2019

# "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*

# CHAPTER 5: STUDY FINDINGS - THE LIFE STORIES

As comprehensively discussed in the previous chapter, Methodology and Methods, the study participants share their life history, but the life stories are co-constructed by the researcher (Plummer, 2001). The life histories told by the study participants became the life stories co-constructed by me as the researcher, and formed the initial part of the study findings. The life stories provide context and understanding to the specific thematic findings in the following three chapters (chapters 6 to 8), as the reader is able to gain perspective about the lives of the study participants. This helps to appreciate each participant's challenges, joys and life happenings; with each narrative a unique story.

All participants were asked to choose their own pseudonym for the study, this process involved much thought and care. It is for this reason that I have kept two very similar names, Rudi (participant four) and Ruby (participant eight) in the study findings and report. For these two participants, their chosen names meant so much to them, having a great deal of personal significance. Two participants asked me to choose a pseudonym for them. It is impossible to include all of the information related to RRMS and other life happenings for the study participants within the word limit confines of this thesis, but these stories have taken the most relevant information from the history to represent a brief life story for each participant. I have included a short summary of the DMT story, because for all study participants, the DMT (or choice not to have a DMT) had some effect on their life journey, as told by the participants. The life stories of all 13 study participants are presented below, in chronological order of the interviews. I added an overarching phrase to each pseudonym, a short title of sorts, to describe their journey and to provide a deeper portrayal of their story with each pseudonym.

### Participant number 1: Piper's story

Pushed around from pillar to post

Piper was 42 years of age at the time of our interview and has lived her entire life in the same rural town where she was born. Piper works casually as a volunteer,

enjoying her time with people and a chance to do something with meaning. Part of a very close migrant family, her extended family is a very important part of her life. Married to her childhood sweetheart, Piper is the very proud mother of two busy and spirited boys. Diagnosed with RRMS just over two years ago, Piper's story is interspersed with periods of mysterious illness of over 25 years duration, countless visits to doctors and a strong sense of determination to find an explanation for her unexplained symptoms.

Despite her bright and bubbly exterior, Piper's life has been tormented intermittently with unexplained physical and psychological symptoms, which at times have been completely demoralising for her, leaving her feeling "like a fraud" and "like a hypochondriac". Piper attributes part of the challenge of understanding her various symptoms to years of living in a rural community with a constant thoroughfare of family doctors called General Practitioners (GPs), "always someone new…starting again at the front end" and never getting to the bottom of her symptoms. Piper's earliest recollection of neurological symptoms occurred at the age of 13 when she experienced the first of many severe headaches, wrapping around her face and causing intense and unbearable pain. These types of pain episodes were to continue on and off for many years.

Piper recalls "always being at the doctors" and having "all the tests under the sun" to find the cause of her unexplained symptoms. From her mid twenties, she describes a regular pattern of "getting checked and never finding anything wrong". Piper suffered a severe episode of depression after her marriage and was also diagnosed with anxiety. She worked hard with a psychologist to turn her life around and change her thought patterns and was also treated with medication for depression and anxiety. Piper has since wondered if this episode might have been due to early RRMS, as depression is a common co-morbidity. Despite the emotional pain, Piper describes this time in her life as a major turning point for her and regards seeking help as "the best thing I ever did...I didn't realise til I was well that I was living half a life".

Over the ensuing years, Piper was diagnosed with other illnesses (such as underactive thyroid, Raynauds, low vitamin D) and also experienced significant back pain from disc issues and also suffered years of infertility. The time leading up to

Piper's diagnosis of RRMS was an especially frustrating time in her journey. Approximately 6 months prior to diagnosis, Piper was bedridden; suffering fatigue, pins and needles, a loss of bladder control and poor memory. She describes this time as feeling like she was "getting old really quickly…all of a sudden". Piper recalls saying to her husband "I think I really am going crazy, like the doctors think I am". After a few weeks these symptoms settled down and Piper decided to go on a holiday to another state and saw a GP there whilst she was away. This GP performed a neurolological examination, surprisingly, her first one ever. MS was suspected and Piper was immediately sent for an MRI scan and then to see a neurologist in the closest large city.

In quick succession, Piper was diagnosed with RRMS and commenced on a DMT, the interferon beta1-b (Betaferon®) and she learnt to self-inject the medication every second day. Piper recalls her overwhelming feeling at diagnosis as being "relieved that I wasn't going mad". Unfortunately the DMT did not control the disease, and she suffered further relapses. Piper has since commenced an oral DMT, dimethyl fumarate (Tecfidera®) which has stabilised her relapses, but not her symptoms, which continue to be a daily reminder to Piper of RRMS. She suffers greatly from fatigue, nerve pain, insomnia and spasms but works through each day as best she can; eating nutritiously, working casually, caring for her family, exercising regularly and "walking through the pain" to be as healthy as possible. Piper's extended family have also been instrumental in providing support and encouragement, particularly when she hasn't felt well or has been experiencing a relapse. They have told Piper that they are amazed at her tenacity and determination.

When recalling her diagnosis, Piper says she was "probably lucky…a lot of people have to wait years and get pushed around from pillar to post". The interesting thing was, whilst listening to Piper's story all I could think about was how *Piper* was "pushed from pillar to post" around a medical system that wasn't really listening to her. In keeping with the new thought patterns she learnt from her therapy to overcome depression, Piper has spent the last two years since diagnosis enjoying life as much as possible. Piper is expanding her social circle (previously she kept to herself and family a lot), travelling overseas at every opportunity and trying to extract as much joy out of life as possible. Piper is making the most out of every day.

**Participant number 2: Margot's story**

Making the most of all I have and getting on with it

Margot, aged 57, at the time of our interview, moved to Australia with her parents and sister when she was just a baby. Margot recalls her childhood being dominated by multiculturalism, speaking, reading and writing English at school and then being required to immerse herself in her original culture once back inside her home. Margot went to university, worked in retail and customer service and eventually met her husband with whom Margot has two sons. Margot was fortunate to maintain good health until 16 years ago at the age of 41, when she suddenly tripped and fell heavily, causing injuries to both her knees. She didn't think much of it at the time, but Margot developed numbness up to her hips in the ensuing days, alternating constipation and diarrhea, and later numb hands. Totally perplexed, she arranged to see her local GP who sent her for some investigations. Margot then saw a neurologist and had a spinal MRI which revealed some "faded spots" on her spine. The neurologist felt it was probably due to a virus. In retrospect Margot recalls feeling like she was "patted on the head" on her way out as the neurologist said "there is nothing wrong with you, off you go" and that "that was the end of that".

As years went by, Margot noticed that she was tripping a bit more and reported to her GP that the nagging numbness from years before had never really totally gone away. She was referred to another neurologist who ordered both a spinal and brain MRI. This led immediately to a diagnosis of RRMS. Margot was convinced until this point that she had motor neuron disease (MND) and describes a feeling of "relief" on hearing she had RRMS. Margot disclosed her new diagnosis to several family and friends who were aware of recent events, however she made a conscious decision not to tell her parents her diagnosis. Margot felt that their limited English, poor understanding of MS, and her father's tendency to "worry", would cause too much anguish and apprehension for them. Margot also elected not to disclose her diagnosis to her workplace at this time.

Margot commenced interferon beta1-b (Betaferon®), a medication she self injected every second day until natalizumab (Tysabri®) was made available in Australia. Margot then attended a monthly hospital visit for an infusion of natalizumab for many years. She tolerated the medications well and was delighted to find when she started natalizumab that she was paired up with other people with MS having the same monthly infusions. This was the first time Margot came into contact with others living with RRMS and found it "fantastic", sharing tips and stories with others and feeling a sense of camaraderie. Margot went on to fingolimod (Gilenya®) tablets after a couple of years relapse free, which she remains on to this day.

Margot considers herself lucky in that she has not had many troublesome relapses and has generally remained well, despite some accrual of disability in recent years. She was working part-time until a few years ago when she decided to retire. Travel has been important, Margot belonging to a tight knit group of friends who travel together regularly.

Margot also sometimes uses a walking stick to help with stability on stairs and uneven ground, mainly to alert others that "there is something wrong with her" and to "be more careful around her". Otherwise Margot is gently ambulant, walking steadily, slowly and with a limp, but determinedly walking. She also enjoys looking "romantic" when out with her husband as they hold hands to aid her stability. She looks forward to more overseas travel with friends, conscious that she wants "to do more travelling, before I can't".

**Participant number 3: Kate's story**

I get knocked down but I get up again, you can't beat me

Kate, a clever and engaging scientist, was aged 42 years at the time of our interview, and has lived with RRMS for almost 20 years. She has recently retired from her career; initially because her job was made redundant and later because her MS symptoms have made returning to the workforce difficult. Kate's husband of 25 years is supporting Kate through this momentous change in her life, which she admits she has still not yet accepted.

At the age of 23, and with a toddler son, Kate suddenly went blind in her left eye, paving the way for several years of uncertainty as specialists struggled to work out exactly what was happening to her. Kate was in the middle of studying part-time and working full time when her episode of sudden blindness occurred. It gradually resolved, only to be followed by several more episodes of unexplained blindness in the following two years. She feared the worst, especially when the first doctor she saw told her it could be a brain tumour. After a year or so, Kate was referred to a neurologist who told her abruptly at their first meeting that she "probably had MS". Kate recalls that at the time she had no idea what this meant. He told her that she "may end up in a wheelchair and you will probably be blind in five years". Kate recalls that she felt "a mess" and he prescribed her anti-depressants to, in the neurologist's words "get over it".

During yet another baffling episode of unexplained blindness, Kate was referred to a physician who immediately told her to throw out her antidepressants, which she gladly did and immediately began to feel "a lot better". This doctor was to become one of Kate's biggest supporters, treating her RRMS with some unusual but forward-thinking treatments at the time. He was always available for her to treat the numerous relapses and symptoms she would go on to suffer. These years were especially challenging as Kate juggled her family life, her full time job and her studies toward a higher degree, always under the constant threat of another MS relapse. Constant short courses of pulse steroids took their toll on Kate emotionally " boy, I was angry…I would get fired up so quickly", causing arguments with her husband, as she struggled with the side effects from the various medications.

It wasn't until a year after these episodes of blindness that the first brain lesions appeared on an MRI, to *confirm* a diagnosis of RRMS. In keeping with diagnostic guidelines at the time, it was still a "probable" diagnosis, but not a confirmed diagnosis of RRMS that Kate had had to contend with. Kate commenced treatment with the self injected interferon beta1-b (Betaferon®) every second day, struggling with the side effects, feeling "totally miserable and really, really sick". She eventually relented and decided to stop DMTs for the next couple of years, continuing to suffer relapses. As new medications became available in Australia,

Kate eventually started on DMT again. She was commenced on glatiramer acetate (Copaxone®). Kate recalls the struggle to find a suitable injection site, being "black and blue around the tummy" from the daily injections. Kate later changed to the three times weekly interferon beta1-a (Rebif®). A couple of years later, once again, the interferon related side effects took their toll and Kate felt she needed to stop treatment.

Up until this time Kate had managed to keep her diagnosis of RRMS secret from her son, thinking "he's a kid, there's no need for him to know...I suppose it's my idea of keeping him safe". When he started high school and she could no longer disguise the side effects from the interferon, Kate felt ready to disclose her diagnosis of RRMS to him. She felt like he took the news well, although "you can tell that he was really upset". About ten years after her RRMS diagnosis, Kate commenced the new monthly infusible monoclonal DMT natalizumab, but suffered a serious side effect which rendered her unable to have further treatment. Once again, there were no options left for Kate, but her tenacious nature saw her enroll in a clinical trial for a new medication. Today, Kate is being treated with oral DMT fingolimod (Gilenya®) and also takes other medications to help with spasticity, her most painful and unrelenting MS symptom.

Kate also weathered many storms through these years of living with RRMS, as her extended family struggled with grief and illness in other family members. As part of a migrant family, there was a sense of family commitment, with Kate vigilantly maintaining all of her family responsibilities, despite her own significant health issues. Kate also suffered significant injuries from a fall which has impacted her mobility in recent years. Since her employment contract was not renewed and Kate was forced to stop working in a job that she loved, she feels the great irony is that now she has the time to do things she enjoys, but sadly her body cannot keep up to do them.

Although Kate believes she is currently at a crossroads in her life, Kate remains a fighter. Kate isn't after a miracle cure, instead she just wants to stay the same and not deteriorate further …"if I can stay like this I'll be happy". Kate left a lasting

impression on me as an absolute powerhouse, as interested as she is in helping herself, it is for the many others also suffering that she goes the extra mile.

**Participant number 4: Rudi's story**

I've been through so much in my life, why more?

Rudi is married and the mother of four lively children and living in a country town, close to the community where she was born. Rudy was aged 42 years at the time of our interview and working part time in a local business, in a job that is "not very stimulating", but affords her reasonable hours and is mindful of the fact that she has "bad days".

Rudi recalls her childhood as difficult and sometimes it was very emotionally painful. Early in the interview, Rudi commented that she wasn't "going there", however Rudi opened up as the interview progressed, and this openness helped me understand some of the childhood trauma she had been through. Rudi described living her childhood with an absent father and a mother suffering from mental illness. A self-declared rebellious teenager, Rudi left home at a young age, before returning years later. Tragically, in later years Rudi was also to suffer the stillbirth of her son, a time that she recalls as immensely painful…"not in my wildest dreams did I think that would ever happen", continuing to experience much emotional pain.

Rudi was diagnosed with RRMS about 11 years prior to our interview at the age of 31. Working out with a personal trainer one day, she suddenly experienced a facial droop. Rudi immediately saw a doctor who wasn't concerned about the symptom. Nothing more happened until 4 years later when Rudi experienced an episode of facial numbness, which quickly developed into slurring of speech and limb weakness. She was rushed to hospital as it looked to others as if she had experienced a stroke. The symptoms gradually resolved over the next week. A subsequent MRI was performed and Rudi attended a visit to the neurologist for the very first time. She was diagnosed with focal migraines. Rudi recovered, although never completely, with some residual numbness down the left side of her body, she then sought a referral to a city neurologist. Rudi was diagnosed with RRMS at this first visit to the new neurologist. This diagnosis was based on Rudi's clinical history, neurological

examination and the MRI scans. Rudi commenced interferon beta1-b (Betaferon®) injections every second day almost immediately.

Rudi recalls feeling "very angry" after the diagnosis, specifically saying that "relief…I didn't find that". Rudi started treatment without wanting to learn more about the disease. Rudi's mother went to visit the local MS Society and brought home brochures, which Rudi promptly threw in the bin. Within three months, Rudi was in the intensive care unit suffering another severe relapse, this time losing her speech completely. During this period in her life Rudi recalls " I was sick for a very long time" with numbness, weakness and balance issues. Rudi was immediately escalated to the oral RRMS treatment fingolimod (Gilenya®). Rudi describes this time as very stressful for her young family. Several severe relapses over the next year and side effects from fingolimod saw another change in treatment to an oral DMT, dimethyl fumarate (Tecfidera®). Although her neurologist has suggested more efficacious DMTs such as natalizumab (Tysabri®) or alemtuzumab (Lemtrada®) Rudi says she's not interested. From Rudi's perspective, the potential side effects are just too dangerous with a young family.

Currently, Rudi looks forward to the future as her four children grow up and opening the door for more travel. Living with RRMS has encouraged Rudi to take more trips away, weekends with friends, and to start travelling more around the world… "I dream of that and I dream of me *walking* in that".

**Participant number 5: Joy's story**

Overcoming adversity beyond comprehension and returning to faith

Joy has suffered through many crises and health issues in her 57 years to the time of our interview, yet remains a strong, determined and courageous woman living with RRMS, while simultaneously defying and astounding her current health care team. Joy's story invokes many feelings; sadness, shock, admiration and inspiration amongst them.

Joy was born in a small country town and her childhood story is one of unbearable pain and neglect, a time she sees as vital to making her the strong person she is today. Joy had limited time playing with other children due to "excruciating" pain, "I was so hypersensitive that she (mother) couldn't even touch me, because with the pain it was like razor blades…I would wake up in the morning and I'd feel like someone had been beating me all night with a baseball bat". She vividly recalls nights of screaming out from leg pain, which nobody believed, or if they did, could not put a name to. Joy recalls that her mother was labeled as having Munchausen's syndrome by the local doctors, eventually nobody believed that Joy was suffering real pain, "they believed this is the child of the Munchausen's mother, well of course she's going to be a hypochondriac".

Things came to a head when Joy was 16 and she developed a complex form of dyslexia overnight, not being about to read text type. Nobody believed Joy, and she left school at 16 years of age despite been dux of the school the year before. Unexpectedly becoming pregnant at the age of 17, Joy married, before developing several complications during the pregnancy including a terrifying loss of vision with no diagnosis. Joy suffered many other health care issues over the ensuing years and eventually her husband left her as a single mother. Joy then experienced further distressing and unexplained symptoms, including irregular periods of vision loss and deafness. Joy recalls that when she visited the local doctors, none of them doctors were interested in looking for a cause "they just didn't believe me, I was a fruit-loop…they thought I was crazy and they weren't remotely interested". Joy later developed right-sided weakness, and reached a stage of utter despair when the doctors still did not send her for any tests or investigations, recalling the feeling that "it nearly broke me".

Ten years after her first son was born, Joy gave birth to second little boy. Joy enjoyed a period of good health during this time with no further attacks of blindness, deafness or weakness. She continued to feel well until her second child was about five years of age, when "the fatigue and the pain…was just indescribable, sickening…my whole body screaming in pain, absolutely screaming". The leg pain Joy had experienced as a child returned and was to become an everyday occurrence. Joy still had no explanation, diagnosis or a HCP who was interested in finding one.

Several years later, Joy remarried and with support from her husband, was referred to a neurologist. This neurologist subsequently diagnosed Joy with RRMS, Joy recalling, "they were amazed that no-one ever bothered to test me before". Joy started on medication for the severe nerve pain and later glatiramer acetate (Copaxone®) daily injections as a DMT to treat RRMS. Joy then recalls feeling unwell and experiencing a "huge, huge reaction" where "I blew up to 3 times my normal body size, just huge". Joy suspected her husband was poisoning her "my husband kept feeding me the medication (to treat nerve pain) and insisting…he would put the tablets in my mouth and I would pretend to swallow them and then I'd spit them out". After about six weeks of pretending to take the medications, Joy eventually started to feel better and drove herself to the hospital for assessment by a doctor to find out for sure what was happening to her. Joy was diagnosed with medication toxicity. Joy believes that "I don't think he necessarily wanted me to die…I will never know". Joy stopped all medications at this point, including injectable glatiramer acetate to treat her RRMS.

An onslaught of migraines in the year that followed led to a referral to a new neurologist and more neurological testing. Joy was then diagnosed with complex partial epilepsy. The neurologist told Joy that there was no way of knowing if her previous symptoms throughout her life had been caused by RRMS, the epilepsy, or both. As Joy recalls "she said…how have you had any sort of normal life…how did you ever learn to walk and talk?". Joy refused the offer of DMT to treat RRMS, preferring to take her chances on no treatment at all and avoid any side effects.

In the meantime, Joy's home life was deteriorating, she was feeling constantly stressed, not allowed to take time off work when her MS symptoms were at their worst. Then, Joy's husband died suddenly. Joy recalls that her husband collapsed "on top of me and squashed me so I couldn't breathe". This led to an intense few minutes where Joy experienced a surge of "I must live…that adrenaline surge…that kicked in because I was dying…I got myself out from underneath him, something…changed something in my chemistry…I started to improve…I made a heartfelt decision that I would get better…no matter what".

Gradually, Joy began to gain independence and returned to the faith she had with God as a little girl. Joy believes she is currently enjoying life to the full, working full time in an advocacy role to help others. Joy is a grandmother and remains very close to both of her boys and their families. Looking to the future, Joy is not keen to take any medications to treat RRMS, "if they can't come up with a cure…I'm not going to take anything that will make me sicker". Joy's message is that it is always possible to change, to make an effort to overcome difficulties and that it is definitely worth the effort.

**Participant number 6 : Jane's story**

Losing what's important to me, but looking on the brightside

Jane, aged 52 years at the time of our interview, has been living with RRMS for about 15 years. She has always worked in the field of education, is single, and has enjoyed travelling the world for both pleasure and work for most of her life. Jane currently lives with her father and is currently working part-time, still in the field of education, having recently attained a higher degree of which she is incredibly proud.

At the age of 37 years, Jane, who rarely saw a doctor, was troubled by a severe headache and consulted a local GP. The GP ordered some scans but did not provide Jane with a diagnosis. Not long afterwards, Jane suffered sudden vision loss when she was cycling and it was recommended that she see a neurologist. After several tests, the neurologist diagnosed Jane with RRMS. Jane recalls saying to her parents at the time "don't worry about it…it's MS" after initially being terrified of having a brain tumour. Jane elected not to take medication at this stage and decided to start her adventures overseas where she worked for many years. Jane came back to Australia regularly to see her family and to stay in touch with her neurologist.

Jane returned to Australia several years later following a severe relapse and began self injecting interferon beta1-a (Rebif®) for the next few years, feeling "disappointed" in starting therapy and beginning a time in her life which she recalls as "really, really, really depressing…I don't think people realise how bad it makes you feel". For about 4 years Jane didn't do any exercise and stopped travelling as she

felt “like a drug addict” carrying her supply of interferon beta1-a needles around with her.

Finally, Jane was switched to the oral DMT fingolimod (Gilenya®) about two years ago and says she now feels “much, much better”. The swap to an oral treatment has opened up her travel options again and her horizons on life. Presently she is working part-time on the advice of, and with the support of, her manager who is aware of her RRMS diagnosis, a diagnosis which has not been disclosed to others in the workplace because she is worried about losing her employment due to RRMS. Support has been essential for managing her severe fatigue, by taking time off in the working week to rest. Currently Jane’s symptoms include visual disturbances, incontinence, hand weakness and balance issues.

Currently, Jane is planning for a future where she may need a wheelchair, but is not dwelling on it, continuing to travel independently. She still worries about “not being able to speak or read or write”; skills she needs to be able to do her job properly, but for now, working part-time in a profession she loves “is phenomenal”.

**Participant number 7: Paul’s story**

I am not going down with RRMS, I’m just not

A 37 year old married father of three young children at the time of our interview, Paul currently works in the travel industry. Paul greatly enjoys his working role it allows him to work from home, travel often and participate in outdoor and adventure sports whenever he can. Initially from a science background, Paul is interested in all things to do with RRMS, often reading science and medical articles and taking a very active role in his own care and treatment decision-making.

Paul recalls a trip to an ophthalmologist to investigate his initial symptom, blurred vision, about eight years prior to our interview and was told that he probably had a virus causing some inflammation and that his vision would go back to normal, which it did. A few of years later Paul woke up with trouble breathing and chest pain. Exhaustive tests were performed but no explanation was found. A further episode

occurred a year afterward when Paul describes feeling “psychologically not right”, a period of time where he recalls “literally a cloud…sitting in this cloud…I looked around and there was this cloud”. With no medical explanation for this sensation he was feeling, Paul was left wondering what was happening to him. Subsequently, his GP referred him to a neurologist who spent two hours with Paul, exploring his symptoms, conducting further tests and eventually diagnosing him with RRMS in 2014.

Paul recalls suffering significant anxiety in the immediate time following his diagnosis. Before starting on a DMT, Paul was admitted to hospital and seen by a second neurologist who unfortunately, negatively affected Paul’s life journey. Paul felt pressured into a research study by this new neurologist investigating an MS treatment. At that time Paul was feeling particularly vulnerable due to his recent diagnosis of RRMS, his anxiety, a recent relapse and a course of intravenous high dose steroids (which can affect mood and thinking). Despite his misgivings, Paul completed the research study assessments because he wanted his negative experiences at the beginning of his RRMS journey to count for something and to help others. Shortly after this experience, Paul began care at a new MS Clinic where he feels he has found great medical support, together with his local GP.

Paul has been discreet about disclosing his diagnosis, choosing to only tell his immediate family, no friends and only one work colleague. Paul feels that he wants to manage RRMS on his own terms and that disclosing to only a chosen and trusted few, gives him the control of RRMS he craves.

Paul’s main RRMS symptoms currently are leg pain, which he describes as “walking on ice in wet socks, crumpled wet socks”, and neuropathic pain that comes and goes. Paul manages his symptoms mainly by grinning and bearing it, and generally gets on with life each day. Although relatively stable on his current oral DMT fingolimod (Gilenya®), Paul has recently acquired a new brain lesion on his last MRI scan. With his science background, Paul voraciously reads science papers reporting on MS therapies and wonders if now is the time for a DMT change to a higher efficacy medication.

Paul has tremendous hope for the future with RRMS, reasoning that science has come along so far in medicine in recent years and that advances in other disease such as cancer will also help in MS. He continues to research new advances in MS and advocate for himself to receive the best care and DMT treatment that is possible. It is impossible to come away from meeting Paul without feeling the same sense of hope.

**Participant number 8: Ruby's story**

If I could turn back time, I'd do things differently for my children

At the time of our interview, Ruby was 38 years old, married, the mother of two young children and currently the main wage earner in her household. Ruby's husband has taken time off to care for the family whilst Ruby works full-time. Working in the field of education, Ruby is a passionate and finds great inspiration and delight in her work. Part of a small but involved extended migrant family, Ruby lives close-by to her relatives who provide much needed support as she works, manages RRMS and looks after her family.

Troubled by some leg cramps on an overseas trip about 14 years prior to our interview, Ruby didn't think much of her early RRMS symptoms, and certainly did not think they were significant at the time or the first presentation of RRMS. Further neurological symptoms of leg weakness and clumsiness several years later saw Ruby consult a neurologist and undergo tests, where she was informed that she had RRMS but not offered treatment at the time. Instead, newly married Ruby was advised to start her own family now and to come back after her family was complete to discuss further management. Two years after her diagnosis when her first child was still a baby, Ruby noticed pain and cramping in her arms, but put it down to physical work that she was doing at the time. Her symptoms worsened and could no longer be ignored. Ruby was subsequently seen by a new neurologist and started the DMT Tysabri® shortly afterwards, but her RRMS continued to progress.

Although it was still early in her life journey with RRMS, by this time Ruby had already gained significant disability, particularly in regards to mobilising and she was only able to walk short distances without help. Adding to Ruby's burden is that

she remains troubled by a decision she made four years ago, when deciding on a DMT after the birth of both her children. Due to concerns about safety and the potential for significant side effects, Ruby decided to take more conventional DMT rather than the more efficacious medication recommended by her Doctor. Unfortunately Ruby has gained considerable disability over the last few years and she feels as if the decision she made at that time, understandably based on fear, has negatively influenced the progression of her RRMS. The drug is now registered in Australia and Ruby has recently commenced the medication, alemtuzumab (Lemtrada®). Ruby has great hope that she will improve and return to living the life she wants, to be a more active mother to her little children.

Being diagnosed with RRMS has caused considerable heartache for Ruby. She misses simple things like walking to the local shops with her children for icecream without any planning or running around with them in the local park. Perhaps one of her greatest disappointments with RRMS is the pressure she feels it places on her husband, her children and on her extended family, "I just wish it wasn't all about me". Ruby would much rather be in the shadows and not the focus of family life. She still hopes that one day this may become a reality.

**Participant number 9: Griff's story**

I'm a pretender to the throne

Griff was 62 years old at the time of our interview, and the married father of two teenage boys. Griff describes himself as a "house husband" caring for the family and home whilst his wife works full time in a demanding job. Initially trained in the public service, Griff worked for many years in a government job and believes he did very well in this position. Years later in his forties, he retrained and ran his own business, only to suffer a serious relapse of MS which led to his eventual diagnosis. This diagnosis and significant symptoms of fatigue, ultimately led to unemployment, and loss of the business. Griff has not worked outside the home since that time.

After a childhood fraught with unrelated lung illnesses, Griff experienced what he feels were the first symptoms of RRMS in his early twenties. He was hiking in the

snow and noticed that he had no sense of where his feet were in relation to his body and experienced weakness in his hands. He decided not to disclose this to his partner at the time and recovered over a few weeks. In retrospect, Griff feels he experienced many more short relapses of MS over subsequent years but was not seen by a neurologist or diagnosed with RRMS and until he was in his late forties. This was mainly because Griff did not report his symptoms or seek help for them from his family doctor.

A tumultuous few years followed Griff's RRMS diagnosis. He was commenced on the injectable therapy glatiramer acetate (Copaxone®) which he needed to administer to himself every day. Griff recalls that this became more and more difficult, he detested the injections and missed many doses. He later started on natalizumab (Tysabri®) necessitating a half day stay in the hospital clinic. These were the most stable years of Griff's journey with RRMS, he suffered no relapses, felt well on the medication and greatly enjoyed the clinic visits at the hospital. These hospital visits were his major social outings and finally gave him the social contact that he was craving. After several years Griff returned a positive JCV test which indicated that he was at a higher risk of the serious side effect of PML if he continued taking Tysabri®. Griff then transitioned to fingolimod (Gilenya®) and has remained on this DMT ever since. Although he has remained relapse free, he is still hopeful of a better and more effective treatment in the future.

Griff feels that RRMS has impacted greatly on his socialisation, largely due to not working but also from the severe fatigue he suffers. As his two children have become teenagers and require less help, Griff feels his days are "spent wastefully" and that he has been a less than optimal role model to his children who see him resting and tired most of the time. The second negative effect of RRMS on Griff's life has been in the area of sexual health. Griff discussed several times in the interview his disappointment that there doesn't appear to be the help available that he needs to deal with sexual health issues related to his RRMS, despite several attempts to do so.

A key event occurred shortly after Griff's diagnosis with RRMS, when he attended an event at the MSL to learn more about his new diagnosis. At that stage Griff showed no signs of physical disability and his major MS symptoms were all invisible

to others. Griff recalls that the mother of a severely disabled young girl in the same meeting "attacked" him, coming over to his group and yelling "What are you? You haven't got MS!" This confrontation left Griff shaken and upset, although he did feel sorry for the mother in her situation. However, this experience has stayed with Griff over the years and has led to him sometimes feeling like an imposter to the MS world and a "pretender to the throne".

**Participant number 10: Will's story**

Fitting everything into life I possibly can…and then some

Will was born overseas and migrated to Australia in his late teens, before his diagnosis of RRMS in his mid twenties. He was aged 35 years at the time of our interview, and is the married father of two children, enjoying an active life with plenty of team sports and individual exercise.

Will experienced a traumatic childhood, after his single mother died when Will was in his teens, he was raised by his grandmother. After experiencing an episode of optic neuritis at 17 years of age, Will had some tests but never attended follow-up visits to find out results. Will travelled to Australia, where he started a new career. A few years later, Will was hospitalised for a number of weeks as doctors battled to diagnose his unusual neurological presentation. Will recalls feeling depressed during this time. Eventually, after several months, Will was diagnosed with RRMS by a neurologist who was consulted on his case. This neurologist continues to look after Will and provide significant support.

Following his diagnosis, Will began treatment with interferon 1-a (Rebif®) and things went along well for a short period of time, but not long afterwards, Will recalls becoming depressed again. He recalls how he lost his focus, quit his job and stopped attending his MS Clinic for follow-up. Very quickly things spiraled out of control and Will had worries for his own mental health and for his future. He called on his resilience from childhood and managed to stop the negative cycle he was in without any medical intervention. He reconnected with his MS care team, started on the monthly infusion natalizumab (Tysabri®) and began to enjoy good health, the

relapses stopped and “I just felt great”. Will started going out socially after months of staying at home, and started making a conscious effort to talk to others, he joined various sporting teams, made new friends and reconnected with old friends. Will then met his future wife and felt like he had true support, embracing positivity and a healthy future.

Will’s continued on this journey to wellness, he was thriving on the new treatment, enjoying his new level of fitness and remaining relapse free for several years. The only thing Will did not enjoy about the hospital visits for his monthly infusions was meeting with other RRMS patients having treatment at the same time. Rather than bonding with them, Will kept a deliberate distance because he did not want to be around those with RRMS who wished to talk about their disease. Unfortunately after several years of disease stability, Will returned a positive JCV blood test which indicated that the natalizumab treatment was no longer safe for him due to a higher risk of PML, and so he stopped the treatment. Shortly afterwards Will commenced a new medication alemtuzumab (Lemtrada®), given in two annual cycles as an intravenous medication, also in a hospital setting. At the time of the interview Will was about three months post his first treatment cycle and still not feeling “back to normal”. However, Will is hopeful this new treatment will keep him healthy, active and able to play sport with his two children. Appearing fit, healthy and strong to others is very important to Will. In his words “I want to be able to tell my son (about RRMS), I don’t want him to notice it first”.

Will’s main symptoms currently include headaches, fatigue and numbness in his hands. He manages his symptoms and prefers not to discuss RRMS daily in his life. He has worked out a system with his wife, as he doesn’t want to complain of his symptoms all the time, he will only tell her *sometimes*. For Will, this works and helps to keep RRMS in the background and happiness and positivity in the foreground. This is how Will wants to live with RRMS.

**Participant number 11: Susan’s story**

Dreams really do come true, you just have to get through a lot first

Susan, 40 years old at the time of our interview, is married and a busy mother of one toddler. Susan works part-time in health care, a job she enjoys. Susan spends the rest of her time nurturing her family. After many years of being single and worrying about her future, Susan met her partner and married at the age of 37 years, she describes her dreams coming true when she later gave birth to her cherished little girl.

Susan began her journey with RRMS in her twenties when she suddenly experienced sensory lower limb symptoms whilst at work. She initially blamed sleep deprivation for her leg numbness, but soon realised that something more serious was happening. Susan sought help from her GP who refused to refer her for assessment and testing, even though Susan was a HCP herself and had specifically requested a referral to a neurologist. Susan realised her symptoms were serious and neurological in nature. Finding help elsewhere, after many tests, and several months of waiting, Susan was eventually diagnosed with RRMS. Susan was living at home at the time and her parents were devastated at her diagnosis, her father in particular blamed himself for her illness with Susan suffering substantial grief watching him try to make sense of what was happening. This led to several years of struggle where she sometimes felt that she would never find a partner to share her life with. She believed it would take a special type of person to accept her diagnosis of RRMS and the uncertainty that goes along with it.

Starting with an injectable interferon 1a treatment soon after her diagnosis and later glatirimer acetate (Copaxone®) daily injections, Susan managed her early DMT years well. She suffered three relapses over the next ten years but recovered well physically from each relapse. She gradually progressed to an oral DMT, dimethyl fumarate (Tecfidera®) in later years and has been relapse free now for some time. Susan had some issues with becoming pregnant and sought the help of a fertility specialist, which resulted in the birth of her only child. She had to remain off DMT for a period of time during the preparation for and during pregnancy, but remained free of relapses.

After struggling emotionally for many years living with RRMS, Susan embarked on a counseling course, which changed her life for the better. She learnt skills with a

group of other people, not with MS but other mental health issues and illnesses, which has transformed her approach to her own illness. Susan applied her new learning and thought processes to her life with RRMS. This changed her mindset from "struggling" to a "can-do" attitude and more confidence. Susan feels this attitude helped bring her future partner into her life and saw the start of her dream to be a wife and mother become a reality.

Currently Susan feels well, remains positive and is excited about her future. Susan continues to work as a HCP and has embraced the learning she has from living with RRMS to apply to her HCP practice, teaching people how to live better with chronic illness. Susan also encourages and helps those newly diagnosed with RRMS by speaking with PwRRMS experiencing difficulty. Susan advocates living healthily, maintaining a nutritional diet, continuing exercise and paying attention to mental health, Susan lives this by example.

**Participant number 12: Davina's story**

A second chance at love, support and happiness

Davina was aged 55 years at the time of our interview and has worked as a HCP for most of her life, a role she greatly enjoys. Davina was due to be married a few weeks after our interview and she was very excited at the prospect of her future. Several years prior, Davina had divorced the father of her four adult children, after a tumultuous marriage that was marked by many years of little support, accentuated by her husband's lack of insight and understanding into RRMS.

Davina was diagnosed with RRMS shortly after her first marriage, when she was in her very early twenties. Davina had just received news that she was accepted into a course and was to embark on a new career. A few days later she developed her first MS symptoms, sensory symptoms along her spine and leg weakness, and was taken to the emergency room and admitted to hospital. After several days she was given the news that she had RRMS and was devastated at the way she was told, by a specialist at the end of the bed who told her that she "likely had MS" and "if children were something you were thinking about, it's better to be a disabled younger mother

than an older one". Davina was devastated, she withdrew from the course she had dearly wanted to complete and sadly received little support from her husband throughout the early years after diagnosis. Following the specialist's comments about starting a family, within a year, Davina had her first baby, then three more children. Although these years living with RRMS and with four children were very demanding, Davina recalled that being a mother gave her the wonderful feeling "that I was finally good at something".

Davina suffered occasional relapses during this time, but always recovered back to her usual function. There were no DMTs available when Davina was first diagnosed, but in later years she commenced an injectable interferon, interferon-1a (Avonex®) as soon as it was registered in Australia, which she remained on for over a decade. Only recently has Davina switched to her first oral DMT, fingolimod (Gilenya®). This was a difficult decision for Davina, although she had felt miserable from side effects self-injecting, she persisted for many years because she felt "safe" taking the medication. The thought of new, oral tablets was attractive, but she was fearful of the unknown side effects on her body and resisted changing therapies for a long time. Although happy with her decision, she still is mindful that things could change at any time. Davina has been relapse free now for several years but still suffers significant fatigue and Uhthoff's phenomenon (a temporary recurrence of earlier relapse symptoms due to heat, infection or stress) from time to time.

Davina's early years living with RRMS were also marred by her extended family arguing over whose fault it was that Davina had developed RRMS. They searched for a genetic link because Davina had a close relative with MS who had been wheelchair bound and eventually was placed in a nursing home, the family refusing to acknowledge that he had MS to others outside the family. This refusal to acknowledge the disease left Davina feeling unsure and vulnerable within her own family unit. Although Davina's mother was very supportive, Davina's husband and father regularly contributed to her sense of low self esteem and loss of confidence, often refusing to believe her invisible symptoms, such as severe fatigue. On one occasion her husband ridiculed her in front of the children when she was extremely tired, telling her "don't play that MS card again". Her husband never attended

medical appointments with Davina and did not want to know anything about the disease. Davina's mother was her primary, and often sole, support and cheerleader.

After many years of struggling, meeting her new partner has instilled a great sense of hope for Davina in her future. Davina was formally diagnosed with depression a decade ago, but had resisted counselling and medication for her mood disturbances. However, recently Davina has sought psychological counselling and feels she is more positive in terms of both mood and attitude to life. Davina looks forward to the future, has supportive, loving relationships with her adult children and believes that she has a life partner who understands and supports RRMS. Davina is keen to do as much as she can living with RRMS, whilst she can.

**Participant number 13: Evie's story**

RRMS, you can run but you can't hide, I'm coming to get you

Evie is a vibrant, strong and fit campaigner, acting as an advocate to others about her life living with RRMS. At the time of our interview, Evie was 38 years old and living with her partner, had never married nor had any children. Evie's career has always been very important to her. She works for a government agency and because of her covert occupation, I have to be very careful about personal life details in this narrative, and unfortunately have to leave out some relevant details because of this situation.

Evie experienced a turbulent childhood, suffering various respiratory and allergic conditions and she recalls being bullied at both school by classmates, and at home by her father. Evie's first MS symptoms started in her late teens just after she finished school. Troubled by sensory symptoms in her hands, she then experienced changes to her gait, which were noticeable to others and she was referred to a neurologist. Over the next two years Evie had extensive testing, without a conclusion, but after another relapse was subsequently diagnosed with RRMS. Despite her young age, Evie took the diagnosis in her stride, understanding fully that she could do well with RRMS, or "she could bomb". Evie has had an extremely challenging journey with the disease,

suffering well over a dozen relapses since her diagnosis, several of the relapses being very serious and requiring hospitalization.

Eventually when it became available, Evie commenced on her first DMT, an injectable interferon beta 1-b (Betaferon®). She describes it as a time which made her unhappy due to this "God awful drug". Evie stopped taking the medication, preferring to be on no DMT for several years than to experience side effects, but after several serious relapses she felt compelled to restart treatment. Evie was happy when natizumab (Tysabri®) was introduced, attending a hospital infusion clinic monthly for the treatment and being relapse free, and almost completely symptom free, for many years. During this time, she was in the best physical condition she had been in many years. However, after several years, natalizumab needed to be stopped after a positive, high titre blood test for JCV revealed that Evie was at considerably high risk for the side effect PML. Evie then progressed onto an oral therapy dimethy fumarate (Tecfidera®), but she suffered a significant increase in disease burden in a very short period of time. Subsequently Evie commenced the new monoclonal antibody infusion alemtuzumab (Lemtrada®). Having recently completed the second of the two annual cycles of alemtuzumab Evie is still waiting to see if the treatment has been effective but is extremely positive about her condition and hopeful for the future. Evie strongly believes a cure *will* happen.

Currently, Evie's main symptoms are fatigue, Uhthoff's phenomena, gait instability and occasional episodes of motor weakness. Despite her many serious relapses, Evie is grateful that her vision has remained relatively unaffected and so she has been able to continue in her working role. To Evie, this is a saving grace of RRMS.

Despite her advocacy for MS, Evie still has times when she would prefer to be known for other things she does than being someone who lives with RRMS. Evie is passionate about showing the bright side of MS and regularly participates in sports and riskier pursuits such as skydiving and rock climbing in order to prove that you can do anything with RRMS. She wishes that these moments were the ones captured and advertised for people living with MS rather than showing people in wheelchairs or with significant disability. Evie is a strong believer in doing everything you can, whilst you can, and has refused to be labeled as only a person with MS. Despite her

significant disease burden, Evie participates in life to the full and is committed to showing MS in the best light possible. Meeting Evie made me, and I am sure others, feel the same.

**Narratives and further findings**

The life stories presented in this chapter highlight the diversity of the study participants, and contextualise their individual suffering, their joys, their strength and their resilience living with RRMS. Each story offers so much to MS Nurses to gain insights into living with RRMS. Each story has a unique perspective about things that have happened along the life journey, independent of RRMS, which may affect the life lived with RRMS. Ultimately, the narratives display a sense of hope, despite the many life challenges the participants have experienced.

The next two chapters will present and discuss the study findings as themes and related subthemes. Each theme will be introduced individually and then be supported with direct quotes and stories from the participants to support the analysis. This is where the participant life stories presented in this chapter will support the more formal study findings, allowing the reader to have some appreciation of the lives of the participants and their journey, in order to better understand the themes abstracted from the study data. Understanding the journey of the study participants also makes the experience more personal and allows a more intimate connection with each story, a concept very much in alignment with qualitative research methodology and with the ontology and epistemology of the current study.