. A gentler approach with Kate that took into consideration her specific context of being a 22 year old balancing terrifying symptoms, full time

work, mothering and part time university study may have ameliorated many years of Surplus Suffering and given Kate opportunities to manage her feelings. Davina still retains the emotional scars of the day her diagnosis was revealed to her, crying and emotional as she recalled the story from almost three decades ago. Similarly for Davina, realisation from the doctor of her previous life experience with MS in a close family member may have resulted in a gentler, more compassionate delivery of her RRMS diagnosis.

Studies have shown the importance of the physician-patient relationship to patients and the effect this relationship has on long-term adherence to therapies and lifestyle prescriptions (Koudriavtseva et al., 2012). In a disease such as RRMS, regular and consistent adherence to DMTs are essential to gain disease control and prevent future disability (Bruce & Lynch, 2011). A recent study of 97 people with “mild” MS using mixed methods of interviews and questionnaires, explored the physician-patient relationship and determined that patients with MS sought a close relationship with their doctor and more disease related information. On the other hand, sources of dissatisfaction included poor management of diagnosis, unavailability and poor accessibility, low levels of psychosocial support and a lack of information (Koudriavtseva et al., 2012). Furthermore, Mead and Bower (2002) identified five dimensions essential in a patient centred approach; a biopsychological perspective, viewing the patient as a person, sharing power and responsibility, practicing therapeutic alliance and also viewing the doctor as a person. Unfortunately, in the stories of Joy, Kate, Davina and Paul, they all believed that their biopsychological position was ignored, they were not viewed as individuals, they were given no power or access to shared decision making and no exposure to therapeutic partnership. Their care (in the stories discussed in this theme) was not patient centred and lacked information and support.

Surplus Suffering inflicted by brush-off

The concept of brush-off was explored in the first theme Piecing Together the Puzzle as study participants reported feeling ignored or dismissed by HCPs in the early days of their quest to identify the cause of their symptoms, in the lead up to a diagnosis of RRMS. As part of piecing together the puzzle, the concept of brush off was anchored

strongly in that theme. However, it is definitely also a form of Surplus Suffering and also belongs in this theme to tell a story of the emotional pain induced by the refusal of HCPs to take symptoms seriously, to investigate symptoms further or to trivialise symptoms. All of the participant stories and quotes from feeling brushed off as a part of Piecing Together the Puzzle also belong here in Surplus Suffering. Rather than repeat them, I will acknowledge their strong links as a form of Surplus Suffering, and also add some other instances where brush off figured strongly in participant stories.

Participants Davina and Susan have both served long careers as HCPs, and were impacted by Surplus Suffering directly from the nurses looking after them during inpatient hospital stays during severe relapses of MS. Both of these cases happened many years prior to the study interviews, but were still as real and distressing to Davina and Susan when I interviewed them. They have never forgotten what they felt as being abandoned by fellow health professionals when they needed them the most, the Surplus Suffering exacerbated by the fact this was from a profession they valued as caring and kind.

Davina worked at the same hospital where she was admitted as an inpatient and tells how the nurses secluded her in the furthest room from the nurse's station, causing her to feel isolated and alone at a time of intense vulnerability. Recalling her memories of what happened induced distress and she cried as she remembered how she felt.

They put me in the end room and the nursing staff on the neurology ward avoided me because I don't think they wanted to face me, that was very, very obvious...how do you treat someone who has just been given the worst news of their life...of which they didn't understand either. Davina line 511

When Susan was an inpatient following a severe relapse, she recalls feeling desperate for support in the middle of the night but received no compassion or guidance from the nurses looking after her.

I was scared and I was crying...and the nurses kept coming in and doing obs...I couldn't sleep and I said to the nurse, I'm very, very scared...I don't know what's going on" ...there was no support. Susan, crying, line 280

As explored in Piecing Together the Puzzle, Susan's GP would not refer her on for tests or to see a specialist despite her neurological symptoms and requests. Although the GP has since apologised to Susan, the impact of the Surplus Suffering from his disbelief of her symptoms remained with her and were expressed during the study interview.

To acknowledge what I was feeling that's all I wanted...and I was angry when it all started with my GP not listening to me...I accept his apology but he needs to listen to his patients, people know their own body. Susan line 1008

Surplus suffering inflicted by HCPs in research care

Paul's story has significant implications for poor clinical research conduct but also for compromised care and Surplus Suffering. Paul had been carrying around the emotional scars from a consultation encounter with a neurologist, not telling anyone else about it until our interview, and carrying the burden of Surplus Suffering for several years. At the time of the Surplus Suffering encounter, Paul was already under the care of a neurologist he trusted and who had recently diagnosed him with RRMS (after several years of Piecing Together the Puzzle) and was about to start his first DMT in a few weeks. In the wait time before his next follow-up appointment he suffered a further relapse and was admitted to the emergency room of a local hospital. He then saw a different neurologist who provided emergency treatment and advised a follow-up appointment to check Paul's progress a week later. As Paul had very little experience with the medical and hospital system, he was unsure of the correct etiquette in this situation and agreed to attend the appointment. Upon arrival to his consult with the emergency room neurologist, Paul was ushered through to another room, unfortunately apart from his wife who had accompanied him. The neurologist asked if he would like to begin a DMT soon, Paul answered that he would, and within minutes Paul recalls that he was signed up to a new clinical drug trial without explanation and without the chance for him to ask why. The neurologist

told him that the nurse would explain it all to him later. Unfamiliar with MS clinical care and procedures, Paul felt bullied into signing the papers and assumed that he would be given better explanations later. However, this did not happen, leaving Paul feeling angry and taken advantage of.

I said “what’s going to, what’s this all about? and he says “Oh well, we can go over all of this later on but what I want to know is to see if you would like to start treatment today or in the near future?” ...and I said “well, you know, obviously I want to get onto something, but what does that mean? ” And he says “Oh well, OK, I’ll take you out to the nurse out the back and we’ll get you enrolled in this trial” ...and I’m thinking...what is this? what is this?...And so, ten minute consult without anything...what the hell is going on?” ...he stood up...he went and stood at the door, just under ten minutes to usher me in and out...it was quite horrific in hindsight. Paul line 250

Not once through that whole episode did he do any neurological test, you know, tapping a knee and all that sort of stuff...and that would at least be baseline stuff that you would be doing? ...I was worried about what sort of results were coming out of this thing...you’ve got to treat these things very seriously. Paul line 371

Despite his misgivings, Paul completed the twelve-month trial commitment as he didn’t want his efforts and time already spent to be in vain. I asked Paul why he continued in the trial and returned for follow-up visits when he felt so violated. Paul recalled how his background in science encouraged him to complete the research trial for altruistic reasons (for others rather than himself) and he was pleased that he did so, despite the personal cost to his piece of mind continuing to be regularly exposed to the neurologist who he believed was the cause of his Surplus Suffering. This was made easier by the fact that Paul rarely ever came across him at research visits; ancillary research staff seeing Paul for most of the trial assessments.

I wouldn’t have gone through it other than thinking you know...if I can help in some way because bloody hell, I don’t want anyone else to...or I would want other people to be helped as well. Paul line 408

As a researcher in clinical trials for many years I was horrified by Paul's story, but more than that, I was affected by the degree of Surplus Suffering this act of disregard for clinical guidelines had on Paul. He tensed up when discussing it, his fists became small balls, he became red in the face and the anger surfaced as he became emotional recalling the day the Surplus Suffering began. Paul's basic right to autonomy was violated, he was not provided with the appropriate information to make an informed choice. In fact, all four of the general principles of international research ethics were violated in some way: beneficence (the welfare of the patient comes first), non-maleficence (do no harm), autonomy (independence, in charge of self) and justice (fairness to patients).

What's happening? Unravelling the cause of Surplus Suffering inflicted by healthcare and preventing Surplus Suffering

All of these encounters have shown areas where HCPs have let their patients down in some way and even though most likely (and hopefully) this has not been intentional, the Surplus Suffering has been felt for years and sometimes decades afterwards. A research study looked at the evidence for quality care encounters alleviating patient suffering (Arman & Rehnsfeldt, 2007). The authors found, that similar to other research, healthcare encounters may actually increase suffering rather than alleviate it (Arman & Rehnsfeldt 2007; Clarke & Fletcher, 2005; Wiman & Wikblad, 2004). Findings also showed that the basis for this suffering was essentially neglect; patients were not seen as whole human beings and their suffering was not noticed by the HCPs. The stories described above certainly fit this category and highlight situations where kindness and compassion from medical and nursing staff could have potentially changed the journey for these PwRRMS.

Compassion has been defined as understanding or being aware of another person's suffering and acting to end this suffering (Crawford et al., 2013) and has been described as an important part of the ethos of nursing (Bradshaw, 2011). Papadopoulos and Ali (2016) explored compassion in nurses and other HCPs in an integrative review and found several overarching themes as the main components of compassion. These included being empathetic, recognising and ending suffering,

being caring, communicating with patients, being competent, connecting to and relating to patients, and involving the patient in their care.

Similarly, “turning toward” is a concept in medicine which involves recognising suffering, becoming curious about the patient’s experience and intentionally becoming more present and engaged (Epstein & Back, 2015). Turning toward is about being authentic, emotionally available and engaged, intentionally tending to the immediacy of the patients experience even when the suffering is horrific and troubling. Expressing loyalty, honesty, shared humanness and non-abandonment to patients can be shown through caring actions, taking an extra minute or two, calling a worried relative, choosing words carefully and caring gestures (Epstein & Back, 2015) and can be long remembered by the patient after the visit.

Suffering occurs when an individual feels voiceless, when their suffering is unheard or when they cannot give the words around an experience (Ferrell & Coyle, 2008). When nurses ask questions and act as confidants for patients, they can aid relief from suffering and reduce physical, emotional, social and spiritual distress (Ferrell & Coyle, 2008). Several participants who recalled experiences of Surplus Suffering in the study interviews contacted me afterwards to say that they felt better for having told “secrets” about their previous care and that they now felt more optimistic about the future. Paul told me that he could now “let go” and move on from his previous bad experience of research in MS care (which he felt was now due to his “good” research experience in the current study) and Joy was equally as happy to have been able to tell her complete story to someone who listened and engaged. I feel humbled that this research study was able to be a catalyst for such positive change. The degree of (often silent) Surplus Suffering experienced by these individuals was distressing at times to listen to, but helping participants to regain some optimism and trust in MS HCPs is extremely fulfilling. I felt that the simple act of telling me their life history and exploring their feelings helped each participant to move forward with positivity and hope, despite this not being a specified aim of the study.

Surplus Suffering inflicted by family, friends and community

In a seminal paper on the lived experience of RRMS, Miller (1997) reported a theme of conflict arising as a result of RRMS in two ways; the first was conflict with HCPs, particularly physicians regarding the diagnosis of RRMS or explaining the disease, as described in the three subthemes discussed above. The second area of conflict involved study participants reporting considerable conflict within their own family (Miller, 1997), a concept that was also experienced by some of the participants in the current study.

Joy continued to suffer greatly, not just from the Surplus Suffering from HCPs already discussed, but also from people she loved. When she was 16 years old and suddenly became blind to typed text (a form of dyslexia) she was not believed by her family or teachers.

No-one believed me, my teachers didn't believe me, my parents didn't believe me, I wasn't taken to the doctor, no-one believed me, no-one cared, no-one did anything about it, nothing...you are lazy, stupid, ridiculous. Joy line 57

Joy's second husband worked in the healthcare sector, his championing her search for a diagnosis and health care connections had been integral to Joy finally being diagnosed with RRMS after decades of undiagnosed symptoms. However, he showed no compassion in relation to Joy's RRMS symptoms and disability. Joy recalls him forcing her to take more medication when she was already showing signs of drug toxicity, something she feels that he would have identified as a HCP. It took Joy some time to realise what was making her feel so sick, finally getting herself to hospital and being diagnosed with valproate toxicity (a drug used to treat epilepsy as well as nerve pain) from overdose.

Over a number of years I ended up going on Copaxone® injections as well as Epilum...I ended up having this huge, huge reaction, I blew up to three times my normal size...Epilum toxic and the Copaxone®. Joy line 694

He did this twice during our marriage...but I figured out it had to be medication induced...He would put the tablets in my mouth and I would pretend to swallow them and then I'd spit them out...that's what got me better and then I would drive myself to the hospital...I don't think he necessarily wanted me to die...I don't know...I will never know. Joy line 743

On a separate occasion Joy's husband forced her to continue to work as she battled a severe relapse, not allowing her to take sick leave (which would have been unpaid) and pushing her to breaking point.

I'm so sick and I can't work and he was..."absolutely not, you have to go to work" ...I was just heartbroken, I kept going but my legs went on me and I started walking with a cane because I was really struggling to walk...and then I lost my job because I wasn't doing my job, so while my husband was screaming at me "you have to go to work", I lost my job, so I couldn't go to work. Joy line 859

The impact of Surplus Suffering from Davina's immediate and extended family brought tears to her eyes as she recalled the unkindness inflicted by her family over many years. This happened initially at diagnosis when her mother and father's families argued openly over whose fault it was genetically that she had developed RRMS. This caused extra angst at a time when Davina desperately needed support. Later, her (now ex) husband did not engage with Davina and she felt at the time that there really wasn't anyone else to go to or confide in. He treated Davina and her RRMS symptoms with contempt and also encouraged their children to do the same. Additionally, Davina's sister-in-law accused her of taking away attention from other family members because of her RRMS.

The problem is... because my husband didn't want to know, he never shared it with them (our children)...he never was supportive of me...so then it became them against me...so if I lost it or I got really tired, I've got MS or whatever, don't stress me so much, they'd turn around and say "Oh, don't pull that MS card again" ...he would never defend me, he'd never say "don't you speak like that to your mother, she's got a condition" ...and that went on for years. Davina line 1264

She (my sister-in-law) said to me that you use your MS as a crutch and said your parents give you so much more attention and provide far more to you than they do to your brother...and out of that came the greatest reign of jealousy...how could someone say that to me? Davina line 1778

MS Nurses managing Surplus Suffering

The three important questions that arise from this data and discussion are firstly, how can MS Nurses ensure that they aren't the perpetrator of Surplus Suffering? Secondly, how can Surplus Suffering in the PwRRMS be managed in a way that may lead to healing and enhanced nursing and medical care for the future? And thirdly, how can MS Nurses educate others (HCPs and family/friends/community) on how to avoid inflicting Surplus Suffering on PwRRMS?

Empathic nursing and “going the extra mile” may be the key to setting up better outcomes for the PwMS in the future (Davies, 2014). The word empathy comes from the Greek *empathia* meaning physical affection or passion, but shares its roots with *pathos*, which means suffering (Stueber, 2011). Unlike sympathy, empathy goes beyond merely acknowledging suffering. When a nurse truly practices empathy with a patient, they share the patient's struggle and feel their pain (Davies, 2014), allowing the nurse to interact on the same emotional level as the patient and helping to establish trust (Ward, Cody, Schaal, & Hojat, 2012). Four components of empathy have been conceptualised by Morse's group in a model to provide insight into developing and expressing empathy (Morse, Bottorff, Anderson, O'Brien, & Solberg, 1992). This includes consideration of moral empathy (unconditional acceptance of another human being when encountering their suffering), cognitive empathy (sensing what another human is thinking), behavioural empathy (nonverbal communication to convey understanding such as a smile or head nod) and emotive empathy (perceiving and sharing the patient's feelings) (Morse et al., 1992). These empathic qualities should be mindfully considered by MS Nurses at every step of the life journey for PwRRMS.

By embracing holistic care and practicing empathy with PwRRMS, the MS Nurse is in the ideal position to establish a relationship of trust, taking into consideration the

vulnerable state of the person who may have experienced Surplus Suffering in the past and may continue to live with it. Discussing past hurts, past compromised care, past disappointments and perceived let-downs can help build a bridge to the future based on common goals and realistic expectations, improving care effectiveness. This does not mean that the MS Nurse ridicules or supports past care or injustices, but that they listen closely to the patient stories, reflect and validate the patient's feelings to enhance mutual respect and understanding. Patients can also find meaning in suffering through personal growth (Pollack & Sands, 1997), if we, as engaged MS Nurses are courageous enough to guide them.

The challenge for MS Nurses is to foster an atmosphere where patients realise that finding meaning in their suffering is a possibility and they may gain skills to help them in current and future situations (Pollack & Sands, 1997). MS Nurses cannot always alleviate suffering, but can listen, support, show kindness and compassion (Deal, 2011) and create a safe, empathetic environment in which patients can heal and gain strength. As Helen Keller reminded us in the opening quote to this theme, suffering can strengthen the soul, and as MS Nurses, part of our mission is to find strength and lend strength until the patient finds their own. To help patients understand the place of Surplus Suffering and to help them to heal.

The following theme of "High (In)Visibility" explores some of the reasons why Surplus Suffering may have occurred in the first place; the occurrence of many invisible symptoms in RRMS, symptoms which cannot be easily seen or understood.

Theme 5:” High (In)Visibility”

*But you look so well, are you sure that's what you have?
Of course I'm sure, I didn't make this up for attention
Attention I don't want and don't need
Maybe if I just hide in the corner and work hard you won't notice
You'll forget
And then I'll never have to try and explain
I'll never have to tell you I'm not the same
That I'm different to you
That I'm different to me
So I hide, I keep secrets
I hide symptoms I can't really make clear
I pretend, I pretend I am the normal person you think I am
I am normal
But if I am normal, why do I feel so wretched
So strange, so unknown to me*

*I wish I could take you on a journey
A journey through my body
Through the sensations, the weird noises
The sharpness of pain and the prickles
The feeling of not being able to move even though I do move
Of looking normal to you but feeling like a log to me
Of fogginess and clouds
Of tiredness and misunderstandings
Not quite here, not quiet there
Not quite anywhere
TB*

For the purposes of this study, I conceptualised invisible symptoms as symptoms which cannot be seen by others. Invisible symptoms are very commonly experienced by PwMS (Ben-Zacharia, 2011) and were experienced by all participants in the current study at some time in their life journey with RRMS. Invisible symptoms in

RRMS are numerous and include fatigue, mental health issues (including mild depression and anxiety), sensory symptoms and pain (pins and needles, tingling, burning), mild cognitive dysfunction (thinking and memory issues), mild sexual dysfunction, mild bladder and bowel issues (urge incontinence, constipation) and visual disturbances (blurred vision, colour loss). I have used the descriptor of “mild” in some of these invisible symptoms, because there are more noticeable features by others in the case of moderate to severe classifications. Additionally, invisible symptoms represent an extra layer of invisibility and complexity because PwMS reluctantly discuss them and MS HCPs may not enquire about them (Lysandropoulos et al., 2015). This may be related to lack of time in a consultation, inability by the patient to express the symptom or to understand its connection with RRMS, or perceived inability to treat the invisible symptoms by the HCP.

The *central organising concept* of this theme is the presence of invisible symptoms and their impact upon life with RRMS. Invisible symptoms may cause chaos with activities of daily living and may also cause misunderstandings with others, but on the other hand they can also provide a refuge from chronic illness and the struggles that MS brings. The fact that invisible symptoms are invisible can have both undesired *and* desired effects, sometimes leading to conflicting feelings in the same person about the same or other invisible symptoms. Some study participants suffered greatly from the effects of invisible symptoms in their lives, but other participants held on to the welcome cloak of invisibility protecting them.

There are three subthemes to High (In)Visibility; striving to make the invisible visible (please see me), reverse stigma (when my MS isn't enough for you) and invisibility as a welcome cloak (the downside has an upside). The subthemes are all linked by concepts of invisibility but all had different effects on the lives of the study participants, clarified further by sub-subthemes.

Understanding the impact of invisible symptoms

Invisible symptoms are not peculiar to RRMS, it is well documented that invisible symptoms exist in many other chronic diseases, such as mental illness (Jackson, 2015), systemic lupus erythematosus (Brennan, 2016), fibromyalgia (Cunningham &

Jillings, 2006; Parsa et al., 2015), Parkinson's disease (Hermanns et al., 2013) and heart failure (Whitehead et al., 2017) to name but a few. It has been suggested that in living with invisible symptoms, PwMS may feel that they are not being seen heard or met properly in the social environment (Lohne et al., 2010). Most people would identify a PwRRMS as someone who has significant overt disability and possibly using a wheelchair to ambulate. The idea of a PwRRMS functioning at a high level with no outward signs of disability at all, but claiming to have significant unseen symptoms, may cause issues for the understanding of MS in the wider community.

In a German MS registry study report (involving over 18,000 PwMS of all MS types) 20% of PwMS lost work capacity due to invisible symptoms despite being able to mobilise independently (Stuke et al., 2009). The impact of MS on quality of life is also emphasised by the high number of persons in the registry who suffered from invisible symptoms (notably fatigue, cognition difficulties and mood disorders), both in the early and the late stages of MS (Stuke et al., 2009). The invisible symptoms of MS, often combined with the difficulty in communicating these invisible symptoms to others, can often cause inattention towards the disease and ignorance (Grytten & Maeside, 2006). It must also be remembered by HCPs that invisible symptoms can often be more distressing to PwMS than visible symptoms (White, White, & Russell, 2008), even if they are not brought up and discussed.

Study participants discussed both positive and negative qualities about living with invisible symptoms, some aspects were complicated for them to understand and often involved more than just the symptoms. For example, Kate was appreciative that she could keep her symptoms of RRMS invisible at work where she had not widely disclosed her diagnosis, but what she wasn't counting on was the fact that her DMT side effects were threatening to give the secret away. The side effects from her interferon treatment, including flu like side effects, temperatures and fatigue led to people at work wondering "why is she so sick all of the time?". Kate couldn't explain to them the reasons why as she did not wish to disclose her diagnosis. Rudi lamented that her husband didn't realise that she suffered invisible symptoms everyday and preferred to keep it to herself; she didn't wish to talk about invisible symptoms as she felt this gave them and her RRMS some sense of control. Paul gave an example of an invisible symptom he found it difficult to explain to others, he

didn't really understand it himself, but he felt it everyday for months before the symptom remitted.

*It's like a cloud...I was sitting on a cloud...I don't understand...it's really hard to describe...a very, very weird feeling and I could sense there is something not right.
Paul line 78*

Balancing whether to tell or not to tell others about invisible symptoms was individual for each participant and each decision had consequences, either for telling, or against telling. On the one hand, participants wished to have invisible symptoms understood, but on the other hand, to disclose the invisible symptoms might mean disclosing the diagnosis of RRMS as well, which was a big step for some. Others disclosed the invisible symptoms but had their experiences devalued as their RRMS was deemed to be not severe enough. Some participants were glad their RRMS symptoms were (mostly) invisible as they could continue hiding their diagnosis whilst getting on with life. The subthemes of High (In)Visibility will explore these concepts in more detail.

Striving to make the invisible visible

Research into another autoimmune illness with predominantly invisible symptoms, systemic lupus erythematosus (SLE or lupus), revealed that others were disbelieving of the diagnosis because the participants looked so well and normal, leading to feelings of psychological invalidation and loneliness for the person living with the disease (Brennan & Creaven, 2016). The researchers also discovered that this lack of meaningful sympathy extended past family and friends to include HCPs and GPs and these experiences may then have deterred participants from disclosing their diagnosis to others or from seeking support afterwards (Brennan and Creaven, 2016). As discussed in the preceding two themes Battling the Demons and Surplus Suffering, similar situations also applied to PwRRMS, with several participants in the current study experiencing invalidation from HCPs and GPs, and for some participants such as Piper and Joy, this was a repeated occurrence. Several participants in the current study also experienced similar feelings of disbelief, invalidation and loneliness from family, friends, work colleagues and the community.

Please see me

Living with an invisible chronic illness raises questions of illness validity where no evidence can be seen by others (Moore, 2013) and is challenged significantly if the disclosure of the illness produces no visible support (Moss & Dyck, 2002). Doubts regarding symptom severity can be raised by family, friends, work colleagues and also by doctors and other HCPs, significantly impacting on identity and self for the PwMS (Skar et al., 2014). In addition, the lack of proof for such invisible symptoms as fatigue and sensory dysfunction can lead to others punishing the PwRRMS for being lazy, malingering and lacking credibility (MacAllister et al., 2009). Many participants in the current study were the recipient of doubts by others on the severity of their invisible symptoms, were not believed or brushed off and felt unsupported in their claims.

Struggling to come to terms with the diagnosis of RRMS diagnosis herself, Susan wished her friends and family could better understand her invisible symptoms, so that they could truly understand her difficulty. Susan took them along to her initial education meetings at MSA, believing that if they attended and learnt about the disease that they might be able to relate to her invisible symptoms such as severe fatigue and sensory loss.

I took a couple of girlfriends and Mum...just so they could understand what was going on because...they see me as I'm OK they don't know what's going on inside...so I wanted them to understand. Susan line 498

Evie disclosed her diagnosis of RRMS in the workplace early on in her journey and had worked with the same group of work colleagues in a senior role for many years. She organised for someone else with RRMS to come into her workplace to talk about what it was like to live with invisible symptoms in an attempt for her work colleagues to appreciate the daily struggles she encountered. Evie felt it helped to provide greater understanding of her situation in her workplace, and it was beneficial that a stranger (rather than herself) did this introduction.

I wanted them to see somebody else other than me. They see me, they see me well, but they don't see me, they've never seen me bad. I wanted them to see something different to me...and they were absolutely floored...most of that I have suffered at some point and some I go through on a daily basis. Evie line 26

Margot cleverly devised a way of protecting herself in crowds when she was affected by invisible symptoms such as dizziness, finding a way to alert others to stay clear and keep herself safe from being knocked over or falling.

People (in crowds) don't know you might be a bit rocky, so you have to be very careful...I take that (a walking stick) with me and it made such a difference, even though I wasn't using it to help me...people thought straight away, oh there's something wrong with her...I'll be careful around her, which is great...that was a very good tool...so even though it wasn't assisting me walking, it let other people know. Margot line 1969

For Davina, a constant struggle was having her invisible symptoms seen and appreciated by others, she wished there was some outward physical sign to alert them of her severe fatigue.

The hardest part for me is when I don't feel a hundred percent...I wished I suddenly developed little green spots or something would happen to me where people would say "Oh, she's not great". Davina line 786

Exposing the "secret one"

Sexuality, in particular, is an invisible symptom which has been significantly neglected in literature and is often neglected in MS consultations (Esmail, Munro & Gibson, 2007). Griff openly discussed what he referred to as "the secret one", the invisible symptom "nobody wants to really talk about", sexual dysfunction in MS. Griff discussed how the concept of sexual dysfunction is hard for HCPs to hear, hard to talk about by patients, hard to treat by doctors and leads to "hushed tones" in MS circles and in Griff's case, led to more questions than answers. Over the years Griff had unsuccessfully sought out treatment and assessment for sexual dysfunction. Griff

felt that but has been left to deal with it on his own, and felt that his neurologist was not skilled in assisting with this symptom or referring him to the appropriate resources and personnel to help.

Nobody ever wants to really deal with that (sexual dysfunction), not even me...I don't want to deal with it either, (doctors) don't want to talk about it...a young fellow me (a fellow person living with RRMS) at a meet and greet came up to and said "what about sex?"...it's all in hushed tones and it's industry wide I think, nobody wants to deal with this...how you express it to your partner, how you even tell yourself that you're not a bad person? Griff line 575

Sadly, Griff is not alone, prevalence reports indicate that 40-80% of PwMS report changes in sexuality (Foley, 2010; McCabe, 2004; Redelman, 2009). Sexual dysfunction has been found to be associated with depression and reduced QOL and to have implications related to relationships, fertility, pregnancy and parenting (Delaney & Donovan, 2017). Additionally, it has been suggested that MS HCPs often wait for patients to initiate discussions about sexual dysfunction rather than bringing up the issue themselves (Gromisch et al., 2016), perhaps restricted by time in a consultation or by inability to actually help with the issue. This is an area that needs immediate action by MS HCPs to improve assessment, reporting and treatment of sexual dysfunction in MS. Interestingly, despite the reported high prevalence of sexual dysfunction in males and females with MS, no other study participants discussed sexual dysfunction in the study interviews. This may have been for several reasons, such as time constraints, embarrassment at discussing sexual health with a stranger, importance placed on other issues they wished to discuss first or the fact that it was not a concern for them personally, or the fact that it is the "secret one", even in the arena of research.

When my MS isn't enough: reverse stigma of RRMS

MS has been described as an "invisible employer who hides their needs as a patient" and can lead to feelings of silence, belittling and ignorance (Lohne et al., 2010). Many participants in the current study with predominantly invisible symptoms of MS felt that their disabilities were less important than others with more obvious and

disabling MS symptoms such as people using a wheelchair or with poor speech. And yet they struggled each day, trying to lead a normal life whilst managing debilitating invisible symptoms. The dichotomy about how the PwRRMS feels on the inside with invisible symptoms, against how the PwRRMS appears on the outside as physically normal, can be difficult to cope with.

One of the surprises to me investigating invisible symptoms with the study participants, revolved around the concept of reverse stigma, the idea that as someone with RRMS, their MS wasn't severe enough to be considered legitimate or to secure empathy and understanding from others. So, rather than suffering from the stigma of a disabling disease, this was just the opposite, it was stigma in reverse. This could happen for two reasons, being compared to progressive forms of MS and RRMS being viewed as insignificant against it, or being "fobbed off" as unimportant when trying to give insight into invisible symptoms to others, because they looked well and healthy and not unwell and sick. Both reasons had the same effect, loss of confidence and self esteem for the PwRRMS.

Seminal work from Goffman (1963) exploring stigma in illness, reports that ignorance from others is an assimilative technique to establish sameness and common identity amongst a group. In the case of participants in the current study, it had the opposite effect and left them feeling vulnerable and isolated. Experiencing others refusing to acknowledge MS is a violation of self and imposes alienation (Grytten & Maeside, 2006). A previous study in RRMS has also reported that PwMS have been discriminated against for being "too healthy" and have taken advantage of the sick role to secure benefit for themselves (Miller, 1997).

I'm not enough of MS for you, devaluing the impact

There appeared to be two distinct sides to stigma in MS described by study participants; one of being ignored, or the MS symptoms being devalued or undervalued ("reverse stigma") and the other of having MS over-emphasised and over-acknowledged (Grytten & Maeside, 2006). Findings from the current study support reverse stigma as being particularly applicable to RRMS, whereas the latter possibly applies to more progressive forms of the disease displaying more overt

disability, and was not reported by any participants in the current study. Grytten and Maeside (2006) also reported that PwMS experienced minimalisation of their illness by others, even amongst friends.

Margot struggled with the “filthy looks” people gave her as she parked in the disabled car spot close to the local shopping centre and then proceeded to walk once she disembarked from the car. For months Margot carefully avoided parking in the disabled parking bay, she struggled with her invisible symptoms of fatigue and pain, sometimes overwhelming her on shopping trips and making it difficult to walk long distances, but she did persevere. One day Margot gave up the fight, put her disabled parking sticker on the dashboard and parked in the disabled bay, only to be confronted with looks from strangers that she felt conveyed a message to her of “ fancy parking there, you’re not even disabled”. Margot went back to struggling after that for some time, parking long distances away from the shops rather than risk perceived judgement from strangers again. In recent times though, Margot has come to terms with the situation and puts herself first.

Davina struggled with acceptance of her invisible symptoms from others, particularly hurtful was that her husband and children often did not believe the severity of her invisible MS symptoms and openly made fun of her. Davina just wanted to be seen, believed and understood.

(I didn't tell my four kids much) I didn't want to burden them I suppose...but because my husband didn't want to know, he never shared it with them...never was supportive of me...so then it became them against me... if I was...really tired...he would never defend me and that went on for years...and then they'd make a joke of me...he (ex husband) would undermine me. Davina line 1263

Recently one of Davina's now adult children recently contacted her after watching a documentary about MS on television. As Davina recalled the conversation, tears fell down her cheeks as it meant such much to her that finally, her RRMS was visible to at least one member of her immediate family.

She (daughter) said... "I just watched this documentary on someone who'd just been diagnosed with MS and I was unaware of what you must have gone through" ...so it's been really hard...it meant that maybe she'd started thinking a little bit about it. Davina line 1298

Interestingly, two participants, Susan and Davina, who reported lack of understanding of invisible symptoms from close friends, both worked in the healthcare profession, as did their friends who failed to understand the difficulties they were under fighting invisible symptoms. Perhaps their exposure to more serious conditions in healthcare desensitised them to the suffering of their friend, the PwRRMS. Davina was particularly surprised that her HCP friends would question her invisible symptoms and devalue her severe fatigue levels.

My (HCP) friends would turn around and say "Oh, what's wrong with you, you can't keep up anymore, you're getting old?" ...and they do it til this day...how dare they...and then they'll try and make me feel better by saying "oh, everybody gets tired" ...but I said, I don't get tired, it's more than that and it can hit me really suddenly and I go down like a pack of cards. Davina line 794

For Susan, although she felt that she has already educated her friends about the invisible symptoms of RRMS, she felt they still didn't fully understand the impact that invisible symptoms of RRMS could have.

People, they don't understand...they see you as you're OK because mine's only mild, but inside...in here, it's hard to accept and hard to make other people understand how you're feeling...it was hard to talk to friends about and if I did say anything, they'd say "Susan, you're OK, look at other people, you're very lucky" ...so I went OK...but I was really sad and thought...well, what about me? Susan line 670

Jane was fundraising for MS awareness and research in an endurance bicycle event. The riders were to cycle a long distance in extreme heat and the day prior to the event Jane expressed her concern to the organisers that fatigue and Uhthoff's phenomenon (when the body overheats and old MS symptoms reappear from previous nerve damage) would be a problem for those with MS in completing the

course. Jane requested an earlier start time to avoid the midday heat for herself and the fellow MS riders taking part, but this request was refused. Jane was then forced to leave the ride without even starting it, causing her to lose the significant amount of fundraising money she had been promised to take part in the event. Jane felt that she had been shamed for speaking up and verbalising her issues, her invisible RRMS symptoms. The irony of the situation is overwhelming, raising awareness of MS and MS symptoms in a fundraising event, only to have her own invisible MS symptoms overlooked and devalued by the very group that should have the greatest understanding.

They thought I was being demanding...it was so disappointing...I said...I have MS...I know what it's like. I had to leave the trip early, it wasn't possible to do...very disappointing, people had sponsored me and I had to tell them I couldn't do the ride for these reasons...I raised a lot of money but I didn't do the ride like I said I was going to...it was so disappointing. Jane line 798

A “pretender to the throne”

Griff's tale of reverse stigma is as poignant as it is astonishing. As a newly diagnosed, vulnerable man diagnosed in his forties with RRMS, he was navigating his first MSA meeting and getting to know more about MS and the invisible symptoms he had been battling silently for many years. After the seminar there was a chance to meet other PwMS. Griff was surprised when the mother of a severely disabled and wheelchair bound young lady came over to Griff and verbally “attacked” him, accusing him of not having MS and not being serious. This public humiliation threatened his newfound confidence, and although he understood the reasons behind the reverse stigma, the emotional scars are still borne by Griff today. He felt like, and still feels like, a “pretender to the throne” of MS.

Compared to so many other people, I am light years ahead...which brings its own problems in fact...I coin the phrase “pretender to the throne” ...when I was at a welcome to your disease meeting, there was a girl...probably early twenties...and in one of those wheelchairs you never really get out of...her Mum's with her and absolutely distraught, saw me and maybe 3 other people chatting...we have much

lower damage...and she came over and attacked us...I was upset at the time but I wasn't cranky at her...I'd hate to think what she was going through...(she) had a go at me because "what are you? You haven't got MS!"...that's always been at the back of my mind, that I'm a bit of a "pretender to the throne". Griff line 532

Invisibility as a welcome cloak: the downside has an upside

Many people living with chronic illness don't look so different from those healthy people around them, and it can be a huge burden to make the invisible visible (Siouta et al., 2016). Some PwRRMS decide to keep the diagnosis private and the invisibility of many MS symptoms suits them very well. Previous studies regarding living with MS have noted that PwMS often wish to deal with their disease privately (Clair, 2003) and this may be due to several reasons including stigma, embarrassment and (perceived) career advancement. Several participants in the current study were able to continue working and functioning at a pre-RRMS symptoms level and were able to keep their diagnosis of RRMS hidden from those they did not wish to disclose to. However, not disclosing their illness could also expose the PwRRMS to real threats of physical and emotional well being rendering PwMS "damned if they do, damned if they don't" in regards to disease disclosure (Vickers, 1997). If they were not sure what to do, participants in the current study tended to err on the side of caution by withholding the diagnosis and practicing information control. For some participants such as Kate, Paul and Jane, this was the great benefit of invisibility; there was definitely an upside to the downside. Keeping a diagnosis of RRMS concealed from a public that knows little about the disease of RRMS has been previously reported (Miller, 1997) and this may help the PwRRMS retain the identity they wish others to see and avoid being labelled.

The presence of invisible symptoms could also be seen as a blessing to some participants. At times the invisibility of MS symptoms was an added bonus and seen in a more positive light, especially when there was reluctance to disclose the MS diagnosis to others, such as in the workplace or to extended family or friends. This is a form of information control, not just in deciding disclosure just after diagnosis, but continually along the life journey living with RRMS. The presence of invisible symptoms allowed decision making by the PwRRMS, who received what

information, how and when was then up to each individual. Will wished to control what his family sees of the disease, especially his wife as she is caring for a new baby. Piper also keeps her symptoms from her children, acting as she always has and pushing herself to live and look as normally as possible.

The invisible stuff...I hide it from my family...my wife's pretty fragile, we've got two children, we've got responsibilities...I need to be that strong person. I don't want her worrying about it...she'll see what's going on...she just leaves it alone because she knows that's how I deal with it...I keep it to myself. Will line 64

My kids don't see the impact of MS, I guess they don't see it because I just...if I...stopped every time there was something wrong I would do nothing basically and I'm not like that...I'm a do-er...the kids I guess don't see, a lot of people don't see it...all the symptoms anyway because of my way of day to day living...I will do it...I will push myself and I will do it. Piper line 838

Not disclosing the diagnosis and not being “called out” on it led to feelings of success in keeping MS hidden, success mainly due to the predominantly invisible symptoms. Paul and Kate were both successful in controlling who knew about their diagnosis of RRMS in the workplace; Paul also kept the diagnosis secret from his many friends and extended family.

Nobody else knows, I much prefer to keep it that way...my wife's parents don't know, only my Mum and Dad and my brother know...(I haven't disclosed to any friends) I doubt they would think they could catch it...but I don't know. Paul line 1004

(I was offered a new job and the Boss knew I wasn't well) but due to invisible symptoms he said “no-one needs to know, you can do the job”...and I thought, why not? I'd hide my relapses and treatment and it worked quite well. Kate line 590

MS Nurses can educate PwRRMS that it is helpful to have a few close confidants they can talk to about their symptoms (invisible and visible) and how they are feeling, openly and honestly. The confidant can also help advise on sensitive issues such as disclosure and can provide a “sounding board” for feelings. Having a

sounding board to practice with can also help improve communication skills and provide systems to make it easier to explain invisible symptoms to others. This is especially important at the beginning of the journey and many MS clinics will advise new patients to bring someone trusted with them to the first few appointments for this reason. Becoming skilled at explaining invisible symptoms will take time and practice, but is possible with the right guidance.

MS Nurses also need to become skilled at assessing for invisible symptoms in PwRRMS and providing opportunities for open discussion and education. Setting time aside to discuss fatigue, cognition, pain and sensory symptoms, mental health issues, sexual dysfunction, bladder and bowel issues are just as important to the PwRRMS as scan results, DMT prescriptions and laboratory tests. Discussing invisible symptoms provides the words, phrases and framework to talk to others about the symptoms and the difficulties they face. PwRRMS then learn the terminology and they discover that the symptoms are understood by others, there are reasons for the symptoms and that they are considered genuine. This instils confidence in managing the life journey with RRMS.

This final theme of High (In)Visibility concludes chapter 6 of the thesis, Walking the Low Road. The skills that have been learnt and practiced by the study participants and the things they have learnt about themselves and others along the life journey so far has prepared them well as they embark on “Taming the Beast”, the next and opening theme to the following chapter , “Finding the High Road”. This really marks the start of a brighter future and a time of much personal growth and development. This is the time when PwRRMS begin feel a sense of taking control of their lives, living with RRMS, not living against RRMS.