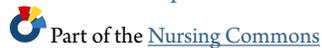

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"Taming the beast": Exploring the lived experience of relapsing remitting multiple sclerosis using a life history approach

Therese Burke
The University of Notre Dame Australia

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CHAPTER 7- “FINDING THE HIGH ROAD”

The following chapter “Finding the High Road” outlines the final three themes from the data analysis and explores a distinctly different overall feeling from the previous chapter Walking the Low Road, where despite some occasional glimpses of brightness, there was more a sense of confusion, of negativity, of unanswered questions and of battle. Finding the High Road feels exactly like the metaphor it is taken from, taking a turn in the road for a higher path, to be able to reach higher ground and look down on the muddy waters below. A journey of self-discovery, of finding previously unknown talents and gifts, of packing a personal “toolkit” to live the best life possible with RRMS. A time of immense personal growth and achievement, sometimes noticed by others and sometimes not. But always active, always engaging, are the choices in Finding the High Road.

The three themes making up Finding the High Road and their related subthemes and sub-subthemes are listed below in Table 5. The only subtheme in this chapter requiring elucidation is the sub-subtheme “decisions driven by fear” which is placed under the main theme of “The DMT Dance”. This sub-subtheme also relates to the concept of fear, which was introduced in the third theme Battling the Demons in the previous chapter. However, I have included decisions driven by fear in this chapter and theme because it is part of the negotiation of successfully completing The DMT Dance and an important element of perhaps later reaching “decisions driven by hope”. This sub-subtheme also forms an opposing force to decisions driven by hope and for this reason I felt DMT decisions driven by fear and decisions driven by hope belonged *together* for clarity and understanding, both being key components of The DMT Dance.

Table 7. Summary of themes six to eight of the study findings; demonstrating central organising concepts, subthemes and sub-subthemes developed from the study data.

Theme	Central organising concept summary	Subtheme	Sub-subtheme
6. Taming the Beast	Finding tools and packing a toolkit to live with and manage RRMS, the different ways that PwRRMS regain control of their life	Finding my North Star Getting a handle on RRMS symptoms and relapses Maintaining physical and mental health and wellness Choosing my medical A-Team Harnessing support from family, friends, organisations and workplaces Riding high on resilience	
7. The DMT Dance	Negotiating and coping with the medication therapies to treat RRMS	The hardyards: making decisions about DMTs and adherence Switching to a better life	<ul style="list-style-type: none"> • decisions driven by fear (“I’d rather be in a wheelchair than dead”) • decisions driven by hope
8. Holding Hands with Hope	Hope and positivity about reaching happier times and the beginnings (or totality) of acceptance of RRMS into life and how looking to the future with hope brings its own peace and rewards	Hope in its many forms Purposeful positivity	<ul style="list-style-type: none"> • functional hope • restorative hope • curative hope • defiant hope • optimism and a positive outlook • searching for meaning • harnessing a sense of humour • faith, religion and spirituality • giving back and being involved

Theme 6: “Taming the Beast”

*Now I have arrived
Armed in my combat gear
I'm taking you on
Gone is my negativity, my fear
This time I'm ready
I've read the rules of the fight
This time I'll take you
I'll show you my might
I've gained so much
I've lived and I've learned
I'm a new person now
Full of positivity I've yearned
TB*

The theme of “Taming the Beast” represents a turning point for PwRRMS, a time where they start to conquer the demons they have battled since suffering their first RRMS symptoms, a time where they have gained some experience living with the disease and now have some knowledge about what RRMS actually is, and is not. It is a time for positive change, for the beginnings of acceptance, sourcing the best support, sharing tips, gaining confidence and for recognising the incredible things they have achieved since Piecing Together the Puzzle, working on (Re)defining Me now that I have RRMS, Battling the Demons, managing Surplus Suffering and learning how to live with High (In)Visibility. Taming the Beast brings life firmly into the foreground, working to be a person living with RRMS, not an RRMS person. Evolution is key to this theme, as the nature of RRMS means that change is always potentially around the corner and nothing is static. Adapting to change and living with uncertainty has become a major life achievement.

The **central organising concept** for this theme is packing a metaphorical “toolkit” to live with and manage RRMS, the different ways the study participants found to regain control of their life. Taming the Beast comprises six subthemes: finding my North Star, getting a handle on MS symptoms and relapses, maintaining physical and

mental health and wellness, choosing my medical A-Team, harnessing support from family, friends, organisations and workplaces, and riding high on resilience. Several sub-subthemes will add further clarity and explanation to these subthemes.

Finding My North Star

This subtheme goes beyond the “getting acquainted with MS” subtheme of (Re)defining Me now that I have MS discussed, in the second theme of the previous chapter. Finding my North Star is after the settling in period, where the initial shock or devastation of the diagnosis and the thirst for knowledge or running away from knowledge has advanced into more of an acceptance of RRMS. This subtheme has a positive feel, in recognition of the qualities this stage has invoked in the participants, finding new meaning in life and finding a place where both the person and RRMS can cohabit the same body. For some participants, these feelings of regaining control were still very new and developing, and for others the sense of control had been well established for years prior to the interviews, yet was always constantly evolving.

The North Star, or Polaris, is the brightest star in Ursula Minor. The North Star does not appear to move in the sky to the naked eye, remaining fixed above the North Pole to mark the way due North (Hirsch, Kett, & Trefil, 2002). The North Star in the sky guiding and lighting the path due North captures the sense of PwRRMS finding their inner light and a way to move forward in life living with RRMS. Even though RRMS was ever changing, the study participants could find their way to their fixed point of control, their North Star, to keep travelling in a positive direction.

The turmoil and upset explored and discussed in the earlier themes started to settle as education and learning brought confidence, as symptom mysteries unravelled, DMTs were commenced and disease control started to become a reality. Although a difficult concept for MS Nurses to explain to patients, the simple notion of *time* assisting assimilation with the disease is real. Study participants Paul and Davina describe how time can be the friend PwRRMS need, how time helps PwRRMS to understand that life can be about more than RRMS, especially with some tools.

As time rolls on and nothing happens, you tend to become a little more complacent I guess...I'm always a bit cautious, so just a little more planning involved with things. Paul line 937

I'm comfortable in my own skin now, I think I've accepted wisdom that comes with age rather than worrying...I have got a wonderful partner, best friend...we have our own quietness. Davina line 1746

Research has identified that several key skills are beneficial to successfully adjusting to life living with RRMS. These include positivity, perceived control over life situations, self-efficacy in disease management, optimism, hope, benefit finding and spirituality (Dennison et al., 2009). Additionally, patterns such as developing strategies to combat difficulties, making extra time to manage daily needs and avoiding making MS the life focus, begin to develop as confidence and experience living with MS grows (Dennison et al., 2010). Several study participants incorporated some of these skills into their new existence living with RRMS and chose to change their feelings and attitudes about RRMS as a conscious and deliberate choice. I conceptualised this as slowly progressing in Taming the Beast. Joy contemplates how she chose to look at RRMS in a new light rather than being bitter and angry about feeling different to others.

That was my gift...it actually was my gift at birth to be given this brain that didn't function the same as other people's, so I just didn't see the world the way other people saw it...and it gave me something more to work with...I am blessed. Joy line 2009

Similarly, Rudi describes how she purposefully changed her attitude to see RRMS as a gift in her life and a facilitator for positive change, the chance to finally travel and see the world.

As a mother you just get on with it...as hard as it is. 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...I just have a different outlook on life...I tend to care less about things now so I view it as a gift...MS is not such a bad thing. Rudi line 835

After initially struggling with what he termed depression for many months, and not adhering to his DMT or treatment plan, Will realised he needed to actively make some changes to his life to successfully live with RRMS. His life turned around as a result and he learnt what he needed to do for himself to secure happiness, finding his North Star.

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

A recent study explored the experiences of 10 PwMS after being diagnosed with MS (unfortunately the MS subtype was not defined) and reappraising their lives (Flensener & Rudolfsson, 2016). The authors explored feelings about changing from a healthy, strong body before MS, to experiencing altered bodily functions and the possibility of changes to life activity. Much like the concept of Finding my North Star in the current study, Flesner and Rudolfsson's (2016) work revealed that PwMS "learn to fly with broken wings" by getting to know their new foreign body and "building a new living space" for the body to function. Building a new living space took time, requiring adjustment, reappraising and creating new meaning in life, and was sometimes uncomfortable. Many participants in the current study displayed features of these themes as they partnered with RRMS in a new life, learning to fly with broken wings over time.

Susan suffered greatly in the early years of her RRMS diagnosis, and being a HCP herself, she was frustrated that she couldn't seem to make sense of her new MS world and make positive progress. For many years she was sad, lonely and deeply fearful of what her future life was going to be. Being single, she felt intensely alone and that nobody would want to partner her in life with RRMS. One day after a

relapse that all changed, Susan decided enough was enough. It was time to find her North Star.

What I was looking for was to help myself to be able to understand these little demons...to then thinking you are good enough...don't listen to them...to be strong and I could also help others...to just accept it, to embrace it because it doesn't mean the end...that was a new beginning for me. Susan line 773

MS doesn't make you the person...that's not you, there were other things before that and there's going to be more things, that's just there and you deal with it. Susan line 1299

Coming to terms with the occasional need for wheelchair assistance if her mobility was impaired by a relapse or severe fatigue was a huge stumbling block for Margot, steadfastly refusing her husband's attempts to try a wheelchair so that she could still enjoy outings and travel. But, once she tried it, she was amazed at the difference it made to both their lives and how easy things became now that the stress and worry about possible falls was taken out of the picture. Finding her North Star to include the occasional use of the wheelchair or walking stick with relapses or severe fatigue brought new perspectives for Margot.

It was a real mental block (tearing up)...it's really hard to do...it's the elephant in the room. The thing is it was so stupid...you do become more accepting...but it was fantastic. Margot line 1533

I thought I can't believe I didn't do this sooner, it was the best thing...it was the initial embarrassment but once I sat the first time...this is fantastic...now I'll take my wheelchair and the girls will wheel me around shopping. Margot line 1701

Starting to see unexpected benefits from situations that previously caused angst can be a positive catalyst for change as well. Rudi turned the dismay she felt at not being able to work due to her severe MS relapses into a positive as she was able to spend more time with her four young children.

Whilst it (our lifestyle) may not be extravagant, I'm just doing a lot more and loving it...loving it...I look at this as I'm lucky because I get to spend this time with my children...whilst it was tough financially, we adapted, as you do. Rudi line 950

Evie took a different approach, yet one that firmly changed her future path to one of positivity for not just herself, but for others with RRMS. She began talking to others as an MS advocate and sharing her story to change public perceptions about RRMS, improving her own outlook on MS along the way. Evie's North Star was all about others and less about herself.

If I'm going to have it I may as well do something with it...that was the way I saw it...I want to help others and make a difference, I want people to see people who aren't disabled by MS...it's not all doom and gloom. You shouldn't focus on what you can't do, it's what you can do, what you want to do...yeah it's going to feel like shit sometimes and you're going to get angry and upset, but you need to pare that back and take a different perspective. Evie line 1210

As study participants were able to look back on their journey with RRMS, their MS experience generally gave them confidence about how they viewed the disease in the future. As discussed in the literature, over time, PwMS tend to develop expectations about their disease path, and often with minimal input from MS HCPs in regards to prognosis (Dennison, McCloy-Smith, Bradbury, & Galea, 2016). As confidence grows, PwMS begin to make more decisions, to make plans and to become more actively engaged as their knowledge increases and they regain a sense of control over what is happening (Clair, 2003). Taking on a more active role in treatment decisions is something that PwMS tend to opt for as they become more educated and engaged as the life journey with MS continues (Heesen et al., 2004). This prepares them for new challenges on the life journey, guides them in finding their new North Star and allows them to start building positivity and hope, which will be discussed in greater depth in Theme 8, "Holding Hands with Hope".

Getting a handle on MS symptoms and relapses

The course of RRMS is characterised by unpredictable relapses interspersed with periods of remission from disease activity (Halper, 2007a). Relapses can either be mild and barely noticed by the PwRRMS, cause a myriad of sensory and motor symptoms, or be catastrophic in their effect causing paralysis, blindness and gait disturbances. Although most people living with RRMS usually recover from early relapses, some residual effects can remain and over time, relapse recovery tends to lessen (Mills, Mirza, & Mao-Drayer, 2017). To add to the mix of confusion and unpredictability for people learning to live with RRMS, “pseudo” relapses which feel like a new relapse coming on but are not inflammatory in nature, can occur in the setting of infection or changes in body temperature (such as with exercise or overheating) and can be very frightening to the PwRRMS (Mills et al., 2017). Working out the difference between true relapses and “pseudo” relapses takes time and experience, none of which are accessible to the patient in the early stages of living with RRMS. For most participants in the current study, coming to terms with various RRMS symptoms and managing relapses was initially difficult for them, but as time passed and with education and experience, their confidence in managing MS symptoms and relapses grew as they began Taming the Beast.

After initially being worried about new onset symptoms and not understanding the meaning of them, Piper gradually set up a system of communication between her local GP and her MS clinic, which was located several hours drive away from her rural town. Relapses became a nuisance rather than the cause for deep concern, which she had felt in the early days.

They're just a nuisance...I get a build up of things...you go to the doctors...I do converse with my neurologist which is really good and so between here and there, they get this agreement...you just hope they are not as bad or severe as before. Piper line 1240

Piper's husband set up an excel spreadsheet for her, with separate columns to score her symptoms daily in an attempt to help Piper try and work out what triggers her symptoms, her bad days or high fatigue days and hopefully avoid those triggers in

the future to improve her quality of life. It is his way of providing support and has been key for Piper to uncover ways of managing her own MS symptoms and Taming the Beast.

Everyday I fill out a spreadsheet with all my meds, and symptoms, give myself a pain score, how many hours I've slept, exercise, diet...we've even got the weather...so the idea is we'll see a graph and there might be some pattern. Piper line 1522

Becoming experienced and educated in RRMS provided Kate with the plan she needed to instil confidence that she could manage her relapses, whenever and wherever they occurred, which was important as she planned to travel overseas. Kate felt as if she had regained some control over RRMS.

Being relapse free for four years was fantastic because you could plan your life...I felt a lot better and my doctor gave me his mobile number, steroids to take and told me what to do...so I thought I felt a lot better knowing that I had a backup plan. Kate line 1247

For study participants Rudi, Margot, and Joy, the initial (undiagnosed) relapses became less of a worry for them once they knew that it was MS and not something they viewed as more sinister such as a stroke or brain tumour. This was particularly so for Rudi, who suffered rapid onset and serious relapses which often resulted in admissions to hospital.

Everyone else got panicky around me but I know it's the MS so I don't...I don't feel highly stressed...I know I'm not dying, I'm not having a stroke...I tend to cope better than everyone else around me. Rudi line 252

For Margot, letting go of household chores that worsened her MS symptoms has made a positive impact on her general health and fatigue levels. This has been an effective tactic in Taming the Beast.

I've pulled back on domestic duties, I don't do cleaning anymore...I think you just let things go really, but it's not that important...I accept things a lot more...I'll walk past dust in the hallway...it's not important...I've become more patient with MS. Margot line 952

Kate suffers terribly with pain from spasticity, a condition caused by nerve damage from MS where her leg muscles become tight and painful. A new drug has recently become available internationally, which has had good results reported in reducing spasticity symptoms. Although she is yet to try the medication, Kate is on a crusade to bring the new drug to Australia because no treatments she has tried so far have given any relief. Kate is determined to bring this quality of life-sapping MS symptom under control, even if it means organising her own treatment to engage in Taming the Beast.

I need it, I desperately need it...I don't need it in three years time I need it now...I've called the PBS...this is the problem and I need to do something about it...you have to be on everyone's back...I put that on the backburner until next week when I get another burst of energy. I really do feel like I have to be my own advocate. Kate line 2158

Rudi suffered from severe bouts of fatigue, particularly after relapses. Rudi had to find a way to deal with this debilitating symptom so that she could reclaim her life as a busy and engaged mother of four children. Balancing rest and life enabled Rudi to get a handle on her MS symptoms and to take on Taming the Beast.

I do recover...when the symptoms disperse, it's very draining...it's like I've been hit with a truck...very tired...I go straight to bed basically cause there's nothing else I can do, and I will sleep...usually I recover pretty well. Rudi line 1087

There's periods where I would have to go to bed...because I feel like I've been hit with a truck...I've learnt...I can play hard but I also have to rest hard...because I've done it before where I just keep going and pushing and pushing and I crash and burn...so I've found I just have to balance. Rudi line 1769

Maintaining physical and mental health and wellness

MS poses challenges to both physical and mental health and wellbeing, and increasing disability over the course of the disease is associated with increasing burden and transformation of life plans (Rommer, Suhnel, Konig, & Zettl, 2017). Indeed, the adjustment process in RRMS does not conclude when early stage PwRRMS get used to their MS symptoms, it continues as future disease status changes occur, as their life journey goes on (Dennison et al., 2010). Learning to manage health and wellbeing is therefore an important part of the life journey with RRMS and one which is in a constant state of flux depending on symptoms, relapses, medication side effects, as well as general life, work and family commitments and responsibilities. It has been reported that after diagnosis, PwMS often say they won't be able to cope in certain situations or with certain symptoms, but longitudinally as life progresses and the changes happen, they do learn to cope and often very well (Dennison et al., 2010). This pattern was displayed by most participants in the current study, capturing the concepts of Taming the Beast, so vital not just to coping with the disease, but for thriving with RRMS. Maintaining physical and mental health and wellness is an important step in this process.

The "Shifting Models Perspective" (Paterson, 2001) believes that people choose to have a predominant focus of either wellness or illness in the foreground of their lives and that encounters and experiences are selected which will support their preferred perspective. During the time of Piecing Together the Puzzle discussed in theme 1, study participants demonstrated that a perspective of illness lay in the foreground leading up to RRMS diagnosis, with the tests, many consultations, hospital visits and uncertainty. As time progresses after diagnosis, symptoms dissipate, relapses come under control and PwRRMS generally become more settled, their focus often starts to shift from the initial illness in the foreground to one of wellness in the foreground. Holding the burden of illness in the background sustains a sense of well being, and many study participants concentrated on a wellness plan for physical and mental health.

As mentioned in theme 2, (Re)defining Me Now That I Have RRMS in the subtheme dare to compare, Will took the view that he wished to stay away from others with

RRMS during his DMT treatment in the day admission ward of the hospital where he underwent his monthly infusions. Will chose to look after his mental health and commit to mental wellness, deliberately sitting with patients being treated for cancer, rather than his fellow MS colleagues. Staying away from others with MS and out of the so-called “cripple club” (Dennison et al., 2010) distanced Will from MS stereotypes and helped him place his RRMS in the background. Will also chose not to read up on RRMS or engage with education programs for the same reason.

I don't want to read the bad sides of MS because I can't influence them and I can't change the way they feel...I don't need to hear it...I know some people are geared to go out there and really advocate, be positive and speak about their problems...that doesn't work for me. Will line 301

Will's attitude to others with MS was in the minority for the study participants, most of whom embraced being with others with RRMS, talking with them, sharing tips in Taming the Beast and looking forward to their treatment infusions for this reason. Margot looked forward to the monthly infusions of her DMT in the hospital day admission ward and was disappointed when her DMT changed to an oral medication and she no longer spent time with people living with RRMS. It had become an important part of her mental health wellness strategy.

In the hospital you met other people with MS, which was fantastic...because people had little tips, they had stories...you'd exchange how long you'd been diagnosed, what your reactions were...and there were people from all walks of life. Margot line 503

An important facilitator for resilience in MS is physical wellness including exercise, stress reduction and energy management (Silverman, Molton, Alschuler, Ehde, & Jensen, 2015). Studies have shown that continuing physical exercise behaviour over time predicts a continuation of enhanced QOL for PwMS (Dennison et al., 2009). The most dramatic turnaround from illness to health and wellness in the current study was from Joy, who described how she felt in the aftermath of her husband's death when her RRMS symptoms were at their worst and she attended his funeral

aided by two walking sticks, making a decision that day to reclaim wellness to the forefront of her life and take back control.

At my husband's funeral I made an absolute heartfelt decision that I would get better no matter what...something switched on...when my husband died...I had to choose life...this resurgence wants to do what I wanted it to do, there must be another pathway...I started fighting for my own health...I felt like I had the power to control my health...I made it true...I was suddenly aggressively and passionately seeking wellness and I have done ever since...I took back control of my life...the disease doesn't control me, I control my body. Joy line 983

Making the active decision in Taming the Beast by becoming healthier physically was more than just a decision to move forward for many of the study participants, it was also an act of defiance, challenging the very essence of what RRMS takes away in physicality and mental health to do the physical activity which is threatened by the disease. Many study participants described how maintaining or commencing acts of physical health, exercise and sports helped them to feel better, stronger and more connected in both physical and mental wellbeing. Piper was proud that she pushed through her symptoms to maintain her physical health.

Just get out there and do stuff while you can and I do that everyday, I like going for walks or runs...I do it because I can...I've got my own gym...even when I am fatigued with MS I still do it, I will still do my walk, it actually makes me feel better...if you move you'll be amazed at the difference. Piper line 990

Margot has recently started gym work and has already felt the benefit, feeling stronger physically. Rudi and Evie have also found that physical activity has helped regain control with specific symptoms, as well as being a mental health boost of positivity for Evie.

Since I've finished work I haven't had many falls at all because I've started going to the gym. I had an assessment and program done and now I go twice a week which has been the best thing...my legs are stronger. Margot line 1341

I do regular yoga...I started playing team sports...I'm absolutely loving it, whilst I could be more active, I have consistency...and I paddleboard to help with the balance. Rudi line 993

I've gone back to gym now, my muscles needed it...keeping fit and healthy...just to remind myself that I was being more defiant...you can knock me down but I'm going to get up. Evie line 1358

Susan embraces the holistic view of improving both her physical and mental health and also in educating others living with MS and sharing her tips to living life better with RRMS.

I always tell others with MS just try and do all the good things like eating good food and exercising...the whole wellness thing is what you need, MS medications are part of that but exercising, eating well, rest, seeing friends...that's what makes you healthier in mind and body...you have to be healthier up here too. Susan line 1305

Choosing my medical A-Team

The subtheme of “Choosing my Medical A-Team” is all about the PwRRMS gaining some control in Taming the Beast by selecting members of the health care team to be on their side, to take charge of their own care, to engage with self-management strategies and to make decisions about who makes them comfortable and who they trust to manage living with RRMS. Often when symptoms first strike, patients are referred for consults and tests to people they have never met before and they don't have choice in who they see, especially so if they are referred by GPs or present through emergency rooms. After diagnosis and the settling in period however, it appears important for PwMS to choose their A-Team for the long life journey ahead with a chronic neurological condition. It has been reported that PwMS choosing their own doctors and health care teams helps the PwMS to take charge, a concept which is extremely important to moving forward and gaining some control (Clair, 2003).

Several participants described scenarios where their MS HCP, in particular the neurologist or MS Nurse, went “over and above” what was required to advocate for

them, securing trust and instilling confidence in the care they were receiving. Will was unable to gain financial assistance from the government for the expensive DMT he needed due to residency issues. The medication cost was almost the same amount as his earnings at the time. Will became very emotional as he recalled the day his neurologist advocated for him and sought compassionate use for the medication, meaning it would be provided at no cost to him.

He said don't worry about it, you focus on what you have to do and we'll work out the rest...since that day I still make sure I come to him because he's just the best. Will line 672

I broke down in front of him...I don't know what to say...it's probably the greatest thing anyone has ever done for me. Will line 877

After many years and failed attempts to secure a diagnosis for his intermittent symptoms while Piecing Together the Puzzle, Paul was referred to a neurologist who gave him plenty of time, spending two hours with him on the first consult and finally providing a diagnosis and treatment plan.

My neurologist was brilliant...he had a number of MS patients...he had a massive checklist he was going through, the first consultation I had with him would have been over two hours and he was wanting to solve this...he later retired but not before sending me to the best MS Neurologist...he's the one in Australia that you want to be with and he organised all that for me...he was wonderful. Paul line 112

The family doctor or general practitioner (GP) can often be the first consult when PwMS develop their first symptoms (Giovannoni et al., 2016) and an important part of the health care team during the lifetime living with a chronic illness. A systematic review has shown that being under the care of an empathic family doctor improves patient adherence to medical advice, decreases anxiety and distress, improves clinical outcomes and improves patient enablement (Derksen, Bensing, & Lagro-Janssen, 2013). Paul was also fortunate to secure a GP who supported him at every opportunity, becoming an important member of his Medical A-Team.

My GP, she's another one who spends hours with you, she's learning from me about MS, so whenever she's at conferences she tries to go up and find out a little bit more with neurologists, she's told me she's loving having me because I'm the only one that she's got. Paul line 481

MS Nurses have been perceived by patients as being ideally situated to discuss practical and emotional issues relating to MS (Dennison et al., 2016). MS Nurses play an integral role in helping patients and families come to terms with diagnosis (White, 2012) and across the entire disease trajectory providing expert information, relapse intervention and decision support (Mynors, Bowen, & Doncaster, 2016). MS Nurses cover many domains, including advocacy, empowerment, disease expertise and education (Halper & Harris, 2016) and have an important role in preventing unnecessary emergency and hospital admissions (Quinn et al., 2014). Rudi and Ruby both valued the support of MS Nurses who advocated regularly for them and were both interested and available as members of their A-Team.

I've got a great GP, she's advocated on my behalf, I've had her great support and the whole MS clinic has been great...if I ring and say I need to see someone, they know I'm sick and they will get me in...the MS Nurse, the fact that I can ring her, that's awesome because you probably have more contact with them than you do with the doctor and she can answer your questions. Rudi line 1871

My neurologist, he's just beautiful, he loves what he does and the MS Nurse...she takes the edge off going, I've never met a more efficient woman in my life...the nurses are divine and it's a comfortable environment. Ruby line 494

Harnessing support from family, friends, organisations and workplaces

Social support systems can vary greatly between countries and cultures but mostly comprise of family, friends and HCPs (Rosland et al., 2013), as well as organisations, societies and work places. Immediate family, significant others and close friends also play an important role as the first line of support, especially true for spouses of PwMS who are often sharing the burden of MS on a daily basis (Aymerich, Guillamon, & Jovell, 2009). When appropriate support is provided it can

be positive and affirmative for the PwMS, however, sometimes social isolation can occur as family and friends may withdraw from the ill person, especially if they feel there is nothing they can offer in terms of help (Reade, White, White, & Russell, 2012). As discussed in earlier themes, for Davina and Joy sadly this was the case many times during their lives with RRMS as those dearest to them withdrew their love and support, refusing to acknowledge the impact of RRMS in their lives. However, for the majority of the participants in the current study, family and friend support was present in abundance and became a welcome refuge from RRMS and an important factor in Taming the Beast.

Ruby and Paul described how their immediate families rallied around and provided support when they needed it the most.

My husband's become a pro at managing it now, I'm very blessed...Mum and Dad bought a house around the corner and my sister wants to move closer...Mum and Dad are just there which is a godsend with the children and this has brought us closer together for sure. Ruby line 1122

My family first and foremost got me through that first year...my parents are just out of this world, but my wife is just the best. Paul line 861

I try and give my wife time off MS, let me look after the kids for a while, but she's like no, we'll do everything as a family...I'm very, very lucky. Paul line 947

For Susan, after many years of worrying and searching for a partner who would accept both her and RRMS into their life, she was fortunate to find someone who was willing to partner wholly with her in living with RRMS.

He was beautiful...such a gentle soul and I told him about my MS and he was so accepting of it and he said that doesn't worry me, he was so loving, he was very supportive...I'll do it with you...and then I forgot about my MS, it wasn't the focus any more when I had been focusing on that for the last whatever many years before I met him...I was more. Susan line 884

Simply holding the belief that others will provide appropriate support has been shown to increase patients perceived ability to cope with chronic illness and to lower their stress levels (Uchino, Cacioppo, & Kiecolt-Glaser, 1996) and actually receiving support from loved ones can be an integral part of the illness journey (Kiecolt-Glaser & Newton, 2001). MS focused research has repeatedly demonstrated that greater social support is associated with better mental health outcomes (Koelmel et al., 2016) and that the presence of social support can protect against stress and improve the sense of purpose for PwMS (Bambara, Turner, Williams, & Haselkorn, 2011; Kirchner & Lara, 2011; Krokavcova et al., 2008). Additionally, social relationships are known to play an important role in stress and coping (Wirth & Bussing, 2016), factors that are absolutely vital for PwMS in the unpredictable RRMS journey ahead.

High quality social interactions have been shown to lead to higher levels of life satisfaction and also lower levels of depression and anxiety in a study using a mixed methods questionnaire in 103 PwMS, most of whom were living with RRMS (Reade et al., 2012). Supporting these findings is a recent Iranian study which demonstrated that increased social support for PwMS was also positively associated with more effective coping strategies and also enhanced psychological well being, both so important for quality of life living with MS (Farran, Anmar, & Darwish, 2016). In order to be effective, it appears that social support needs to be of high quality, worthwhile and appropriately applied to times of need for the PwMS. Examples of social support that did not fit these categories in the current study included Jane's mother providing her with MS information at diagnosis which was well meaning, but outdated and wheelchair-focused, and Paul's mother "canoodling" him with worry and over emphasising MS. However, the great majority of participants in the current study described situations where family and friends provided much needed support and encouragement at just the right time, were consistent in their support and greatly assisted them in Taming the Beast. In Piper's case, her social world widened significantly after her diagnosis and she took every opportunity to participate in life, laughing as she recalled the toll her new social life took on her.

I've met another girl and she's become a good friend of mine...she was the one who recommended the neurologist...we sort of catch up nearly every other week and have coffee...her experience with MS has been different but it's actually nice to have someone who understands. Piper line 695

I'm probably doing more than ever...my social life is more than I can take...I've had that many weekends away...I'm actually a little tired of it! Piper line 683

A study exploring stigma in MS found that PwMS were sometimes ignored in social situations and interpersonal relationships, described as “polite inattention” towards the illness (Grytten & Maseide, 2006). Kate felt a sense of losing friendships when her friends learned of her diagnosis with RRMS. However, Kate also felt that the worthwhile friendships were able to withstand her life with RRMS and she takes comfort in the strength of these current friendships.

Your real friends stick by you...friends that I've come to learn were more like acquaintances...the minute you get sick and you can't do things that you used to do...they are no longer your friends...you're in the too-hard basket...good friends make the effort, they make the effort to come and we have developed strong friendships. Kate line 1994

Rudi felt the support from her country town environment, where everybody pitches in to help those who need it.

I'm very lucky, I couldn't have had more support and friends...in small towns people are so willing to help...people that you're friends with, but you don't really associate with...give me a call...I'll pick kids up, can I cook you something? So, I'm very fortunate. Rudi line 1721

MS Societies and organisations can be an important source of social and emotional support and can be vital in strengthening morale for PwMS as they adapt to their disease (Ebrahimi et al., 2017). Additionally, connecting with social support from other PwMS is an important positive coping behaviour (Rommer et al., 2016). Several participants in the current study reinforced the importance of sharing stories

and being supported by others with RRMS, people who truly understood how they were feeling and the battles they were facing. This could happen in organisations such as MS Australia, or more informally at MS clinics and infusion centres where PwRRMS tend to gather together at common times for consultations and treatments.

The MS Society is brilliant, I love them...I used to love the blogs but I can't handle the negative...I'm quite a positive person. Ruby line 995

Natalizumab (Tysabri®) is a DMT infusion that needs to be given regularly every four weeks in a hospital clinic, usually for a period of several years if all progresses well. Patients would often be scheduled to receive their next infusion on the same day four weeks later, leading to meeting up with the same fellow patients regularly. For some study participants such as Margot and Griff, this led to strong friendships being forged and a sense of support from others living with RRMS and having the same treatment. Griff also valued the chance to see other diseases he viewed as worse off than his own, appreciating the perspective this brought to his life.

You had a common thing, MS...I made friends there and it was nice... different experiences rather than just yourself, the Tysabri® days were fun and I still keep in contact. Margot line 506

Tysabri® became my social world...it was a big part of my social life...one of the great pleasures was actually keeping the disease in perspective, I'm sitting there with people having their cancer drugs as well...you've got to just do it...it was such a good social environment. Griff line 958

Work places and work colleagues can also provide support at difficult times, providing understanding during sudden relapses or on “bad days” when MS symptoms were overwhelming. Having the ability to choose to work days and hours to assist with fatigue management was seen by several participants as being a great advantage in Taming the Beast. Rudi was able to chose hours that suited her RRMS symptoms best and allowed her a rest time in the afternoon prior to collecting children from school.

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

For both Ruby and Susan, having their immediate work manager understand their unique needs has led to them feeling supported at work and able to continue balancing work and life with RRMS.

I've just asked next year to have part time reduced hours to have a day off in the week...my body's really craving to move...my boss has been really good so far...work's been really supportive, so I feel blessed to be in that work environment. Ruby line 657

They looked after me and understood...I was very grateful, very blessed...two days on, one day off, two days on...and I rested and felt healthy. Susan line 591

Riding High on Resilience

Resilience can be defined as the human capacity to persist, to bounce back and to flourish when faced with stressors (Bonnano, 2004). More formally, resilience is the capacity of an individual to successfully maintain or regain their mental health in the face of significant adversity or risk (Stewart & Yuen, 2011). In disability and illness, resilience has been identified as an important contributor to QOL (Terrill et al., 2014; Silverman et al., 2015). Moreover, in the case of RRMS, the very nature of the unpredictability of the disease can present unique challenges in resilience right through the life trajectory (Silverman et al., 2017). For all of these reasons it is imperative that MS HCPs are aware of the benefits of resilience for PwRRMS and that they themselves acquire skills to enhance and develop resilience for patients under their care.

After only the first few interviews in this life history series, I was humbled by the stories of resilience I was hearing from the study participants. This pattern continued throughout all of the interviews and was one of the study highlights for me personally. I have consulted thousands of patients over the years of my nursing

career, and even more intensely since working in the field of MS, but, I questioned myself, have I ever asked a patient to talk to me about previous life difficulties and how they overcame them? Had I ever asked a patient with MS to relate stories from their life that told me about some of their life challenges and how they managed them? To my great embarrassment I could not recall ever asking that particular question. But very quickly during this research study I became acutely aware of how important resilience was for PwRRMS to Tame the Beast and what an essential part of the life journey with RRMS that resilience occupied.

The stories of past resilience in the lives of the study participants differed of course, but the common thread they all had was overcoming difficulty and moving forward in life, sometimes even managing to thrive along the way. Some stories were incredibly sad, comprising of very harsh and neglected childhoods and family situations. Will had endured a home situation of an absent father and a mother who died from alcoholism when he was thirteen, Joy had overcome a lifetime of abandonment and neglect to be thriving, and Davina and Evie had both survived bullying during school years and traumatic home situations from their fathers. Margot and Kate were the children of ethnic parents who moved to Australia, without speaking English, and later becoming translators for their parents and taking on family responsibility beyond their years. Ruby, Piper and Susan also suffered issues with infertility, and Rudi was to suffer incredible grief as her full term son was stillborn. Surviving these traumas provided a strong base and an individually acquired skill set for their later battles with RRMS.

During a particularly dark time in her RRMS life journey, Joy was desperate to reconnect with her old, happier self and spent time trying to recall a time when she felt carefree and happy. She wanted to use these memories to conjure up a new direction for herself and in the process, Joy provided an excellent example of harnessing resilience and moving forward to conquer demons.

I thought about when I felt most alive and full of joy and it was when I was in my twenties, I used to wear stilettos and I really enjoyed it...the joy part is around the high heels I hadn't worn them for years, I had to wear flat shoes (because of instability walking from MS)...so I thought, well, let's give this a try. So I bought

four inch high heels...I felt amazing, I felt amazing...I was walking better and I was much more conscious of the way I walked and carried myself...I adjusted my gait for wearing the high heels and then I walked towards the mirror with confidence, I was so empowered and I felt so strong, so joyful. I felt like I got my whole life back...I would walk downtown, dance all night long...that was a special time. Joy line 1151

Although most of the study participants did not outwardly recognise their great achievements in resilience, several participants did recognise that previous challenges had helped them gain valuable life skills to help navigate life with RRMS. Piper and Margot both did realise that their special challenges had given them resilience to shape their lives today.

People don't see all the symptoms because of my day to day living...even if I'm having a bad day with MS I know now that I am in control of my thoughts and I can change that thought process...I think I've become more resilient along the way. Piper line 1772

I think having MS was the big thing that impacted on my life...I think growing up in an ethnic background with parents who didn't speak English for a long time...you are growing up in two different cultures...I think it gave me resilience...and a bit more empathy for people. Margot line 1424

Rudi also recognised that the hardships she has endured throughout her life have also helped her to deal with life so far and this resilience will help with whatever the life journey is going to bring for her.

We've been through a fair bit...I think so very much...and I look at that as a gift as well...and you know people had it worse than me, but people had it better...it does give you resilience, not that it's any easier, but it gives you something to be able to get through it and get back on track. Rudi line 1275

I had Max, not in my wildest dreams did I think that would ever happen (his stillbirth)...so yeah, it's been tough but...you obviously carry some sort of strength...the death of my son changed everything. Rudi line 1320

Resilience is a learnable behaviour (Manning, 2015) and interventions can be created for patients to provide training in resilience enhancement, important for the entire life trajectory with MS (Mealer et al., 2012). A recent study explored the impact of resilience in chronic illness and on later life disability (Manning, 2015). This research supported the observation that high levels of resilience can protect against the negative impact of disability in later life and that teaching resilience from the beginning of the journey can have a profound effect in protecting against chronic illness and disability in a normal aging population (Manning, 2015). The message for MS Nurses is to take every opportunity to develop resilience in PwRRMS, as the benefits may be life long and may even lessen later disability.

It is also important for MS Nurses to be aware that resilience is dynamic, it is under constant negotiation and is often contextual (Ferguson & Walker, 2014). A recent three year longitudinal study of 31 adolescents with chronic illness found that a key component of living with chronic illness was the desire to live life as “normally” as possible, as highlighted in the second study theme (Re)defining Me Now That I Have RRMS; even in the face of challenges, and to focus on opportunities and optimism (Ferguson & Walker, 2014). Similarly, participants in the current study were keen to focus on the positive aspects of the situations they found themselves in instead of focusing on the negative, although this was sometimes a struggle for the participants to remain positive as some hardships were particularly difficult to deal with (death of a child, childhood parental neglect). Participants were able to describe how they faced challenges, developed new ways of looking at the problems and continually moved forward with the help of family, friends and community.

MS Nurses have an important role in helping families through both the diagnosis of RRMS and living life with RRMS, being in a unique position to facilitate normalising the response to extreme events (such as diagnosis and relapses or medication changes), ideally by providing narratives of families in similar situations (Chesla and Leonard, 2017). Talking about stories of how other families successfully overcame difficult or challenging periods instils confidence and practical information to consider for the PwMS and is an important educational role for MS HCPs. Of course, no two families are exactly the same, but knowing others have survived such challenges can be immensely helpful for those navigating difficult times and can also

be helpful for novice clinicians and HCPs to enhance their own learning and development (Chesla & Leonard, 2017).

Sharing experiences and narratives through reflection also helps to strengthen resilience in people living with chronic illness, showing the possibility of mastery in a situation and fostering connectedness between the HCP and the patient (Kralik, Van Loon, & Visentin, 2006). However, it is important to remember that this is contextual for the PwRRMS and is not a one-off discussion, and PwRRMS may need additional resilience assessments and education at each clinic visit. It is important to reassess scenarios with patients and not assume they are at the same level of resilience as the last clinic visit. They may have shown high levels of resilience at the last appointment, but the nature of living with a chronic and evolving illness such as RRMS means that they may also have lost some momentum along the way with life and may need a reminder of the importance of fostering and developing resilience.

Approaches MS Nurses can use to nurture and build resilience in their patients include discussing the importance of maintaining social connections both within and outside the MS community, using strategies such as using humour, discussing ways to creating a normalcy in their life, the benefits of maintaining a positive outlook, methods of practicing self compassion, and the importance of planning ahead and managing commitments (Silverman et al., 2017). Almost all of the participants in the current study reported using at least one of these techniques to help when Taming the Beast and many participants used several techniques. Harnessing resilience is an important and valuable skill in the life story of PwRRMS, and a skill that can be developed with the help of the MS Nurse.

Theme 7- “The DMT Dance”

Shall we dance?

The first dance of the night is with me

Alone and fragile

Scared about the first steps and where my feet shall go

Some lessons, some guidance, a show

I start to feel a little more confident

But still not ready

The waltz commences, regardless of me

Stepping on toes

Feeling clumsy I suppose

I start to learn the steps

I sail through the air

I continue my lessons, I practice, I step this way and that

Life has more in store than I imagine

I change my dancing partners

This one feels more comfortable

These steps I know

My confidence starts to show

I can salsa, I can two-step, I can sway

I am now a dancing master, but in my own way

TB

The **central organising concept** of “The DMT Dance” consists of negotiating and coping with medication therapies to treat RRMS, the DMTs. There are two distinct subthemes within this concept, the first subtheme “The hard yards: making decisions about DMTs and adherence”, further subdivided into DMT decisions driven by fear and DMT decisions driven by hope, and the second subtheme switching to a better life.

Although the past 25 years has seen the development of the first effective treatments for RRMS with DMTs, there is still no curative treatment for RRMS (Torkildsen, Myhr, & Bo, 2016), meaning that relapses on therapy are still possible (Anderson &

Philbrick, 2014). Nowadays it is widely accepted that early treatment with a DMT will reduce both MS relapses and MRI activity, which will ultimately delay disease progression (Smith, Cohen, & Hua, 2017; Comi et al., 2017). Whilst DMTs have improved the disease course of RRMS dramatically, they have also added a layer of complexity to RRMS care (Comi et al., 2017). Managing DMTs provides challenges for both patients and MS HCPs and requires close communication to improve clinical outcomes and QOL for PwRRMS (Tintore et al., 2017).

The current focus in RRMS care is on both early diagnosis and prompt commencement of a DMT in order to modify the disease course and result in better outcomes for PwRRMS (Kobelt, Eriksson, Phillips, & Berg, 2017). That seems straightforward, but PwRRMS and their HCPs are faced with complex decisions regarding which treatments will be most effective and appropriate for them (Bottomley, Lloyd, Bennett, & Adlard, 2017). As discussed in previous themes, this is often at a time when *Piecing Together the Puzzle*, *(Re)Defining MS* now that I have RRMS and *Battling the Demons* have led to increased vulnerability and distress for the PwRRMS, further impacting on DMT decision making. Assessing the relative benefits and risks for individuals of each DMT can be confusing and complicated for the PwRRMS. Additionally, potential side effects (risks) of some DMTs can be very serious, adding further worry, stress and uncertainty about treatment decisions. These serious side effects include progressive multifocal leukoencephalopathy (PML), an incurable brain infection which has contributed to many deaths in PwRRMS (Chataway & Miller, 2013) and also autoimmune blood and kidney conditions which have also led to fatality in PwRRMS (Coles et al., 2012). There is also preparation needed at the start of the DMT journey regarding family planning and pregnancy, as most DMTs have pregnancy related risks and considerations (Wingerchuk & Carter, 2014). With many PwRRMS diagnosed and commencing treatment during their child-bearing years, this is an important factor in *The DMT Dance*.

Evidence from clinical trials and from daily clinical practice has demonstrated that not all patients respond satisfactorily to a given DMT, the response to medications and their effects are highly individual (Comi et al., 2017). Switching between DMTs is common in RRMS, particularly if the patient does not respond well to the medication (e.g. experiences a relapse or has new lesions on the MRI) or experiences

significant side effects (Costello, Thrower, & Giesser, 2015; Giovannoni et al., 2016). This often leads to a PwRRMS experiencing several different DMTs during their lifetime, all with their own particular set of risks and benefits. This scenario was referred to by Ruby in the current study as starting “*the wave of medicines*” (Ruby, line 110).

In Australia, the first DMT to treat RRMS was Betaferon® and was registered in 1995 (Broadley et al., 2014b). This injectable interferon was followed in 1998 by two more interferons (Avonex® and Rebif®) and in 1999 by another class of drug, glatiramer acetate (Copaxone®) (Broadley et al., 2014b). All of these DMTs required PwRRMS to learn how to self inject the medication at various intervals ranging from daily to weekly administration. The first infusible (by intravenous infusion or “drip”) medication was natalizumab (Tysabri®), being registered in 2006 and the first long awaited oral medication to treat the disease, fingolimod (Gilenya®), was registered in Australia in 2011 (Broadley et al., 2014c). Fast forward to 2018 and there are currently 12 DMT choices for PwRRMS registered with the Therapeutic Goods Administration (TGA) in Australia. Currently, all of these DMTs are available at a heavily government subsidised cost on the Pharmaceutical Benefits Scheme (PBS).

There are variable modes of administration between the DMTs ranging from subcutaneous injections just beneath the skin, to oral tablets to intravenous infusions that need to be administered in a hospital or clinic setting. This results in truly individualised MS care where the best drug can be selected for the right patient at the right time, without having to consider step-wise approaches, insurance company preferences or other ‘red-tape’ which may govern DMT prescribing in many other countries. Australia is one of only a few of countries in the world with so many effective treatments available first line and at a low cost to the patient (Broadley et al., 2014c). Many other regions, such as some areas in Europe and the USA, can have restricted access to DMTs or restricted government or company reimbursement (Wilsdon, Barron, Mitchell-Heggs, & Ginoza, 2014; Comi et al., 2017), causing DMTs to be out of reach financially for some PwRRMS. For example, some insurance companies in the USA require a PwRRMS to experience treatment failure on a DMT before being permitted to start a more highly efficacious drug (Owens,

2013), thereby missing the early time in RRMS when the anti-inflammatory effects of the drug may be the greatest (Hauser, Chan, & Oksenberg, 2013). In an ideal world where the evidence points to the need for early and effective treatments in RRMS, there would be DMT treatment access for all PwRRMS and the full range of DMTs available to PwRRMS and supported by national bodies, regulatory authorities and reimbursement agencies (Giovannoni et al., 2016).

The hard yards: making decisions about DMTs and understanding adherence

As the course of RRMS is heterogeneous, a confident prediction of long term individual prognosis of RRMS on a particular DMT is not yet possible (Wingerchuk & Carter, 2014). This can be frustrating and confusing for patients as they are faced with making DMT decisions when the long term benefits are unclear and the degree of side effects and risks they may experience are also uncertain. A recent UK study found that most patients with RRMS wished to be part of the decision making process regarding their DMT and that shared decision making underpinned effective disease management, especially when supplemented by MS Nurse support (Colhoun, Wilkinson, Izat, White, Pull, & Roberts, 2015). However, there is very little literature available exploring how PwRRMS make decisions about the best DMT to suit their situation, their beliefs, their values, their disease state and their lifestyle or how they balance treatment risks and benefits. By taking into account factors such as patient preferences, lifestyle, how patients view risks and benefits, personal tolerance, acceptance of side effects and the time commitment required for treatment and safety monitoring, shared decision making between the MS HCP team and the PwRRMS can be made.

People living with a chronic medical illness must balance the probability of current side effects with treatment with the probability of long-term benefits (Bruce et al., 2016). For a disease such as RRMS where disease remission and return to baseline or 'normal' functioning occurs between relapses, it can be very difficult to reconcile the side effects from DMTs that make patients feel unwell with the fact that they often feel better without any treatment. Jarmolowicz et al. (2016) reports that side effects can often make patients feel much worse in the present moment, causing the patient to consider balancing their current QOL (reduced by the taking DMT now) with the

potential of reduced QOL in the future (reduced by *not* taking DMT now). Unlike drugs such as analgesics where an immediate benefit may be felt, DMTs in chronic disease are preventative medications to reduce the probability of negative future effects with no immediate observable benefits (Jarmolowicz et al., 2016). Additionally, DMTs do not typically improve acute symptoms in RRMS and so PwRRMS do not usually experience observable improvement while taking the medication (Bruce et al., 2016).

Adherence has been defined by the World Health Organisation (WHO) as “the extent to which a person’s behaviour - taking medication, following a diet and/or executing lifestyle changes - corresponds with agreed recommendations from the HCP” (WHO, 2003). Studies have shown that DMT adherence in RRMS is particularly problematic, with up to 25% of PwRRMS non-adherent to their DMT (Devonshire et al., 2011). No medication is going to be effective in controlling a disease if the patient is non-adherent, as former US Surgeon General C.Evert Koop stated, “drugs don’t work in people who don’t take them” (Osterberg & Blaschke, 2005). Maintaining DMT adherence in MS has been described as comprising of three actions: those of acceptance (the patient accepting that therapy is needed), persistence (continuing to take the treatment over time) and compliance (taking the treatment as prescribed at the right time and right dose) (Remington et al., 2013). This subtheme will define adherence as taking the prescribed DMT as directed by the MS HCP.

Recognising adherence and non-adherence to DMTs is a crucial part of the MS HCP role (Costello et al., 2008). The Global Adherence Project (GAP) was a worldwide study of 2,648 participants, the goal of which was to evaluate the degree to which patients with RRMS adhered to dosing schedules for DMTs as outlined by their neurologist (Devonshire et al., 2011). Several factors were found to relate to greater DMT adherence: being female, the ease of administration, satisfaction with therapy, treatment at a designated MS centre and the presence of family support. Of further importance in the GAP study was that adherent patients reported higher QOL scores than non-adherent patients. This finding is significant for MS HCPs, as it suggests that by targeting strategies to improve DMT adherence, there may also be indirect improvement in patient QOL.

Adherence to DMTs in RRMS can be difficult to quantify and the specific combination of factors influencing an individual patient's likelihood to adhere to a DMT can be difficult to determine (Remington et al., 2013). Patients who are non-adherent to DMTs usually follow one of two patterns; either missing doses and taking the DMT less frequently than prescribed (Wicks et al., 2015) or by abandoning therapy completely, usually within the first six months (Rio et al., 2005). Adding to the complexity of adherence or non-adherence on DMTs, there may also be a wide range of emotional and cognitive factors present which are specific to RRMS (Wicks et al., 2010), with mood and anxiety disorders prevalent in the disease (Feinstein, 2011; Feinstein et al., 2014).

Increasing the complexity of DMT decisions further for PwRRMS, is the fact that the more highly efficacious (more effective) therapies have rare, but potentially serious side effects and unfortunately, the safest therapies have much lower rates of efficacy (are less effective) in controlling RRMS (Smith et al., 2017). Very little is known about how patients decide between oral (tablet) therapies and parental (injection or infusion) therapies, or how patients 'trade off' the convenience of oral therapies against treatment frequencies or side effects of the other medications (Lynd et al., 2016; Utz et al., 2014; Wilson et al., 2015). Additionally, not all patients respond satisfactorily to DMTs and a 'one-size fits all' approach is not attainable in RRMS (Comi et al., 2017). Ideally, the best treatment option would be the safest treatment that eliminates disease activity (Hauser, 2013), but the identity of this DMT is not known at the beginning of the RRMS journey. This is currently an area of intense research interest and hopefully biomarkers (measures such as blood tests or scans which can determine responses to a medication) will be able to shed light on this in the future (Hegen, Auer, & Deisenhammer, 2016).

Understanding how the PwRRMS makes decisions about which DMT will suit them best is vital for MS HCPs to understand, but there is limited literature to provide guidance and support for MS HCPs in this regard. A recent study of 189 PwRRMS in Canada used focus groups and individual interviews to determine attributes of DMTs that were most important to patients. The researchers concluded that overall, the most important attributes were the avoidance of side effects and the improvement

of symptoms (Lynd et al., 2016). Unfortunately, both of these attributes cannot be guaranteed for patients with the current DMTs. As the adherence data discussed above has suggested, actually taking the DMT as prescribed is a particular problem area in RRMS, and an area where the MS Nurse and other MS HCPs can target understanding to enhance adherence in the future. Unravelling how these decisions are affected by other factors is poorly understood, however participants in the current study shed some light on how these decisions were driven, some decisions appeared to be driven by fear and some decisions driven by hope.

DMT decisions driven by fear: “I’d rather be in a wheelchair than dead”

As discussed briefly in theme 3 Battling the Demons under the subthemes of facing fear and weary with worry; fear and worry can be major barriers contributing to adherence issues in RRMS, especially fear of medication administration and worrying about potential side effects (Anderson & Philbrick, 2014). This fear and worry can be further impacted by mental health issues in RRMS (for example depression and anxiety) leading to negative cycles that threaten DMT adherence (Anderson & Philbrick, 2014). Indeed, fear and worry can sometimes influence a patient’s decision to take any form of DMT, with some PwRRMS preferring to stay unmedicated and take the risk of further relapses and possible disease progression over what they perceive as unacceptable potential side effects. A one percent risk of a serious side effect can reduce patient preference for a particular DMT fivefold (Wilson et al., 2015).

A recent study using focus groups in PwRRMS found that patients who opted out of DMT entirely felt that this was mainly due to side effects they experienced, feeling that their present QOL was more important to them than future disease progression (Mortensen & Rasmussen, 2017). In the current study, this was the case for Joy, who adamantly refused to take the advice of her neurologist and commence a DMT. Joy suffered greatly from side effects on earlier DMTs, at one stage needing hospitalisation from medication toxicity. This experience made Joy reluctant to try a new DMT, preferring to feel well in the present moment and take a risk with possible disease progression in the future.

I don't see any point on going on a drug that could potentially kill me...I don't see any point on going on a drug that's not going to cure me and when it doesn't really alleviate the symptoms. Joy line 1651

I don't believe that medication is the answer for me...if they can't come up with a cure then, really...I'm not going to take something that may make me sicker. Joy line 1687

The Health Belief Model (HBM) looks at anticipated gains and losses balancing present and future QOL (Rosenstock, Strecher, & Becker, 1988). Using the HBM, health behaviour can be determined by personal perceptions about the perceived susceptibility and seriousness of a disease together with the perceived threat and benefits from a given behaviour, that is, in order for an individual to take a certain medicine, potential gains must be considered greater than losses (Mortensen & Rasmussen, 2017). Adding complexity to this theory in RRMS is the uncertainty of the disease and the lack of prognosticative ability in the future (Wilson et al., 2015) and if the chosen DMT will have the desired effect at all. On a background of fear and worry, there is no definitive answer that can be given to a patient on what their individual risk might be for a given DMT, and for some, the fear is too great. Piper had researched the newer DMTs in preparation for a change to a DMT with improved effectiveness, but was unconvinced this was the right move for her. She preferred to take her chances with the disease than mindfully expose her body to potential fatal side effects.

With the newer, unproven medications, I just think the risk is too great...I get that these people are in a real state of bother, they're probably prepared to give anything a go...but I just think I'd rather be in a wheelchair than dead...I just think the risk is too great. Piper line 1960

The list of reasons to be fearful about starting a DMT, often outlined in great detail by MS neurologists and MS Nurses when considering DMTs (and supported by product brochures and internet research) can sometimes be more frightening for the PwRRMS than the disease itself. This is particularly so in recent years with the advent of more efficacious (effective) therapies with more potent side effect profiles

and where deaths have been reported in PwRRMS receiving the various DMTs. The introduction in Australia in 2006 of the monthly intravenous infusion natalizumab (referred to in the interviews by patients as the trade named Tysabri®) was exciting because at that time it was the most highly effective treatment for RRMS and showed long term benefit (Smith, Cohen, & Hua, 2017). However the occurrence of a potentially life threatening brain infection called PML (Chataway & Miller, 2013) forced the drug off the market shortly afterward. Natalizumab was reintroduced to the market a year later, with a safety warning about PML which necessitated special safety monitoring when using the drug. As of December 2017, there had been 756 reports worldwide of PML associated with natalizumab therapy, with 25% of the cases being fatal (Biogen, 2018).

In more recent years, PML has also been associated with some of the other DMTs (fingolimod and dimethyl fumarate), although not in numbers as high and as predictable as with natalizumab (Faulkner, 2015). Several participants in the current study openly discussed PML as a great fear for their current and future treatment. Piper was adamant in choosing possible disease worsening from RRMS over potential death from PML.

And that PML keeps popping up and I don't like the sound of that...and what does scare me about it is how do you know it's PML or an MS symptom? And it's not curable. Piper line 1362

A blood test called the JCV test can measure for a specific antibody and give an indication of whether a PwRRMS has a higher risk of contracting PML on natalizumab treatment (Torkildsen et al., 2016). For Rudi, knowing that she was JCV positive influenced her decision to refuse treatment with natalizumab (referred to by Rudi as Tysabri®) and to risk further disease progression on her current oral DMT, which had so far been not been able to control her relapses.

One medication they're considering is Tysabri and I refuse to go on because I carry the JC virus, they tested me for that and I'm just not willing to (take that risk). Rudi line 501

Participants also experienced fear when changing treatments after many years on the same DMT, even if it was perceived by the MS HCP as a change for “good”; such as changing from an injectable therapy to an oral therapy. This was the case for Davina, after many years of struggling with the side effects of a weekly self-administered intramuscular injection, to contemplating a daily oral medication. The fact that it was a change at all was frightening for Davina, even if there were benefits expected from the treatment switch by her MS HCP.

Changing treatments...that was really hard, I'm not good with change...so to change a medical treatment was really scary because I'm going on the hearsay of someone who knows more about it...but hasn't actually received it...so I had to think a lot about that...it's a bit of an unknown, I don't know if I'm going to have problems in the future. Davina line 1423

Having a son before her diagnosis of RRMS, Kate made the decision not to expand her family and have another child after her diagnosis, even though she did once wish to have more children. From a science background, Kate was deeply concerned about the possible effects of the DMTs she had previously taken on a foetus, especially as Kate had needed less conventional and more toxic treatment options in the time before many of the modern DMTs had become available.

Being on all of these drugs, I thought...I'm not going to have a child that's going to turn out to be sick. I've got no idea what these drugs are doing to me...and what they're going to do to a baby. Kate line 1393

There are very few qualitative studies addressing patient perspectives in regards to preferences in selecting a DMT in RRMS. However, a recent study explored patient perspectives on DMT choice by interviewing ten PwRRMS and using hermeneutical phenomenological methodology to analyse the findings (van Capelle et al., 2017). Researchers found themes of “constant confrontation with the disease” voiced by study participants who felt frightened at the prospect of having to use medication with possible side effects for the rest of their lives, reflecting similar themes of participants in the current study. Emotional fear as a theme was also described by van Capelle (2017), including a fear of injections and the act of injecting oneself

making the patients feel ‘different’ to others. These themes were also supported by current study participants, most notably Jane, who felt that her need to self inject her interferon DMT curtailed her ability to travel freely with the medications to remote countries (as she loved to do) and left her feeling disappointed and ‘different’ to others.

I can't do this now...you have to inject three times a week and it's just a pain, you're travelling with syringes and everyone thinks you're a drug addict, and I absolutely hated it...it was really, really depressing...I thought I may as well just give up and do nothing. Jane line 338

DMT decisions driven by hope

For other study participants, their choice of DMT, and indeed their choice to remain adherent to the medication, was driven more by a positive sense of hope for future good health rather than by fear of DMTs or potential side effects. Adhering to one's DMT is also an important way that PwRRMS can take control of their disease (Settle et al., 2016). This appeared to be a conscious choice for Paul in the current study, who performed considerable scientific research to decide on the DMT he thought would give him the best result in the long term.

I was happy to go on Gilenya because at the time there was going to be some neuroprotective effect and it looked like a better option than 2 pills and possibly being sick all day...I was happy going on Gilenya at that point. Paul line 635

A little later on in his life story, Paul suffered a further MRI relapse with a new lesion in a delicate area of the brain, of which he was considerably fearful. With a science and physics background, Paul introduced the concept of “front end loading” which I had never heard applied to DMT decision making before our study interview. “Front end loading” is an industry or economic term involving developing strategic information to address risk and to make decisions to commit resources early in a project in order to maximise the potential for success (Morrow, 2012). In Paul's case, he was using the term to describe how he preferred to use one of the newer high efficacy DMTs now before he deteriorated, rather than continuing the moderate

efficacy DMT he was currently prescribed and risking further disease progress. His neurologist did not agree to change treatments at this time and preferred that he stay on his current therapy with close supervision. Paul argued that with an unpredictable disease such as RRMS it was better to “front load” and possibly stop the disease and he was willing to risk the potential serious side effects, which he felt were manageable with his level of education and understanding of what they meant. With a young family, an exciting new job and a love of the outdoors, Paul argued that he had a lot to lose not escalating his DMT to a higher level and would continue to seek out support to change therapies with another neurologist.

I've developed a new MS brain lesion and I'm not real happy about that. My thoughts on how I want to proceed with all this are...front load risk, I would much prefer to have it out and discuss with my neurologist again. I don't want to be at a stage where it is something they think about, you know, around the world at the moment they're using it as a front line...I'm aware that there's lots of therapies. Paul line 522

The best drug on the market is alemtuzumab, I mean, it does come with a lot of risks, but they're even more manageable than MS is...so if I take a thyroid medication for the rest of my life, that's great...a better outcome. Paul line 600

After experiencing significant deterioration in her physical condition over a short period of time, Ruby placed hope in her new DMT (alemtuzumab, also known as Lemtrada®) to be able to improve her mobility and prevent further decline so that she could enjoy her two small children and participate more actively in family life.

I hope from the alemtuzumab (the DMT) to be able to walk...I don't feel so weak...I hope so...this time last week I couldn't even strengthen my own body to come up so this week I woke up and I can actually get up by myself...it's no marathon, but for me it's pretty good, so fingers crossed. Ruby line 598

I was really excited about Lemtrada®...so hopefully it will start working and I'll be really happy. Ruby line 868

Several participants in the current study described nursing support as an integral part of successfully managing their DMT and a reason for their DMT adherence at various stages of undergoing DMT therapy (such as complying with blood tests and other safety monitoring). This was particularly so for those study participants diagnosed for longer than ten years, who only had access to the self-injectable medications in the beginning of their treatment journey and relied on nursing support to teach them the injection techniques and injection site management. Margot had an MS Nurse visit her to introduce her to the injectable DMT in the comfort of her own home and surroundings.

A nurse actually came out and showed me how to do the injections which was fantastic, she showed me how to do it and she made it so easy. Margot line 475

Hope in a DMT refers to more than just statistics of how well a DMT works to control RRMS, hope also refers to feeling positive and confident about adhering to treatment, with family and nursing support being an important factor in commencing, continuing or changing DMT (van Capelle 2017). In the current climate of so much choice, complicated therapies, monitoring programs, and evidence for using early, effective DMTs, MS Nurses are more integral than ever to managing RRMS by implementing patient-centric programmes and supporting PwRRMS (Giovannoni et al., 2016).

Switching to a better life

Almost all of the study participants had stories to tell about past unhappiness on earlier DMTs, particularly as two thirds of the participants had previously been taking interferons or glatirimer acetate injections before the newer oral and infusible medications were introduced. For these study participants, they were switched to newer therapies as soon as they became available. Difficulties for patients with the early injectable medications are well documented, particularly in terms of PwRRMS suffering from skin reactions, injection site reactions, flu like symptoms and feelings of depression as side effects (Costello et al., 2008). As these side effects and patient experiences are already well documented (Miller & Jezewski 2001; Miller & Jezewski 2006), only a selection of participant comments will be presented here.

These participant stories also have a role to play for the MS HCP to consider the resilience shown by PwRRMS in overcoming challenges, as discussed in the previous theme of Taming the Beast. These insights from Davina, Will, Evie, Griff and Kate also give some background for the MS Nurse to understand why adhering to DMTs can be difficult, and how the effects can infiltrate all areas of life.

*When I started on the interferon...that feeling of desperateness, hopelessness...so if I felt like that on the day I had the injection, it would make it a hundred times worse.
Davina line 1083*

My symptoms were getting worse, depression set in pretty bad and I became non-compliant...I went unmedicated and I quit my job. Will line 884

I went onto the interferon Rebif®, God awful drug...I don't have a problem with needles, it was the reactions...site reactions made me look like a red and white checkerboard and the cold and flu symptoms, the headaches, the pains, the fevers...you just wanted to curl up basically...I didn't take the treatment properly...I wanted to do it...but...I feel fine, so I stopped it. Evie line 835

*(Injecting glatirimer acetate) I hit a vein once, or a capillary and straight into my bloodstream and I thought I was going to die...it scared the shit out of me, it knocked me flat...and I had limited sites it was getting to the stage where I was hitting scar lines...(as a consequence) my compliance was getting sloppier...because it was fucked, I hated it and the thought of having to wake up everyday and do it again.
Griff line 892*

I was on the Betaferon® which I really couldn't tolerate, it was just like getting the worst flu...I just couldn't function...I'd have my injection and the next day I'd be totally miserable and really sick...and going to work people would just be thinking ...well, why is she sick all of the time? And you just couldn't explain it to them. I've always been quite vocal about how I feel and I said to the Neurologist "I don't like this, it's making me sick, it's not making me better and I don't want it. Kate line 743

Several of the non-adherence scenarios described above were first reported to the MS Nurse rather than to the neurologist. Physicians have been found to miss indicators of poor adherence in patients (Osterberg & Blaschke, 2005), possibly due to the subject not being brought up in clinic encounters and MS patients not being keen to report non adherence to their physician themselves (Schwartz et al., 2017). Implications for HCP practice include the need to check at every clinic visit and care encounter (email, text, phone) on the status of adherence for DMTs. Often adherence is difficult when patients are faced with intolerable side effects, especially when mental health is also affected (Costello et al., 2008). The value of the MS Nurse as someone the patient can confide in about true DMT adherence and also to discuss issues they are having to maintain adherence are important aspects of the MS Nurse role (Burke et al., 2011).

It is rare that the more serious side effects reported with the use of RRMS DMTs actually do happen in clinical practice but when they do, the consequences can be horrific. Kate suffered one of the first reported anaphylactic (allergic) reactions to natalizumab (referred to by Kate as Tysabri®) and recalls the horror of that day when hope in her new DMT suddenly was taken away. After this event, Kate was switched to one of the new oral treatments and has thankfully remained well since that time.

This Tysabri® was a nightmare, after three months it was stopped, it was working really well and I was quite excited about the whole thing...I went back on it and I had an anaphylactic reaction...that was horrible...I think I was the only case at the time...that was absolutely horrific...I felt my back was itchy but before I could even finish saying anything my face swelled up and the doctor's trying to get a thing down my throat...I was just terrified. Kate line 1076

For some study participants, specifically Griff, Margot and Susan, moving on to a new DMT after suffering at the hands of their first treatments led to improvements in their quality of life. Additionally, for both Griff and Margot, starting natalizumab (referred to by the participants as Tysabri®) widened their social circles as an unexpected benefit of a DMT change as they spent a half-day at their local hospital day admission unit for the DMT infusion with other PwRRMS. These feelings about

natalizumab were in stark contrast to those study participants who had earlier refused to consider natalizumab because of the potential side effect of PML in the first subtheme decisions driven by fear. Life just felt better on this DMT for these participants, despite the reported risks.

On Tysabri®, I just felt flat afterward and then 36 hours later it was gone and I had the rest of the month to myself, it was a joy and it was a big part of my social scene. Griff line 954

I had Tysabri® for four years, that was actually really good. When I went to have the Tysabri®, you met other people with MS which was fantastic...it was sort of like a day out really. Margot line 494

For the first time in years Susan felt “normal” taking tablets rather than self injecting her DMT.

I feel more relaxed...it's just a little tablet, I take it, I don't have to get up, it doesn't hurt...the injections were hurting. It's improved, I don't have to take injections with me, to find a freezer or to have a letter on the plane about why I have syringes, so now I feel normal taking tablets, I feel better and I feel positive. Susan line 1179

Oral treatments, especially when taken once daily, have been widely reported as being preferred by the majority of patients with RRMS over injections and intravenous infusions (Utz et al., 2014; Thach et al., 2016; Mortensen & Rasmussen, 2017). A recent study in adolescents with RRMS found higher levels of DMT adherence since the introduction of oral therapies in this population than in past studies (Schwartz et al., 2017). Over half of the participants in the current study were now taking an oral DMT and were happy with the change in terms of lifestyle and ease of administration.

To enable a DMT to have the maximum impact on the course of RRMS, adherence to the prescribed regime is essential. Maintaining adherence involves developing strategies to manage side effects, successful and safe DMT commencement and monitoring safety and drug tolerance as vital aspects of the role of the MS Nurse.

When The DMT Dance moves elegantly, controlling the disease with minimal side effects, with the engagement of an educated empowered patient, a reliable support network and an approachable invested HCP team, the results can be outstanding. Switching to a better life is achievable. The treatment goal with RRMS is clear, early and effective DMTs in a shared decision making environment (Giovannoni et al., 2016), performing The DMT Dance. Although some decisions are initially decisions based on fear, that doesn't mean they will always remain so. At times, another relapse, a severe relapse or progression of disease (either by EDSS disability assessment, by reduced mobility or by MRI progression) may prompt a PwRRMS to reconsider their past DMT decisions, and the basis for these, and change their thought process and direction. As demonstrated within this theme, a major part of this revolves around decisions based on hope and switching to a better life, and merges well into the final theme from the study findings, theme 8, which is all about Holding Hands with Hope and developing purposeful positivity.

Theme 8: “ Holding Hands with Hope”

Hope summons, hope heals

Hope can see me, hope can share

Hope understands, hope feels

Hope teaches, it helps me to bear

Hope wakes with me each bright new day

Hope teaches me to think in brand new way

Hope, stay with me

Hope, help me to be

TB

Linda Morgante passed away in 2007. Linda was based in New York and was an exceptional MS Nurse researcher, author, clinician, teacher and leader (Halper, 2007b) who became well known for her belief in the concept of hope being an essential component of living well with MS. As a noted speaker and writer in MS nursing, Linda inspired and encouraged nurses from all over the world to instil hope in MS care, both in their patients and in themselves. Linda Morgante wrote, spoke, taught, lived and breathed hope.

“Hope is an essential element of life - it embodies our vision of the future, our opinion of ourselves and others, and our sense of control over the events and direction of our lives. The presence of hope for someone experiencing an illness can provide the energy necessary to promote health and well-being.” (Morgante, 2000, p.9)

Looking back over the transcripts again in preparation to explore themes of hope and positivity revealed a startling, yet irrefutable, pattern. Almost every interview with participants in this research study commenced with stories of worry, of uncertainty, of the uninvited guest of RRMS invading lives and causing havoc in many forms, and almost all interviews ended with stories of hope, of some form of acceptance, of resolve and a will to do well in the future. This should not have been wholly unexpected by me, as the participants all volunteered to be part of the study and to share their stories (suggesting a purpose to help others and an essence of positivity). Nonetheless, it was a striking feature of the study and I was left astounded.

This theme of “Holding Hands with Hope” encompasses ideas of hope, positivity, defiance, and spirituality, giving back to others and sharing stories. I also felt a sense of determination, where PwRRMS held on tightly to their newfound peace and positivity, often borne after many years of struggle. Holding Hands with Hope also reflects the way fingers intertwine to provide support, not by a single finger, but by many fingers and a thumb working together to link perfectly inside one another. It reflects touch and sensitivity and it reflects hard work to get there. These hands are not soft and protected; they are often calloused and tough. PwRRMS hold many hopes and dreams in them, for themselves, but also for others living with RRMS and progressive forms of MS, and also for the people working in the field of MS as well.

The *central organising concept* of this theme is hope and positivity, it is all about reaching happier times, of the beginnings (or totality) of acceptance of RRMS into life and how looking to the future with hope brings its own peace and rewards. Expressions of hope differed greatly between participants of course, but the essence of hope remained remarkably similar. It was palpable and it was present in every study participant I interviewed. It often left me leaving the interviews smiling and

happy, reflecting on the remarkable achievements of my informants, even if there were tears and sadness interspersed regularly during the interviews. This theme is divided into two subthemes and several sub-subthemes to provide additional clarity. The two subthemes, “hope in its many forms” (including the sub-subthemes of functional, restorative, curative and defiant hope) and “purposeful positivity” (including the sub-subthemes of optimism and a positive outlook, searching for meaning, harnessing a sense of humour, faith, religion and spirituality and giving back and being involved) provide exploration of the role of hope in the lives of PwRRMS and the various ways PwRRMS express this hope and positivity.

Despite the anguish, ambiguity and suffering that appears to be part of the life journey with RRMS discussed in the earlier themes, participants often lingered after the end of the interview to ensure I understood the entire story. The fact that happiness and hope were a very important part of that story, even if it took years for some participants to feel hope, or even if it was more of a temporary or fleeting feeling. It was still present and it was overwhelming in intensity. As the MS Nurse is a pivotal part of the team in ensuring the PwRRMS maintains a sense of hope throughout the lifetime living with the disease, understanding the role of hope in the disease is critical for MS Nurses (Morgante, 2000). I have never felt, or believed this more, than after hearing the stories of these study participants.

What is hope? Why hope?

Defining hope for this particular theme was difficult, primarily because there are so many different variations of the concept of hope, with literature spanning many, many decades. Haase and colleagues (1992, p.143) sought to clarify the concept of hope for nurses, reviewing the available hope literature at the time and defining hope as:

“Hope is an energised mental state involving feelings of uneasiness or uncertainty and characterised by a cognitive action-orientated expectation that a positive future goal or outcome is possible”.

Noted hope researcher and writer, Snyder (2002) also embraced the concept of goals as an important component of hope and emphasised the active role needed to achieve these goals. Snyder (2002, p.249) defined hope as:

“Hope is defined as the perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways”.

As a complex concept to describe, Clarke (2003, p.164) resonated strongly with my own feelings, noting that:

“We know hope when we see it, feel it intensely when it is gone. But it is hard to describe”.

The literature surrounding hope in both chronic illness and nursing care in general is substantial and stretches back for decades. Less common is literature specifically exploring hope and MS, although recent years have seen studies emerging, particularly in areas of allied health and MS (Soundy et al., 2012; Soundy et al., 2013; Soundy et al., 2016). Herrestad and colleagues (2014) have suggested that instead of generalist work in hope, what is needed to understand hope more deeply, are in-depth and context specific hope studies. As this theme developed and the data evidence to support hope as a theme was extensive, I was keen to explore and define hope in a way that captured the very essence of hope in this specific population. Even in the absence of supporting literature, the data from the participants demonstrated that hope is important to PwRRMS, and as MS Nurses, we have an obligation to at least try and form some sort of understanding of what hope might mean for patients under our care. If we make this effort, then we can recognise hope, we can facilitate hope and also introduce strategies to inspire and coach hope in others. We can take the beginnings of hope and help mould them into achievable goals and aims and strategise pathways to reach these goals. We can partner with our patients to make hope an important, active and achievable part of their health care plan.

Dialectic relations between hope and despair have been referred to as the existential paradox of chronic illness (Barnard, 1995). The line between hope and hopelessness

can often be very fine and sometimes blurred. Several study participants spoke about hope and hopelessness in the same sentence, feeling that talking about one necessitated mentioning the other. Living the paradox means those suffering chronic illness simultaneously confront their limitations and losses at the same time as leaning towards hope and possibility. The concept of therapeutic hope in MS was explored by Slater and Yearwood (1980). The need for a positive, affirmative mental attitude in MS management by HCPs was proposed to counteract the natural tendency toward negativity in PwMS (Slater & Yearwood, 1980). We, as nurses in general, have a responsibility to notice, acknowledge, understand and verbalise the possibilities, the abilities and the skills to live with chronic illness and to develop strategies with patients to do this successfully (Chesla, 2005).

In healthcare, hope is of special interest because of the disruptive nature of illness that requires considerable healing resources for recovery to occur (Tutton, Seers, & Langstaff, 2009). For MS Nurses, understanding hope may also help to understand the individual's experience of the recovery process and identify effective support strategies. In the field of MS, hope has been described as an essential element of the life journey, and the very presence of hope may help a patient to continue functioning more successfully or to remain independent for longer, bolstering self esteem and well-being (Morgante, 2000). Every person has a perceived future and in this dimension of existence, hope lives (Cassell, 2004).

Hope research and hope theory

“In studying hope I observed the spectre of human strength. This reminds me of the rainbow that is frequently used as a symbol of hope. A rainbow is a prism that sends shards of multicoloured light in various directions. It lifts our spirits and makes us think of what is possible. Hope is the same – a personal rainbow of the mind.”
(Snyder 2002, p.269)

Stepping back from the enormity of the hope literature in academia, exploring hope theory and its origins is necessary to give insight into how our thinking about hope has evolved over the years and how hope fits into life with RRMS. Early general hope literature recognised the desire to seek goals as part of hope (Cantril, 1964;

Frank, 1975) and the concept of hope as a way of thinking, as a cognitive process, was beginning to be recognised (Snyder, Irving, & Anderson, 1991). This led to hope being defined as “a positive motivational state based on an interactively derived sense of successful agency (goal directed energy) and pathways (planning to meet goals)” (Snyder et al., 1991, p.287).

In the following years, Snyder became a leading theorist on hope, believing that having a goal is the cognitive component anchoring hope theory (Snyder, 1994), the goal providing the targets of mental action sequences (Snyder, 2002). The means to achieve goals Snyder refers to as “pathways” (Snyder, 2002); what we would recognise as actions, the plan of what we would do to achieve a goal. An important part of hope theory also rests with the motivation to reach these goals, the “agency thinking” to achieve them. Hopeful thinking necessitates both “pathways” and “agency thought”, and they often feed off each other (Snyder, 2002). Thus, for PwRRMS, hope can be inspired and sustained by developing goals, making plans on how to achieve these goals, discussing contingency plans in case of obstacles, and maintaining the motivation to see the goals through to achievement.

Snyder’s theory of hope conceptualises hope as a cognitive-motivational construction, which relies on the perception that goals can indeed be met (Snyder, 1989) and therefore, realistic. Further research by Snyder and colleagues (2006, 2014) suggests that people with high-hope (thinking characterised by specific and clear goals) are more successful at harnessing the resources needed to achieve their goals and at negotiating alternatives when obstacles appear. In contrast, people with low-hope (characterised by vague goals) tend to ruminate and rely on avoidance, and repeat cycles of goal blockage, escape and failure (Snyder, 2002).

The MS Nurse is in an ideal position to assess the hope status of the PwRRMS. Identifying exactly where the PwRRMS is positioned in terms of low and high hope potential could prove helpful to the life journey as early intervention and guidance can provide the PwRRMS with both tools and resources to successfully self-manage the condition. When considering an unpredictable disease such as RRMS, with many losses along the way, with relapses, with an uncertain prognosis and with no cure, it is easy to see how easily a lack of hope can penetrate the thinking processes for

PwRRMS, block goals and impact on goal attainment. Indeed, RRMS can erode well-being and interfere with goal pursuits on many levels (Madan & Pakenham, 2014) for example, interfering with cognition, mood and energy levels. However, if hope related pathways and agency thinking can be engaged and supported by MS HCPs, adjustment to RRMS may be improved, despite the losses (Madan & Pakenham, 2014). If MS Nurses have a basic understanding of hope theory and the importance of goals, they can help PwRRMS develop goals, articulate aspirations and strategise pathways to goal achievement and also discuss alternative routes (pathways) in the event of upheaval along the way. Additionally, as hope theory suggests that hope is a cognitive process, the high rates of cognitive deficits seen in RRMS (Chiaravolloti & DeLuca, 2008) may also have an impact on the ability of the PwRRMS to set up goals, and the agency thinking and pathways skills needed to achieve their goals. The MS Nurse can assess, intervene and help the PwRRMS in the case of issues with cognition with both goal setting and strategies to achieve goals, promoting both agency thinking and pathways.

There are very few studies investigating hope specifically in MS, however a recent Australian study surveyed 296 PwMS (two thirds with RRMS) using various hope scales in an attempt to explore concepts of MS disease adjustment and hope (Madan & Pakenham, 2014). Findings from the study suggested that greater hope was associated with better adjustment to MS. Greater hope scores also predicted better life satisfaction, positive states of mind and lower depression, consistent with the earlier work of others (Foote et al., 1990; Lynch, Kroencke, & Denney, 2001). It is interesting that even though there were several decades between the studies, they showed similar results, despite the introduction of DMTs in the interim. This suggests that concepts of hope are just as important in the present time, even though treatments and prognosis have greatly improved, essentially leading to greater levels of hope. Hope has also been identified as a potent protective resource for coping with MS (Madan & Pakenham, 2014), and a resource that the MS Nurse is perfectly positioned in the health care team to recognise and assist with (Morgante, 2000).

Hope in the nursing literature

“Hope is central to life and specifically is an essential dimension for successfully dealing with illness” (Fitzgerald Miller, 2007, p.12)

Various conceptualisations of hope have also been posed in the nursing literature. As difficult as it is to conceptualise hope into a simple and neat definition, it is an important model for nurses to understand as it underpins our views about strategies to use with patients, especially during different stages of health and illness (Fitzgerald Miller, 2007). Hope has been described in theoretical terms for decades, but recognition of hope as a concept in nursing is a more recent development (Herth, 1990), which continues to grow (Cutcliffe & Herth, 2002). Before any inductive nursing studies were undertaken, Miller (1985) explored the empirical literature on hope and identified elements of hope that can be demonstrated and taught to patients and families by nurses. These elements included radiating hope, expanding the patient’s coping skills, teaching reality surveillance, helping with setting and obtaining goals and helping to renew spirituality (Miller, 1985).

In the 1980’s, the first inductive nursing studies of hope were performed, looking at the role of hope in specific groups such as adolescents and those suffering cancer (Hinds, 1984; Owen, 1989). Hind’s study used grounded theory methodology to define hope as the degree to which an adolescent believes that tomorrow exists (Hinds, 1984). The research in cancer also used grounded theory methodology to develop a conceptual model of hope, resulting in six themes: goal setting, positive personal attributes, future redirection, meaning in life, peace and energy (Owen, 1989). Indeed many of the key elements and themes of hope as expressed by Miller, and later by Owen, were also important for participants in the current study and will be discussed at length in the two subthemes to follow.

Further work in the following two decades built upon these theories and concepts of hope with Stephenson (1991) reviewing over 50 papers to develop conceptual attributes of hope. These attributes included viewing hope as a basic human experience, providing meaning in life, being fluid in nature and not static, being multidimensional and being associated with nursing (Stephenson, 1991). All of these

attributes could be applied to the current study participants and particularly the concept of hope being fluid and not static. This has deep connections to the variable disease course of RRMS, with unpredictability and periods of remission. Several years later Morse & Doberneck (1995) reported the concept of hope as being poorly understood, despite the growing nursing research, and proceeded to interview patients themselves to gain a deeper understanding of hope. This resulted in seven universal components of hope being identified: a realistic initial assessment of the threat, envisioning alternatives and the setting of goals, bracing for negative outcomes, a realistic assessment of personal and external resources, socially mutually supportive relationships, continuous evaluation for signs to reinforce goals and a determination to endure. Whilst all of these hope components were seen in most of the current study participants, a determination to endure was also present in all of them.

There is a paucity of hope related nursing research specifically in MS. However nurse researchers in other areas of chronic illness have found that patients showing signs of higher hope (characterised by specific and clear goals) have been associated with better adjustment in spinal cord injuries (Elliott et al., 1991; Lohne, 2001) and breast cancer (Stanton, Danoffburg, & Huggins, 2002). A nursing study of hope which fits well with the life story of MS is from a study exploring hope and its meaning in patients with spinal cord injuries (Lohne, 2001). In this study of 10 people one year after their initial injury, Lohne (2001) found that every participant in the study had hope, although for some it was sometimes silent hope, which was left unexpressed. Hope was described as intensely personal, as giving inner strength and as being a motivational spark (Lohne, 2001). Lohne developed this concept of hope in later years, describing hope further as a universal and dynamic concept, which is personally significant (Lohne & Severinsson, 2006). Similarly to how Lohne described hope in spinal cord injuries, hope appears to be universal, dynamic, motivational and personally significant in RRMS as well.

Morgante (1996) provided the first insights into hope, PwMS and the role of the MS Nurse. MS Nurses can be a healing presence in the lives of their patients due to their nurturing care, empathy and support of PwRRMS (Morgante, 1996). Additionally, nurses who care for PwRRMS and their families can provide resources to inspire

hope and prevent hopelessness (Morgante, 2000), often maintaining hope whilst untangling a web of false hope (Morgante, 1996). MS Nurses are in an ideal position to develop strategies with their patients to explore personal goals, to utilise support and resources and to formulate care plans to enhance the likelihood of goal achievement, which has been demonstrated to be a vital component of hope. Hope may also help a patient with MS to continue functioning more successfully, remain independent for longer and may also have a synergistic effect on medical therapies (Morgante, 2000).

The overarching theme of Holding Hands with Hope can be further developed into two subthemes to explore these concepts in greater depth - hope in its many forms (how hope is expressed by PwRRMS and different types of hope) and purposeful positivity (actively seeking out positivity to express hope).

Hope in its many forms

Our personal ideas of hope will be shaped considerably by our own personal experiences, and no two life experiences will be exactly the same. During the interviews with participants for the current research study, I was struck at times by the different types of hope people fostered, although during the interviewing phase I had difficulty in defining exactly what these types of hope were, and how hope fit into the wider model of MS care. A recent study from the physiotherapy/rehabilitation specialty in neurological diseases and injuries has shed some light on several different types of hope that PwMS may possess and use in their MS journey, including concrete hope, hope in possibility, active hope and transcendent hope (Soundy et al., 2013). Further work by Soundy and colleagues (2016) used thematic synthesis to examine 47 studies of MS to identify expressions of hope in MS patients as hope for a cure, hope for improvement, hope for normality and hope to cope. I did not recognise all of these elements of hope in the current study participants, possibly because Soundy et al.'s 2013 study primarily focused on spinal cord injuries and stroke, and to a lesser extent on MS. However, all of these concepts of hope helped me build a clearer picture of the types of hope I was being informed about by the participants. I was guided in some of my hope descriptors on concepts from Soundy and colleagues (2012, 2013, 2016) research work in hope, but

also extended them to be more inclusive of the personal stories I was hearing and types of hope that have not previously been reported in this population.

Previous qualitative nursing research on the experience of living with RRMS reported that PwRRMS hoped to manage and maintain function as part of their future (Miller, 1997). As Miller's study (1997) was conducted prior to the introduction of DMTs to control RRMS, it was interesting to explore if hope to maintain function would still be as important to PwRRMS today now that disability outcomes have greatly improved. The answer was a resounding yes, it was extremely important for many of the current study participants, and in several different ways, which will be discussed in further detail below.

The specific types of hope I developed from the study participants during the interviews included the following: functional hope (wanting to retain functional ability, especially the ability to walk unaided), restorative hope (to be returned to their previous state of health), curative hope (hope for a cure) and defiant hope (challenging and resisting RRMS). To a smaller degree, realistic hope (acceptance at the current situation and a good understanding of the possibilities ahead) also had a place in almost every story, but was more inferred in their storytelling and overview of their condition rather than discussed openly as a form of hope. In addition, I believe that every participant harboured personal/secret hopes which live inside of them, mostly unsaid and perhaps never truly examined, shared and explored. I felt this because I witnessed the looks of longing, the pensiveness in conversation, the struggling to grasp something when discussing hope and put it into words. I am unsure of why this may be. Perhaps the participants were frightened to share their feelings of hope in case they are not shared by others and therefore may be extinguished, resulting in devastation. Or perhaps, speaking them out loud takes away some of the mystery and reveals too much of their soul. Or perhaps, these secret hopes are simply too complicated to summarise into words and feelings. In a study of hope in spinal cord injuries, the researcher felt that every participant in the study had hope, although for some it was "silent hope", remaining unexpressed when physical progress stagnated, but requiring courage and endurance (Lohne, 2001). Perhaps a similar concept could also apply to PwRRMS, hope remaining even in

times of distress or crisis, just remaining unexpressed at that particular time. But not far from the surface.

Hope has also been identified as both an active process and as a more passive one (Soundy et al., 2013). Active hope can be seen in patients who can identify and act on a goal, possessing connectedness and demonstrating optimism (I see this as being aligned with Snyder's version of high-hope) as opposed to those patients demonstrating more passive hope where they may have a vision of hope but cannot use that vision to move forward, often kept back by fears (I see this as being aligned with Snyder's (2002) version of low-hope) (Soundy et al., 2013). Most of the types of hope uncovered in the current research study are quite active in their character, perhaps participants did not express more passive hope in keeping with the nature of the concept. Being able to identify different types of hope in patients enables MS Nurses to be able to engage more deeply, to gain more from interactions with patients and perhaps most importantly, to be able to help patients in adjusting to RRMS and to ensure the best possible outcomes, assisting with realistic goal setting, pathways management and goal achievement.

Functional hope

Functional hope captures the hope of retaining functional capacity, the ability to perform activities of daily living such as walking, showering and getting dressed. Functional hope aligns somewhat with Soundy et al.'s (2013) description of adaptive hope, which centres on the hope to manage and retain functional ability in neurological conditions. However, functional hope in the current study appeared more urgent, more determined and more centred on *keeping* function rather than adapting (as shown in the quote from Paul below). Expressions of functional hope were very common in the interviews and pertained mainly to ambulation and the ability to walk. Functional hope was expressed by the study participants in one of either two ways; to stay out of a wheelchair/walking aids or to be actively walking and ambulant. Two sides of essentially the same hope, to retain walking function. Optimistic, goal directed cognitions are aimed at distancing a person from negative outcomes (Gillham et al., 1995), which is slightly different to hope theory where the person aims for future positive goals and the methods to achieve them (Snyder,

2002). In the current research study, the participants most often expressed this as an overt wish to stay away from anything to do with wheelchairs and ambulation aids such as walking sticks and canes. Thinking optimistically to distance from negative outcomes, this would be a desire to not be wheelchair bound or requiring a walking stick. Thinking in terms of hope theory, it would be a desire to stay fully ambulant, to be walking “as normal” and the methods to achieve this state, such as participating in yoga classes, taking DMTs as directed or seeing a physiotherapist for an exercise prescription.

As discussed in an earlier theme, (Re)defining Me now that I have RRMS, under the subtheme dare to compare, Paul expressed determination to stay out of a wheelchair in the future, having glimpsed a little of what that type of life could entail during his unhappy, early visits to MSA meetings not long after his diagnosis (he refused to attend these meeting again). What he witnessed there made him determined to avoid the “wheelchair scenario”, demonstrating optimistic goal directed cognition. This was also Paul’s reasoning in the theme The DMT Dance with his wanting to front end load and have a higher efficacy DMT despite the side effect risks. Paul did not want to end up in a wheelchair as a result of RRMS, his functional hope active and determined. Paul’s quote is breathtaking, almost childlike in its simplicity about camping being the other option to a wheelchair.

I don't want to be in a wheelchair, I want to be able to go camping. Paul line 727

For Rudi, Margot, Ruby and Piper, the physical act of walking holds personal importance for them, and their hope for the future involves being ambulant and functional, and the reason they pay such close attention to their own health, fitness and well-being.

I see life being good and I hope to continue to travel and do the things I want...I see my future as I am today...I dream of me walking in that. Rudi line 1707

So the future I see...I hope that I don't get to the stage where I need a wheelchair all the time...but hopefully...I think, use it or lose it...I make myself do things. Margot line 2459

I'm going to walk...to do things with my husband...let's go do this, let's go do that...my son really wants to go to Hawaii, so I hope my legs can work enough to take him. Ruby line 1560

If I wasn't being treated it might be a slippery slope downwards...I feel more confident knowing that a lot of these drugs are showing positive results...I do envisage myself hopefully never being with a walking aid, purely because of the medications...that's what I'm hoping for. Piper line 2021

Restorative hope

Similar to functional hope, restorative hope is mainly about retaining function, but differs from functional hope in that it is more of a hope to be returned to previous levels of function, before the onset of RRMS. This would have been considered impossible even a decade ago, but some of the newer DMTs have been reported to improve function and reduce disability, for the first time in MS care (Coles et al., 2012).

For study participant Ruby, recently completing a course of the DMT alemtuzumab encouraged her to be hopeful for a complete recovery and return to earlier function, of restorative hope. Rudi had experienced bouts of hopelessness after several severe, debilitating attacks, but also gained confidence from her neurologist that the newer DMTs may restore her to better health.

I don't feel so weak...I was walking yesterday, it's no marathon but for me it was pretty good...so fingers crossed I really hope so, I want the function back...I used to be able to walk with the kids everyday when we first moved here...so I want that sort of function back. Ruby line 629

Normal, I just want a very normal lifestyle...I just don't want to be in bed or on the sofa...I want to be moving...just a very simple life...and not all about me, it would be nice if it wasn't all about me. Ruby line 1575

(The neurologist said) with treatment we don't hope to keep you where you are at, we hope to keep you better...so I think...I had a bit of confidence in her...great. Rudi line 1635

Curative hope

Of course, hope for a cure in the future was also very common in this group, fuelled by recent advances in DMT development and in new therapies. For many participants, they felt lucky to be diagnosed in a time where a cure could be possible, and this was expressed as a form of hope. Will and Susan feel certain that a cure for MS is imminent. Evie was also hopeful of a cure, but not in her lifetime, perhaps also exercising a form of realistic hope.

In this small amount of time we're only getting better, we're getting more efficient at what we do...it's only a matter of time...a cure is going to happen so I know for me it's not going to be an issue, but now I need to make sure I keep on top of myself. Will line 374

I believe that some type of drug...will be a permanent solution. I believe there will be something. Will line 1507

I feel very positive about the future and with all the new medications, all the support out there...a cure...and with all the research and new medications, there's a lot there to help people to lead a normal life. Susan line 1047

All of this research happening, one day they'll find a cure and I might be dead by that point, but it's going to happen...you need to be optimistic about it, the future and what you can do...there's a lot of good people doing good work. Evie line 1458

Defiant hope

I really don't do things by halves...getting back to gym so soon after treatment was very important to me...I was being more defiant...it helps...you know what, MS? You

can knock me down, but I'm going to get up, and then you bounce back, kinda defiant. Evie line 1299

Defiance has also been referred to as a “fighting spirit” as the PwMS shows determination to battle MS (Reynolds & Prior, 2003), demonstrated succinctly by Evie in the quote above. One of the hardest aspects to accept for patients can be the drastic change to their identity brought about by MS, often hoping to return to their pre-diagnosis identity (Soundy et al., 2012). A recent study of 11 PwMS, five of whom had RRMS, used content analysis and thematic analysis to explore patients expressions of hope in a rehabilitation setting (Soundy et al., 2012). Some study participants set themselves a challenge to overcome, to defy MS and the expectations and passiveness that other patients or clinicians had towards MS, by taking action they were doing something to progress hope (Soundy et al., 2012). After several interviews in the current study, I identified this type of defiant attitude as a direct expression of hope, almost at its most bold and daring and key to the participants in their hope journey. Defiant hope provided a way to challenge the expected prognosis and progression of MS. Defiance didn't come easily for most study participants and involved more than positive thoughts and an optimistic outlook; defiance needed deliberate action, clear goals, and to be supported with plans, resources and active engagement. The majority of the participants in the current study openly challenged their RRMS, issuing a resistance that at times captured the very essence of defiance.

After twenty years of living with RRMS, Evie still offers resistance to RRMS and remains positive about the future, regularly challenging her physicality and expressing defiance as a means to show others that RRMS doesn't stop her doing anything.

I did go bungee jumping six months later (after MS diagnosis) just because I could...trying to prove a point and now I'm almost 40 and I still do those things just to prove a point...I went indoor rock climbing a few weeks ago...you're not going to get me, it's not going to happen...sky diving, same thing. Evie line 657

Piper tries to live each day issuing resistance to MS, becoming even more defiant when she is troubled by debilitating symptoms of MS such as fatigue and nerve pain.

OK...just get out there and do stuff while you can...and I do that everyday. I like going for my walks and runs...people say to me “why do you do that to yourself?” and I say “well, I do it because I can...because I know what it’s like to not be able to walk”...Even when I’m feeling lousy and I’m feeling fatigued with the MS in particular, I will do it, I will push myself and I will do it. Piper line 990

Kate was working full time, mothering, looking after sick parents and studying for a higher degree when she experienced many debilitating relapses. Although many would have reduced their workload at such a busy time, for Kate, studying was her lifeline, her turning point against the disease. Kate describes achieving her higher degree as her greatest life accomplishment and representing active defiant hope against RRMS.

MS would just pop up it’s ugly head but I didn’t make it important...I tried not to. I did not place too much emphasis, it was an inconvenience yeah, but it was not my biggest problem...I thought...you’re not going to beat me, I’m going to do what I want. Kate line 1777

Joy was confined to wearing sensible, flat shoes due to her significant gait issues and depended on a local shoe shop in her small rural town to order her supplies. Trying to recapture positive and happier times, Joy decided she wanted to try high heels. Of course, the shop assistant used to Joy’s usual symptoms didn’t think this was a good idea and questioned her choice, but Joy was determined. This simple act of defiance led to a simple, yet remarkable turnaround.

So I took a deep breath and I stood up in these high heels...so I stood up, adjusted my gait and then I walked towards the mirror...I walked with my head held high, with confidence...I was so empowered, I felt so strong...I felt like I got my whole life back...it was really special. Joy line 1291

The study participants seemed to garner more hope with their defiance, perhaps because this meant that they were actively taking a stand and actively taking control, rather than MS taking control. Defiance gave a certain sense of purpose, a reason to get up in the morning, a reason to exercise, a reason to take DMTs even when the

going gets tough. Defiance is a form of hope and an expression of being hopeful, of belief in oneself. MS Nurses can foster defiance in patients by helping them to understand their current capabilities (not just their disabilities), to resist comparisons with others and to concentrate on the resources and value that they already have and which can be developed even further.

Nurses have been identified as having a crucial role in facilitating hope in patients and their families (Tutton, Seers, & Langstaff, 2009). It has been suggested that nurses are an important source of hope for people that are vulnerable and ill (Herth, 1990; Herth, 1996; Cutcliffe & Gant, 2001) due to their constant and prolonged contact with those who are suffering, forming close connections and being in an ideal position to influence feelings of hope (Travelbee, 1971). Nursing strategies to inspire hope involve the presence of another human who demonstrates unconditional acceptance, tolerance and understanding (Cutcliffe & Herth, 2002). Other hope promoting strategies include fostering interpersonal connectedness with others, assisting with attainable aims and goals, encouraging spiritual practice in those who value spirituality, encouraging personal attributes such as a sense of humour and affirming the worth of a person (Herth, 1990), benefit finding, expanding coping skills and sustaining caring, therapeutic relationships (Miller, 1991), functions all at the heart of the MS Nurse's role. Communicating one's own sense of hope is also an important strategy for inspiring hope in others (Fitzgerald Miller, 2007), and for the modern day MS Nurse, this is a somewhat easier task than in years gone by, with so many new, proven, efficacious DMTs and many promising treatments on the horizon. As demonstrated by the forms of hope discussed above, for PwRRMS today, hope burns brightly as the possibilities for the future, for treatments and for the Holy Grail, a cure, are for the first time very real.

Purposeful positivity

I think there's a measure of optimism, I think it's not even control, I think you can decide what path you're going to take...if you're being negative all the time it's going to be bad for your MS, if it's negative, it's down, it's feeling awful, woe is me...it's getting out of that perpetual cycle of negativity, it's being optimistic about the future, about looking forward to something going well. Evie line 1435

Throughout the interviews I detected a sense of purpose for many participants when they were discussing hope and remaining positive through their journey, a process where they actively engaged with being positive, which I later termed “purposeful positivity” to capture this intention. It didn’t seem to just happen randomly, as highlighted by Evie in the quote above, purposeful positivity was a very active process which was more conducive to living well and happily with RRMS for the study participants. Examples of purposeful positivity included choosing and sustaining optimism, benefit finding, searching for meaning, harnessing a sense of humour, expressing spirituality, and giving back to the MS community.

Perhaps one of the most poignant examples of purposeful positivity came from Joy, whose obese husband suffered a sudden fatal heart attack, falling on top on her and crushing her beneath him. She managed to crawl out from underneath him and survive, the incident starting a new path for Joy where positivity became key to regaining control.

That instant (my husband died unexpectedly) was beyond devastating...but that surge of whatever it was when he fell on top of me...that choosing life...whatever it was that surged through me at that point did something in my chemistry...at his funeral I was battling into the church to walk...but I started to improve, in fact I made an absolute heart felt decision that I would get better no matter what...something switched on, I chose life...if my body won't do what I want it to do...there's got to be another road...I started fighting for it...I felt like I had the power to control my health...it may or may not have been true, but I made it true. Joy line 969

Optimism and a positive outlook

Being diagnosed with RRMS in the current climate of breakthroughs in scientific research and newer, more efficacious DMTs gives rise to the possibility of greater positivity and optimism. Additionally, the huge variability in possible RRMS symptoms and disease severity can also inspire confidence. A recent study exploring parents’ experiences of their child living with RRMS, interviewed 31 parents in semi-structured interviews and used grounded theory to analyse the results (Hinton & Kirk, 2017). One of the important findings identified in managing the uncertainty

of MS was “optimistic thinking”, hoping for a future where their child would be minimally affected and lead a “normal life”, the huge variability of RRMS by its very nature aiding optimism in this regard (Hinton & Kirk, 2017). Although this was the viewpoint of the parents and not the PwRRMS, the concept of the latitude for hope and positivity in an uncertain disease is an important one, and also has applicability to adults living with RRMS. As MS Nurses, the unknown disease variability forms the basis of many consultations with our patients and allows positivity and hope to always have a place in our care.

Often the diagnosis of RRMS can cause negative reactions in the PwRRMS, as explored by the earlier themes of this study in chapter 6. Over time however, many PwMS report positive changes in terms of values and outlooks, as well as an increased appreciation for life (Irvine et al., 2009). It has been reported that thoughts are effective tools in garnering the motivation necessary to commit to behavioural change and that positive thinking may benefit motivation in MS (Hall-McMaster, Treharne, & Smith, 2016). Positive thinking is an active behaviour and entails having a goal in mind, being self sufficient, letting go of the past and reinforcing positive actions by doing something good (Hall-McMaster et al., 2016). Once again, as with hope theory, it is postulated that positivity takes deliberate cognitive action and working out what is necessary to reach goals, of possessing determination (Hall-McMaster et al., 2016). Traumatic events challenge beliefs, with the result that humans make active efforts to restore, or to enhance their beliefs and exercising positivity is a way to cope with adversity (Taylor & Armor, 1996). Dennison’s model of adjustment to MS suggests that those who adjust more successfully to the diagnosis use the following resources: positive reappraisal, optimism, hope, benefit finding and spirituality (Dennison et al., 2009).

Strategies to sustain optimism include avoiding being around those with negative views who challenge (sometimes fragile) hope (Hinton & Kirk, 2017). Staying away from negativity in others could involve distancing from family members, friends, work colleagues and sometimes MS organisations in some cases. In the current study, participants Will, Paul and Jane elected not to become involved with the local MSA meeting groups to avoid being reminded of the negative aspects that MS could

bring and to maintain and instead to nurture optimism and positivity from their own family and friends.

Patient attitude has been identified as a major influence on overall disability burden in MS in a large, cross sectional Belgian study of 1372 participants living with RRMS (D'Hooghe et al., 2013). This study reported that those patients who scored higher on health promoting behaviour (such as physical activity, spiritual growth) were significantly less likely to reach a level of disability where they needed assistance to ambulate (a single walking stick) (D'Hooghe et al., 2013). As patient attitude is an area of possible control for the PwMS, educating patients about the importance of a positive attitude could significantly contribute to better and more positive outcomes (Lysandropoulos et al., 2015).

Both Piper and Griff exercise the power of positivity, of being in control of the disease and verbalising a better future. A sense of control appears to resonate heavily with a sense of hope and positivity. Piper has had extensive counselling so that she can feel in control of MS and enjoys the challenge of keeping the disease in check. This leads to hopeful feelings for her future health. Griff, ever the optimist, simply regards himself as lucky and is pragmatic about what may happen in the future.

Even if I'm having a bad day with MS I know that I'm in control of my thoughts and I can think whatever I want...I can change that thought process. Piper line 1772

I think I live almost day by day...I can't picture what it's going to be like...if I look to a future with MS I do believe that I'll be dead and buried before my MS puts me in a wheelchair...I just don't think it's going to happen. I'm lucky. Griff line 1367

Susan, unhappy with the way RRMS was controlling her emotions and keeping her from her dreams, embarked on a counselling course so she could learn to take back control of her life, and understand herself better in the process. Susan regards this course as a life-changing event for her, finally enabling her to enjoy life, help others in her role as a HCP, exude positivity and put years of despair firmly behind her. Susan uses the skills she learnt during the course now as a new mother with RRMS and fatigue, to see things differently and remain optimistic and positive.

Accept it, embrace it, because it doesn't mean the end...and then I looked at it...that it was a new beginning for me...I did look after myself more with what I ate and I exercised. Susan line 806

You always have to hold on to your dreams because that's what keeps you going...what you are striving for...you have that to help you get up each day and get on with life and make yourself a better person and stronger to help others around you. Susan line 1128

I feel positive about the future and people being diagnosed with MS now...this medication will be able to help them...there's a lot that's happened. Susan line 1202

MS Nurses can foster positive thinking in patients by encouraging a focus on positive aspects of their life and by using positive self talk (Roger et al., 2014). MS Nurses can also remind patients that cultivating optimism and hope will assist with self confidence and regaining control of their lives, and taking part in programs such as intensive wellness programs can also improve self efficacy and positivity (Ng et al., 2013). As a positive attitude helps with regaining control over MS and more positive outcomes overall (Lysandropoulous et al., 2015), providing education on the importance of positivity and methods of achieving a positive state of mind can potentially have a significant impact on the future for the PwRRMS.

Searching for meaning

Searching for meaning is another expression of positivity and has been described as a cognitive process to find order and purpose in illness (Sharpe & Curran, 2006). Creating meaning in life for PwMS can involve participating in meaningful activities, developing new interests, and engaging in life with more purpose. This concept was captured in a recent study where participants learning to live with MS were likened to “learning to fly with broken wings” (Flesner & Rudolfsson, 2016). Several of the participants in the current study expressed feelings of gladness that things changed in their life, sometimes for the better, as a result of MS. Rudi described the time where she couldn't work due to recurrent severe relapses leaving her with residual neurological dysfunction for several years. At the time she was

raising four young children and really needed the money to support the family. However, she chose to look at the situation differently and saw meaning in the illness as giving her time to spend with her family during some very important years.

When I lost my job, I thought I can be down and think I'm unemployable...I can't work...the path I chose to take was that work's always going to be there 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

Choosing to rise above the possibilities of the diagnosis and concentrate on a life well lived with MS is a conscious, positive choice. Kate looked inward to find her life meaning and Rudi changed her perspective on money to live life to the full and uncover new meaning. By seeing RRMS as something she lives with, but not the entire story, Evie makes a choice to find meaning in all she can do rather than what she cannot do.

It gave me strength to think, whatever this is, I want to get over it...I've got things to do...more important things...and that's the way I was driven. Kate line 388

Finances play a big role with anyone and I had lost my full time job (because of RRMS) but you know, stuff it, it's just money, so we went to Fiji last year...I'm just doing a lot more and loving it...you change perspective. Rudi line 910

MS is not the main life...it doesn't define who I am, yes I have it, but it isn't who I am...I do not let it define me, I have it, it bothers me, it drives me insane and it makes me angry, but it is not the core of who I am as a person. Evie line 1184

It's not all doom and gloom like people might think...if I ever go rock climbing again I want some photos because I want to upload to MS Society so people can see that you can do these things...you shouldn't focus on what you can't do, it's what you can do, it's what you want to do. Evie line 1232

Harnessing a Sense of Humour

Another strategy to maintain a positive sense of self whilst living with a neurological condition is to use humour (Roger et al., 2014). A qualitative study interviewed 27 women with MS and used interpretative phenomenological analysis to investigate the results, finding that positive thinking and finding “jewels” in their situation were important themes when living with MS (Reynolds & Prior, 2003). Participants were found to consciously value special and positive moments, actively looking for benefits, maintaining social relationships and enjoying fun and humour (Reynolds & Prior, 2003). Similarly, an earlier study reported exercising a sense of humour, along with maintaining a positive attitude, as important tools to living a life well with MS (Gulick, 2001). Several study participants demonstrated a healthy sense of humour during our interviews, at times telling me poignant or distressing stories but laced with laughter, giggles and the ability to have a laugh at their own expense. It has been reported that humour is a way to maintain a positive sense of oneself and play down the challenges in life, playing an important role in encouraging positivity in neurological diseases (Roger et al., 2014). Kate and Margot in particular, perhaps the two most physically disabled participants in the study, recalled sad stories at times, but quickly focused on humour to see the funny and bright side.

Kate was describing to me a time when she had to do a presentation but was crippled by severe spasticity which affected her gait. Recalling the situation, which could have also been portrayed with torment, Kate laughed and re-enacted the walking motion in front of me.

I can't bend my knees...and when I walk, I walk like, you know, the Tinman! (laughing) in the midst of all this I had to give this lovely presentation (giggles). Kate line 1343

Margot, who initially experienced so much angst thinking about the possibility of a wheelchair as her mobility gradually and intermittently deteriorated, saw the funny side of a wheelchair mishap on holidays with her husband overseas.

We unwrapped the wheelchair...it was all bubble wrapped that's got fragile all over it...everything was chucked on top...and one of the struts on the side was bent, so (husband) is manoeuvring it (laughs boisterously) and he ended up breaking it (more laughing)...and broke the strut...so off we go...(bouncing on) cobblestones all through (the town) (giggles). Margot line 1633

Margot also told a story of rising from her wheelchair in a shop to shock the shop assistant, walking slowly away from the wheelchair and proclaiming at the assistant's puzzled look "I know, it's a miracle!". For some, a touch of humour (at the appropriate time) can be a more comfortable way to address some of the more uncomfortable aspects of living with RRMS. MS Nurses can also support and encourage PwRRMS in the value of humour in their life journey.

I did wonder if Kate and Margot laughed at the time of the incidents, or if time allowed them the luxury of being able to look back on an initially emotionally painful event with a new sense of humour. But, getting to know Kate and Margot through the life history interviews, I suspect they both did feel the brighter side of the situation at the time.

Faith, religion and spirituality

Improving the health and well-being of the whole person, mentally, physically and spirituality has been at the forefront of nursing since inception (Nightingale & Skretkowicz, 1992; Reinert & Koenig, 2013), therefore considering the impact of spirituality in the life journey of RMMS is essential. For the purpose of this study, concepts of faith, religion and spirituality will be viewed as not just as traditional religious faith, but as belief or belonging to any sort of higher being or spirit and will collectively be referred to as "spirituality".

It has been suggested that spirituality is related to better adjustment to illness, providing a sense of coherence and meaning, purpose and the courage to endure suffering (George, Larsen, Koenig, & McCullough, 2000). However, there are very few studies exploring spirituality in MS and those that have been published have somewhat contradictory messages regarding the importance of spirituality in MS. An

early study in Australia surveyed a group of 101 participants with MS (phenotype not specified) and reported that those PwMS who derived high levels of meaning from personal belief systems also experienced high levels of quality of life and psychological well-being, as well as lower levels of depression and anxiety (Makros & McCabe, 2003). A small study of seven PwMS (type not specified) found that PwMS did have an increased appreciation for spirituality in their lives (Irvine et al., 2009), which has also been supported by others suggesting that spirituality may be a helpful resource to cope with chronic disease in general (Bussing et al., 2009; Bussing et al., 2013; Levine, Aviv, Yoo, Ewing, & Au, 2009).

However, contrasting with this work are early empirical findings in larger studies which have suggested that PwMS may be less engaged in spirituality when compared to patients living with other chronic diseases (Bussing et al., 2005). A more recent study of 213 participants, half of whom identified as RRMS, found relatively low levels of faith importance in the study sample, with only 10% of participants reporting reliance on faith to carry them whilst living with MS, most participants citing family or themselves as their source of support in the MS journey (Wirth & Bussing, 2016). It is worth noting however, that this particular study enrolled younger participants between the ages of 25 and 40 years, possibly influencing the results as it has been suggested that age is also positively related to higher measures of spirituality (Bussing et al., 2005).

In the current study, Joy expressed positivity from actively practicing spirituality, when she recalled stories about the disciples of Jesus healing a cripple, which is how she used to see herself. She used this story to inspire positivity in herself and a belief that miracles could happen.

I was reading my bible one day and I read this passage that talked about the disciples and there was a beggar there crippled from birth...they said "in the name of Jesus Christ rise up and walk" and then the cripple stood up...walking and leaping and praising God...and this really impacted me....suddenly I could relate to it...if that kind of miracle is possible, what does walking, leaping and praising God look like in my life? And I pushed my body to walk. Joy line 1120

In western religious thought, individuals strive to maintain an idea of self that is in harmony with the universe and God and suffering has a purpose and provides a way for humankind to enter a divine relationship with God (Goodrick-Clarke, 2008). It is important for the MS Nurse to have an awareness of the cultural/spiritual beliefs of the patient, as it is helpful to form the basis of individualised and patient-centred care, and can be incorporated into the nursing care plan.

When things aren't going so well in life, spirituality can provide an avenue of support that adds another element to purposeful positivity. For Evie, this was an important support in her hour of need, for Joy as a child it was the only real support she had, and for Davina, re-engaging with spirituality during a dark time gave her new insights, although she started off angry and disbelieving.

It doesn't scare me because I think there's more...there's more...I have always believed there's more...call it God, or whatever religious faith, I don't particularly hold any, I consider myself very spiritual...you have to turn to your faith when life isn't so great. Evie line 683

Faith was really the only thing I had growing up as support. I took myself to church from age six...faith is a huge part for me...in spite of everything around me...I couldn't explain that to people...it was my faith that kept me going especially when I lost my ability to comprehend (when Joy became dyslexic). Joy line 1819

The other thing I got back that's really helped me...I got my faith back...after I was diagnosed with MS I went back to church...but I went back really angry. Davina line 1152

The minister helped me I was this screaming possessed woman and he turned my life around, got me in contact with women in the church who had been in really bad situations overseas, older women...having my faith back actually made me a bit stronger, it has helped me tremendously...I feel a bit more supported. Davina line 1176

Expressions of spirituality were not confined to participants in the current study. At times, spirituality was an important coping mechanism for their loved ones as well. Susan's family engaged in regular prayer groups after her diagnosis, drawing strength from others in the group, whilst Susan elected not to become involved. Kate's mother was deeply religious and although Kate herself was absolutely terrified of her symptoms, her mother was convinced from her spiritual beliefs that RRMS was going to go away. Because of the natural relapsing and remitting evolution of the disease, this may have enhanced this aspect of hope for families as symptoms disappeared and their loved one regained usual function, possibly as a result of their faith.

Giving back and being involved

Another strategy to inspire hope and positivity demonstrated by the participants was a willingness to become involved in the fight against MS and to give back to the MS community in some way. Kate expressed one of the most incredible stories of selflessly giving back to the MS community. Kate had experienced a miserable time on an interferon DMT and eventually ceased it due to intolerable side effects, despite persevering for some time. Kate was keen to help medical science and "give back" and sought information on a new clinical drug trial. Kate made enquiries and was disappointed to find that the trial involved being randomised (randomly allocated) to one of two medications - a new oral medication that she was keen on trying and the older DMT she had suffered greatly with. Kate elected to participate in the trial and was randomised to the old interferon DMT. Not only did Kate administer the DMT again for another year, suffering significant side effects, Kate also completed all of the trial requirements, demonstrating both persistence and altruism.

Evie acts as a mentor for newly diagnosed PwRRMS and also as a speaker and advocate in the MS community, regularly participating in MS events and raising awareness of the disease and the impact of RRMS. Evie is adamant that she wants to show the world the positive side of RRMS and what can be achieved, to be more positive in the message.

I want to believe in other people, that's why (I advocate for MS), so I want to make a difference and I figured that I can talk to people, I can write really well...if I'm going to have it, I may as well do something with it...I want people to see people who aren't disabled by MS. Evie line 1205

Other participants such as Griff helped out by educating newly diagnosed PwRRMS or those that are new to infusion treatments by performing a meet and greet role at the local MS infusion centre, especially being available to help young men during this challenging time. It was an important way of displaying positivity to others by demonstrating living positively with the disease by example.

Raising money for MS research was an important display of positivity for Susan after her diagnosis, becoming involved in fundraising bike rides even though she had never ridden a bike before. Susan also made herself readily available to help others newly diagnosed if they needed someone experienced to talk to, enhancing positivity for others as well.

I thought well, OK, I can do something for myself...so I started entering the charities...the MS bike rides...and I raised money. Susan line 538

My friends would ask me...can you talk to so and so...people who have been newly diagnosed...and encourage them and give them ways that they can help themselves...so they feel more positive and not to think that you'll end up in a wheelchair. Susan line 1225

Of course, by way of volunteering in the current research study, being willing to tell their stories and give up time for others in the hope of contributing to MS research, demonstrates being involved and giving back to the MS community for every participant involved in the current research study.

Towards a definition of hope in RRMS

After researching the hope stories of the study participants, the evolution of hope theory, hope nursing literature, MS specific hope literature and considering the

thousands of MS patient consultations I have performed over the last 15 years, I have come to my own beginnings of a definition of hope in the context of RRMS for MS Nurses. I say beginnings, because the hope story has such a long way to go in RRMS, and is likely to change as our understanding of hope deepens and as new research adds certainty to current uncertainty in RRMS. In addition, further disease-specific hope research is greatly needed in all aspects of MS, in both RRMS and in progressive forms of the disease, before we can truly understand its significance.

My current definition: The experience of hope is a future inspired phenomenon, remarkable for its elements of promise, possibility and positivity. Hope is essential to human life, can be inspired, sustained and coached in others and is contagious in nature. Hope is tangible and a very important aspect of living well with RRMS. The MS Nurse can be, and often is, a beacon of positivity and potential for PwRRMS, providing inspiration and hope in words and in actions.

A final word on hope

In order to assess, recognise and to inspire hope in others, MS Nurses need to feel hopeful themselves. This has been aided tremendously in recent years as the first DMTs have been developed to halt progression of the disease and prevent future disability, with MS Nurses often administering the medications and monitoring progress and therefore at the forefront of positive change in RRMS. However, in order to inspire and sustain hope, it has been well reported that MS Nurses need to strategise self-care within themselves (Morgante, 2000). As workload increases dramatically, patient numbers grow and as DMT monitoring becomes more time consuming and critical due to potential life threatening side effects, self-care becomes even more important than ever before. Networking with peers, exercising regularly and eating nutritiously, using confidantes, nurturing supportive relationships, expanding knowledge bases, sharing expertise, taking holidays and stress reduction are all methods the MS Nurse can use to nurture self care (Morgante, 2000). Feeling hopeful themselves is also a way that MS Nurses inspire hope in others (Morgante, 1996). This should be a priority for MS Nurses, not just for themselves and their own health, but because it will shine through and inspire in all

interactions with PwRRMS, their loved ones and other HCPs working in the speciality.

Take one's adversity

Learn from their misfortune

Learn from their pain

Believe in something

Believe in yourself

Turn adversity into ambition

Now blossom into wealth

Emily Dickinson

This theme concludes Chapter 7, Finding the High Road, and the thematic and poetical findings of the current study. Following along the lines of hope and positivity which completed the formal study findings, the next chapter will discuss the study themes in relation to the life journey of RRMS. How the ebbs and flows of life and the life history methodology fits together with the study findings to further enhance the participant stories and bring the key concepts of the lived experience of RRMS alive.