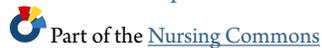

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"Taming the beast": Exploring the lived experience of relapsing remitting multiple sclerosis using a life history approach

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CHAPTER 8: THE LIFE JOURNEY – EBBS AND FLOWS OF LIVING WITH RRMS

*I have many faces, I am never still
Today I am here, tomorrow I am gone
I haunt you for days and then I leave
You can never work out what to believe
Darting in and darting out
I cause havoc and play games with your mind
I cause you to second guess yourself, to self-doubt
And before you know it I'm in and I'm out
My face tomorrow looks completely new
I can still creep up, I can still surprise you
But then you change, you get better at this
You learn, you discover, you realise what I am
You start to beat me down and tell me I'm a sham
I've now met a considerable foe, you're ready for a fight
We'll face up against each other and you'll show me your might
TB*

The life journey of RRMS takes many twists and turns; it is never a linear journey, but rather one of continual flux, which is mainly due to the innate unpredictability and uncertainty that comes with the diagnosis of RRMS. I have been surprised many times in my clinical work by the stability of a patient's condition at a routine appointment, only to see things change dramatically and seriously, within a matter of days. Nothing is set in concrete in this disease. The great advantage of the life history approach is that it reflects the entire life journey; with and without RRMS. By using this process I was able to uncover many aspects of each participant's life, which had an impact on their later journey with RRMS. In particular, many participants described events in childhood, which gave rise to the development of resilience, such as childhood neglect, illness and migration from non-English speaking countries. This resilience was then to serve the study participants well in later life, drawing on coping skills to help them through the difficult and challenging times of RRMS. In their narratives, I was able to uncover details about the participants which profoundly

affected their RRMS story, even if they were unaware of it or of any connection between other life events and their personal development and understanding of RRMS. Even the process of telling the life history helped the participants to understand where they came from and where they were situated now. They recognised their achievements, revelled in their joys and respected their lows.

Although presented theme by theme in a logical succession, the eight themes presented in these study findings do not always follow in sequence and definitely do not always “end” with hope and positivity. Instead, the themes intermingle with each other to reflect the ebb and flow of life. They tell the story of possible stops along the life journey with RRMS and the constant moving backwards and forwards. For example, a newly diagnosed PwRRMS might go through various aspects of the first three themes in fairly quick succession, Piecing Together the Puzzle, (Re)defining Me Now That I have RRMS and Battling the Demons, then encounter theme seven, The DMT Dance with an attitude of theme eight’s Holding Hands with Hope. Then an unexpected pregnancy throws everything into chaos. The PwRRMS is right back to Piecing Together the Puzzle, (Re)defining Me, Battling Demons and having to face difficult decisions about whether to proceed with the pregnancy considering their exposure to medications known to cause foetal harm. Putting together a medical team to help support and solve this problem will form part of Taming the Beast and then (hopefully) using skills from Holding Hands with Hope to move forward.

Thereafter may be a year of stability and quiescence living with RRMS, with perhaps the occasional Battling the Demons making an appearance on days of significant fatigue or with the occurrence of a bladder infection. Then the uncertainty presents again with the development of a severe motor relapse just days before a big work event. A hospital admission and many tests follow, unleashing Piecing Together the Puzzle and Battling the Demons (worry, anxiety, despair) as their perceived world falls apart. The DMT Dance is set to start again as the specialist highly recommends changing to a new, higher efficacy DMT, with several potentially life threatening side effects. Whilst trying to use the skills learnt in Taming the Beast, the PwRRMS is unable to see past the side effect profile and Battling the Demons threatens to take over all they have learnt so far. Will I walk again? Will my Boss want to sack me? What about the mortgage? Maybe this is my life now? Will my husband want to

leave me now he can see what is possible with RRMS? I've always been unlucky, surely I will get that side effect that kills...and there starts the long road back to Taming the Beast, The DMT Dance and Holding Hands with Hope to reign in positivity and belief about the future. As symptoms subside, the new DMT starts to take effect, work allows time off to recover and life starts to settle again, Holding Hands with Hope moves back into the foreground of life. Until a year later when a work opportunity means a move to another town without an MS Specialist...and the possibility of either Battling the Demons, or Taming the Beast arises. It could go either way.

Using ethnography methodology, and the life history method in particular, to uncover the study themes works in skilfully with the life trajectory of RRMS. The most effective way to demonstrate the linking of the life trajectory, life history methodology and the themes uncovered by this research study, is to illustrate the life course of several study participants and the interlinking of the study theme findings with their individual stories. The true value of the life history methodology can then be clearly seen as the themes overlay their life lived with RRMS. The ebbs and flows are shown below in four examples of life stories and recurring themes of Susan (Table 6), Will (Table 7), Griff (Table 8) and Piper (Table 9). These participants have been selected to represent a cross section of male and female experiences, short and long term diagnoses, a range of other health issues and a range of disease severity living with RRMS. Similar tables for the remaining nine study participants have also been completed and can be located in Appendix 13.

Susan's life story instilled in me a sense of resilience acquired by many years of suffering, mostly in silence. Susan absorbed much of her parents' grief and blame when she was diagnosed with RRMS and remained strong as those around her crumbled. It wasn't until many years later that Susan realised she was dormant in her journey; she wasn't able to move forward. Working as a HCP, Susan was well aware of the journeys of others with chronic illness, further complicating her view of self and how she was progressing compared to others. Determined to change, Susan began a counselling course, which set her on a new path (finding her North Star) and life gradually began to change for the better. Today Susan is thrilled with her family and totally in love with life, despite continued hardships along the way.

Table 6: Susan's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>Child of a migrant family</i> • <i>Severe illness of glandular fever as a child</i> • <i>Physically and emotionally demanding employment</i> • <i>Working in healthcare</i> • <i>Living and working overseas</i>
Onset of first symptoms	<p>Piecing Together the Puzzle</p> <p>High (In)visibility (strive to be visible)</p> <p>Surplus Suffering (brushed off)</p>
Symptoms worsen	<p>Piecing Together the Puzzle (what's happening?)</p> <p>Surplus Suffering (brushed off)</p> <p>Piecing Together the Puzzle (tests, tests, tests)</p> <p>Battling the Demons (fear, worry & anxiety)</p>
Hospitalised, it could be MS	<p>Surplus Suffering (inflicted by clinical care)</p> <p>Battling the Demons (fear, worry & anxiety)</p> <p>Holding Hands with Hope (purposeful positivity)</p>
Confirmed diagnosis of RRMS	<p>Piecing Together the Puzzle (the day my life changed forever)</p> <p>Re(defining) Me now that I have RRMS (getting acquainted)</p> <p>Battling the Demons (fear of burden)</p> <p>Holding Hands with Hope (faith)</p>
Learning to live with RRMS	<p>Re(defining) Me now that I have RRMS (getting acquainted, dare to compare)</p> <p>Battling the Demons (fear, worry & anxiety, despair)</p> <p>High (In)visibility (strive to be visible)</p> <p>The DMT Dance (hardyards: decisions based on hope)</p>

	Battling the Demons (fear of the wheelchair)
Sharing journey with family and friends	Re(defining) Me now that I have RRMS (getting acquainted, reverse stigma, normalcy) Taming the Beast (support from family, friends and community)
Relapse	Piecing Together the Puzzle (what's happening?) Battling the Demons (fear, worry & anxiety) High (In)visibility (strive to be visible) The DMT Dance (hardyards: decisions based on fear <i>and</i> hope)
Completes life counselling course to better understand self and illness	Taming the Beast (support from family, friends and community)
Relapse	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare) Piecing Together the Puzzle (what's happening?) The DMT Dance (decisions based on fear <i>and</i> hope) Re(defining) Me now that I have RRMS (working out work, normalcy)
Living with RRMS alone	Battling the Demons (fear, worry & anxiety) Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, search for meaning)
New beginnings	Re(defining) Me now that I have RRMS (normalcy) Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, finding my A-Team) Holding Hands with Hope (purposeful positivity, defiant hope)
Searching for a life partner	Battling the Demons (fear of being a burden) Holding Hands with Hope (purposeful positivity, defiant hope)

Relapse	Battling the Demons (all fears, worry & anxiety) The DMT Dance (hardyards: decisions based on fear <i>and</i> hope)
Meeting husband and beginning relationship	Taming the Beast (support from family, friends and community) Holding Hands with Hope (purposeful positivity)
Infertility issues	The DMT Dance (hardyards: decisions based on fear) Taming the Beast (resilience) Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS)
Pregnancy achieved	Holding Hands with Hope (purposeful positivity, optimism) Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, finding my A-Team) Battling the Demons (fear of being a burden)
Life parenting with RRMS	Taming the Beast (support from family, friends and community) Holding Hands with Hope (purposeful positivity, optimism) Battling the Demons (fear of being a burden) Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS)
Change of DMT	The DMT Dance (decisions based on fear & hope) Holding Hands with Hope (purposeful positivity, optimism) Re(defining) Me now that I have RRMS (getting acquainted)
Serious illness for husband	Battling the Demons (fear, worry & anxiety) Holding Hands with Hope (purposeful positivity, optimism, defiant hope)

Taming the Beast (support from family, friends and community, resilience)

Life settles with RRMS- current status quo **Holding Hands with Hope (giving back and getting involved)**

Taming the Beast (support from family, friends and community, maintaining health & wellness)

Will's life story also reflected several years of hardship as he battled depression after his diagnosis and fought his way back to a happier life, determined to live life to the full. One of his most difficult challenges came about when the DMT that was successful in controlling his relapses, natalizumab, needed to cease due to an unexpected high-level JCV result, which put him at higher risk for the serious and potentially fatal side effect, PML. Will had experienced many years of disease stability up until this time and this came as a shock. However, as his life journey reflected, this time when challenge presented itself, his life circumstances were different to earlier in his journey, and he now had the close support and love of his wife helping him in Taming the Beast.

Table 7: Will's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>Fractured family life, childhood neglect</i> • <i>Death of mother when he was 13 years old</i> • <i>Experience of MS from a close friend who suffered progressive MS and was severely disabled and blind</i>
Onset of first symptoms at 17 (with no follow-up)	<p>Piecing Together the Puzzle (what's happening?)</p> <p>Battling the Demons (fear)</p> <p>High (In)visibility (welcome cloak, hide)</p>
Living well, no symptoms	<p>Battling the Demons (fear, worry & anxiety)</p> <p>Taming the Beast (maintaining health & wellness)</p> <p>Piecing Together the Puzzle (tests, tests, tests)</p>
Travelling overseas, working	Taming the Beast (maintaining health & wellness)

hard

Onset blindness and unexplained neurological symptoms, hospitalised with no diagnosis for weeks

High (In)visibility (welcome cloak, hide)

Battling the Demons (fear, worry & anxiety)

Piecing Together the Puzzle (what's happening?, tests,tests,tests)

Surplus Suffering (misdiagnosis)

High (In)visibility (welcome cloak, hide)

Diagnosis of RRMS

Piecing Together the Puzzle (the day my life changed forever)

Re(defining) Me now that I have RRMS (getting acquainted, working out work, non-disclosure)

Battling the Demons (fear of burden, worry & anxiety, saboteurs, uncertainty)

Holding Hands with Hope (purposeful positivity, optimism)

Learning to live with RRMS

Re(defining) Me now that I have RRMS (getting acquainted, dare to compare)

Battling the Demons (fear, worry & anxiety, depression & despair, uncertainty)

High (In)visibility (welcome cloak, hide)

The DMT Dance (decisions based on hope)

Holding Hands with Hope (defiant hope)

Taming the Beast (Finding my North Star, choosing my A-Team)

Battling depression

Piecing Together the Puzzle (what's happening?)

Taming the Beast (support from family, friends and community)

The DMT Dance (hardyards: decisions based on fear)

Battling the Demons (depression & despair, I'm

	never free, social isolation)
	High (In)visibility (welcome cloak, hide)
	The DMT Dance (hardyards: decisions based on fear <i>and</i> hope)
	Taming the Beast (Finding my North Star, choosing my A-Team)
Recovering from depression and living well with RRMS	<p>Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, searching for meaning, harnessing a sense of humour)</p> <p>The DMT Dance (hardyards: decisions based on hope, switching to a better life)</p> <p>Re(defining) Me now that I have RRMS (working out work, balancing losses & gains)</p> <p>Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)</p> <p>High (In)visibility (welcome cloak, hide)</p>
Well and relapse free on natalizumab	<p>The DMT Dance (hardyards: decisions based on hope, switching to a better life)</p> <p>Taming the Beast (support from family, friends and community, finding my North Star, resilience)</p> <p>Holding Hands with Hope (purposeful positivity, optimism)</p> <p>Re(defining) Me now that I have RRMS (balancing losses & gains, dare to compare, normalcy, working out work)</p>
Meeting life partner and starting a family	<p>Taming the Beast (support from family, friends and community, finding my North Star)</p> <p>Re(defining) Me now that I have RRMS (normalcy, parenting with RRMS)</p> <p>Holding Hands with Hope (purposeful positivity, optimism, searching for meaning)</p>

Missed JCV blood test and then a positive high titre result- immediately cease natalizumab	The DMT Dance (decisions based on fear)
	Battling the Demons (fear, worry & anxiety)
	Taming the Beast (support from family, friends and community, resilience)
	Re(defining) Me now that I have RRMS (balancing losses & gains)
Decision to start alemtuzumab	Taming the Beast (support from family, friends and community)
	The DMT Dance (the hardyards: decisions based on hope)
	Holding Hands with Hope (purposeful positivity, optimism, restorative hope)
Living with RRMS, finding life balance	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
	Holding Hands with Hope (purposeful positivity, optimism, curative hope)
	Re(defining) Me now that I have RRMS (normalcy, working out work, balancing losses and gains, parenting with RRMS, disclosure)
	High (In)visibility (welcome cloak, hide)

Griff feels that he has lived for many decades with RRMS, despite not being diagnosed until his late forties. He recalls symptoms he covered up in his twenties and thirties that indicate he may have been living with RRMS for much longer than 15 years. This situation gives Griff confidence to view the future as bright, knowing he is (relatively) mildly physically disabled by RRMS after so many years of living with the disease. However, there is a flip side to this scenario, one where this confidence was severely impacted. This was discussed in Chapter 6, when Griff

attended an MSA meeting and was confronted by the mother of a severely disabled young lady with MS. To this day Griff often feels he isn't as worthy as others to have the diagnosis of RRMS. This is because he feels he doesn't have the added suffering and disability that more severe MS entails.

Table 8: Griff's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>Severe illness as a child and young adult- multiple respiratory conditions, hospitalisations</i> • <i>Working in government agency</i> • <i>Death of parents</i> • <i>Several long term relationships</i> • <i>Marriage separation</i>
Onset of first symptoms in early twenties	<p>Piecing Together the Puzzle (what's happening?)</p> <p>High (In)visibility (welcome cloak)</p> <p>Battling the Demons (fear, worry)</p>
Intermittent symptoms continue for next 20 years on and off	<p>Piecing Together the Puzzle (what's happening?)</p> <p>Battling the Demons (fear, worry)</p>
Diagnosed with Guillian Barre 12 years prior to RRMS diagnosis	<p>Piecing Together the Puzzle (what's happening, tests, tests, tests)</p> <p>Battling the Demons (fear, worry)</p> <p>Surplus Suffering (misdiagnosis)</p>
Personal relationship issues with partner, separation	<p>Battling the Demons (fear, worry)</p> <p>Holding Hands with Hope (purposeful positivity)</p>
Relationship strengthens through separation, back	<p>Taming the Beast (support from family, friends and community)</p>

together, children	Holding Hands with Hope (purposeful positivity)
Severe relapse at work	Piecing Together the Puzzle (what's happening, tests, tests, tests) Battling the Demons (fear, worry)
Confirmed diagnosis of RRMS	Piecing Together the Puzzle (the day my life changed forever) Re(defining) Me now that I have RRMS (getting acquainted, disclosure, working out work) Battling the Demons (fear of burden) Holding Hands with Hope (purposeful positivity, optimism)
Learning to live with RRMS	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare) Battling the Demons (all fears, worry & anxiety, saboteurs, social isolation) High (In)visibility (strive to be visible) The DMT Dance (hardyards: decisions based on hope) Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
Comparing self with friend with progressive MS	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare) Battling the Demons (fear, worry & anxiety) Taming the Beast (support from family, friends and community, getting a handle on RRMS)
Unemployment and role as "house husband"	High (In)visibility (strive to be visible) Battling the Demons (fear, worry & anxiety, saboteurs, uncertainty, social isolation) Re(defining) Me now that I have RRMS (working

			<p>out work, dare to compare, parenting with RRMS, losses & gains)</p> <p>Holding Hands with Hope (purposeful positivity, optimism, searching for meaning)</p>
Confrontation at MSL meeting with mother of a severely disabled girl			<p>Re(defining) Me now that I have RRMS (getting acquainted, dare to compare, parenting with RRMS, normalcy)</p> <p>Battling the Demons (fear, saboteurs, uncertainty, social isolation)</p> <p>Surplus Suffering (inflicted by community)</p> <p>High (In)visibility (strive to be visible)</p>
Sexual health dysfunction			<p>Piecing Together the Puzzle (what's happening?, tests, tests, tests)</p> <p>Re(defining) Me now that I have RRMS (losses & gains, normalcy)</p> <p>Battling the Demons (fear, worry & anxiety)</p>
Struggling with glatiramer acetate	with DMT		<p>The DMT Dance (hardyards: decisions based on hope)</p> <p>Battling the Demons (fear, worry & anxiety)</p> <p>Re(defining) Me now that I have RRMS (losses & gains)</p> <p>Taming the Beast (getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)</p>
Treatment change to natalizumab		to	<p>Holding Hands with Hope (purposeful positivity, defiant hope, restorative hope, functional hope)</p> <p>The DMT Dance (switching to a better life)</p> <p>Battling the Demons (worry)</p> <p>Taming the Beast (support from family, friends and community)</p>
Struggling with severe fatigue /feeling a poor role model to his children			<p>Battling the Demons (fear of burden, worry, despair, saboteurs, social isolation)</p>

	Re(defining) Me now that I have RRMS (losses & gains, parenting with RRMS, normalcy, dare to compare)
	Holding Hands with Hope (purposeful positivity)
	Taming the Beast (resilience, North Star, maintaining health & wellness)
	High (In)visibility (strive to be visible)
Thriving on natalizumab with social interactions at the hospital, mentoring others with RRMS	Taming the Beast (support from family, friends and community)
	Holding Hands with Hope (purposeful positivity, optimism, giving back and being involved)
	Re(defining) Me now that I have RRMS (balancing losses & gains, negotiating normalcy)
	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
Missed blood test for JCV, then high titre JCV blood test positive - ceased natalizumab immediately	Battling the Demons (fear of burden, worry, despair, saboteurs, uncertainty, social isolation)
	The DMT Dance (hardyards: decisions based on fear)
	Re(defining) Me now that I have RRMS (dare to compare, normalcy, losses & gains)
	Taming the Beast (support from family, friends and community, maintaining health & wellness, resilience)
Commencing new treatment fingolimod and refusing alemtuzumab	Holding Hands with Hope (optimism, restorative hope)
	Taming the Beast (maintaining health & wellness, North Star)

	The DMT Dance (hardyards: decisions based on fear, switching to a better life)
	Battling the Demons (uncertainty, social isolation)
Moving forward, living well with RRMS	Taming the Beast (maintaining health & wellness, North Star, support from family, friends and community, resilience)
	Holding Hands with Hope (optimism, restorative hope, searching for meaning, giving back & getting involved)
	Re(defining) Me now that I have RRMS (normalcy, losses & gains)

The final life story presented in this section is Piper’s story, reflecting a shorter life span living with RRMS than the previous three participants presented, but still an abundance of applied themes and subthemes to her story. Piper’s life journey has been marred by many years of Surplus Suffering due to constant brush-offs of her symptoms by HCPs in her small rural community. However, her fierce determination to not be defined by the disease and to live her best life possible is completely overwhelming in intensity. Piper starts every day believing she is capable of Taming the Beast and is constantly on the lookout to do so. Although disappointed by her many years of struggle, she is in no way bitter about it, she still views many other PwRRMS as going through worse scenarios and is grateful that she was eventually diagnosed correctly.

Table 9: Piper’s life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>Child of a migrant family</i> • <i>Debilitating headaches and nerve pain as an early teen through to adulthood</i> • <i>Small rural community upbringing</i>
Onset of first symptoms	<p>Piecing Together the Puzzle (what’s happening?)</p> <p>High (In)visibility (strive to be visible)</p>

	<p>Surplus Suffering (brushed off)- <i>repeated</i></p> <p>Piecing Together the Puzzle (what's happening?)- <i>repeated</i></p> <p>Surplus Suffering (brushed off)- <i>repeated</i></p> <p>Piecing Together the Puzzle (tests, tests, tests)- <i>repeated</i></p> <p>Battling the Demons (fear, worry & anxiety, depression & despair)</p> <p>High (In)visibility (strive to be visible)</p>
Symptoms worsen- come and go over many years	
Depression	<p>Battling the Demons (depression)</p> <p>Taming the Beast (support from family, friends and community)</p>
Recovery from depression	<p>Surplus Suffering (brushed off)- <i>repeated</i></p> <p>Holding Hands with Hope (purposeful positivity)</p> <p>Taming the Beast (support from family, friends and community)</p>
Infertility	<p>Piecing Together the Puzzle (tests, tests, tests)</p> <p>Taming the Beast (resilience)</p> <p>Battling the Demons (fear, worry & anxiety)</p>
Significant relapse with new symptoms	<p>Piecing Together the Puzzle (what's happening, tests, tests, tests)</p> <p>Taming the Beast (choosing my A-Team)</p> <p>Battling the Demons (fear, worry & anxiety)</p> <p>High (In)visibility (strive to be visible)</p>
Confirmed diagnosis of RRMS	<p>Piecing Together the Puzzle (the day my life changed forever)</p> <p>Re(defining) Me now that I have RRMS (getting acquainted, normalcy)</p> <p>Battling the Demons (fear of burden, worry & anxiety, fear of the wheelchair)</p> <p>Holding Hands with Hope (restorative hope, purposeful positivity- searching for meaning)</p> <p>The DMT Dance (hardyards: decisions based on</p>

Learning to live with RRMS	<p>hope)</p> <p>Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, normalcy)</p> <p>Battling the Demons (fear, worry & anxiety, despair, uncertainty)</p> <p>High (In)visibility (strive to be visible)</p> <p>The DMT Dance (hardyards: decisions based on hope)</p> <p>Battling the Demons (fear of the wheelchair)</p> <p>Taming the Beast (finding my North Star, maintaining health & wellness, getting a handle, resilience)</p>
Sharing journey with family and friends	<p>Re(defining) Me now that I have RRMS (getting acquainted, normalcy, dare to compare)</p> <p>Taming the Beast (support from family, friends and community, getting a handle)</p> <p>Battling the Demons (fear)</p>
Side effects from DMT interferon	<p>Piecing Together the Puzzle (what's happening?)</p> <p>Holding Hands with Hope (defiant hope, functional hope, search for meaning)</p> <p>High (In)visibility (strive to be visible)</p> <p>The DMT Dance (hardyards: decisions based on fear <i>and</i> hope)</p>
Commence new DMT dimethyl fumarate	<p>The DMT Dance (switching to a better life)</p> <p>Re(defining) Me now that I have RRMS (getting acquainted)</p> <p>Battling the Demons (all fears, worry & anxiety, saboteurs)</p>
First travel overseas	<p>Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning)</p> <p>Taming the Beast (support from family, friends and</p>

	community, finding my North Star)
	High (In)visibility (a welcome cloak)
New relapse	Piecing Together the Puzzle (what's happening?)
	Battling the Demons (fear, worry & anxiety, saboteurs)
	Re(defining) Me now that I have RRMS (normalcy)
	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
Living with RRMS	High (In)visibility (strive to be visible)
	Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning, sense of humour)
	Taming the Beast (support from family, friends and community, maintaining health & wellness)
	Re(defining) Me now that I have RRMS (dare to compare, normalcy, parenting with RRMS, losses & gains)
Sister has a neurological episode	Battling the Demons (fear, worry & anxiety, saboteurs)
	Taming the Beast (support from family, friends and community)
	Holding Hands with Hope (purposeful positivity)
Relapse at Christmas	Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS)
	The DMT Dance (hardyards: decisions based on fear)
	Taming the Beast (getting a handle, support from family, friends & community, resilience)
	Battling the Demons (fear of being a burden)
	Holding Hands with Hope (purposeful positivity, functional hope, restorative hope)
Moving forward with RRMS	Taming the Beast (support from family, friends and

community, maintaining health & wellness, resilience)

Holding Hands with Hope (purposeful positivity, optimism, giving back and getting involved)

Re(defining) Me now that I have RRMS (getting acquainted, parenting with RRMS, normalcy)

As noted life history author Plummer (2001, p.7) reflects “life is in fluctuating praxis, always in flow and ever messy.” As I began the task of linking each individual’s life events with the themes and subthemes, the process, although “messy”, felt incredibly straightforward despite being very time consuming. This process flowed organically and seemed to fit together very neatly, participant after participant as I worked manually through each transcript. I was surprised at first at the ease in which the themes and life events all fit together so well. I then realised that this organic flow was demonstrating to me that the themes fit back with the data well, and that this was a reflection of good coding and theme development. As Braun and Clarke (2013) suggest, to be able to invoke the original data just by reading the code or theme is the result of capturing the both latent and salient features well, and is a fundamental aim of the coding process. The further inclusion of specific subthemes within each theme category in the life trajectory tables gave the added ability to “drill down” even further into each theme, to identify a feature of the theme that was more descriptive of the life event, but still fell under the same central organising concept of the overarching theme.

Life history gives voice to the ordinary members of a culture as they cope on a daily basis with the joys and challenges of life (de Chesnay & Fisher, 2014), and was embraced and welcomed by every participant in the current study. The use of focused ethnographic life history methodology worked cleverly with the ebbs and flows of living with a chronic illness such as RRMS to reveal themes and subthemes exploring the lived experience of RRMS. As RRMS is most commonly diagnosed in young adults and is usually not life threatening (Compston & Coles, 2008), it represents a long period of time to live with a chronic illness. Hopes, dreams, school, study, sport, work, relationships, marriages, pregnancies, children, friends, relationship breakdowns, grieving, set-backs, loss, pride, happiness, contentment;

these are some of life's typical challenges and joys, occurring with or without the presence of RRMS. Using the life history approach generated rich and detailed data about the experiences of living with RRMS and unearthed some extraordinary insights, which have been outlined throughout the study findings chapters and will be given deep clinical relevance in the following, concluding chapter.