

# **Progressive (dis)ability:**

The experience of living with  
Charcot-Marie-Tooth disease

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## ABSTRACT

This thesis is an Interpretative Phenomenological Analysis of the experiences of six women living with Charcot-Marie-Tooth (CMT), an inherited degenerative neurological condition with a range of debilitating symptoms. It is the first ever in-depth qualitative study into the lived experience of CMT, which is relatively common yet largely unknown.

This is “Paradigm II” disability research (Olkin, 1999) that listens to the voices of those with disabilities to advocate for improved conditions, services and status in the world. Those who are disabled are empowered to speak for themselves. The researcher, too, has CMT and another progressive neurological condition, Parkinson’s. The women’s stories are analysed alongside his own autobiographical narrative.

Four themes are identified and discussed, drawing on literature from across the fields of psychology, psychotherapy and disability studies: loss, discrimination, identity and growth.

Arising from these findings, the concept of “disability apartheid” is developed into a “two worlds” model which can be used to describe how psychological factors such as acceptance and shame can impact the ways in which those with disability identify and engage with a disabling world and with their own lives.

The researcher argues for “one world” where all individual capabilities and limitations are respected.

The findings also inform 12 clinical recommendations for counselling psychologists, psychotherapists or other healthcare professionals working with CMT, other neurological or progressive physical conditions, or disability.

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**Everyone who is born holds dual citizenship, in the kingdom of the well  
and in the kingdom of the sick. Although we all prefer to use only the  
good passport, sooner or later each of us is obliged, at least for a spell,  
to identify ourselves as citizens of that other place**

*—Susan Sontag (1977)*

## **1. INTRODUCTION**

Some years ago, during a walking safari in Botswana, I saw a lame zebra.

Abandoned by the rest of his able-bodied herd, he stood alone in a clearing, waiting for the inevitable moment when he would be attacked, killed and eaten by a predator, most likely a lion. He was entirely vulnerable. Yet I also felt that this magnificent animal seemed calm and dignified. There was a sense of acceptance. It was a powerful image, and it has stayed with me as I come to terms with my own physical impairments.



Fig 1: The existential zebra accepts the givens of life—and death

Mobility a fundamental part of being alive. It is how we separate and individuate as children, it is the means by which we encounter and commune with the world, it is a major part of how we participate in society. Restricting mobility is how we punish people: misbehaving children are confined to the “naughty step,” unruly adolescents are “grounded,” criminals are incarcerated.



Any loss of mobility through bodily damage, disease or disability can be devastating. Writes Wilson: “Damage to the body, which is a source of self-identity and self-regard, can cause severe emotional upheaval, loss of identity and a diminished sense of self-worth” (2003: 23). As well as their physical challenges, the impaired person must also find a way to live in a society that shuns and shames them; they find themselves stigmatised (Goffman, 1963).

This research aims to bring greater awareness of the impact of disability, specifically the effects of progressive physical disability. The focus of the work is a minority group within a minority group—a qualitative enquiry into the lives of people who have the progressive hereditary neurological condition Charcot-Marie-Tooth disease (CMT). This is a chronic condition that can be moderately benign but can also greatly impact the lives of people who have it.

I have long been interested in exploring the unique experiences of others who have CMT and comparing them to my own. I am motivated to offer insight into and understanding about the experience of living with and adjusting to CMT—and, by inference, other progressive physical conditions, too, whether as a result of neurological disorders like multiple sclerosis (MS) or Parkinson’s disease, other conditions like muscular dystrophy, diabetes or arthritis, or simply old age. I will make a contribution by raising awareness of CMT, this silent, secret disease, fostering a greater sense of community among people who have it, and arguing for better psychological service provision.

### ***What is CMT?***

Charcot-Marie-Tooth disease—sometimes also known as Hereditary Motor and Sensory Neuropathy or occasionally Peroneal Muscular Atrophy—is a group of hereditary, slowly-progressive neuromuscular conditions discovered in 1886 by the influential French neurologist Jean-Martin Charcot (whose students included Sigmund Freud and William James), his assistant Pierre Marie, and English neurologist Howard Henry Tooth. It affects either the axons or the myelin sheaths of the peripheral nerves in the feet and lower legs, and hands and lower arms, causing muscle weakness, wasting and loss of sensation, compromising mobility, dexterity and balance, causing fatigue,

and sometimes also resulting in muscle cramps, pain and tremors. The progression of the condition is gradual and idiosyncratic: there are widely differing levels of severity, even among affected family members. Some people with CMT walk with a stick or use a wheelchair. It does not affect life expectancy or cognition. There is currently no cure.

According to some estimates, worldwide CMT is more common than MS. The latter has a median estimated global prevalence of 30 per 100,000 (World Health Organization, 2008: 14), or approximately 2.1 million people worldwide, whereas CMT has a prevalence of 1 per 2,500 people (Yale School of Medicine, 2013), or 2.8 million people worldwide (there is a correlation between incidence of MS and distance from the equator—MS is comparatively rare in high-population places like Brazil, northern Africa and India). Yet CMT is largely unknown, even among some medical professionals. “It seems to be almost a hidden disorder and yet many live the experience,” says Dr. Elizabeth Barrett, a New York psychotherapist and teacher who co-wrote the booklet “What It's Like to Live with Charcot-Marie-Tooth” (personal communication).

### ***My personal involvement***

I have lived with CMT from birth; I was formally diagnosed in 2002. My father has it, albeit with a mild presentation, as is the case with my brother, while one of my older sisters has more significant symptoms, including difficulties with walking and greatly compromised hands.

In my case, aside from having terrible balance, CMT did not really affect me much up until my mid-40s. I could run, ski, and go for long hikes. In the following years, however, my symptoms progressed such that my walk became cumbersome, slow and uncomfortable, standing unaided became difficult, I experienced reduced manual dexterity, and my energy levels often flagged. My relationship with my environment, with others, and with myself—my identity—all changed considerably and will continue to progress and evolve.

As I became more affected, I found that I could no longer cover up my impairment and pretend to be “normal”—what Goffman (1963) describes as “passing”—which necessitated a kind of “coming out” process as I finally took my condition seriously and explained it to others.

The “coming out” process is not easy. CMT was for a long time a taboo subject in my family, a source of shame and blame and guilt. This is not unusual. Says David Tannenbaum, a New York psychotherapist with CMT who runs voluntary sector support groups and online discussions for people with the condition: “A common theme is a sense of great isolation and shame around the disease. Being able to communicate with other people who have CMT, to share experiences and voice those feelings, is a huge step towards adjustment and acceptance” (personal communication).

I am invested in this topic. This is a piece of “insider research” (Rooney, 2005: 6). I recognize that my personal involvement is a mixed blessing. On the one hand, I am highly motivated to carry out this work, and attuned and empathic to others who share the disease. But on the other, I bring to it my own unique experiences and attitudes, which may make me less available to those of others, resulting in misinterpretations, false assumptions, distortions, misrepresentations (Rooney, 2005: 6). I might see and hear myself rather than my research participants.

It has therefore been important for me to take great care to be aware of my own biases and blind spots as I have proceeded with this research—for instance by being interviewed myself about my own experiences with CMT—and to have been transparent about my context and my process throughout the project. As Etherington says: “Our interpretations can be better understood and validated by readers who are informed about the position we adopt in relation to the study and by our explicit questioning of our own involvement” (2004: 32).

This research is not a mere academic exercise, an arm’s-length investigation into a topic that carries no personal or emotional resonance, an intellectual

piece of doctoral writing. The experience of progressive disability is my life, in every minute of every day.

Nine days before I presented my research proposal to the approval panel, in September 2013, I was diagnosed with an entirely unrelated and better-known chronic incurable degenerative neurological condition: Parkinson's.

The Parkinson's diagnosis, though not a surprise when it was finally delivered, was devastating. I was the victor in some kind of cruel and grotesque anti-lottery, literally one in a million; a freak. Life would be much harder from here on in. And yet ... I couldn't overlook the timing, the weird synchronicity of the diagnosis. After a while this was something I was able to take as a kind of affirmation of my research; a sign that I was on the right track, that making sense of chronic illness is one of the things I was put on this earth to do—a purpose.

In the hierarchy of neurological conditions, however, the more challenging Parkinson's trumps CMT in the anti-lottery (and is trumped by ALS and MS). So while Parkinson's may intensify my experience of progressive disability, and amplify my core belief that disease, as well as being damaging, can be enormously awakening, growthful and transformative, there is also a danger that my own experience with Parkinson's might prejudice my research participants' experiences with CMT. My own selection criteria would have excluded me from taking part in this research as a participant on the grounds of comorbidity. Throughout this thesis I have therefore tried to be very clear when I'm talking about me and my experience, and when I'm talking about participants. I have tried to be transparent about which experiences, interpretations and conclusions might belong to which condition. But inevitably, it is impossible to divorce the researcher with CMT from the researcher with Parkinson's. While much research is conducted by people outside of the phenomenon being researched, I am coming at this from the other direction: For better or for worse, I have two progressive neurological conditions where my participants only have one. It is imperative that I listen to,

honour and reflect the participants' experience, rather than being blinkered by my own.

My Parkinson's diagnosis greatly amplified the importance to me and my life of my research, but at the same time made it ever more personally and emotionally challenging. There were years where, while my disability progressed, my doctorate did not.

This has been a very long, challenging, complicated and uneven journey. I am very grateful to have completed this thesis. It is of profound importance in my acceptance of ill-health, an accelerated individuation process, and an existential and spiritual midlife transformation. I'd just turned 50 when I was diagnosed with Parkinson's. In many ways, this is when I began to live.

The title of this work is "Progressive (dis)ability": I take the "progressive" view that regardless of illnesses or impairments, our bodies age in unique and surprising ways, and progressive disabilities run alongside progressive abilities, and each person can inhabit their body and their life in their own way. Ill-health is not always a tragedy. Sometimes it heals.

***Presentation: words, imagery and dissemination***

In producing a qualitative doctoral dissertation, there is a tension between adhering to the academic and institutional traditions, protocols and strictures that are traditionally observed, and taking a postmodern approach that embraces the subjectivity of the enterprise. Too much qualitative research in my opinion seems to be conflicted, practically apologising for itself and presenting itself at least partially still clad in the constricting vestments of positivism.

I am interested in contributing to a broadening of qualitative research in terms of appeal, accessibility and usefulness through an embrace of subjectivity and interpretation, the use of imagery as well as words, and dissemination via a variety of academic and non-academic outlets, channels and platforms.

Before becoming a psychotherapist, my career was working as a magazine writer and editor, both here and in the United States. I believe good writing is accessible. I have little patience for academic writing that is deliberately obfuscatory, dense, boring or littered with unnecessary insider jargon. I have tried to bring a scholarly yet engaging clarity to presenting the complexities inherent to this research.

Phenomenological research in particular demands good writing—van Manen says phenomenology is “a poetizing project: it tries an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice into an original singing of the world ... We must engage language in a primal incantation or poetizing which hearkens back to the silence from which the words emanate” (1984: 39).

I am a writer but also a very visual person—a lifelong photographer and, since my diagnosis of Parkinson’s, an avid, self-taught portrait, landscape and abstract painter. While academic journals may be constrained in the use of art and photography by budgetary or ideological or logistical realities, I am operating under no such restrictions. The photographs and paintings in these pages are all my own; they illustrate that progressive abilities can flourish despite the physical trend in the other direction. Disabled or not, we all have multiple identities, and I wanted to bring my full self to this work.

Even if my images were purely decorative I believe they would heighten the experience of reading this thesis and enhance understanding. Schnotz (2005) for example highlights the benefits of multimedia learning. Further, I believe that images can pack an emotional punch in the way that words don’t. Words and cognitions rattle around in the neocortical “human” brain; powerful imagery and emotion perhaps belongs to the more mammalian, limbic system where they are more likely to endure (Lewis, Amini and Lannon, 2001). I’ve looked at my photo that opens this thesis hundreds of times—a zebra, alone in a clearing, standing tall, about to be visited by a certain, violent death—but each time its impact and the memory of the moment are undiminished.

It is for these reasons that images are increasingly being used in phenomenological research, as a means of communication for both researcher and researched (eg. Goble, 2013; King, 2017). Indeed, rather than justify the use of imagery in a qualitative research thesis, one might instead challenge the prevailing orthodoxy that makes it a rarity. Why wouldn't a deeply personal piece of qualitative insider research use meaningful imagery? If anything, this is a return to an earlier tradition of psychology, before it took a positivist turn, when imagery was very much part of the discourse. This is best exemplified by Jung's paintings, symbols, iconography and mandalas that often accompanied his written words, which I seem to return to, over and over.

In the introduction to "A Reader's Edition of Jung's Red Book," Shamdasani writes of that rich period, the first few decades of the 20th century: "Psychologists sought to overcome the limitations of philosophical psychology, and they began to explore the same terrain as artists and writers. Clear demarcations among literature, art, and psychology had not yet been set; writers and artists borrowed from psychologists, and vice versa" (2009: 2).

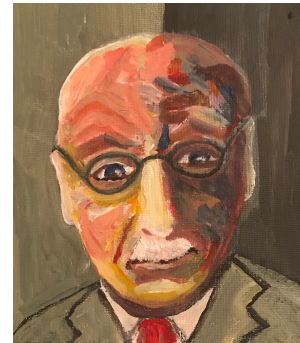


Fig 2: Carl Jung

Finally, whatever its literary and visual merits, a doctoral thesis that exists solely as a leather-bound volume in the bowels of an academic library or on the author's shelf is academic in both senses of the word; it is practically irrelevant. We live in an age of short attention spans—shorter than goldfish, apparently (McSpadden, 2015)—and a proliferation of outlets and platforms, soundbytes, tweets and video clips. I intend to present and disseminate the message of this research both within and beyond the confines of academia. I have for instance written for both the Society of Existential Analysis Journal and Psychologies magazine. I will also write about aspects of this research on my blog ([worldoftherapy.com](http://worldoftherapy.com)) with a link to this thesis in full. And I am working with a New York literary agent on a book proposal on the theme of growth as explored in these pages.

## 2. CRITICAL LITERATURE REVIEW

### *Introduction*

I see research as exploration. Explorers are naturally drawn to uncharted regions, the untrodden dark places of the earth, the *terra incognita*. They might use existing maps both to identify such places and to find their way to them. They will make hard journeys, discoveries. They will plant a flag. They will create a better map of the world.

My aim in this section is to describe my travels amongst the literature, in order both to put my research in context and to justify its pursuit. As with my research itself, for the literature review I adopted a hermeneutic phenomenological approach. I was both systematic and highly subjective in my literature searches, interpretations, reflections and writings, all of which led to more subsequent searches in a repeating, iterative, circular process. The explorer encounters many dead ends, uncrossable divides and unassailable peaks.

My resulting report is in the traditions of a critical review, defined by Grant and Booth as follows: “A critical review aims to demonstrate that the writer has extensively researched the literature and critically evaluated its quality. It goes beyond mere description of identified articles and includes a degree of analysis and conceptual innovation. An effective critical review presents, analyses and synthesizes material from diverse sources ... A critical review provides an opportunity to ‘take stock’ and evaluate what is of value from the previous body of work. It may also attempt to resolve competing schools of thought. As such, it may provide a ‘launch pad’ for a new phase of conceptual development and subsequent ‘testing’ ... while such a review does serve to aggregate the literature on a topic, the interpretative elements are necessarily subjective and the resulting product is the starting point for further evaluation, not an endpoint in itself” (2009: 93).

I started my research with a very large scale map. I wanted to fly high above the terrain, taking in a broad view of the landscape, then find my direction,



begin my descent, land in my chosen place and set off on foot. I will begin therefore with a broad exploration of the ways people have traditionally thought about illness and disability. One can be ill without being disabled, or disabled without being ill. Many people with CMT consider themselves both diseased and disabled (though many deny both); both are therefore examined here. I then survey the landscape of disability research that has been conducted, much of which, as we shall see, is problematic. I conclude with the extremely limited amount of work that has focused specifically on CMT. Having identified and arrived in such neglected, barren lands, my research itself is then defined in Chapter 3, and commences in Chapter 4.

It has been genuinely surprising and disappointing to discover both the paucity and prejudicial nature of psychological research into disability. Counselling psychology and psychotherapy are supposed to be enlightened, progressive and inclusive; these disciplines exist to serve the dispossessed, the alienated, the outsiders of this world. Yet people with disabilities, human beings often most in need of support, compassion and love, remain largely uncared for; untouched and untouchable. Like the zebra, they have been abandoned by the able-bodied herd.

### ***What is illness?***

Is disease a random occurrence brought on by things like infections, inflammations, changes in bodily chemical levels, compromised immune systems, and genetic predispositions? Or are symptoms an expression of a deeper malaise, an inarticulate howl of a suffering soul? Which is more likely to make you ill: a poor diet or social isolation? Why are placebos often just as effective as drugs with active ingredients? Does someone develop tumors in their lungs because they smoke—or because they have a “cancer personality”? Will they need to be “strong” to “fight it”?

The axis around which these kinds of debates revolve has been in place for millennia. Wrote Plato in “Charmenides”: “For the greatest failure in the treatment of disease is that there are physicians for the body and physicians for the mind when the body and mind cannot be separated. But the Greek

doctors overlook that fact and that is why so many diseases elude them” (in Schoenberg, 2007: 13).

Descartes by contrast regarded his soul as entirely distinct from his body. “I think therefore I am,” he wrote—he would still be Descartes even if there were no body (Russell, 2013: 517). A central philosophical conundrum of Descartes’ “Meditations on First Philosophy” in 1641 was how a nonphysical entity, the mind, could have an effect on something physical, the body (Westphal, 2016). In sickness and in health, the union of mind and body is curious, complex and contested.

Today, those on the “body” side of the Cartesian split favour the biological or medical model of disease, the prevailing positivist stance of western healthcare provision. People with illness are regarded as faulty machines that need to be fixed. They are passive recipients of both disease and treatment. Aside from a brief description of symptoms, patients are largely silent. Clinics and clinicians aren’t much interested in a patient’s own phenomenology, their somatic history, knowledge and meaning-making, nor in contextual details about what else might be going on in their lives. Only the first prong of Engel’s tripartite biopsychosocial model (1977) is considered; the psychological and the social are ignored.

Foucault (1963) argued that the epistemic embrace of objectivity in medicine began in the late 18th century in the wider context of the Enlightenment. Under what he termed “the medical gaze,” the patient was now to be seen clinically, as a body, an object. The person became invisible, their subjective experience irrelevant: “The presence of disease in the body, with its tensions and its burnings, the silent world of the entrails, the whole dark underside of the body lined with endless unseeing dreams, are challenged as to their objectivity by the reductive discourse of the doctor” (*ibid*: xi).

Psychology, too, would later abandon its philosophical roots and attempt to don the respectable robes of hard science and scientific method. Watson’s



Fig 3: "Waiting in Blood"

manifesto of radical behaviourism recognized “no dividing line between man and brute” (Watson, 1913: 158). The ghost in the machine was silenced; Watson was only concerned with observable, measurable inputs and outputs.

Some regard the blinkered, purely biomedical model of illness as deeply flawed. Illich opened his critique with the words: “The medical establishment has become a major threat to health” (2010 [1976]: 3). We are plagued, he says, by a society-wide epidemic of iatrogenic (doctor-induced) disease and death. Modern medicine has become a rapacious commercial machine, one that sustains itself through its production of clinical damage, its political furtherance of an unfair, sick society, and its tendency “to mystify and to expropriate the power of the individual to heal himself and to shape his or her environment” (*ibid*: 9).

For those on the “mind” team, individual power is inviolable; they see illness as a deeply psychological process. Symptoms are indicative of something unresolved in the unconscious, a problem in the psyche, a sickness of the spirit. The high priestess of this brand of oppressive psychological determinism is Louise Hay, whose book “You Can Heal Your Life” (1984) has

sold more than 50 million copies. “I believe we create every so-called illness in our body,” she wrote (*ibid*: 1). If you only have joyous, loving thoughts you will stay healthy she says. If you already are ill, fear not: you can heal yourself. Hay claims to have had cervical cancer in the 1970s—the diagnosis has never been corroborated—and cured it exclusively with her thoughts.

In an interview in *The New York Times* (Oppenheimer, 2008), Hay was asked if people are responsible for their own deaths—did victims of genocide, for example, or people killed in the Holocaust, get what they deserved? “Yes, I think there’s a lot of karmic stuff that goes on, past lives ... Yes, it can work that way,” Hay said. “But that’s just my opinion.” I find such opinions to be indefensible.

There is much of this kind of mindlessness from the mind camp, with no shortage of ludicrous claims from false hope-peddling bestsellers like Byrne’s “The Secret” (2006) or Lipton’s “The Biology of Belief” (2005).

Similarly guilty of extreme magical thinking is Wilberg’s “The Illness is the Cure” (2012). Wilberg sees illness not just as a pedagogue bearing wisdom, but as a midwife, too, presiding over the birth of a whole new you. Casting illness as a pregnancy—presumably to be similarly greeted with joy and celebration—feels grotesque and deeply unempathic to anyone who has suffered from their own or a loved one’s ill health, which is to say pretty much anyone. Wilberg, like Hay, is scathing in his assault on western medicine, which he says is a leading cause of death and describes as “a veritable *medical Holocaust*” (*ibid*: 283). Not quite as evangelical but no less celebratory of disease as a catalyst for personal growth is Mindell’s “Working with the dreaming body” (1985). He sees symptoms as akin to somatic dreams, messages from the deep, and thus through interpretation, the “royal road” into the development of the personality. For people who actually have chronic symptoms, however, they can be a never-ending, worsening, living nightmare.

The “mind” advocates can be just as dogmatic as the “body” determinists they seek to critique. Even the more balanced, reasoned works (eg. Maté, 2011; Marchant, 2016) offer victim-blaming explanations or unhelpful metaphors which all-too-often, as Sontag points out in her landmark essay “Illness as Metaphor” (1977) can be moralistic and punitive. “Psychological theories of illness,” she writes, “are a powerful means of placing the blame on the ill ... Nothing is more punitive than to give a disease a meaning—that meaning invariably being a moralistic one” (*ibid*: 58-59).

Cancer is the disease whose victims are most commonly subjected to this kind of oppression—they are led to believe they brought it on themselves by being too repressed; it is then demanded that they think positively and be “strong” to beat the disease. Ehrenreich beautifully describes her experience of this in “Smile or Die” (2010). How many people with cancer have had their last thought on earth be that their death was a personal failing?

At two recent body psychotherapy CPD workshops, I asked a question from the floor: what sense do the speakers make of bodies that stop working or succumb to sickness? Nick Totten replied that symptoms are “an invitation to do some work on yourself”; for Michael Soth they are “symptoms of the soul.”

Challenged in follow-up emails, Totten did not respond; Soth however replied by agreeing wholeheartedly with Sontag’s critique, highlighting what he described as fascistic undertones inherent in much holistic contemporary therapies, but adding that, despite the dangers, he believes a psychological exploration of meaning is possible without moralising. He added that there are “bottom-up ways of working with spontaneous body experience that can help the client ‘discover’ subjective meaning, and that also includes pain, illness, and psychosomatic symptoms. I have plenty of anecdotal evidence that this can become a growthful, expansive experience rather than a top-down, moralising socially normative oppressive one. But it is rare to find (certainly in any pure form, uncontaminated by oppressive moralising attitudes) and does not take away from the validity of Susan Sontag’s critique of much that goes on under the guise of holistic helping” (Soth, 2018, personal communication).

We don't actually know precisely the reasons for the arrival and progression of cancer or any other disease. Cancer is common in all mammals, too, with a few exceptions: Mole rats for instance almost never get it (Pennisi, 2013). Are we to assume they are better at expressing their anger than their fellow rodents? Did they have better attachment experiences in their youth? Sometimes we are "thrown" into disease and there is no reason. With life comes disease, disability and death. No one is to blame.

In my case, I got CMT because a genetic mutation, a duplication of a segment of chromosome 17, was passed on to me by my father, who in turn received it from his father; beyond that the ancestry of our peculiar family heirloom is unknown. I got Parkinson's because at some point in my 40s, for reasons unknown, the cells in the substantia nigra region of the brain that manufacture the neurotransmitter dopamine started to take early retirement and shut down. I believe mind and body are both completely involved in these conditions, their arrival, expression and progression. Instead of the thesis of the medical model that ignores the mind, or the antithesis that too often degenerates into fatuous psychospiritual new age quackery, what is needed is synthesis. I reject the black-and-white thinking of Cartesian dualism. The mysterious marriage of mind and body does not submit to certainties. Writes Suzuki: "Our body and mind are not two, and not one ... Our body and mind are both two and one" (2010: 7). My painting "Waiting in Blood" (page 19) is an attempt to integrate mind and body.

Writes Oken: "Psychological and biological factors are involved in all aspects of human function—healthy and disordered. All disease and health is psychosomatic; there are no 'psychosomatic disorders' because there are no 'non-psychosomatic disorders' " (2007: 831) .

In "Why do people get ill?" Leader and Corfield similarly write "No single major illness is exclusively caused by the mind, just as few illnesses will always be completely exempt from the mind's influence" (2007: 3). They advocate holistic treatments that may include traditional medicine but that also engage with the individual, the ghost in the machine.

In my experience, synthesis is rare. I had an observer placement 3 years ago on a neuropsychiatric ward of patients with unexplained “functional neurological symptoms”—otherwise known as somatoform or conversion disorders. The supposedly multidisciplinary treatment program consisted largely of medication plus a token amount of CBT and physiotherapy. There was almost no interest in unconscious processes, the possible meaning of symptoms or indeed psychotherapy. The variety and apparent ingenuity of symptoms begged to be explored as potential unconscious attempts at solutions: a way to prevent the person from having to do something difficult, or keep them safe, or cared for, or loved. For a lot of the patients, I felt that if they could have been helped to find their voices, their bodies would not have to do all the talking.

Kleinman, a medical doctor, bemoans how the medical care system “does just about everything to drive the practitioner’s attention away from the experience of illness. The system thereby contributes importantly to the alienation of the chronically ill from their professional caregivers and, paradoxically, to the relinquishment by the practitioner of that aspect of the healer’s art that is most ancient, most powerful and most existentially rewarding” (1988: xiv). He advocates a rediscovery of the person of the patient, of their story, of the lost art of symptom interpretation.

Frank’s “The Wounded Storyteller” is an inspiration and guide to developing illness narratives. There are many fine, beautiful examples such as Carel’s “Illness.” It’s true that our symptoms have much to tell us. With the help of therapists we can discover useful interpretations, authentic, affirming narratives, enormous capacities for transcendent spiritual growth.

The purpose of illness narratives for me is not to ask why one gets ill, but to ask what—and how. What is your lived experience; what’s life like for you? And how are you going to accept your illness—and your mortality? How are you going to integrate these givens into your identity, your “being in the world”? What are you going to learn? How are you going to live? As Frankl

taught us [1946], however desperate the situation, we still retain the freedom to choose how to respond.

I will end this section with Kleinman's description of the lived experience of those with disordered bodies: "It has been said of Mozart's music that even where all seems quiet and under control it is best regarded as a formal Italian garden built on the side of an active volcano. The undercurrent of chronic illness is like the volcano: it does not go away. It menaces. It erupts. It is out of control. One damned thing follows another. Confronting crises is only one part of the total picture. The rest is coming to grips with the mundaneness of worries over whether one can negotiate a curb, tolerate flowers without wheezing, make it to a bathroom quickly enough, eat breakfast without vomiting, keep the level of back pain low enough to get through the workday, sleep through the night, attempt sexual intercourse, make plans for a vacation, or just plain face up to the myriad of difficulties that make life feel burdened, uncomfortable, and all too often desperate" (1988: 44).

### ***What is "disability"?***

The official British definition of disability is: "You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities."

"Substantial" is defined as "more than minor or trivial, eg. it takes much longer than it usually would to complete a daily task like getting dressed." "Long-term" is defined as "12 months or more, eg. a breathing condition that develops as a result of a lung infection" (Gov.uk, 2010).

The Americans with Disabilities Act defines a person with a disability as someone "who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment." Major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking,



standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working (ADA, 1990).

These legal definitions pigeonhole a vast number of people with an extraordinarily wide array of challenges. There are more than 11 million people with a limiting long term illness, impairment or disability in Great Britain—18 percent of the population—and the most commonly-reported impairments are those that affect mobility, lifting or carrying (Office for Disability Issues, 2013). More than a million people in the UK have a disabling neurological condition (Neurological Alliance, 2003). In America, there are 43 million people with disabilities—14.3 percent of population, making it the largest minority group in the U.S. (Olkin, 1999: 16). Approximately one in five has a chronic illness or disability (Livneh and Antonak, 2005). There are more than a billion disabled people on the planet (Shakespeare, 2018: 1).

Yet psychology has been slow to embrace disability (Olkin and Pledger 2003; Goodley and Lawthom, 2005; Siebers, 2008). While the psychotherapeutic profession is increasingly interested in working with difference and diversity in an enlightened way, especially in terms of contexts of “race,” sexual orientation, class, gender and age, this multicultural interest does not seem to extend very far to disability. Counselling psychology is somewhat silent on the subject. There is no chapter on disability in the otherwise comprehensive *Handbook of Counselling Psychology* (Woolfe et al, 2010). Disability does not feature in counselling psychology training programmes in the U.K. The extensive reading lists provided for my counselling psychology professional doctorate included not a single reference on disability. The field of body psychotherapy, which could be enormously beneficial to those with impaired bodies, is almost entirely silent on disability; its totalitarian rejection of anything other than idealised, normative, healthy and pain-free bodies is disappointing and oppressive.

### ***Models of disability***

There are three principal ways that disability is viewed (Oliver, 1996; Olkin 1999). The “moral model” of disability, which is as old as humans, regards the

disabled person as inherently sinful, evil or guilty of some supposed moral lapse and thus deserving of their fate. As with illness (Sontag, 1977), the victims of disability are blamed, often with a religious, supernatural or psychological rationale. In more collective societies the entire family tends to carry the shame and stigma. In the long distant past, children born with birth defects were considered to be a curse. They would typically be taken out into the wilderness and left to the will of the gods. The tale of Oedipus in Greek mythology is a cautionary one: born with a club foot, he survived such an abandonment but went on unwittingly to murder his father and marry his mother, bringing ruination to the kingdom. Many cultures have similar stories (Stiker, 2017: 149).

The dawning of the Enlightenment saw the advent of the “medical model” which, by contrast, sees disability as being about abnormal, pathologised body parts which need to be fixed or managed. This unfortunately promotes a binary us/them split, in which the “us” people project all their fears, anxieties and horrors onto the “them,” as Wilson (2001: 679) points out. This is the prevailing orthodoxy in western healthcare provision today. The physical defect is to be labelled, pathologised, treated, fixed, managed or accepted, and a beneficent and tolerant society will take some steps to accommodate disabled people, for which they should be grateful. Writes Olkin: “The main contribution of the medical model is its repudiation of the view of disability as a lesion on the soul. Further, the medical model has spurred medical and technological advances that have improved the lives of people with disabilities” (1999: 26).

But the model is normative. The disabled person is aberrant if not abhorrent. Many times I have sat in a lecture room full of people with CMT as a CMT-free CMT expert explains what our “abnormal” axons, feet or gait look like, and what they “should” look like. “Thus, the individual with a disability, regardless of personal qualities and assets, understands that he or she belongs to a devalued group” (Smart and Smart, 2012: 63).

By contrast, the “minority model” or “social model” (Hahn, 1985) regards disability as a continuum, a fluid social construct, and takes a systemic perspective—the problem is seen less as with the person than with the prejudiced environment and population that fail to accommodate them (Smart, 2001; Terzi, 2004). Olkin: “Solutions are universal design, education of those without disabilities about persons with disabilities, laws ensuring equal access and protection, and better enforcement of such laws” (*ibid*: 27).

According to Olkin, persons with disabilities are united in the difficulties, barriers and prejudices that are located in the able-bodied world, not in their physical selves; their commonality is their shared experience of that world (*ibid*: 28). They are systematically excluded from the system; the prejudice and discrimination they face is more enduring and pervasive than that experienced by any other group (Smart and Smart, 2012: 69).

These three models represent a progression, an historical, cultural and philosophical advance towards fairness and enlightened societies. The latter model, however, is contested. It has been used to great effect to bring about political change, but by entirely focussing on a presupposed monolithic oppression, ignoring the contribution of any physical impairment to a disability, individual differences and identities are erased; furthermore, branding everyone with the same label serves to exacerbate the very them/us division that disability activists seek to destroy (Owens, 2015: 389; Shakespeare, 2018: 19).

A commonly-used hybrid of the medical and minority models is the World Health Organization International Classification of Functioning, Disability, and Health (WHO, 2001) which sees each person as unique, their level of disability dictated by the dynamic interactions between their health condition and their socioeconomic and psychological context—what Lewin (1935) called their total “life space” (Chan, da Silva Cordos and Chronister, 2009).

Owens proposes a new, more nuanced conception of disability based on Arendt’s writings on power and plurality, one that “allows for an elaboration of

the complexities, contradictions and common aspects of disabled people's experiences, instead of incorporating them into one collective understanding that excludes aspects of each person's experience" (2015: 394).

### ***Types of disability research***

Olkin (1999: 314) and Olkin and Pledger (2003) identify two broad kinds of disability research. What they call "Paradigm I" research tends to be static, pathology oriented, and about but not by people with disabilities. These studies reflect either the "moral model" or the "medical model"—research into what "we" think about "them": attitudes toward the disabled (eg. Jabin, 1987), the countertransference of therapists with disabled clients (eg. Segal, 1996), or client transference towards a therapist with a disability (eg. Anisfield, 1993). A recent study (Ashworth, 2017) found that therapists working with people with neurological conditions can be unsettled and worry about their own health; the clients are present only as mute vectors of therapist unease.

"Paradigm II" research, by contrast, inquires about health and resilience as opposed to deficit. Paradigm II reflects the "minority model" of disability; it highlights the agency, voice and lived experiences of the disabled and actively strives to improve their conditions, services and place in society. It is often conducted by disabled researchers.

There is precious little research on disability—one review of five leading psychology journals between 1990 and 2010 found it amounted to less than 2.7 percent of the total (Foley-Nicpon and Lee, 2012). And of the disability research that is conducted, the vast majority, argues Olkin, belongs squarely to Paradigm I. Such work, she says, often not only fails to produce any positive changes but reinforces unhelpful stereotypes (1999: 308).

Researchers form a negative hypothesis about a pathology that they don't suffer from, and then construct research around verifying that hypothesis, which becomes a *fait accompli*. This kind of research assumes that a pathology causes suffering: "Researchers then use a pathogenic filter which looks for and inevitably finds pathology ... Prejudices, stereotypes, and myths

about disability are infused into every stage of the research process until the inevitable outcome is to verify these misconceptions” (*ibid*, 1999: 311).

### **Research into CMT**

There are many qualitative research studies of the experiences of people with various conditions such as MS (eg. Edmonds *et al*, 2007; Borkoles *et al*, 2008); Parkinson’s (eg. Hodgson *et al*, 2004; Bramley and Eatough, 2005); muscular dystrophy (eg. Nätterlund, 2001; Boström and Ahlström, 2004); sight loss (eg. Dale, 2010; Thurston, 2010); stroke (eg. Jones and Morris, 2013); diabetes (eg. Watts *et al*, 2010); chronic fatigue (eg. Dickson *et al*, 2007; Arrol and Senior, 2008); pain (eg. Smith and Osborn, 2007).

There are none for CMT. What little psychological research into CMT there is tends to be pathologising, Paradigm I-type work of a positivist, quantitative nature. Vinci *et al* (2001), for instance, found reduced scores in a quality of life measure among 121 people with CMT compared to “healthy subjects”; Padua *et al* (2006) found “highly significantly deteriorated” quality of life scores among 211 people with CMT when compared to the general population; Padua *et al* (2008) similarly found what they call “abnormal” quality of life scores among 89 people with CMT.

Vinci *et al* (2007), however, point out that standard psychometric measures—Padua *et al* for instance used the Beck Depression Inventory—can lead to biased results when applied to the CMT population. They write: “For example, ‘I get tired more easily than I used to’, ‘I am worried about physical problems such as aches’ ... bias the score toward depression when, in fact, easy tiring and pain are real symptoms of the disease.” (Vinci has CMT.)

And sometimes people with CMT, who are supposed to be suffering, rather inconveniently can score quite well on quality of life measures. Carter *et al* (1995) did not find elevated depression among people with CMT; Vergili *et al* (2007) found that quality of life and depression were poorly correlated with the severity of CMT; Vinci *et al* (2009) found no difference in psychological distress between 53 people with CMT and the general population. Shy and

Rose (2005) are surprised when such “unexpectedly high levels” of quality of life are reported in studies of chronically ill and disabled people, something they describe as “the disability paradox”—a “discrepancy between the person’s perception of his or her ideal state and his or her *real state*” (my italics), as though people with disabilities must be delusional to imagine they have a good quality of life. The “objective” researchers are baffled that people with disabilities don’t conform to their negative prejudices.

Regardless of the merits or otherwise of these quantitative studies that can’t seem to agree on the psychological state of people with CMT, what is missing, in all of them, is the voice of those people. There are very few studies that are even remotely interested in that voice.

Ramdharry *et al* (2012) conducted focus groups with people with CMT and used qualitative methods to explore their experience of fatigue. While interesting, it is fatigue that is foregrounded; CMT seems incidental. And this was not an in-depth study with individual participants—as Ramdharry says, the study “was qualitative with a small ‘q’ ” (personal communication).

Shapiro (a CMT patient) and Phillips Goldfarb (1991) conducted a survey of 10 men and 10 women with CMT—how CMT affects their life, body image, relationships, children, education, work. But the questions were of the yes/no variety, and though some comments from the participants were recorded, they were illustrative rather than focal. Similarly, Beyer and Daino (1991) surveyed 22 parents of children with CMT to find out the impact of the condition on families and family life. And finally, Barrett and Birdsall (2008) conducted an online survey of people with CMT and published the results in a short booklet “What It’s Like to Live with Charcot-Marie-Tooth.”

These studies are interesting but lacking in phenomenological depth, rigour, and applicability to counselling psychology and psychotherapy.

### 3. RESEARCH AIMS AND QUESTIONS

One of the most difficult things about being diagnosed with a chronic health condition is sharing the news. No one wants to be the bearer of bad tidings. And in my experience, many people do not respond well. Some act as if you have said nothing at all and quickly change the subject.



Fig 4: "Solitude": People with disabilities often suffer in silence

Some take the opportunity to tell you all about their own

travails—when I told a colleague I had CMT, he responded by spending the next 20 minutes on a bump on his finger which was diagnosed as harmless, and which, after a couple of months, disappeared. Some assume you must be devastated; other insist that you be positive. People will offer to pray for you. People you might have known for decades might not respond to the email and are never heard from again. It feels as if few people are particularly interested in what you might have to say. When your condition is disabling, you are further disregarded.

The unwillingness or inability to engage on a basic human level—by asking for example “how is that for you?” or “how is that affecting you?”—seems beyond not just some friends, colleagues, and family, but many of the healthcare professionals who treat you, too. And researchers. From the literature—or lack of it—it is plain to see that disability receives scant attention. And when disability is researched, it is often done so in a biased, prejudicial and oppressive manner.

CMT is an unfashionable disease with a peculiar name, bereft of celebrity spokespersons. It turns its chosen few into people who are ungainly, clumsy

and slow. Few people have heard of it, and it often comes with a lot of intrafamilial shame and blame. It isolates and excludes, and it only ever deteriorates. It affects every aspect of one's way of being in the world, and the only constant is change as the unstoppable condition unfurls. People with CMT suffer in silence.

This is the first ever in-depth, rigorous, qualitative, Paradigm II study of the unfolding, ever-changing experiences of people living with CMT. It explores in depth those disparate experiences—and meanings, understandings and interpretations of those experiences—and identifies resonant themes so that tentative conclusions may be drawn about this population and, by comparison, about people in general.

This thesis is mostly borne of my own individual health challenges. I want CMT to be better known and better treated. I want to give people with CMT a voice, and I want to find my own. But there are broader lessons to be learned that might be resonant for people who have other chronic disease or disabilities. Increasingly, too, I recognize that CMT supplies a concentrated version of the universal challenge of being human: How to accept that we are essentially alone, and on an inexorable downward path that ends in certain death. CMT asks us: How to live?

My research questions are: **“In our own words: What are the unfolding experiences of people living with Charcot-Marie-Tooth disease? And what are the implications of those experiences for counselling psychology and psychotherapy?”**

### ***Contributions to the field***

I believe this research will achieve the following aims:

- Educate counselling psychologists and psychotherapists about CMT and the needs of people who have it, as well as of people with other progressive physical disabilities and compromised physical function and mobility, although the latter extrapolations might be largely conjectural. This research will be invaluable for any therapist that might be working with such a client.



- Expose the neglect and discrimination experienced by people with disabilities from the psychotherapeutic community, including from therapists, researchers, education/training organisations and discourse. In a modest way, contribute to the body of knowledge around disability and disability studies, especially on post-traumatic growth and the existential benefits to be gleaned from life's difficulties.
- Improve the nature of psychological support around CMT. Outside the voluntary sector, there are no specialist counselling or psychotherapeutic services for people with CMT. As Thomas and Siller write: "The role of psychoanalysis in the treatment and rehabilitation of those with disabilities (physical or other) has withered in the face of the imperative of physical and functional improvement, the institutional context where care is often given, and the multifaceted nature of rehabilitation" (1999). I want my research to be required reading in peripheral nerve clinics and neurological medical departments.
- Foster a greater sense of community, voice and visibility for people with CMT and also raise awareness and draw attention to this chronic, enduring, progressive condition that remains largely unknown among counselling psychologists, psychotherapists, the medical profession and the public at large. My research will appeal to anyone who has CMT. There is a sense among people with the condition that one should not grumble or even talk about it, because "there are far worse things out there." I want to reduce the isolation, invisibility and sense of shame of people with CMT, and give credence to the idea that seeking help and support if needed is both possible and normal.

## 4. RESEARCH DESIGN

**Doubt is not a pleasant condition. But certainty is absurd**

—Voltaire (1770)

### ***Introduction***

My undergraduate research on depression in children adhered to the prevailing positivist, quantitative logic of the British university system of the 1980s. Aside from providing instructions on how to fill out a questionnaire, it did not involve talking to any children. It was a largely pointless and unsatisfying experience.

Quantitative research, it is true, has made many useful contributions to psychology but in general our species refuses to conform to a worldview that seeks to understand and explain the human condition in terms of hard science, biological determinism, statistics, mental health questionnaires and diagnostic labels.

Impartial scientists are fallible victims of the very thing that they seek to deny: human subjectivity. Published research often produces findings that conform to researchers' biases, or are career-enhancing, or politically self-serving. In 90 percent of studies on anti-psychotic drugs, the best-performing drug was manufactured by the pharmaceutical company that sponsored the research (Cooper, 2008: 4). The NHS believes in evidence-based treatments, especially CBT, but the evidence for CBT is greatly contested (eg. Bolsover, 2002; Orlans and Van Scoyoc, 2009; Holmes, 2002). Concludes McLeod: " 'Big' research is always conducted within a political context" (1999: 8).

Fortunately, the philosophical approach has not been defeated by positivism. A descriptive, subjective, phenomenological psychology lives on, requiring for Merleau-Ponty "a foreswearing of science," which he regarded as "always both naïve and at the same time dishonest" (1945: ix).

Qualitative research rejects objectivity as not only not possible, but also as not desirable. The unique histories, qualities and biases of the researcher and participants are not denied; they are embraced, as are constructivist and social constructionist approaches which claim no grand narratives or fixed absolutes, and instead see reality as temporary, partial, local. For McLeod, “the primary aim of qualitative research is to develop an understanding of how the world is constructed” (2001: 2).

### ***Interpretative Phenomenological Analysis***

My research is an investigation into the lived experience of progressive physical disability through the voices of people living with CMT. I am interested in research participants’ experiences, understandings and interpretations in their own words. This leads me towards a qualitative, phenomenological method. Counselling psychology has witnessed a flourishing of postmodern methodologies, giving rise to a great diversity of approaches, topics and findings (Ponterotto, 2005).

If I were to take a traditional, Husserlian phenomenological approach, I would attempt to bracket my own experiences of CMT and seek to understand with objectivity the unique experiences of my research participants—I would be attempting to get to the essence of those experiences, what Husserl called “the things themselves” (Husserl, 1927; Smith *et al*, 2009: 12).

For Husserl’s erstwhile student Heidegger, however, such bracketing was seen as impossible; indeed for Gadamer, the very attempt is manifestly absurd (in Lavery, 2003). In Heidegger’s eyes—and my own—one cannot separate one’s self; one cannot be an impartial, objective “scientific” observer. Instead, the researcher’s own subjectivity and interpretations are embraced. This is the essence of hermeneutics.

Husserl advanced the idea that “experience is of a system of interrelated meanings” ([1913] 1983), but for Heidegger those meanings are highly contextual. Humans are “thrown” into existence, he wrote, and must adapt to and be shaped by their unique environments. We cannot be divorced from our

*Befindlichkeit*—our subjective, felt sense of ourselves in the world (Heidegger, [1927]; Gadamer, [1975]; Stolorow, Atwood and Orange, 2002).

Through self-reflection, the hermeneutic researcher becomes aware of their own biases and assumptions, not in order to bracket them off, as a Husserlian phenomenological researcher might do, but to make them a central part of the interpretative research process. Writes Lavery (2003): “The overt naming of assumptions and influences as key contributors to the research process in hermeneutic phenomenology is one striking difference from the naming and then bracketing of bias or assumptions in phenomenology.”

Hermeneutics and phenomenology thus appear at first glance to be at odds with each other. “Hermeneutic phenomenology” may seem like an oxymoron. But the twin approaches can be reconciled; both can be viewed as “integral, complementary aspects of any satisfactory way of knowing about human existence” (McLeod, 2001: 59). Phenomenology is what Heidegger saw as a “fore-understanding” to hermeneutic enquiry (*ibid*).

Hermeneutic phenomenology may thus be seen as a postmodern method that is aligned with the intersubjective, integrative values of counselling psychology.

Interpretative Phenomenological Analysis (IPA) is the offspring of this unlikely union between hermeneutics and phenomenology, conceived in 1996 (Smith *et al*, 2009: 4) and now reaching respectable adulthood. Writes Smith: “IPA requires a combination of phenomenological and hermeneutic insights. It is phenomenological in attempting to get as close as possible to the personal experience of the participant, but recognizes that this inevitably becomes an interpretative endeavour for both participant and researcher. Without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen” (*ibid*, 2009: 37).

IPA is well suited to the study of the idiographic experiences of a homogenous group of people with a shared circumstance; for understanding how people

perceive the “particular situations they are facing, how they are making sense of their personal and social world. It is especially useful when one is concerned with complexity, process, or novelty” (Smith & Osborn, 2003). It has been widely used for exploring issues in the personal, specific experience of health and illnesses. There is now a large body of IPA work on a variety of health conditions; indeed health psychology was where IPA first found its voice (Brocki and Wearden, 2006).

Research methodologies, too, are subject to interpretation. Larkin, Watts & Clifton (2006) suggest that IPA is best regarded as a research perspective rather than a discrete research method. For this piece of research, I have broadly followed the principles of IPA. I choose not to swallow blindly any strictures and protocols, however, nor indeed any qualitative methodology since such “schoolism” would violate the underlying foundational belief in human meaning-making and knowledge. Instead I offer my interpretation of IPA. For instance, I eschew terminology that has positivist reverberations—“data,” “coding,” and “validity” are examples; another is referring to oneself in the third person—in favour of language that is more congruent with an inclusive, integrative approach.

### ***My approach***

I have an old wise dog, Daisy, who often sits with one ear up and one ear down. She listens to the world and she listens to herself. Daisy gets through life—with dignity and aplomb—by combining phenomenology and hermeneutics.

Similarly, in my former career as a journalist, I came to appreciate that the best writers are those who harvest information from the world through extensive reporting, but who then knowingly combine it with their own



**Fig 5: Daisy navigates through life with one ear up, one down**

experience and interpretations. The use of their subjectivity is deliberate, reflective and transparent.

And in my work, too, as an integrative psychotherapist, I choose not to practice in either a solely phenomenological or a hermeneutic way but rather to fuse these approaches. I tend to emulate advocates of interpretative, psychodynamic and existential methods that help the client clarify and shape their story and experience of life (eg. Frankl, 1946; Boss, 1963; Yalom, 1980; Bugenthal, 1999), as opposed to those who favour a more purely phenomenological, client-led stance (eg. Laing, 1960; Spinelli, 2007; Van Deurzen, 2012). Indeed, besides research, I believe IPA could also be usefully viewed as a specific integrative therapeutic methodology.

The epistemic position of pure phenomenology is that there is an objective reality that can be known and understood through science and reason. Pure hermeneutics, by contrast, sees human understanding and knowledge not as fixed “out there” realities waiting to be unearthed but instead as socially constructed and a matter of interpretation. Nietzsche wrote in 1887: “It is precisely facts that do not exist, only *interpretations*” (in Kaufmann, 1954: 458). Hermeneutics is born of a relativist ontology: each person is seen as inextricably embodied and embedded in a particular historical, social and cultural context.

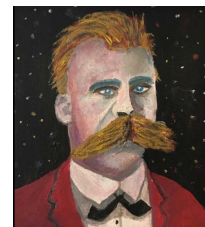


Fig 6: Nietzsche

I see no reason to exclude either position. Like Daisy, I don't deny a realist epistemology—there are some truths and there is a real physical world; “facts” indeed do exist. But I also believe that to understand the psychology of human beings, it is meanings and meaning-making that need to become the focus of attention. There are no absolute truths—human knowledge instead is partial, contingent, contextual; a dynamic, social construction borne of cognitive schemes and embodied interactions with diverse environments (Polkinghorne, 1992: 147). I am thus perhaps best described as a “critical realist” (Maxwell, 2012). I believe, as Lynch states, “that there is an objective order and meaning to reality, but that our knowledge of it is always partial (contextual and local, rather than universal)” (1996: 146).

We humans do our best, but we each have a particular and highly circumscribed apparatus with which to understand our lives. Our “doors of perception” (Huxley, 1954) are only partially open. We cannot be expected to know the truth of the universe any more than an ant can be expected to read the book upon whose open page it walks. This reflects my spiritual viewpoint that there are greater truths that we cannot know, only glimpse. I put my faith in the mystery and uncertainty of life.

Qualitative research thus embraces uncertainty—what the poet Keats referred to as a “negative capability” rather than an “irritable reaching after fact and reason” (Voller, 2010)—because there is no certainty.

I believe that it is in the subjective interplay and tension that exists between phenomenology and hermeneutics that truths—as opposed to *the* truth—are discerned, truths that are rather more modest, provisional and contextual than anything purporting to be factual. I am thus very much drawn to IPA, a rich, engaging process that with humility respects and honours the inherent complexity, changeability and mystery of human life.

I also was encouraged and guided by van Manen’s four interconnected and interacting aspects of hermeneutic phenomenological research (1984: 39):

- a. Turning to a phenomenon which seriously interests us and commits us to the world.
- b. Investigating experience as we live it rather than as we conceptualise it.
- c. Reflecting on the essential themes which characterise the phenomenon.
- d. Describing the phenomenon through the art of writing and rewriting.

I could have used one of various phenomenologically-informed narrative methods of enquiry (eg. Ricoeur, 1981; Polkinghorne, 1988), but these would tend to require a bracketing and diminishment of my own testimony. At the other extreme, I could have taken a solely autoethnographic approach (Etherington, 2004; Denzin, 2013), but that would have imprisoned me in my own experience of progressive disability. I very much wanted to reach out and

connect with others who might similarly feel alienated and disconnected by CMT.

I see hermeneutic phenomenology as an organic, live conversation between the therapist and client or researcher and research subject—a “double hermeneutic” (Smith *et al*, 2009). “The process of interpretation is dynamic and iterative, engaging the concept of the hermeneutic circle in an interplay between parts and whole and between the interpreter and the object of interpretation” (Shinebourne, 2011). The circle then encompasses the reader, who will bring their own context and subjectivity to bear in their interpretation of the work and their contributions to the wider conversation.

Hermeneutics and phenomenology however are not always easy dance partners. Writes van Manen: “As soon as we turn to reflect on an experience that we have in this very moment, we inevitably immediately have stepped away from or out of the living sphere or sensibility of the livedness of lived experience. The instant of the moment we reflect on a lived experience, the living moment is already gone” (2017: 832).

But we do the best we can. And given its embrace of the researcher’s interpretative inputs in the work, and given that we cannot make interpretations that are objective and without presuppositions (Shinebourne, 2011), it is vital in qualitative studies that researchers adopt an ongoing commitment to critical reflexivity such that they can own and make transparent their points of view.

For instance, my subjectivity, my interpretations, my every thought and idea expressed in these pages—all are rooted in my own unique history and point of view; there are inevitable prejudices and biases inherent in being white for example, in being male, being British; me. Additionally, a vital and unique aspect of this research is that I, too, experience the phenomenon that is under investigation. Moustakas (1975, 1994) extolled the virtues of the use of self in the research process, especially as participant self-reports can be banal or limited. Warns Polkinghorne: “People do not have complete access to their



experiences...People do not have a clear window into their inner life” (2005: 138). My experiences of CMT and progressive disability are just as valid as those of my research participants. Beyond using my subjectivity to interpret the latter—and cultivating my own reflexivity to raise my awareness of potential biases and blind spots—the former warrant scrutiny, too, and form part of the work.

A critical realist is inherently quite a different animal from an “objective,” “scientific,” “bracketing” researcher. Social science research is messy (Law, 2004), founded on human subjectivity and choice, defined as much by what is left in as what is left out: “What is being made present always depends on what is being made absent” (*ibid*, 83). The critical realist is thus a critic, intentionally political, believing “that a discernable reality exists, but that this reality reflects the oppressive influence of social, political, and historical factors. The researcher’s role is both interactive and proactive, with the explicit goal of facilitating change and emancipation from restrictive social conditions” (Havercamp and Young, 2007: 268).

Through the years of carrying out this research—and for lengthy periods, avoiding it—my own story was unfolding. It became increasingly obvious that this story would not just inform my research but be an important part of it.

This project is for me one of great personal, professional and political significance. I felt a growing desire to include a chapter on my experience, drawing on my self-interviews and a lifetime of reluctant cohabitation with CMT to tell my story—my illness narrative, which in many ways is a story of growth, maturation and healing. This would follow the chapter that details the findings from my research participants. Both chapters would then inform the ensuing chapter of discussion.

Such an approach, however, is unorthodox. I have endeavoured to signpost clearly when I was telling my story so that readers could understand my point of view in conducting this research and the kinds of biases and blind spots that might creep into it, and when I was telling my story as an additional

research participant. I have sought feedback from able-bodied “critical friends” to ascertain how well this kind of transparency is achieved, and to identify instances where my “insider” status threatens to occlude those readers without CMT. Having CMT might help me build a bridge to my participants and others with the condition; it also has the potential of becoming a wall to the reader.

To explore this further I contacted IPA founder Jonathan Smith himself and he very graciously agreed to meet me to discuss my project. He echoed the above concerns. “There’s a danger that your experience could completely flood this research and drown out your participants,” he said. “They have to come first. But in principal I have no ideological problem with your approach. If you present your participants’ accounts first and this is then followed by what is clearly signaled as your own personal account in a separate chapter, I can see that can offer a useful extra perspective” (Smith, 2018, personal communication).

### ***Interviews***

The standard (but not only) method IPA employs to elicit first-hand experiences of a phenomenon is in-depth semi-structured interviews with a small number of research participants (Smith *et al*, 2009).

The IPA interview process is itself a blend of hermeneutics and phenomenology. The researcher prepares a list of open-ended questions based on their interpretation of the research enquiry and what they imagine the participants’ experience might be. Smith *et al* (2009) recommend starting with broad questions—my first question was the simple invitation: “Tell me about your CMT”—before narrowing the focus to specific areas. But the list of questions (see Appendix II) is not rigidly adhered to. It is important to listen, to follow up when there appears to be more to say, to open up the space for the participant’s phenomenality. For researchers and journalists alike, this active and reactive interplay between questions and answers, with one ear up and one ear down, lies at the heart of good interviewing.

I elected to conduct two interviews with each participant—an initial interview lasting ideally at least 60 minutes and then a follow-up interview a few weeks later with the intention of exploring participants' experience at greater depth. The second interview also gave participants time to reflect on the first, as well as another fresh opportunity to tell their story. This is important since fatigue is a very common symptom of CMT, and symptoms can fluctuate depending on mood, stress, sleep, diet.

I also asked a colleague to conduct two interviews with me. As well as informing my own CMT story, the self-interview also helped to identify my own biases and preconceptions and thus develop a clearer understanding of my participants, as well as providing me with helpful insight into being an interviewee, informing my interview questions and how I might best conduct the interviews. I wanted to make my interview questions as free from implicit assumptions and biases as possible, and I wanted my participants to feel comfortable and relaxed.

### ***Participants***

Qualitative research generally aims for depth rather than breadth. IPA research is usually carried out with a small, homogenous group who all have experience of the phenomenon under investigation; Smith *et al* (2009) recommend between 3 and 6 participants.

My main selection criteria obviously was that participants must have CMT. I wanted participants who had been diagnosed at least 10 years ago, and consider themselves disabled, such that their symptoms, history and experiences with CMT are rich and significant.

I thought about including a requirement, too, that participants need to have had some experience of psychological treatment with regard to their CMT, and thus be likely have some degree of psychological-mindedness and fluency with regard to the condition. But on balance I decided against this as finding subjects whose experiences of CMT are unmediated, untherapied and perhaps to some extent unresolved might be richer and more revealing. To

keep the focus on CMT, I did not consider participants who had other co-morbid progressive physical conditions—which paradoxically would have made me ineligible to be a participant in my research—or any mental health diagnoses. Participants needed to live within 100 miles of London for ease of access, too.

### ***Method***

I hoped to find participants at the National Hospital for Neurology and Neurosurgery in Queen's Square, London, where I am an outpatient. However, this ambition was hindered by time pressures and NHS protocol and bureaucracy. I turned instead to the membership of CMT United Kingdom, this country's support group for people affected by the condition (currently approximately 1,600 members).

I wrote a short participant recruitment notice (see Appendix I) which was posted on the charity's Facebook page. I also emailed it to the members of a small support group I had set up for people in London with CMT which at the time I was running. I was concerned that people who have joined the CMT support group might have found it easier to accept their condition and integrate it as part of their identity and thus have less to say about the struggles of psychological adaptation. But on balance I have come to realize the opposite might be true: people who have not accepted their CMT really don't want to talk about it.

Everyone who responded to the recruitment notice was contacted by phone and verbally provided with more information about the scope of what their commitment might be, the potential pros and cons of participation, and assurances of confidentiality. Those that were interested in proceeding were sent an information sheet (Appendix II), a resources sheet detailing sources of emotional and practical support (Appendix III), and a consent form (Appendix IV). Potential research subjects were informed they might find talking about CMT to be a difficult, distressing experience, and that their participation was voluntary and they could withdraw at any time, without giving any reason.

I initially planned for four participants, intending to select them on a first-come-first-served basis such that people who were not chosen to participate might be less likely to feel rejected. Seven people applied who met the criteria and who were willing to participate and who signed the consent form. In the end, I elected to interview all of them. I felt that they wanted to tell their stories. And I wanted to hear them. The participants consisted of six women and one man.

Arrangements were made for subjects to be interviewed face-to-face at a quiet, convenient location. Six participants chose to be interviewed at home, the seventh at work. Before the first interview began, each participant was again provided with the information sheet and a list of sources of support should they be needed. They were reminded that they could terminate the process at any point. They were further reminded that their ongoing consent was not assumed; the consent form states: “I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. If I choose to withdraw, I can decide what happens to any data I have provided.”

The interviews were all recorded (permission for this was granted in the consent form). In the interests of transparency—and perhaps to facilitate greater participant ease and freedom of expression—I disclosed my personal involvement in this project and the fact that I have CMT.

At the end of each interview the participant was debriefed, we reflected on the interview together, and arrangements were made for the follow-up interview. In the course of the first interview with the male participant, it transpired that he had been diagnosed only four years prior. This fact, coupled with IPA’s recommendation of a relatively homogenous group of participants, guided me to exclude him from the process. He was thanked and debriefed. The final lineup of participants was six women with ages ranging from 25 to 68.

**Fig 7: Table of participants**

Participant*	Age	Gender, ethnicity	CMT Type	Age diagnosed	Relationship Status	Children	Working
Fay	25	F, white	1a	8	Single	No	Yes
Liz	33	F, white	1a	16	Divorced	Yes	No
Kay	44	F, white	1a	35	Divorced	Yes	Yes
Jill	46	F, white	1a	20	Divorced	Yes	Yes
Pam	59	F, white	2	23	Married	Yes	Yes
Mary	68	F, white	1a	55	Single	No	No

*\* Participant names have been changed to protect confidentiality*

### ***Ethics***

To be a participant in a piece of qualitative research—as I have been—can be a challenging, demanding and upsetting experience. It’s much easier to fill out an anxiety inventory for instance than to talk about your anxiety in a long face-to-face interview with a stranger. There are thus moral and ethical questions to be considered. Conducting this kind of research carries a great risk of doing harm to people, and researchers thus bear a great responsibility and duty of care. The nature of IPA research is open-ended and organic, without fixed methods and protocols, and complex and unexpected issues can arise. State Strawbridge and Woolfe: “many situations are vague and uncertain, decisions must be made, actions taken and accounted for” (2010: 14). Ethical guidelines are a helpful but crude map for navigating these challenging waters, which the researcher must do with sensitivity, a grounding in humanistic values and plenty of critical reflexivity (Etherington, 2004; Josselson, 2007). And supervision. The emotional depth of qualitative research is both its greatest strength and its biggest challenge.

CMT can be a devastating, debilitating disease that can invoke difficult feelings such as despair, shame, anxiety, depression, resentment. And

isolation: Some of my participants had never before spoken about their experience of CMT and the impact it had on their lives.

I felt a great sense of protectiveness towards my research subjects, heightened by my own struggles with CMT. As a result, I implemented a number of safeguarding measures:

- Both verbally and in the information sheet provided to participants, I was explicit in disclosing in full the nature of the research project and its objectives, what would be expected of participants, the complaints procedure, and the possibility of risk. Consent to participate was obtained in writing.
- During the encounters themselves, I reminded subjects that they had the right to terminate the interview and withdraw from the project at any time—this was also stated in the information sheet—and I also explained the potential of harm arising from distressing thoughts, feelings or images being evoked in the course of our discussion. Given the weight of material that was explored in the interviews and the potential vulnerability of the subjects, I tried to be highly attuned in the moment to the interviewee's state of mind and wellbeing. I repeatedly checked in with the participant as each interview progressed and was fully prepared to take breaks and offer to postpone or terminate the interview and where appropriate switch roles from researcher to provider of emotional support. I allowed plenty of time for briefing participants before the interview and recovery and debriefing and an exploration of the experience afterwards. I enquired if there was anything I could do to help the participant, and explored their support system and any other resources that they may have available. I also provided a list of resources, phone numbers and websites that could be used to seek further support, for example CMT online forums that offer emotional support, counselling directories, the Samaritans. I also offered myself as a point of contact for follow-up, not to provide ongoing emotional support but to assist the participant in the practicalities of finding access to help (I wanted to maintain the boundary between researcher and therapist). The fact that I did two interviews with each participant rather than one perhaps also allowed for a more supportive, immersive encounter overall.

- Anonymity and data protection were assured throughout, in accordance with the Data Protection Act. All interview transcripts were kept free of any identifying personal details, and stored on a password-protected computer. Interview recordings were erased once the transcripts were completed. In this thesis there are no specific biographical details, unique experiences or other identifying details that might compromise a participant's anonymity.
- I familiarised myself the ethical guidelines of the Metanoia Institute, the HCPC and the BACP, which were followed throughout this research process. Ethical approval was sought and obtained from Metanoia's Research Ethics Committee.

Finally, my duty of care extends to myself, too. Self care is something I have finally come to understand and take seriously, though still sometimes struggle to implement. I have however relied heavily on therapists, supervisors and a support network of family, friends and colleagues to help me navigate through the process. I have had lengthy periods where this project lay dormant and I did not have the capacity to proceed.

In a way, undertaking this research is itself an act of self care. The short-term challenge has been great, but the long-term rewards have been life-changing. This has been a way of truly honouring myself, my CMT and Parkinson's, and my relationship with progressive impairment and disability, which play such a central role in the landscape of my life.

### ***Quality***

Quantitative research goes to great lengths to observe rigorous quality control procedures, use large sample sizes, statistical protocols, and peer review, all in the name of ensuring objectivity and validity. How is qualitative work to be judged? What validity, reliability, truth or meaning is there to be found in a researcher's subjective engagement with a small sample of participants?



McLeod (2001: 183) suggests three considerations. Firstly, is the work grounded in epistemological principles—does the research remain faithful to an underlying authentic and coherent philosophy and associated values and literature? Secondly, are quality control standards observed—is there clarity and detail of procedures, what the researcher actually did—the process of recruiting participants, for example? Relatedly, how transparent, open and reflexive is the researcher about their own background, qualities, biases and personal engagement with the research topic? And thirdly, is the report any good—is it interesting, compelling or useful?

For some, the flexibilities and ambiguities that are inherent in the process of IPA call into question its worth as an academic endeavor. Demonstrating a willful ability to miss the point, Giorgi (2010) for instance bemoaned IPA for being insufficiently prescriptive in how it should be executed, not replicable, and not “scientific.” This is the challenge of postmodernism: the old “rules” no longer apply, and anyone who is faced with a piece of work must decide for themselves whether or not it has merit. For a piece of qualitative insider phenomenological research such as this, Rooney argues that rather than considering validity and trustworthiness, more helpful terms might include “authenticity, credibility and understanding” (2005: 5). Yardley advocates these principles as a guide to quality: sensitivity to context; commitment and rigour; transparency and coherence; impact and importance (2000).

I have attempted to live up to these ideas throughout this project, striving to be as honest and transparent as I can about my own context, reflections, interpretations and processes, especially by including a chapter on my own illness narrative. I want readers of this work to be in an informed position from which to construct their own interpretations, meanings and value judgments.

I believe my deeply personal involvement in this project does not detract from it; rather, it carries “the potential to increase validity due to the added richness, honesty, fidelity and authenticity of the information acquired” (Rooney, 2005: 7).

## ***Analysis***

In a research workshop at the Metanoia Institute during my training, I played a 12-minute segment of one of my research interviews, with participant “Mary” (all participants’ names have been changed to protect confidentiality), to my colleagues with the intention of then conducting a data analysis exercise using the transcript. Mary’s voice filled the room. We were all moved by her anguish at having to give up her beloved hiking. At the end of the segment, with half the room in tears, it felt preposterous to reduce Mary’s powerful testimony to a deconstruction of words on paper. We abandoned the coding exercise. Instead, we discussed Mary, and the raw emotion of loss.

This experience crystallised my ideas about what constitutes “data” in qualitative research and how understanding and meaning are to be pursued. I decided to consider my interviews from a variety of “altitudes”: at the highest, with the widest lens, were the interviews themselves, descending and narrowing to the audio recordings of the sessions, the transcripts, and finally right down to the granular line-by-line scrutiny and coding process.

After each interview I wrote free-flowing, unstructured notes about my impressions, reflections and feelings surrounding the encounter. This process was repeated when, two years later and wishing to re-engage with the project, I listened to the audio recordings again. In the meantime I had had all 12 interviews transcribed (owing to the volume of recordings and my hand tremor and weakness, I felt unable to do this myself). I read through the transcripts, writing further notes.

Finally, I carried out a more granular analysis of all the transcripts. I find the traditional characterisation of the process of “coding” can be somewhat prescriptive; an attempt to add an element of apparent positivism and objectivity to the proceedings by those who feel uncomfortable about the qualitative nature of their research. Such an attempt is both unsuccessful and unnecessary. Subjectivity in qualitative research is to be embraced, including in the identification of resonant themes.

IPA does not use the terminology of codes or coding (Smith, 1996). Nevertheless, to complete the process of analysis, I conducted an in-depth analysis of the text that essentially was a coding exercise. Saldana defines a code as “a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data” (2009: 3). Codes can be clustered together into patterns which can be considered alongside earlier reflections.

My engagement with, reflections and writings on interviewees, recordings and transcripts, as well as my own experience, contributed to what Gadamer called a “hermeneutic circle” (in Lavery, 2003) on which this project turned. Says Shinebourne: “The process of interpretation is dynamic and iterative, engaging the concept of the hermeneutic circle in an interplay between parts and whole and between the interpreter and the object of interpretation” (2011). The dance around the hermeneutic circle is a complex one. Smith *et al* warn that the process “will not be a linear one, and the experience will be challenging” (2009: 80).

For van Manen, the purpose of phenomenological enquiry and research is to arrive at “meaningful insights”; this is “not conducted through sorting, counting, or even systematic coding efforts. Rather, phenomenological inquiry proceeds through an inceptual process of reflective wondering, deep questioning, attentive reminiscing, and sensitively interpreting of the primal meanings of human experiences” (van Manen, 2017: 819). He describes what he calls a “nonmethodical method” (*ibid*: 820): sometimes insights, meanings, understandings and other epiphanies arrive only once the quest to unearth them is abandoned. What I was looking for was some sense of the overall taste of life with CMT, plus an identification of the principal ingredients that contributed different flavours.

Considering multiple viewpoints, stages of interpretation and shifts of the camera lens allowed meaningful overarching themes to come into sharp focus. I found this to be an organic, iterative process. My immediate response to the interview subjects and the interviews themselves, coupled with my own

experience, suggested several possible broad, overarching themes. The in-depth scrutiny of the transcribed interviews, on the other hand, identified a comprehensive list of all possible themes worth considering (see Appendix VI). These subthemes coalesced into groups that influenced and were influenced by the initial list of overarching themes. This back and forth dialogue crystallised four main themes: loss; discrimination; identity; growth, each with attendant subthemes, some of which were used and some not—in general I favoured subthemes that best reflected participants' lived experience. On countless discarded pages of scribbles, the four main themes eyed each other nervously at first, then began to interact and make sense of each other before finally taking their positions: four pillars of disability around which an imperfect house of understanding was constructed.

## 5. VOICES

### *Introduction*

The six participants spoke at great length and depth about their experiences with CMT. The recorded interviews totalled 22 hours and 38 minutes of testimony. How are the truths within the interviews best uncovered? For Heidegger, unconcealment and concealment are conjoined twins: You cannot have one without the other (Heidegger, 1927). Truth is thus always a mystery, shrouded in untruth.

Having identified four broad, overarching themes—loss, discrimination, identity and growth—originally I intended to use as much of the interview transcripts as I could that exemplified these themes. The participants' words were only minimally edited for clarity—I kept such changes to a bare minimum, as I did with regards to any commentary and explicatory text from me. My intention was to let the voices of the participants be heard, and speak for themselves; to offer a glimpse into the lives of six people who grapple with CMT every day.

But I came to realize that this is a somewhat disingenuous position. I cannot embrace the subjective, insider nature of this research then suddenly claim that the participants' testimonies are somehow pure and true and immune from any influence from me. In both the interviews themselves and the analyses afterwards, my experiences and my ontological truths informed the proceedings.

I found the interviews to be extraordinary encounters. None of the participants had spoken about CMT at such depth before; three of the six had never discussed their feelings about CMT with anyone. Additionally, the fact that I too have CMT generated an enormous sense of kinship. The interviews were not just a meeting of minds but of bodies too, bodies that shared the same peculiar kind of brokenness. These were deeply intersubjective, embodied encounters. Merleau-Ponty wrote: "It is through my body that I understand

other people” (1945: 186); it was through the shared physical vulnerability wrought by CMT that I and my participants connected.

I interpreted “interview” in the true, original sense of the word: both parties were “seeing each other.” I felt fully present as myself, and available to the interviewee; together we co-created an egalitarian space of “reciprocal mutual influence” (Stolorow and Atwood, 1992: 18). I view intersubjectivity as a largely unconscious, embodied process (Gallese, 2015), one that emerges from the interaction between my subjectivity and that of the client, with both being altered by the dynamic. This is my understanding of a dialogic attitude (Buber, 1958; Hycner, 1993). I experience it as an altered, higher state of consciousness.

Given the highly-charged and deeply-personal nature of the subject matter, the interviews inevitably were at times very emotional. The distinction between my role as a researcher and my normal working role of therapist time and again became largely theoretical. I believe this contributed to the richness of the testimonies.

At each meeting, both interviewee and interviewer were altered by the exchange, in a couple of cases profoundly so: As a result of the interview process, of starting to speak of the unspeakable, two of the participants subsequently took counselling courses with a view to making a career change.

In rewriting this chapter, I have given up the pretence of myself as silent witness and instead have been judicious in my choice of transcripts and wholehearted in my attempts to provide commentary that to me clarifies, unconceals and unpacks the layers of meaning in my participants’ words. This is necessarily an incomplete, imperfect illumination, one that is highly subjective and personal. It is thus very much in keeping with the approach and flavour of this entire thesis.

A summary of the participants:

*Fay, 25, single, singer and mental health practitioner*

*Liz, 33, divorced mother of two, former child care home worker*

*Kay, 44, divorced mother of two, senior pharmacist*

*Jill, 46, divorced mother of one, self-employed consultant*

*Pam, 59, married mother of two, self-employed retailer*

*Mary, 68, single, retired art gallery librarian*

I am very grateful to these women for the generosity they showed me in sharing their time, wisdom, emotions and life stories.

## **THEME 1: LOSS**

### ***The impact of CMT: “it’s beating me”***

This thesis essentially asks a simple question: what is it like to have CMT? As a way of introducing the topic and the participants, I begin by highlighting how the symptoms of CMT affect every day life. As you will see, CMT casts a shadow on everything: work, social life, romantic relationship, autonomous sense of self. And it’s a shadow that is ever-growing. The losses accumulate. CMT can rob people of work, people and activities that they once loved. It can make people a stranger to themselves.

When I sit down with Liz for my first interview, she hands me two sheets of paper stapled together. She had typed at the top “How CMT affects me ...” Under the headings of Dressing; Hygiene; Mobility; Pain; Household chores / cooking; and Miscellaneous, Liz had identified 56 symptoms that challenge her. For this divorced mother of two young children—both with CMT—life is hard.

She says: “This is everything I struggle with on a daily basis.”

Liz wants me to know that CMT is a constant, unwanted presence in every facet of her life. There is no respite, and no grounds for optimism either given

the progressive nature of the disability. She can only walk short distances now, with a cane. She also has a wheelchair and a mobility scooter. She had to give up her work in a children's care home at 23 and many beloved activities—swimming, dancing, going for long walks, exploring castles—are no longer possible.

"I'm 33," says Liz, "but I feel like I'm in the body of a 70 year old."

Mary is rather distressed when I meet her for her second interview. The day before she'd met with a physiotherapist who supplied her with a new, somewhat bulky lower leg and foot splint to help her walking. Mary, 68, has suffered a lifetime full of physical decline and loss, but this new piece of equipment—which did indeed help her mobility—felt like a fresh affront, yet another "new normal" to adjust to, one more chunk of physicality chipped away. Listening to Mary, I really had a sense of her ontological insecurity—you are always on shaky ground with a progressive disability.

"It was a bit shocking because I thought, you know, I really am disabled," says Mary, who never married or had children and lives alone. "It's been disturbing. The whole year it's been like this ... but then this is just all sort of ... [*sighs*]. I mean it's still great that there are still things that one can do, but at a certain point, you can't. Like I can't now get money out of my purse any more you know. My fingers just don't work. There's nothing they can do."

CMT forced Mary to take early retirement from her work as a librarian and administrator at an art gallery, which she greatly enjoyed. But her biggest regret is having to give up hiking.

"It's been really important to me over the years," she says, "because I wasn't any good at sport, but also, I've got a very strong feeling for nature and being outside, and I've had that all my life. Walking in nature was what I did with friends. Now when I go to those places, I often have to sit and they go off and do the walk, you know up to the cliff top, which might take them hours, and I sit at the bottom looking at the sea, which is wonderful and everything, but I



feel a real longing to do the walk and I do feel left out. I take a book too so that I can read while they go off and do the more active thing but of course there is a part of me that is very unhappy about it.”

Kay is challenged by CMT in her work as a senior pharmacist.

“Sometimes I think oh, I’ve struggled today, like it’s beating me ...,” she says tearfully. “I just think I’ve worked so hard to get to be doing what I am, and then um, it’s gonna be taken away. I just get frustrated with myself, because it’s silly things, like I can’t open bottles and I can’t stand up for long periods. I’m getting to the stage now when I think I’m not gonna be able to do this for much longer, so what am I gonna do? Just recently, I’ve given up a day’s work and gone to a four-day week because I was just getting so tired.”

Kay used to love drawing and painting, too, but now struggles with her hands. “It just saddens me,” she says. “It’s depressing, because it’s something you enjoy doing and it’s slowly being taken away.”

CMT also robbed Fay of her onetime dream of being a famous singer; she now uses music in her work as a mental health practitioner. And it robbed Pam of her career teaching first aid and lifesaving for a variety of organisations. “I can’t teach anymore, and that hurts,” she says, “I taught for years. That was my motivation.”

CMT comes in different genetic forms and varied epigenetic expressions. Each CMT experience is unique. But all the participants struggle with the progressive, degenerative nature of the condition—things will only get worse. Cruelly, many believe the progression of symptoms accelerates in difficult or stressful times. For Pam this happened around the time of her mum’s death, her diagnosis, working on a new business and her children going off to university. The nerve pain in her feet got so bad she considered double amputation. She says: “I could walk, and then six months later, I’m on crutches. There was just so much change going on.”

***The shock of diagnosis: “I was dumbstruck”***

CMT is a slowly-progressing condition whose symptoms can be mild and commonly don't start to bite until adulthood or midlife. This means diagnosis is often slow, after years of struggle. Or it doesn't happen at all—someone with undiagnosed CMT might have their difficulties explained as just having “funny feet” or not being “sporty.” Some people with CMT report relief at receiving their diagnosis, finally having a concrete reason for their fatigue, ungainly walk or clumsiness. Some feared or had been told they had something much worse. But nevertheless diagnosis for many was a brutal introduction to the kingdom of sickness. There are too many tales of bad news badly delivered.

Says Liz: “My first memory, and I think it is the hardest one to cope with, is when I was 15. I remember going to the doctors, and they're saying to my mum and dad, in front of me, that by the time she's in her 30s she won't be walking. But then nothing else was said to me about it. And mum and dad, um, it was very quiet at home. No one said any more to me. It was like I'd done something really wrong. I got very good at burying my thoughts and feelings.”

Right from the start, Liz learned that CMT was unspeakable. Jill's experience of diagnosis was similarly painful: “From the age of 10, I knew there was something not quite right and that carried on until I was about, 18, and I went to the GP because I'd been falling over a lot. And he just sent me away, patted me on the head and said, there's nothing wrong with you, you know, go away. And I fought right up until I was 21 with GPs and I got referred to a psychiatrist, because they thought that it was mental. It's only when I spoke to the psychiatrist about symptoms and how I was feeling and what was physically happening, that they sort of clicked that this is a physical problem and it needs sorting.

“So I was in there for three weeks, and they did the electrolysis test, lumbar puncture, blood tests, um, and, I remember one morning about 7 o'clock I woke up, and the doctor came and sat on the bed, he said, er right we've got your results back, and I can confirm that you have got hereditary motor

sensory neuropathy otherwise known as Charcot Marie Tooth. 'It's a progressive disease,' he said, 'er, er, that's it.'

"Then he said, 'The best thing I can advise you is to never have children.'

"And then he just went.

"All I ever really wanted was to have kids, to have a family, and I felt CMT had snatched that away. I was 21, and I'd just lost my dad, and my mum wasn't around, I didn't know anybody, I was just, I suppose I was dumbstruck."

The message inherent in the doctor's advice is that it would be better if people with CMT had never been born. Such a view, such disregard for ethical standards, has no place in medicine.

### ***Emotional reactions: Feelings behind "the wall"***

Post-diagnosis, participants experience an ever-changing kaleidoscope of responses to living with CMT. All participants reported times of low mood and anxiety. Perhaps the commonest reaction is anger: We can no longer do what we used to be able to do, the everyday things that other people take for granted, and we lose patience with our failing bodies, and we snap.

Mary: "I get pissed off really. You can't grip your credit card, you can't get your change out properly, and you can't...you can feel something down in your bag and you can't actually grasp it to get it out. And we live in a world where people don't notice you, they practically knock you over if you hesitate or you're fiddling round with your money.

"There are times when I get really upset about little things I can't do. When I see people walking down a staircase, not holding the bannister and maybe carrying something, well, it looks like a miracle.

"Sometimes I'll just lose my temper which isn't very good ... recently it was raining, it was dark, and I was trying to get on a bus in the rain to get home,

and I did have a raincoat of some sort and I got on the bus, and I couldn't find my travel pas. And the driver wouldn't let me go and sit down and find it. I said look at me, you can tell that I'm an older person. I've got a Freedom Pass, I just can't find it. And I just got really really angry with him and angry with myself. It was just sort of really horrible and it's that kind of thing. Tiny things, just not being able to find your travel pass. And I was with a friend who has her own disabilities, and I, I was in such a bad state, and I knew it kind of upset her as well and I still really feel ashamed about that."

Pam: "I think I get more cross than anything else, because it's so inconvenient," she laughs. "That was the overriding feeling, the irritation. You know, I want to get on, but I can't do this and I can't do that, and I've got to plan where I can go, where I can park the car so that I can get the wheelchair out, or, can I get in there in crutches, how do I get in and do that? It's all the inconvenience of physical things, rather than the mental challenge. It really bugs me, the inconvenience of the physical."

The physical vulnerability that CMT confers often necessitates a degree of psychological protection. Liz describes this as "the wall." She keeps her emotions away from others but to a significant extent, she keeps them away from herself, too.

Says Liz: "I don't feel things. People can tell me things that for them would be upsetting, and I don't understand why they're upset. I would like to feel more. I should feel more feelings but I don't. I'm odd. Sometimes I think I'd like to cry and then straight away tell myself no, that's not gonna happen.

"I went to the doctors a while ago and she said she felt the CMT was affecting my bladder because I was leaking and going to the toilet quite frequently. And I came out and I got this overwhelming sadness, and I allowed myself to cry for about 10 seconds and then that was it. It was shut off. It was just like [*sharp inhale*] and then I shut it off and I've not thought about it since. So I allowed myself to be upset for a little bit and then stopped. And then like I am having new surgery next month, but I won't think about it until I'm there. And

that's to protect me, because if I do think about things, I could slip into a depressive state and I don't want to be like that.

"I have very much trained myself. I always say I'd like to go into the middle of a field, and have the most, biggest tantrum going, like a two year old, and let it all out, and no one can hear me, just have like a massive paddy, and just scream my head off. I'd love to! You know, no care in the world. Just be angry. I'd like to have a massive wobbler."

The "wall" also means that Liz is reluctant to ask for help. "I need to be the strong one," she says. "People don't see me cry. I don't like people seeing me sad, or that things get to me. I've tried to open up to a few people but they just shut me down, so I don't bother now. They don't understand you know. They haven't got a clue. They have got no clue how I live every day."

Jill too recalls a kind of denial in her youth that she had CMT or that there was anything wrong—both to others and to herself. When she started working and making friends, she kept her CMT a secret.

"I didn't want to face other people not coping with it, or me not knowing enough about it. Just buried my head in the sand I think. I knew I'd got it, but there was nothing I could do about it, couldn't change it, couldn't make it better um, so I'm like just, yeah well, you know what, forget about it, let's get on with life. That helped a lot."

### ***Adaptations and adjustments: Disability as the mother of invention***

The participants' desire to keep their struggles to themselves has made them all enormously self-reliant and resilient in managing their day-to-day challenges from CMT. Disability can be the mother of invention.

"Actually I'm very resourceful," says Mary. "I will try and do things myself. I do what I can, and I'm actually quite inventive at using things that they weren't intended for, or doing things in different ways. You have to be quite creative. Yeah, and you get a sense of satisfaction out of that."

“When I was in the hospital the first time, I just got an apron from home, which had a little pouch in it, and so when I was on my crutches, I’d just put all my stuff in the pouch and you know, went off to the loo or whatever I had to do in the hospital, and everyone was amazed at what a good idea this was.

“I can’t carry a cup of coffee, or anything liquid, but I will make a flask of coffee or something in the kitchen, put a lid on it, put it in a bag, carry it to another room, sit down and have it. You know, I have worked out all sorts of things that help, lots of little things around the house.

“I do think I also have a sense of humour, which really helps. One of the things I do like about talking to friends or talking to my sister on the phone is that we can start off and we’re all feeling a bit low and everything, but usually by the end of the conversation we’re having a bit of a laugh you know. And um, I think I’m quite good at that.”

Aside from reduced mobility, Pam’s CMT symptoms also include joint pain and restless leg syndrome at night. Pam has found her own ways of treating these intrusions.

“If I totally concentrate on breathing, I can get through restless leg syndrome,” she says. “I can’t always, but very often I can. Sometimes I have to get up and walk and have a cup of tea and then go back to bed and start again, but I can certainly put myself in a better place.”

As a child, Pam nearly drowned in the sea when a wave knocked over her grandfather who was carrying her. She has been an avid swimmer ever since. Far from reducing the amount of time she spends in the water, CMT has provided an incentive to swim more. Much more.

Says Pam: “I swim, Monday, Wednesday, sometimes Thursday, Friday, Sunday, and I’m trying to get Tuesday and Saturday in too if I can. I swim around 10 miles a week.

“If I get in the pool, I can’t think about anything else. You’ve got to concentrate 100 percent on what you’re doing. Yes I hurt when I get out, and yes I am in pain the next day, but the feeling overall is great. And I do Iyengar yoga five sessions a week, most weeks, five hours a week. I’ve been doing that for 14 years.”

***Wanting and not wanting help: “No one can help”***

All six participants cherish their independence and privacy, but to varying degrees all seek help at times, from family, friends, strangers and healthcare professionals. All feel ambivalent about help. Few have found helpful help.

Participants find help from the National Health Service to be a mixed bag. “Doctors haven’t got a clue,” says Liz. “I told a doctor once that I have CMT and she said, yeah I’ve heard of that, it’s related to the patient having syphilis. I’m like no! Not at all!”

A chance meeting with a more empathic, better informed care worker however was transformative. Says Liz: “She come in and she sat down and she read the report and she turned around and she said to me, ‘I think you’re in a lot more pain and a lot more tired than you let on.’ And that was the first time someone had said that to me. Yeah, it was nice. And ever since then she’s been really good at offering me support, really good. She’s helped me in so many ways.”

Liz relies on a close friend, and a neighbour who comes round for chats and to help out with practical matters Liz finds difficult like cutting her toenails. And she was just beginning to open up to her parents, too. Between our two interviews she spoke honestly to them during a phone conversation for the first time, and became tearful. Her parents responded with love and care.

“I’ve had tons of help, you know from professionals,” says Mary. “All of them. Recently I’ve had special hand people look at my hands and give me suggested exercises and suggested bits of kit and gloves, special gloves for

the winter and all this, you know, because when your hands get cold, everything goes a lot worse. I've just had so much help, but there's a certain point where the help can't go any further."

Pam does not regard herself as someone in need of help, though she might occasionally ask her grown-up sons for practical or logistical assistance.

Says Pam: "I can be sad, I mean I can, I can sit there and cry my eyes out sometimes, but then you realise that it doesn't matter, you get to the stage where, you realise that it doesn't matter how much you cry, or how frustrated you get or how bad it is, no-one's going to do anything to help. If you don't pull yourself out, you've lost it, it's your life gone, so you've got to do it. No one does help, no one's gonna help. There's no one out there that can help."

I was struck by Pam's fierce refusal to be dependent on anyone. So I asked her: "What do you need from other people?"

"I want people just to accept that I'm me, this is me. And get on with it.

Jill, like Pam, tends to eschew offers of assistance. "I try to avoid help, any which way really," she says. "I adapt, you know, there are things now that I can't do, that maybe a year ago I could, and, I suppose now I am starting to think ah, you know, if it carries on like this, how am I gonna get through this? But I will."

Even Jill, fiercely independent, concedes however that there may come a time when she will accept some help. "I'll have to, won't I?" she laughs. "I won't get away with it all me life, you know, as much as I'll try."

Jill did have some counselling 25 years ago, after her dad died. Here is our exchange about that:

Me: "How was that?"



Jill: “They were quite good, because they gave me the skills to deal with it, to shelve it, to compartment it, and put it away and close it off. I’ve never really lost those skills. You know, I’ve used them in multiple situation.”

Me: “That’s your strategy—you’ve found what helps is to shut things away.”

Jill: “Yeah.”

Me: “A psychotherapist might want to open up all those boxes and process what’s ...”

Jill: “Oh my god, I would be, I’d be a wreck. Best not to go there really.”

Having been let down by so many humans, Jill does take enormous comfort from animals—beloved dogs and horses in particular. During a kind of breakdown in her youth precipitated by her diagnosis, Jill was looked after by Jeb, a border collie.

“He was just ace because he was there, you know?” she recalls. “Everytime I sat down, he was there, everytime I went out he was there. Everything I did that dog came with me. He never answered back. He didn’t care about CMT, you know? As long as he got his food and his cuddles, he was happy.”

## **THEME 2: DISCRIMINATION**

### ***At school: In the “dark tunnel” of being bullied***

People with disabilities often first become acutely aware of their difference in school. Many find that their vulnerability attracts the interest of bullies. In those fragile years when children are building a sense of self, those with disabilities find that self can take a battering—sometimes literally. It’s understandable from these experiences that people with CMT often try to keep their disability hidden, cut themselves off from their emotional reactions to it, and deep down develop a sense of shame.

Jill: "I was always picked on at school, because I was different. Because people could see that I walked differently, I couldn't wear the shoes that everybody else wore, I couldn't do sports. I was bullied a lot. There was one particular girl who was really popular in school, and she knew she could get at me. She knew she could bully me. She used to pull my hair, you know, she used to come up behind me and push me, because she knew I hadn't got very good balance. Or you know, when I was walking past, people would deliberately put their foot out and trip me up."

Liz: "They used to call me Forrest Gump and laugh at me, or they'd say, oh you walk like you know, you've been to the toilet. Just cruel things that kids would say. I used to not be able to say CMT without crying. I'd cry instantly. And then over time I got stronger, so when they used to call me names I just used to tell 'em to do one. And it didn't really bother me any more and that is the truth."

Fay: "So I was kind of like bullied a little bit. My mum made me wear a blazer to school, whereas like no other kid in school wore a blazer. You know in 'The Inbetweeners' when he's called the briefcase wanker? I was always the blazer twat."

"I did quite a lot of like theatre stuff and I was always really really tired after rehearsals and I could I never really do like the dancing. And I just found that really humiliating and sometimes I look back on that and I get quite angry at the thought that some people just have no understanding of disabilities, and actually don't understand that someone cannot do it, and you cannot push them to do it because their body will not allow them to do it."

Kay: "It was mainly PE. PE I found very very difficult. They just thought I was clumsy and not trying. I always remember them trying to make me jump over this big horse thing. And I just said, 'I can't jump,' and they said, 'Course you can, everyone can jump.' I just remember sort of running up to it and just sort of leant over it, and I said, 'I can't jump, I can't jump'."

"I remember one PE teacher particularly trying to make me do hurdles and I was just like, I can't jump, so how am I gonna be able to jump over a hurdle? And she was like don't be stupid, everyone can jump over a hurdle."

Me: "Tell that to Stephen Hawking."

"Exactly."

Pam: "You got bullied and accepted it. You just did other things out of school that they didn't do, and had friends out of school, that's why I did Red Cross, I did lifesaving, and I was accepted in all those things. If girls wanted to be bitchy in school, I got on with it."

Me: "Were they bitchy to you?"

"Yes, oh yeah, it was a girl's school, they're bitchy."

Me: "Because of the CMT you think or ...?"

"Because I couldn't do some of the things that they did. They could run faster. I couldn't run. There'd be cross talk and side talk and banter. A snide side comment. And when they're picking sports teams, you're the last one to be picked."

Me: "Did it get you down?"

"Oh yeah. I never took my O-levels."

Pam's teenage years were a bleak period of CMT, bullying and depression. One psychiatrist told her that her problems were caused by a lack of sex. She was 14.

Eventually, at 21, she would discover that her depression seemed to have an

organic cause: "I'm allergic to meat," she says. "If I eat meat, I am truly depressed."

Being a teenager who was bullied depressed and disabled was an experience she describes as "being in a dark tunnel."

***At work: "He just made me feel totally useless"***

Two of the participants are employed, two are self-employed, and two retired. All have experienced workplace discrimination and even bullying. It's certainly hard enough battling CMT at work, but this is cruelly amplified by having to battle the prejudicial attitudes of fellow employees too.

Kay tells her story: "The only provision I've got is that there is a chair in the pharmacy, but I have to go and get the chair out of another room when I'm tired, you know. And if I do, I just feel a bit guilty again then because someone says, 'Oh, you're sitting down again, what's up today? You're sitting down a lot lately.'

"Then I had a new manager, and he took the chair away totally. I weren't allowed to sit down at all. I said I need the chair because I've got a disability, and he just dismissed it totally, he said no and that's the end of it. And I went to my HR and um, they sort of sided with him. It was horrible. Obviously I was very stressed. I thought they were going to use it as an excuse to get rid of me. It sort of got personal, and I couldn't do anything right and my confidence just went right down to nothing. He just made me feel totally useless at my job. I got to the stage I didn't want to go into work.

"So then my occupational therapist that I was seeing at the time referred me to Remploy, and this man come out and sort of assessed me, and had a meeting with HR who said, 'Oh, of course we'll do whatever we can for Kay,' and it was basically having a fight with everyone at the time. I even got a human rights organisation in London involved.

"After about a year, I won. We were in an office and I had two of the senior

management there, and I'd just found out so much information and I'd researched everything, and I just blurted it all out in front of them, and he just sat back. After the meeting they told me to put a chair back in the pharmacy. It shouldn't have ever got to that stage. Not long after that, he left."

Me: "So this chair is hugely symbolic, you've had to fight for this chair but still you don't use it! Or feel guilty when you do!"

"I do try to use it when I get to the stage where I can't stand anymore. But then you know, now and again I get little comments from this one lady."

Me: "It should be more like a throne. I think you've earned it."

***From the NHS: "You want to bring a disabled child into the world?"***

Pam refuses to buy into other people's judgments of disability, but still she is sometimes taken aback by unhelpful assumptions: "One time I was having a better day, and I thought, well, I'll leave the wheelchair behind and go and see the doctor on crutches. I went in the door, and he's in front of his computer and he's like, 'Oh hello, what have you been doing to yourself?' Not, 'Oh wow, you're out of the wheelchair.' That really upset me. He just saw crutches, not a person. I came home fuming, I changed GPs, I went to a new practice, I couldn't handle it."

At their most extreme, discriminatory attitudes can even extend to questioning the right of someone with CMT to exist.

Jill ignored her doctor's oppressive advice at diagnosis to never have children and many years later found herself pregnant with her beloved daughter, now a teenager. She was asked to have amniocentesis to check to see if her child also had CMT.

"I'm not doing it," Jill told the doctor. "It wouldn't make any difference. You can write all the referral slips you like, I'm not doing it."

Jill later took a referral slip out of a nurse's hand and ripped it up.

"There were these two nurses," she says. "They were so vile to me. They were really, really horrible to me. The one lady said, 'Well, don't you want to know if the baby has what you have? Would you really want to bring a child into the world that's disabled?' "

Jill later heard from her partner, the baby's father, that members of his family were expressing similar sentiments.

"I don't do anything through third parties," says Jill. "So I went right up to them and said, 'I hear you have a problem with me deciding to have this baby?' And they went, 'Well, we just don't think it's fair if there's a chance that this baby's gonna come out disabled.'

"Then my partner's nan piped up and said, 'Well, if that child is disabled or deformed in any way, I don't want nothing to do with it.' "

***Social situations: "I'm becoming a bit of a hermit to be honest"***

Discrimination is not always so overt and explicit. What is most disabling is not CMT's symptoms but a world that is not designed to accommodate CMT. This is apparent in everyday social situations.

Liz describes the horrors of simply going out to a restaurant: "I went for a meal the other day and I couldn't use the knife properly to cut my food up," she says. "My elbows go out and I end up elbowing someone, and then the food flies off the plate. There's anxiety in situations like that. I don't really like eating in front of people. Then I got locked in the toilet. I didn't have the hand strength to unlock the door.

"It's embarrassing and it's just constant," she says. "I'm constantly thinking, oh that step looks a bit high, or that slope's a bit steep or that path's a narrow. Your brain's constantly monitoring. Winter's a nightmare. I only feel safe at home. I'm becoming a bit of a hermit to be honest."

“Yeah socially it does limit you,” says Kay. “Recently in a restaurant I was sitting there trying to cut a roast potato and I couldn’t hold my knife properly and I, and then you think well everyone’s looking at me, because I can’t hold my knife, and it’s just things like that you know that um...[sighs].

“People ask if you want go rollerskating or something. I’m not gonna be going [laughs]. You know, you need to know your limits. It’s OK. I think the only thing that has always really got to me, probably true for every woman that’s got CMT, is shoes. You get a nice dress, and you’re going to a wedding or whatever, and then you’re thinking: what on earth am I gonna put on my feet?”

All six participants spoke of the difficulty of finding attractive and comfortable footwear that also offers support and often must accommodate bulky lower leg splints or other ankle-foot orthoses.

“Yes I am young and slim and I want to be able to wear like 5 inch heels like any other 25 year old girl,” says Fay. “But I can’t. I love shoes and just being able to have that kind of stride and confidence that some women have as well ... I’m always a bit like [laughs] stuttery on my feet.

“I get like really tired. I want to stay up til 4 in the morning, and drink loads of wine, but um, yeah I just know I don’t have that same physical energy as other people, yeah. Which, I struggle with sometimes, because I’m quite a social and chatty person.”

***In relationships: “I don’t want to be looking after you”***

CMT has a major impact on participants’ romantic relationships. Disability can be such an abhorrent experience that people with disabilities often cannot imagine anyone would want to be romantically involved with them. Sometimes this is borne out by experience.

Says Fay: “In relationships I get really worried about my CMT—has that been

the reason why people have broken up with me, or will it have an effect on relationships in the future? I don't know."

During her 12-year marriage, Liz saw her symptoms worsen and her husband become increasingly unsupportive, critical and emotionally abusive. She divorced him three years prior to our interview and has no expectation of having a new partner.

She says: "So obviously now I'm single. And the actual thought of dating, or being with anybody else—I can't see that. Because of the CMT. So, yeah, that stops me getting too close with anyone. A relationship frightens me because then they'd see me, wouldn't they? Struggling to get in and out the bath and not being able to cut my toenails—that's quite a frightening thought, letting someone in, having them see that."

Jill recounts her experiences: "The first relationship I had, it broke down because he just couldn't cope with the fact that I had CMT. He just didn't want to acknowledge that I'd got anything and you know, he didn't want to be with anyone that had any form of disease. He was ignorant.

"We had a relationship for five years, and, um, he came home one day and said, 'I've had enough, you, you need to pack your bags and go.' And it was his house, and it all came out of the blue. I went, 'I don't understand, you know, what's going on? What have you had enough of?' You know?

"And he said, 'Well, I don't want to upset you, but it's there and I can't get away from it, I can't, I can't live with you, knowing that you may end up in a wheelchair, or that you're going to be crippled. I can't live with that, because I don't want that. I don't want to be looking after you.'"

***Shame: "I hate my body"***

Not surprisingly, a lot of the negative views that able-bodied people may harbour towards disability—"Did you hear? Such a shame"—can become internalized, magnified and projected. Shame is a common, overriding



response to discrimination. People with CMT often say they don't like walking in public, for example, because their ungainly gait makes "people think you're drunk," though few can offer any evidence for this supposition.

In one heartbreaking part of her interview, Liz delivers a volley of negative comments about herself that she has internalised and imagines other people think of her too: "People think I am lazy ... I eat like a pig ... I don't feel feminine ... my feet are horrible to look at ... I hate the way I walk ... I feel like I get in everybody's way and hold people up ... I stand aside to let people pass me but I have just as much right to be there ... people judge me because I walk funny ... people think I'm some drunken mother, a bad parent ... I hate my body; I don't like people looking at it ... I don't feel attractive."

At another point in the interview, Liz says: "But I'm not ashamed of it. I'm not ashamed I've got CMT."

The world however offers up some regular experiences of shaming.

"So I did a music degree," says Fay. "And I was selected to go and do this masterclass in some very high art festival with a top singer. I sang an operatic aria that required quite a lot of physical strength and stamina and this lady, who was in her 70s, was critiquing me in front of this whole audience in this very posh venue.

" 'Oh come on,' she said. 'I need you to support your body, sing into your back, use your muscles—put some strength into it girl.' And I was like, oh god, oh no. And then she was trying to pull me and then she was dragging me across the stage. And she was like, 'Oh come on, that's pathetic.' Like I'm an old lady. I was 22. I just felt like, completely ostracised and humiliated. I actually physically couldn't do it, but I couldn't say in front of a whole like room full of people. And then as soon as I sat down I was just like, choking up with tears. And as soon as the masterclass was finished, I was just uncontrollably crying. I was humiliated."

Pam has a different perspective on her CMT, having worked extensively for the Red Cross with people with often quite severe disabilities, organising activities for children with spina bifida for example, or children affected by thalidomide.

“I’m not gonna be embarrassed about it,” she says. “I’ve worked all through that. My mantra has always been that whatever someone’s got wrong, you look at their eyes, and you get through any physical disability. You talk to them and it’s not a problem. You treat them like humans. I don’t want to feel sorry for them, and I don’t want anyone to feel sorry for me, I don’t want pity. I want someone to accept that, just, I’m me, this is me, get on with it.”

Pam’s other rule is that any help is offered, not imposed. You do only as much as you need to do. And always on their terms. Pam has no handles on her wheelchair. “Don’t like being pushed,” she says. “Don’t do with being pushed.”

### **THEME 3: IDENTITY**

#### ***Ambivalence: “Am I disabled?”***

As for anyone with a disability, participants’ reactions to their CMT fall on a negative-to-positive continuum. Those at the negative end of the spectrum regard themselves as a helpless victim of a completely incapacitating condition. Their expectation of themselves is low. At the other end, people can be relentlessly positive, either denying that there is anything wrong with them at all, or else denying that it impacts them negatively in any way. They will only reluctantly ask for or accept help from others. These different reactions can be observed between different people with CMT, but also within those people: participants’ mindsets can fluctuate within a day or even within a sentence.

This ambivalence manifests itself in all aspects of the lives of people with CMT. It’s as though there are two identities. One is: I’m okay, I don’t need help, I can exist in the world just fine. The other is: I’m not okay, I struggle, I’m

vulnerable, and I need help. People with CMT often toggle back-and-forth between these two identities, as the following extracts reveal.

Fay might look forward to a night on the town, a charity walk, or a backpacking trip to Cambodia. She wants to be included. But she doesn't want to hold anyone back.

“Yeah that’s kind of the fine line isn’t it?” says Fay. “You want to be treated the same as everyone but then when you’re treated the same in some situations you find yourself getting into difficulty, which is quite common. But you don’t want to go to the other extreme of always telling people about your disability and then being treated only like a disabled person. I don’t want to be defined by it, I don’t want to be one of those people that like, they become their illness or disability, not that that’s wrong, but I don’t, I don’t find that particularly attractive nor do I want to be that person.

“ ‘Disabled’ is a funny word that I don’t really like. Am I disabled? Um. Probably...yeah. But I don’t think of it as a really clear sort of stamp. I have a disabled blue parking badge but I feel guilty about that as well. It is part of me but I don’t want it to define who I am. I know I am weak, and sometimes I feel like it affects my femininity. But then sometimes I think that’s really ridiculous, like, some people can’t walk. I don’t know.”

Fay’s ambivalence towards her CMT is complicated by a childhood in which her mother embraced it so wholeheartedly. She says: “There’s a benefit of being disabled, and I think my mum sort of got a lot of attention off saying, ‘I’ve got a disabled child.’ So I found that affected me. I don’t want everyone knowing.”

I had the feeling of just how much Fay yearns to be like any other 25-year-old. As with many people with CMT, she often tries to keep it at arm’s-length. But CMT moves inexorably closer.

Kay sometimes feels her disability is not serious enough to warrant any

special attention: “Well when I see other disabled people, I think well, at least I can still walk. I got a disability parking badge, and I don’t use it sometimes. My mum says why on earth don’t you use it? I just think someone else might need that space more than I need it.

Me: “Hmm, it’s hard for you to take what’s rightfully yours.”

“Once I’d parked and put my badge up and I got out of the car, and this woman behind me turned round and said to her husband, ‘What on earth’s she got a badge for? There’s nothing wrong with her.’ You know, and that’s why I think, that’s why I feel guilty when I use my badge a lot of the time. You know, if someone’s thinking that, because they can’t see that you’ve got your AFOs [ankle-foot orthoses] on, I just feel guilty. It’s invisible, and that is, I think, a very big part of the problem. Yeah I feel guilty.”

Me: “What are you guilty about?”

“Because there’s people a lot worse.”

Me: “That will always be true, unless you’re the person in the world who really is the worst off.”

“Yeah, yeah I know. I wasn’t diagnosed when I was young and I’ve had to get on with it because I didn’t know what it was. Now I have got a reason why I’m tired or why everything hurts but then I think, well, it could be worse so I should just keep carrying on.

“We went to the Shard yesterday. We were looking at the prices and they’ve got a disabled ticket. But I just paid full price. I had my CMT alert card on me. But no, I didn’t ask.

“It’s silly.”

Mary: “Some people would say I will soldier on, I’m just gonna be like

everyone else, I'm not gonna complain and I'm not gonna ask for special treatment. My autonomy is important. I live on my own and I have to do everything for myself, and I have to get around by myself in the city and there's no one to just help me get dressed or drive me.

"I'm trying to cling onto my identity as an independent person who loves walking and has a very strong feeling for nature and being outside, and I've had that all my life. I don't know what my identity is now. I do need help sometimes. I kind of want people to recognize that I've got a problem.

"I was a very shy child actually, I was shy about everything. But I've become this obnoxious kind of person who sometimes can be extremely cheeky. I have been known to get on the bus and look at people and say, 'Which of you is going to give me their seat?' You've gotta have a fair bit of confidence to do that."

An unexpected consequence of CMT: Mary progressed from a shy person to one with "a fair bit of confidence."

Jill: "You're on your own, you know? Me, myself and I. A lot of people with CMT are full of self-pity, woe is me, I can't do this and I can't do that, why me? Get on with it. I could have just lived off the state. I haven't. I've worked. I've got my own house."

We can see from these passages how people with CMT sometimes deny and disown it, but at other times, especially when it becomes more severe, they have to accept it and own it in order to be accommodated in the world at large.

***Help and helplessness: "I didn't want to be here anymore"***

Ambivalence towards CMT manifests itself in the people who have it and their feelings about asking for and receiving help. This interview exchange with Kay exemplifies the mindset:

Me: "Is it difficult to ask for help?"

Kay: "Yeah, Yeah."

Me: "What happens?"

"I just, I dunno, I would sooner go without getting some food rather than ask other people to help me get it. I don't know, I think it's because I'm quite an independent person."

Me: "Right so if you ask for help, what does that mean?"

"I'm giving in to it."

Me: "Giving in?"

"Giving in to it. It's silly because I always say to my daughter, Meghan, if you need help, you know, you've just got to ask someone to do it for you. So I'm trying to push it on her that she mustn't be frightened ... I'm quite a shy person and I just don't like asking for help."

Me: "Don't want to make a fuss?"

"Yeah yeah, because then people are thinking, well, why does she need help, what's her problem? I don't know."

Me: "So you can't take your own advice in other words."

"No" *[laughs]*.

Me: "Why is it one rule for your daughter and another one for you? What kind of person would you be if you were somebody who needed help and asked for help and got help? What would that say about you?"

"I don't know, it's my silly rules I think."

Me: "We so often feel like we have to present a smiley face to the world."

"Yeah I'm very good at doing that."

Me: "But if, if all we ever all of us ever do is walk around with a smile on our face, we never actually really connect."

"No."

"Have you ever asked for help?"

"Er, not really, the only time I did ask for help was when I ended up going to Mind because things got so bad I got to the stage that I didn't want to be here anymore."

Kay was imprisoned in a kind of fortress of her own making. Her CMT was unacceptable, and it was unacceptable for her to be vulnerable and in need of help, so no one was allowed in. At one time her isolation made her suicidal. Today she has plenty of people and love in her life, not in spite of her CMT but, in part, because of it.

It's interesting how Kay struggles to take the good advice she gives her daughter. It's a similar story for Jill: "I've fought hard for my daughter to get all the help she needs. I've always fought so hard. I've fought against everybody, from day one, for her to have the things that I didn't, and to have the input that I didn't, to have the care, to have the understanding."

Me: "Yeah that's the kind of paradox, you want her to get help, but you don't want help yourself."

"Yeah, because I don't want to. I suppose I'm the kind of person that will ask for help but it'll probably be when its at crisis point. I'm not one to whinge and

moan. I'll get to a point where I'll know, it'll all fall apart, and be like, I can't do this anymore."

Me: "So it has to fall apart before you ask for help?"

"Yeah."

Me: "Yeah. What do you make of that?"

"Well, I'm an idiot really, but that's just the way I am."

Me: "That's the way you've learnt to be."

"I have to be because every time I've tried to rely on somebody, I've been let down and I can't do that anymore, I can't do it, I can't take it emotionally. I have to cut off. It's my only way of dealing with the emotional side. I have to cut it off."

Liz struggles to ask for help. In a restaurant she might ask someone to cut up her food for example. "But then I think what are people around me thinking if they are seeing someone chop my food up? So yeah, I worry about that. I'd feel I'd have to explain. And I don't want to. I don't want everybody to know there's something wrong with me."

***Among family and friends: "There's nothing wrong with you"***

Sometimes people with disabilities cover up or minimize their struggles—and sometimes the people closest to them do likewise.

Kay is often informed that there's nothing wrong with her, such as by her then-partner's father. "He's funny," she says, "because he does know I've got something wrong with me, but he just says, 'Oh you've got funny legs ain't ya,' you know, or 'Oh you're alright girl, there's nothing wrong with you'."

Liz: "If I tried to talk to people about it I'd quite often make jokes about myself."



So I may say something in a joke but actually inside I mean it, but, I don't know how to express it seriously. So I'd always laugh at myself. But inside I want to say, I'm sad because I can't run and jump anymore."

Me: "And why did you do that do you think? Make light of it."

"To protect me, because I don't like people seeing me sad, or that it gets to me. It's comments, you know, oh, you're always tired, you're always going to bed, you're always so slow. You know, I said to my friend yesterday I would go to the shops with her. She wanted to walk and I said, oh, I'll have to get the bus because my feet are hurting. She went, well my feet hurt—I've got hard skin and a bunion. And I thought, you just don't get it. You haven't got a clue. You have no idea. You've got no clue.

"And you know, sometimes you really feel like you're taking a risk telling somebody about it, and when you don't get the right kind of response, you just sort of think oh well, you know, I'm not gonna bother.

"I mean, I don't want sympathy, I just want understanding."

***In relationships: "Who'd want to date someone with a disability?"***

A lot of people who are ambivalent about their disabilities inevitably project their doubts onto others—especially partners or potential partners. Liz for example cannot imagine her CMT is acceptable to a partner as it is not acceptable to her. Except that sometimes it is.

"I mean, to accept me, the way I am...I'm not a normal girl am I?" she says. "Who'd want to date someone with a disability? In 10 years, 20 years you know, do they want to be with someone who they might have to be looking after, when they could have a woman that they don't have to? You know, who would choose to look after somebody? But then my head says, I would do that for someone, so there are people out there, you know there are going to be men out there that think like that."

Kay: “When I’ve been on my own, I always think, oh, I’m on my own, how am I gonna ever find someone else to be with, are they gonna accept what I’ve got? How are they gonna cope with me when I get older, when I get worse? Who is going to take that on? Some people can deal with people that have got disabilities and some people can’t. I always worry that I would never meet anyone again, and get sort of frightened, and shut myself away really.”

After having been dumped explicitly because of her CMT, Jill’s next relationship went to the other extreme. “We sort of became friends,” she says, “and then I spent a lot of the time trying to make him dislike me, and rejecting him, I didn’t want anything to do with him, but I think a lot of that was probably fear on my side, you know, trying to protect myself. He was quite good actually, for my CMT, in the beginning, you know, because he, he did find information out and helped me. But then he got into a position where he was starting to take over my life, because of the CMT. Doing everything for me, not letting me do stuff. And he’d use my disability as an excuse not to work. After 10 years, I managed that relationship to come to an end, because I couldn’t cope with it. I felt very suffocated, you know, I still need to do things, I still need to be independent, to keep this disease at bay for as long as I can. I can’t allow that to happen—I can’t allow someone to take over my life.”

***Intergenerational ambivalence: “I have felt guilty”***

Four of the six participants have children, and all are sometimes troubled by guilt for passing along the pain and suffering that can come from CMT.

Jill: “I have felt guilty, but not to the extent of, oh my god I brought this child into the world and she’s disabled. That guilt only comes and goes, it’s only at certain milestones that it rears its ugly head. She’s the best thing that has ever come from my life, ever, you know, and I wouldn’t change it for the world.”

Pam: “The kids haven’t been tested. I’m aware that I might have passed something on, but then both their attitudes are that if they have it they’ll deal with it. I think now I would accept it. If they’d been diagnosed when I first was

diagnosed, I would be feeling very guilty. I probably would feel less guilty now, because they are now choosing to have children of their own, therefore they're taking the same decision as I've taken."

Perhaps the most painful aspect of CMT for Liz is the impact on her children, especially her role as a parent.

"I'm not a bad parent but there are things I just can't do," she says through a veil of tears. "Little things, like going to the park or the beach or something as simple as swimming. I wish I could do more but sometimes I just don't have the energy.

"I couldn't carry them that well as babies. If they fall and hurt themselves I can't get to them quickly. They've missed out on such a lot. And so have I" [sobs].

"I look at some mums and I think, you just have no idea how lucky you are."

Mothers with CMT want to shield their children from the negative effects of CMT. For Liz this means love and support and lines of communication that are always open. "I grew up not being able to talk about it," she says. "I wasn't going to repeat that with my two."

For Kay, it's important to be a good role model for her teenaged daughter who has CMT—a role model she didn't have: "My mum gave up years ago. Totally gave up. And that's probably why I push myself so hard. She will sit in her chair, wasting her life away, and moaning to everyone about it. I am hard on myself, because I don't want to end up like that."

For Jill, it's a refusal to accept a world than can be unaccepting of her teenaged daughter's disability: "She's got me to fight for her, which I do, every minute of the day because she ain't gonna go through what I've been through, no way."

Two of the participants don't have children. For Mary, this has nothing to do with CMT—her diagnosis came after she was of childbearing age. For 25-year-old Fay, however, it is a problem: “I think oh god, I really wouldn't want my kids to have CMT. And then people are like, oh Fay like, but you know you've got a really good life, you've got good friends, you've got a nice family, like you go out, you've had attractive boyfriends, blah blah blah blah, and I'm like yeah, I know all that, but I just feel like I wouldn't want my child to have to live with it.”

Fay's perspective on motherhood is rooted in her experience of daughterhood: “My mum tried to use my disability for herself and I think maybe tried to make it define me. She got every bloody benefit under the sun off it and um, kind of lived off that, which I resented as well—all my friends parents work and you're just sitting at home doing nothing.

“She also made me go to this specialist impairment unit at my school. No disrespect, but some of the other kids in that place were quite physically impaired and, though I don't know whether they had learning difficulties, they were certainly socially and emotionally behind. My fear was that people are going to treat me differently, or that they're going to think I have a learning disability as well.

“In some ways, it actually made me more independent, because I was always fighting against people knowing about my CMT. I've always tried to keep it hidden. I've got this image of being at this zoo by my mum's side, and she'd just be like, ‘Yeah, my daughter's got this neuromuscular condition,’ and I remember as a five-year-old just being like. ‘Oh my god, I just want the world to swallow me up.’ As a child you don't have any voice. And I just think that's really affected me.

“I'm quite a sort of feminist independent like woman, and I think that's a manifestation of resisting my mum's kind of control. Actually, like, I am so much more than my disability.”

## THEME 4: GROWTH

I asked all 6 participants if there was anything good about having CMT, its impact on their day to day practical or spiritual life, the impact on them and their thoughts about the future. I have divided this section by participant rather than topic; each serves as a kind of personal potted philosophy; a closing argument. I have chosen to let these segments stand without commentary or analysis.

### ***Liz: "Letting people in"***

"I believe in a god. A god of my understanding. And I did look into god and disabilities, and why there are people with disabilities. And I came across this Christian website and I've never felt so sick in my life. It said all disabled people are mongrels and an abomination and should be put down. It was awful. It was an American Christian church. They said you should cross the road if you see someone with a disability. I was shocked.

"I believe what I believe and if god has given me a disability, maybe it's to learn from it. Hard times, yes, but learn from them.

"I get to the point where I'm like [*sighs*], 'Why me?' But then I go well hang on a minute, yes you can't do this and you can't do that, but look at what you have done, and what you can do. I'm very good at talking to myself about how lucky I am compared to others and that does help. I know it sounds corny but it's true. I do lead a relatively normal life. I am grateful for what I have.

"You know, I was feeling sorry for myself one day recently. I was like, oh I've had enough of this. Then I got on the bus and there was a girl in a wheelchair, and she couldn't walk, and she was younger than me and I just thought, there's my answer. I'm moaning, but I've walked to the bus stop, I'm with my friends, I'm going out shopping and yet, that poor girl is on her own, in an electric wheelchair and she's like 19, and I just thought, well I'm lucky to be where I am.

“I feel a sense of freedom now. Freedom and finding myself. And finding new friends. Letting people in, like my neighbour. He’s like a brother to me, and it’s lovely to have.

“To let someone else in, they’ve got to accept me for how I live and who I am, how my body is. I think that’s my next thing: my self-esteem. Working on that. And I have got an attitude. If they don’t take me for who I am then that’s their issue. They can Foxtrot Oscar. I need to build my self-esteem up now around that.

“My relationship with my children is really good, because I’m a lot more calm and a lot less stressed. And I open up to them a lot more now. I’m not afraid to say that I love them. With my mum and dad, I don’t remember that I was loved or cuddled or anything. So I always said when I had children that I would always tell them how I’m proud of them, even if I find it hard, because I do find it hard.”

Me: “Is it hard to say things to them that you don’t say to yourself?”

“Yeah, but I always want them to go to bed knowing I’m proud of them and that they’ve done well.”

Me: “Are you proud of yourself? Have you done well? The way you’ve coped with everything?”

“Yeah, yeah I think I’ve done pretty well. I’ve done alright [*laughs*]. It’s all made me the person I am today. Which isn’t a bad thing.”

**Mary: “The CMT probably does bring out the determination”**

“It’s good to not spend too much time on your own because you can get so selfish, so set in your funny little ways and so lacking in perspective. I believe that you should try and get outside everyday. Somewhere, even if you’re just going down to buy a newspaper or something, which is harder in the dark wet days of winter. Going outside is good for you, because you’re in a bigger

world, and you immediately see all sorts of unexpected things. You see animals and you see people doing weird things, you just kind of know there's life going by. You realize you're in a larger universe.

“And talking to other people, being aware of other people's lives, puts things into a bit of perspective, you know. Because, you know, everyone's got problems or they've got sadnesses and sometimes some unimaginable things, either physically wrong with them or in their social relationships, and you just think well, you're not the only one. I don't know, I've probably always been a bit sorry for myself. And I've always been of a pessimistic rather than an optimistic persuasion. And all my life in some ways I've felt alone even when I wasn't. I do like people and in some ways I'm sort of confident socially, and I've always have friends, so in that sense, I'm um, pretty good. And I do like time on my own. But often I've got too much time on my own.

“It's not a good idea to think about the future too much because anything can happen but it is a bit of a shadow out there. I'm not one of those people who has these wonderful revelations every six months where they suddenly find a new insight. It just doesn't happen. It doesn't happen for me in therapy, it doesn't happen in mindfulness, and yet I know other people who are doing these things, and who do have amazing insights, you know, ‘Oh wow, this is the way!’

“I think sometimes I'm a bit negative. But I do want to be more open to possibility, and not just say, oh, I can't do that or I won't do that or that's nonsense. I am trying to be a bit more sort of open about things. The CMT probably does in some ways bring out the determination.”

***Jill: “It's made me the strong person I am”***

“CMT has made me the person I am, the strong person I am, you know. I'm thankful for that. And I can actually, honestly, take credit for what I am and where I am. I don't have to look over my shoulder and say, well you know what, that person helped.”

Me: "It's really striking, what you've had to contend with and how you've had to do it on your own."

"Yeah, I have, I know I have. You know, I had a conversation on the phone about my ex, that he didn't want to be with me because I'd got the CMT you know, that he'd said he couldn't cope with it, he didn't want to be with me if I was in a wheelchair, blah blah blah. And I came off the phone and Ben [a relative] said to me, 'Did that really happen, did somebody really say that to you?' And he went, 'That's outrageous.' And I was quite gobsmacked because he's only 21, and I went, 'You know what, I'm hopeful for my daughter growing up with CMT. I'm hoping that she grows up with people like you, people that don't actually see the bad side of it, and support her in what she needs, not smother her, not put her in cotton wool, but let her go and do things she needs to do and just be there, catch her if she needs catching. Things like that make me hopeful for the next generation. You know, these elderly people go on about youngsters, but give 'em credit where it's due, you know. If you don't give them respect, you don't get it back."

**Kay: "This is gonna be my time"**

"CMT, or rather my mum's reaction to her own CMT, has made me who I am today. I've been going flat out. I'm stubborn, but I am slowly realising that I've pushed myself too hard. To avoid being like my mum. I work a 4-day week now. I'm learning to have a bit of time for me now. The children are older and they're looking after themselves more."

Me: "It feels like things are sort of changing for you, for the better."

"Yeah. That's exactly how I feel at the minute. So this is gonna be my time."

Me: "About bloody time! *[both laugh]*."

"I'm quite looking forward to it. It's been a hard road but a very interesting one. If I didn't have CMT I would be a totally different person. It just makes you more compassionate, I think, to other people, I think so. Erm. In doing the job



I do, I get a lot of self satisfaction from helping people. I'd find it hard not to do a job where I was helping someone."

***Pam: "I'm gonna find a way"***

"You have to live in the moment. I breathe. I am present. You can't undo what's done, you've got to move forward. You can't let obstacles get in your way. I'm a firm believer that things are sent because they're there to try you. The amount of time that I spent nursing and with these kids who've got no quality of life really, yet they're happy and smiley. You've got to get on with it.

"When we've been on cruises, sometimes they've said people with wheelchairs can't get off at this stop because the gangplanks are the wrong width. And I just say, 'Watch me.' And he [husband] takes the wheelchair and he holds it above the gangplank and he walks down and I go down the gangplank on my arse. I've been up a glacier on crutches."

Me: "Have you?"

"Yep."

Me: "It just feels like nothing's going to stop you from doing what you want to do."

"If I wanna do it, I'm gonna find a way."

Me: "Swimming five times a week, climbing a glacier on crutches, half marathons, competitive sailing. How are you so driven?"

"I don't know. I think it comes from childhood, it comes from mum. I mean mum couldn't do what she wanted to because of the war, she wanted to be a teacher. Dad couldn't do what he wanted either—he came out the army, went to the employment office, there was only one job: shoe repairer. They went into business together. They both did it. So it's the same for me: I'm gonna make the best of what I've got.

“My nan had a poem about worry, which said you’re either going to live or you’re going to die. If you’re going to live, then there’s nothing to worry about. If you’re going die, you’re either going to go to heaven or you’re gonna go to hell. If you go to heaven, again you’ve got nothing to worry about. And if you go to hell you’ll be so busy shaking hands with all your friends you’ll still have nothing to worry about. And so I try and, you know, to live in the moment. I try and do that. It doesn’t always work but that’s what I live, try and do.”

Me: “Do you have any sort of religious or spiritual beliefs?”

“No. Not particularly no. There’s a sense there’s something up there, and in some way what you do down here will be judged. I’m almost a believer in that you do a length of time before you become good enough not to come back again.”

Me: “Yeah that’s kind of almost a Buddhist idea.”

“If anyone asked I would say I am Church of England. But I don’t believe in what they’ve been doing over female bishops. That got me annoyed. So there’s no one religion that’s right for me. I’ll take a bit of all of them.”

***Fay: “CMT shaped me”***

“My mum being overprotective I think made me quite independent. I just feel like I want a sense of adventure all the time. But I put a lot of pressure on myself being like, oh I’ve not done this and I’ve not done that and I’ve not been to the gym today. I like to be stimulated, kept busy, otherwise I do tend to get a bit low. But I am quite good at just being, telling myself to get a grip.”

Me: “So there’s some kind voices in there as well somewhere?”

“Yeah. Might be a little quiet. A little mouse in there [*laughs*]. It’s like you’re not all bad. My clients are quite good at bringing me back, sort of grounding me a bit. I think, yeah, it is nice to have a job where people are always telling

you that you're great [*laughs*]. It's funny, it's so funny. I was like, you don't really have that many jobs that people tell you that every day. Actually, maybe I should just count my blessings.

“One of my dementia clients was like stroking my hand, and he's like, I just love coming to see you, you're one of my favourite people, you're just so kind, but you're one of these kind people that are actually kind, I can tell that you're genuinely kind, not just because it's your job.

“Sometimes I think if I didn't have CMT, would I be as musical? Because I couldn't do sports, my mum, my parents really encouraged me to do music—they got me a piano at six. My mum was very encouraging. I was like doing all my grades in piano, and singing in competitions, and yeah, I've done quite a lot. I trained with a big opera before I went to uni—there were only like 10 places in all the country. I sang all over Europe, eastern Europe and Russia. I've sang in the Royal Festival Hall, I've sang for the Queen and the Duchess of Gloucester and all this sort of thing. And I'm only 25. So, yeah, like, my mum's not all bad [*laughs*].

“CMT shaped me. I've got a colleague actually whose daughter's got this stunning voice, but it's like she just doesn't show any emotion when she sings. She's had a really lovely upbringing and nothing bad's ever happened to her. She's only 15 bless her, she's not had any heartbreak. And she just stands there and sings—it's stunning but there's no emotion behind it. And she's like, 'Oh maybe you should start beating me up' [*laughs*].”

Me: “Life will probably do that to her.”

“Yes. Life will beat her up.”

## 6. MY STORY

### *Introduction*

It is a Sunday morning in April 2015, and I am sitting on the sofa at home in London, surrounded by all my worries and disappointments and newspapers full of bad news, all gathered together in a pitiful, unholy congregation.



Fig 8: Word cloud from two self-interviews in 2014. The topic of the interviews? My CMT

My marriage has begun an inexorable disintegration. Far from rediscovering a fine relationship that had started 21 years previously, the couples counselling sessions over the winter has instead glaringly highlighted how neglected it has become, and how little we care. The descent happens slowly at first, then quickly, crash landing two years hence with a bumpy divorce that would prove very costly emotionally as well as financially. Our shared future, who we were as youths, a sense of security, this very home—all would be gone.

I am nearing the end of a long and expensive training for a career in psychotherapy that I didn't think I could do. My old career in journalism and I parted ways by mutual consent years earlier (though we still get together

sometimes)—I am thus caught between worlds, not belonging in either, anxious, unexpectedly emotional at inopportune moments, lost in space.

My body is giving up on me. I'd always struggled physically because of CMT but 18 months previously, having just turned 50, I was diagnosed with Parkinson's Disease. Both conditions are starting to make their presence felt, turning me into a shuffling, shaking shadow of my former self.

My mother is starting to show signs of dementia, brought on by a brain tumor that in two years would kill her. The last day she and dad spend together, the last time they see each other, is their 63rd wedding anniversary. A couple of weeks before that, in the hospital, she talks to me about her four children. "You won't tell John what's going on, will you?" she asks me. "Promise me you won't tell John what's going on."

It is spring but everything feels like death.

Mournful, badly-sung hymns enter from the church next door, doubling down the mournful dirge inside my head. "How weary, stale, flat, and unprofitable seem to me all the uses of this world," says Hamlet. Life is "an unweeded garden that grows to seed; things rank and gross in nature possess it merely."

I put on the TV. The London Marathon is on. Great. The annual reminder of failure and regret. My personal Everest whose summit was beyond me.

Twenty-five years earlier, I ran it but dropped out, in pain and semi-delirious, after 20 miles. I always wished I'd finished the race. And I always intended to have another go. But the years rolled by, life got in the way, and my running days quickly became a distant memory.

I tell all this to my 8-year-old daughter as we watch the lycra-clad human gazelles on TV effortlessly breeze through the London streets. She has heard it all before a year ago, and no doubt the time before, and the time before that. I am about to launch into a fatherly pontification about regret and the

road not taken when she yawns and says: “Do it next year, Daddy. You can just walk the whole thing.”

Antoine de Saint-Exupéry said: “Grown-ups never understand anything by themselves, and it is tiresome for children to be always and forever explaining things to them” (1943).

This confoundingly beautiful, simple suggestion would transform my life.

### ***Lived experiences***

- ***Infancy***: An early memory: I am about 4 and mum takes me to go and see a specialist doctor about my feet. I have no arch (flat feet from mum) and am a bit slow running (CMT from dad, though we were decades away from knowing that). The doctor thinks exercising my feet will help. He recommends putting a toothbrush on the floor trying to pick it up with my toes. When we get home I put a toothbrush on the floor and try to pick it up with my toes. I can’t do it. The exercise is abandoned. As are my feet, my *pes miserabilis*. There is no further parental involvement.

- ***School days***: My CMT, kept hidden for much of my youth, is sometimes dramatically and humiliatingly exposed. At school I am last to be picked for sports teams. I am last or near-last, too, in “The Steeps,” the annual, hideous, dreaded cross-country race for the whole school through the rain, lagoons of mud, and the stench of fear and adrenaline.

I despise gym, especially anything involving hurdles. My dad almost never talks about CMT, but I did once ask if it affected him at school—a strict, regimented English boarding school between the wars. He remembered having to do the hurdles at a sports day, and he couldn’t do it—he kept crashing into the hurdle, falling to the floor, going round and trying again and again and again, his legs covered in blood. And he remembered hearing a parent saying, “My god, that young man does keep trying doesn't he?”

Since school, my dad has strenuously avoided any exercise. “Whenever I felt like exercising,” he likes to say, “I would lie down until the feeling wore off.” He is 94.

- **At university:** I go roller skating and fall my way to the middle of the massive auditorium. Then there is an announcement on the loudspeaker: “Clear the floor please, experts only for the next 15 minutes.” I am suddenly exposed, frozen, limbs awkwardly splayed, like Mr Bean. With everyone now watching from the sidelines, I walk, fall and then crawl all the way back to the exit. On my first ski trip, I spend a week falling on the bunny slopes then on the last day, in a bid for freedom, I fall all the way from Tignes to Val d’Isere.

Paradox: Sport becomes my life. As a young adult I am a keen golfer, I take up long-distance running and commence a career as a sports journalist.

- **March 1998:** It’s the end of a glorious week of skiing in France (I did finally learn how to do it). I am here on my own, writing a travel story for *The New York Times*. My bags are packed and I am waiting for the coach and the long journey back to New York. Then something odd happens. I unzip my big ski boot bag, remove my giant ski boots, and place them on a ridge on a nearby wall; a kind of offering, or sacrifice, or cleansing; a disposal of the vanities. It is as if I am watching someone else perform this solemn ceremony (there is evidence that action precedes thought; that consciousness is always late to the party). I am powerless to stop it. Having mastered skiing despite my CMT, I appear to be giving it up (rather than waiting for the inevitable time in the future when it gives up me). I never ski again.

- **November 2002:** I get my formal diagnosis of CMT. It’s fine. I knew I had it. I have spent the past decade in America, living, working and travelling, without problems. I am confident that when I return to live in the UK in the spring, CMT will impact my life only minimally, as it has for my father.

I ask the neurologist at Yale whether he thinks it’s OK to have children. And he says, “I wouldn’t let it stop me. Everybody’s got something, you know.

There's ways of managing it, it doesn't affect your longevity, and there will probably be better ways of managing it in the future, maybe even a cure." I am comforted by these words.

- **April 2008:** At the start of a self-development workshop, the participants all stand in a circle and introduce themselves. After a few seconds, I realize with horror that I can't do this. The simple act of standing still, unaided, is now beyond me. I voice my confession and ask if I can sit down. A chair is provided. There is no fuss. I feel warmth from the teacher and the group throughout the day. But I am alarmed: My symptoms seem to be worsening speedily. So much for my CMT being like my dad's.

- **February 2009:** One evening I walk into the Central London branch of the Samaritans in Soho for a volunteer recruitment event. Of all the places I've been, all the steps I have taken, this might be the scariest. A step into a disturbed, alien, largely invisible world of human suffering and despair. I become a volunteer. I have set off on a new path.

- **July 2010:** I am covering the Open golf tournament in St. Andrews, Scotland. I am walking on the golf course with a colleague but really struggling, self-conscious and embarrassed. And I just blurt out: "I'm really sorry but I'm not really able to walk normally today." I'd never said that to anyone before. She is kind and curious. She says, "Oh well let's just walk really slowly. We'll walk together." With CMT, perhaps I don't any longer have to walk alone.

- **May 2012:** In class at the Metanoia Institute I am about to make a presentation to my peers, outlining my doctoral research project. I am nervous. "Sometimes the idea is right in front of your face," first-year tutor Paul Hitchings had advised. But CMT feels too close. The presentation goes well. Afterwards, there is a good discussion. I am choked up and unable to speak, because what is happening is simply revelatory: People are talking about CMT!



- **August 2013:** After genetic testing, a confusing results letter, and two conversations with the consultant neurologist, another definitive letter arrives confirming the result: My daughter, 5, does not have CMT. This makes me deliriously happy.

- **September 2013:** “The scan was abnormal,” says Dr. Edwards. “The results are consistent with Parkinson’s Disease.” My brain cells that are supposed to produce dopamine, the rock star of neurotransmitters, are taking early retirement. They’ve had enough; they want to retire. They probably started shutting down years ago, for reasons unknown. The Parkinson’s is entirely unrelated to CMT.

Dr. Edwards has a gentle tone. He is smiling slightly as he delivers the news, kindly, as if to say, hey, you know, this is going to be OK. He has an optimistic outlook on management, medications, prognosis, the race for a cure, life expectancy and living with Parkinson’s. The words are harsh but they fall softly. I thank Dr. Edwards, then stumble out of the neurology hospital, into the indifferent London streets.

In the afternoon, I return to my placement—what was I thinking? I don’t tell anyone my news. I see clients. There is an envelope for me at reception. Inside there is a card. “All change” it says on the cover. It is from one of my first clients here, a lovely person; our sessions had ended in January. “I was really struggling, and the time I spent with you has made a huge difference ... I am so much more able to live the life I want to live ... you really have made a significant difference to my life.” I have kept it together all day; this beautiful card does me in.

Much later, I lie awake wondering: How am I going to tell everyone? What will people think, or say? I am not prepared for the outpouring of kind words and offers of help from friends and family scattered around the world. A colleague in America offers to raise funds to pay for treatment. Another in China says he will explore eastern remedies and herbal medicines. A friend in India invites me on a drive into the high Himalayas. A new term is about to begin at

Metanoia. I send a group email with my news. I am met with simply kindness and love.

- **July 2014.** I am interviewing Donald Trump in his office in New York for a magazine article. As I set up the voice recorders on his desk, my tremor—a kind of barometer of stress and nervousness—is really bad. “Sorry about my hand,” I tell him. “I have Parkinson’s.”

“Oh that’s great,” says the future president. “That gets better as you get older, right? Some of my friends have it—they do great with it.”

Of all the many varied and sometimes baffling reactions from people to news of my neurological ill-health, Trump’s was the most surprising. Parkinson’s is degenerative? Fake news. Such deluded, reality-denying, pathologically positive automatic thinking might be dangerous for, say, the president of the United States, but I have to say it was a welcome change from the awkward silence, the mumbled sorry, the story of some relative who suffered and died.

- **August 2014:** Actor and comedian Robin Williams takes his own life; later it emerges that he had recently been diagnosed with Parkinson’s. Lots of commentary on social media. “No wonder he topped himself,” wrote one man. “I’d do the same if I had Parkinson’s, I wouldn’t want to be a burden on anyone.” I find this really upsetting. I write a riposte that highlights all the advantages of Parkinson’s. A reply says I am guilty of “New Age blue sky thinking.”

- **September 2014:** I see my first private client, at home. It goes well. I feel very comfortable. Maybe I can do this work after all. As with journalism, I’m still trying to understand people, working with words, but now I am trying to bring my whole, present, feeling self to the endeavour. And for someone with a disability it’s perfect: I don’t have to travel and I get to sit down all day. Five years on I am very glad to have changed careers.

- **October 2014:** In preparation for carrying out this research, I conduct two

pilot interviews: a colleague interviews me. The first one is in May. I am struggling at the time. There are lots of stories and feelings around shame and humiliation and bodily unease. I claim not to be angry, but seem to be picking fights with people close to me.

Long sleepless nights are the norm. I am embarrassed by my new ankle/leg supports, but I need them to be able to walk with a semblance of normality, which I need to do if I am going to pass for the person I think I am or need to be. I say in the interview: “It’s probably very good for me actually, to give up any pretence of vanity or any effort to try and be normal, um ... but there’s something about being seen, and about being defective.”

The second interview is in October. I am doing a bit better. My physical vulnerability can no longer be covered up. I am determined to embrace what I have always felt myself to be: an outsider. I can “come out” as me. This is liberating.

“You know, I’m gonna deal with this better than anybody,” I tell the interviewer. “I’m gonna have people sit and wonder and say, ‘He’s done so much, and you know, he’s got CMT *and* Parkinson’s, he’s incredible.’ I do think there is a little bit of that kind of narcissism going on—wanting everybody to applaud from the sidelines about how marvelously I’ve responded. That’s not particularly healthy. But at the same time, maybe more pertinent is not wanting to be defined by other people’s expectations. I don’t know what I can do, and what the future holds, but I’m not just gonna give up. I’m going to live. I’m going to live well.”

• **December 2014:** It is 3am. Yesterday I had a hernia operation—my second of the year. The first one in April didn’t work. The hernia was probably caused by overexertion: When I was diagnosed with Parkinson’s, I attacked it with

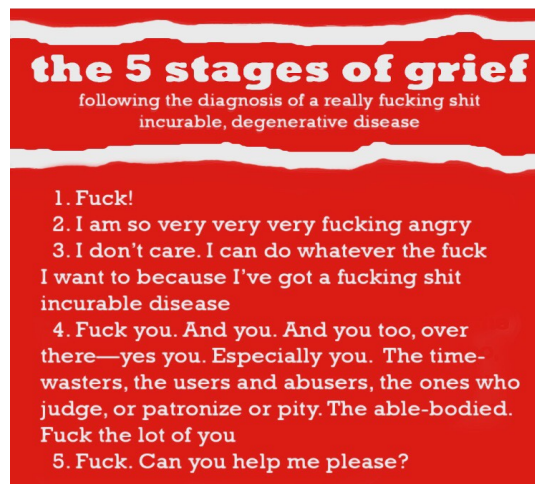


Fig 9: The ‘other’ 5 stages of grief

exercise. Then I went to the other extreme. I completely gave up exercise. I gave up on me. I would devour family-size bags of chocolate at 3am, washed down with too much red wine and self pity. I was so angry. It's been a terrible year. It's better to have an adolescence finally, in one's 50s, having been too busy being good the first time round, than never to have one at all. But the results are not always pretty.

But right now, all is well. I wake from a deep, post-op sleep, in the middle of night. I feel a profound sense of wellbeing. Maybe it is from the kindness and care I received in the hospital yesterday. And the existential thrill of surviving, of being alive. And the drugs. Yes, my rapture is probably morphine induced. I put my music on shuffle, and every song—"Prayer" by Charles Lloyd, "Codex" by Radiohead, Mozart's Clarinet Concerto (Adagio)—seems really intense, profound, numinous. All the hurt gently drifts away, out into the night. I am filled with gratitude. I am serene. I am connected to something eternal. To an extent, this feeling remains to this day.

- **April 2015:** I am out for my usual Sunday morning bicycle ride around the quiet streets of London. It's been getting harder to do: I no longer have the strength to push off from a standing start or pedal at slow speeds. Somewhere near Notting Hill, I hesitate at a junction, start to wobble then topple over; a spectacular crash. I have enjoyed my adventures on two wheels. I cycled to Germany one summer with some school friends. Another time I cycled from London to Madrid. But it's over. I sell the bike.

- **June 2015:** I am at London Zoo with my daughter, and we're sitting there at this little outdoor cafe, eating fish and chips, enjoying the sunshine, minding our own business, when suddenly in this cage near us a little monkey pops up and stares at us. My left hand is shaking as usual. The monkey starts mimicking my tremor, shaking his left hand so convincingly that he looks exactly like a monkey with Parkinson's. Is he laughing? I am being ridiculed by a rare Vietnamese Francois langur. Is this a bit of interspecies ableism? Or is it a message from one monkey to another: "Hey you, lighten up."

• **August 2015:** On a family holiday in rural Suffolk, I stay up to 3am most nights trying something new: painting. I've always loved art but never

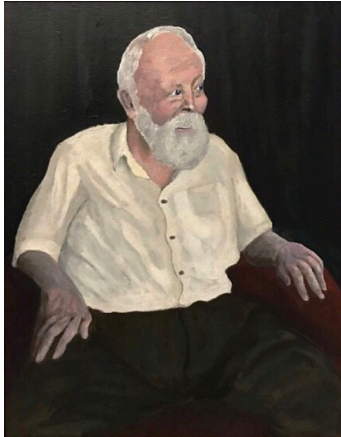


Fig 10: Dad, 94

seriously had a go at creating it. I do a portrait of my dad. I don't know what I'm doing; messing around, trying things out. I discover a passion for the process, which seems to matter more than the end product. It is absorbing, meditative, soothing; tapping into higher and previously uncharted realms of my own and a collective unconscious. The painting comes alive: It suddenly looks like my dad. He is 94.

He is looking off to the side, perhaps at whatever is coming next, with a sense of anticipation, excitement even. I feel close to him. The painting is later shortlisted for the Summer Exhibition at the Royal Academy.

• **April 2016:** On a gorgeous morning, I find myself in Greenwich Park, at the very back end of the amassed 36,000 marathon starters, alongside a man in a rhino costume, another dressed as a giant ear, and another wearing a cardboard lighthouse. There is said to be someone doing the marathon carrying a tumble dryer, but he is nowhere to be seen.

I am the only one with a walking stick.

I walk the Marathon in two days, accompanied at different times by various family and friends, stopping for fortifications at hostelrys along the way, and for Sunday night at a hotel right beside Tower Bridge, the halfway point. By Monday afternoon, despite little sleep, a missed turn somewhere in the Isle of Dogs and an exploding blister in Poplar, I find my groove. We route-march along the Embankment in the rain. I feel stronger and taller with every step. The group grows, joined by my brother, sister, and the mastermind of the whole operation, my daughter, with some of her school friends in tow. We all power along Birdcage Walk and the sun comes out, as if in benediction, then past Buckingham Palace, cheered all the way, and into the home stretch, the Mall, where a sea of blue and white balloons, banners and bodies awaits—

Parkinson's UK has laid on a special finish. I have raised over £17,000 for them and CMT UK. I have received so much support and love. I cross the line hand-in-hand with my daughter. I am last. But I feel like the champion. "The time to live is now," I say on the little film that Parkinson's UK made (46,000 views). "I feel like I really lived today."

The distance between my old life and my new life, from hopelessness to hope, breakdown to breakthrough, victim to victory, was 26.2 miles.

- **March 2017:** A young man comes to see me. He is talented, handsome, popular, with a beautiful fiancé and a cool job. But he has all kinds of telltale symptoms of some kind of chronic underlying neurological condition. He has just completed a battery of diagnostic tests, the results are in and they are devastating: he is completely healthy. He is convinced that a mistake has been made, paralysed by fear of an uncertain future, anxious to the point of incapacity. I cannot reach him; my words fall short and pile up on the carpet between us, to be disposed of along with the used tissues at the end of the session. Much is expected of this man; he feels too small to inhabit his own life. The only words that will soothe him, that will give him an honourable discharge—"yes, you're ill"—I cannot give him. He does not return for another session. Developing a disability cruelly strips you of the image of the person you thought you were, or were becoming, or who others want you to be. In its place emerges a progressive ability: to be and become you.

- **May 2017:** After two chaotic years of my marriage disintegrating, a lot of rather fluid relationships, a full-blown midlife crisis, I meet someone. She is beautiful, clever and funny. Compassionate, passionate. She sees me; she sees through me, beyond my pathologies and pontifications to me as a person. Some things die; others, like love, or being a psychotherapist or an artist, can grow.

- **July 2017:** Mum gets up one morning in the care home and has breakfast. It is a fine day. Then she goes back to bed, to sleep. At some point, instead of returning to wakefulness, she travels onwards. She leaves this world.

She was strong, unconflicted about death. “I want to die!” she had loudly announced in the busy doctor’s waiting room a few weeks earlier. After her appointment that day she had told me not to be sad after she has gone. She had a hard life born of a 5-year separation from her parents during the war, from age 10 to 15. She was tired, she was ready. She had a great sense of humour. I am glad she was my mum. My portrait of her hangs above my desk. As with dad’s portrait, she is looking out of the frame at what the future holds. Her expression is rueful, wary perhaps, but her sense of humour is never far away. Every day I feel her presence/absence. The comfort/ache of love.

*People can be removed from the world  
They don't tell you that, but it's true  
I mean, they do tell you, but they don't tell you  
People you love can be removed from the world  
(They can remove themselves)  
They will be removed from the world  
Didn't anybody ever tell you that*

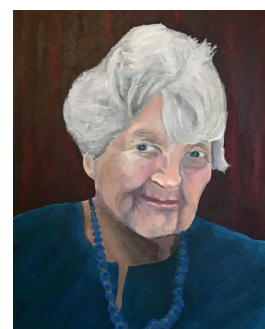


Fig 11: Mum

—Emily Berry (2017)

• **August 2017:** “What’s the most important thing you’ve learned here?” It’s the last day of an intense week at the European Parkinson Therapy Centre in the spa town of Boario in northern Italy, and Sylvia, the psychologist, wants to know how I am doing.

I am bereaved. I am heartbroken. The week has been healing. I learned so much here. I learned that sometimes the best way to advance in life is to go on a retreat. I learned that goodbyes are never really final. That you can say goodbye to the loved one, but keep the love.

I learned how to walk and talk and eat all over again. I learned that in a way, everyone has Parkinson’s: to be alive is to be ageing, and to be ageing is to have one’s dopamine levels in inexorable freefall. Life is fatal. We are all heading to the same destination, albeit by different paths. I learned that the

No. 1 symptom of PD is slowness. This helps me enjoy the Italian summer—and feel better about my unwritten doctoral thesis languishing at home.

Sylvia is waiting for an answer. I think back to a couple of days earlier, when the group had been doing our “power moves.” The whole wall facing us was a mirror. I noticed a man doing the exercises while sitting in a chair. He looked familiar. In a split second I realized I was looking at myself. I did not feel the need to look away. The man looked OK.

“I learned that I really do have Parkinson’s,” I tell Sylvia. “And I’m OK with that.”

### **Loss**

I can no longer play golf—it’s just too hard physically to walk so far on numb, wasted feet; to hit a stationary ball when everything else is moving. I play my last game, alone, at the place where, four decades earlier, I played my first, with my dad. My magazine article about it last summer explores farewells, loss, mortality, fathers. The feedback is tremendous. The article is widely liked, shared and tweeted and I get hundreds of messages from colleagues, friends and strangers.

“Accepting loss is hard,” I wrote in the article. “In my work as a psychotherapist I meet all sorts of people who can’t or won’t. They cannot accept the death of a loved one, or a relationship, or a dream, or the image of the person they thought themselves to be. They cannot accept the troubled childhood they had, the life they have led, all the terrible things that have happened to them. Or, like King Lear, they cannot accept their mortality.

“The poet Robin Morgan regards Parkinson’s not as a diminishment but a distillation. Like a blind person whose other senses become heightened, constraints can facilitate growth, too. You can embrace time’s harsh editing of your life, and live it. Old worn-out ideas, activities and relationships can be sloughed off, as can vanity, pretense and polite conversations about the



weather. And so, in the same year I had to say goodbye to my mom and my marriage, I decided to say goodbye to golf, too.”

Today I get out of bed and I’m exhausted. I haven’t slept well in years. I am running late. I am always running late. I have slowed down but my internal clock has the same factory settings as it did when I was 21. I totter and bounce off the walls and cupboards in the kitchen as I make a cup of tea that I don’t feel confident about carrying to my desk. Buttons are a daily wrestle, as are the stubborn blister packs that contain my morning medley of meds. It takes me 10 minutes to put on my shoes and foot/ankle supports with all the straps, buckles and strips of velcro.

A great unlearning is taking place: Things that children struggle with—tying shoelaces, say, or handwriting—have become a struggle once more, only this time I am descending the mountain of mastery, banished against my will, rather than heading excitedly for the summit. I am systematically being divested of basic life skills. I glance at my notes from yesterday’s supervision session. They are entirely unintelligible.

I head outside with my walking stick into the street, a fast-flowing river of commuters elbowing their way to the office. I am slow. I am in the way. My walk is clumsy, weak, shaky today. A jogger runs past. There is an astonishing beauty in the way she moves, a kinetic ease, a graceful efficiency that she perhaps isn’t even aware of. She does not yet know that this can be taken away. Will be taken away.

Every minute of every day, in everything I do, I am compromised, challenged by physical inability, tremors, weakness, poor mobility and dexterity, and fatigue. CMT has wasted my feet, systematically diminishing their strength, support and shock-absorbtion. It is like having one’s feet and lower legs injected with muscle relaxants then being made to wear lead boots. Add to that the effect of Parkinson’s on the commands from the brain—like a series of flickering intermittent power cuts—and I am unable to walk with any kind of rhythm, style or ease. So I don’t feel like walking. But if I don’t, I accelerate the

deterioration. If I don't use it, I will lose it. I've said farewell to running, golf, skiing, cycling, hiking. I can still move. I can go out and engage with the world. I can be. But the decline is progressing, the clock is ticking, the bell is tolling.

On the tube, a woman offers me her seat. Sitting down is easy; getting back up is not. I only have a few stops. I thank her but decline. She glowers at me: Such ingratitude!

I meet a friend. We catch up over breakfast. We talk about clients, partners, mothers. It feels good. I walk all the way home. The rest of the day is filled up with clients, naps, admin, reading, messing about on my phone and—much later, much too late really—writing this. I am typing painfully slowly with two fingers and the thumb of my right hand. They are weak and inflexible, but they are the best I've got.

I find grief to be a useful analogy in considerations of disability. The process of adjusting to and coming to terms with progressive physical disability in particular—as opposed to sudden disability through an accident or amputation, for example—is inextricably also a process of gradually mourning the loss of many things: mobility; certain previously-fulfilling activities; a former identity; able-bodied relationships with others, work, leisure, and the world; a “normal” lifestyle; an imagined non-disabled future. Some dreams and hopes must be put away.

The American comedian Steven Wright has a line about how he avoids thinking about the past because “it just brings up all these memories.” For me, grief is an ongoing process of letting go, a kind of forgetting. I am forever saying farewell to the me I used to be; every day some more doors close behind me. There isn't much capacity to reflect wistfully on the passing of an able-bodied past or worrying about a drooling, incapacitated future when there is such vibrancy in the present. There is a fresh, raw and challenging newness to engage with—my disability keeps me living in the moment.

Tonight I feel sick and tired. I am sick and tired of feeling sick and tired.

There's a strange ache in my abdomen, too. My legs feel really heavy. My teeth hurt. But I feel good in spirit. I had a good day. There is music in my head, a little wine in my heart. Tomorrow is another day.

### ***Discrimination***

Earlier this year a friend messages me: she has a spare theatre ticket. We meet for a meal and arrive in the upper stalls just before the curtain goes up. But the only way to get to our seats is to walk up a steep aisle, then along the back, then down the steep aisle on the other side. The latter—a series of irregular, steep, narrow steps with no handrail—is my downfall. I can't do it. But I set off anyway. I wobble and stumble. I feel under pressure; my performance is in front of an actual audience. This makes me even shakier, wobblier, weaker. I fall backwards and am sitting in a man's lap. He and an usher try to lift me to my feet. A woman with a clipboard and a walkie-talkie appears. I have created "a situation." When I finally get to my seat, rejoining my bemused friend, I feel shamed, embarrassed, exhausted. The overriding thought is: "You don't belong here."

These incidents happen. Another time I go to a spa. I have to sign a form saying that I don't have any health conditions ("You must sign or you can't come in," says the woman at the desk.) There are no disabled changing rooms. No handrails. To get into one of the thermal pools I have no option but to crawl across the slippery marble floor. This spa—like so many gyms and swimming pools—caters to people who need it least: the young, toned and able-bodied. The beautiful people. Those who need it most—the unkempt, disfigured, wheezing masses—are not welcome. Those who are deemed repellant will be repelled.

I am now judged as different. There has always a tension between my impairments and the expectations and norms and rules of school, family, the social and relational world, the workplace, society, and there always will be. But I have built a life that largely accommodates my peculiarities. Any discrimination I now face is generally benevolent—offers of help when I don't

want or need it, for example, or well-meant but patronising remarks about how well I am doing.

### ***Identity***

In October, 2017, my partner and I attend a reception for Parkinson's UK at 10 Downing Street. Prime Minister Theresa May says we should “renew our determination to step up the fight against Parkinson's. For two centuries on from Dr James Parkinson's ‘Essay on the Shaking Palsy,’ we have simply not done enough or come anywhere near far enough.”

She says the government is investing more than £1 billion a year in health research. She does not mention the impact of her government's austerity program on the treatment of people with disabilities, which was described in August by the UN—in most un-UN-like language—as a “human catastrophe.”

Billy Connolly is there. I thank him for all the laughs. “Ach, that was easy,” he says softly. “Parkinson's is hard.”

It's good to be among fellow Parkinsonians. There is a sense of bonhomie. Nobody minds the spilled drinks and canapés on the floor. But I don't especially identify with these people. I have been to one Parkinson group social and a few CMT UK events. Generally they bring me down. I'd prefer to get together with other people, for other reasons.

A couple of months ago, I am on a bus with my daughter, now aged 11. A little old man who clearly has Parkinson's gets up to get off the bus but then freezes. “I can't move,” he says. “I'm stuck.”

A voice rings out from his wife or carer, a voice of compassion and impatience in equal measure: “Come on Jerry.”

Jerry finally lunges forward and gets off the bus. We find this little tableau to be highly amusing.

“That’s you in a couple of years Dada,” jokes my daughter. “Come on Jerry.”

I am at first horrified that my daughter sees me this way, but I come to see the incident as heartening. Jerry seems OK. The woman’s plea has become our rallying cry whenever we think someone is making a fuss—usually me—or a motivational mantra to the self when faced with a challenge.

We don’t do victimhood. Or we try not to.

I realise that I am not Jerry, and everybody does disability in their own unique way. I realise, too, the importance to me of role models, not necessarily people I want to emulate, but people who subvert the doom and gloom mainstream view of disability. Confident, inspiring people, who wear their physical challenges with style and ease. People who show what is possible.

Come on Jerry.

Aside from Jerry, and the six women who volunteered to take part in this research, a lot of others have helped and/or inspired me. They have shown me how to be ill, how to be disabled. My role models are described in Appendix VII (page 169).

### ***Growth***

My disability came gradually, and in midlife, giving me time to establish roots personally, professionally, emotionally and financially. It came in the midst of training to be a therapist, so I was both in therapy and surrounded by lots of caring, loving colleagues. It all came together: disability, career change, bereavement, divorce. Hard teachers, hard lessons. I recall an old affirmation tape by Susan Jeffers saying: “Everything is unfolding in a perfect way.”

When some things are denied, other things become more cherished. Or discovered for the first time. When you can no longer do the things you used to love to do, you can devote your energies and appreciation to a heightened ability to experience new things.

I am grateful that I have no pain. That my tremor is in my left hand; I am right-handed. I am grateful for medical science: No amount of journaling, chanting, crystals, hypnosis, meditation or yoga will change the fact that I have CMT and Parkinson's. The only thing that might is medical science. For all the problems of applying the medical model to human beings, from the NHS I have received a staggering amount of excellent care. I have met brilliant, kind and empathic doctors and nurses. I take various medications, without which I would scarcely be able to function. For all the profiteering and cynical marketing of big pharmaceutical companies, I am grateful for my morning cocktail of pills: synthetic neurotransmitters, agonists, enzyme inhibitors, vitamins, herbal who-knows-whats and why-nots. Caffeine helps too.

I am grateful for my bad feet. They have done good work. They have kept me grounded. Given my background, it might have been easy to lead an unexamined, unempathic life. The humblings and humiliations wrought by CMT and Parkinson's have done me good. Like the cracks in Rumi's cave, perhaps they let a little light in.

I am now OK with the whole death thing. A decade ago that was not true. Still not looking forward to the process, the bleeping hospital machines, the indignities, having visitors or, worse, not having visitors. And I still have loads of things I'd like to do. And I want to enjoy my relationships for as long as possible especially with my daughter. A few more decades with a sound mind if not body please. But in a sense, there aren't too many regrets, loose ends or pieces of unfinished business. I am ready for whatever comes next.

Jung wrote: "Thoroughly unprepared, we take the step into the afternoon of life. Worse still, we take this step with the false presupposition that our truths and our ideals will serve us as hitherto. But we cannot live the afternoon of life according to the program of life's morning, for what was great in the morning will be little at evening and what in the morning was true, at evening will have become a lie" (2014 [1933]: 111).

This research project has been a transformative, transcendent process. In the morning of life I was able-bodied. Now I am not. For the best part of a decade, as I've trained and started working as a psychotherapist, got divorced, lost my mum and got Parkinson's, it has been high noon. At times I have felt lost, in the dark wood of Dante's "Inferno." But completing my doctorate marks the end of this transition. The afternoon of life is beginning. The forecast is good.

Another quote, uncited but attributed to Confucius: "You get two lives here on earth, and the second one begins when you realise you only have one."

Nothing is a more effective realisation of that than a brush with death—of a parent, a marriage, a dream; your health. Your youth.

Eventually you have to get over yourself. Disease and disability especially divest you of pretense; they are a middle-fingered salute to your vanity, the false selves, the fantasies. They make a mockery of the image of the person you thought you were or thought you had to be.

In your Second Life, you are stripped of layers of narcissistic armor and you are vulnerable, which is to say you are free at last to love. Energy flows. Your Second Life is illuminated; illuminating. It feels like coming home.

### LOVE AFTER LOVE

*The time will come  
when, with elation  
you will greet yourself arriving  
at your own door, in your own mirror  
and each will smile at the other's welcome,*

*and say, sit here. Eat.*

*You will love again the stranger who was your self.*

*Give wine. Give bread. Give back your heart*



Fig 12: Homecoming

*to itself, to the stranger who has loved you  
all your life, whom you ignored  
for another, who knows you by heart.  
Take down the love letters from the bookshelf,  
the photographs, the desperate notes,  
peel your own image from the mirror.  
Sit. Feast on your life.*

—Derek Walcott (1986)

### ***Reflexive research***

Progressive disability is a deeply personal, embodied, ever-present process that impacts everything I do. I cannot be objective about what calls Merleau-Ponty my “lived body” (1945). Every day—when I struggle to walk, spill my food, can’t sleep—I am conducting ongoing qualitative research in how best to live. This research project thus is not a passing, academic investigation into a particular arcane human phenomenon. This chapter is not a mere bolted-on bit of reflexivity; a box-checking exercise. This thesis is an expression of my lived experience; a snapshot of what I regard as a primary purpose of life: to accept, make sense of and find meaning in our mind, body and spirit, in the environment we were “thrown” into—to examine our existence (Heidegger, [1927]). This process—including having the opportunity to interact at depth with the similarities and differences of others facing the same ontological challenge of progressive disability—has immense intrinsic value. If it has led here to some instrumental, provisional conclusions, some small truths, albeit limited by my viewpoint, about how to face the future, so much the better.

Etherington writes, “The judicious use of our selves in research needs to be essential to the argument, not just a ‘decorative flourish’ for it to be described as reflexivity” (2004: 37). I have been wholehearted in my approach. I have exposed the most painful aspect of my life to rigorous examination. I have invaded my own privacy. I am both researcher and researched. I have expressed myself in words and images. I am proud at what I have produced, and I am keen to share what I have learned. What I most want to do now is choose to live well.



## 7. DISCUSSION

### *Introduction*

The voices of the six participants speak for themselves. They are powerful, raw, eloquent. Every interview was a moving experience. The participants each invited me into their own world of CMT—a largely private and sometimes lonely world. The colossal weight and intensity of their testimonies, of their individual experiences, emotions and hardships, are things they keep to themselves. It was a privilege.

In this chapter, the four themes are revisited and analysed in light of the participants' testimonies and the relevant literature. After that, an integration of the four themes is offered in the form of the “two worlds” model of disability; an overarching representation of the apartheid nature of disability life, with “abled world” and “disabled world” separated by psychological and political borders that I argue should be further dismantled from both sides. One world is a better world.

Lastly, I advocate better provision of psychological support for people with CMT and other disabling conditions, and offer 12 clinical recommendations arising from the four themes.

Hovering above this chapter is the question of sameness and difference. I tentatively propose an imagined typical person with CMT, below, and the kind of challenges they face—a fictional composite of the participants in this research that it might be useful to keep in mind in this chapter as we draw conclusions from the research. However, we must be cautious in making any broad assumptions or claims. Firstly, there is enormous variety in types, manifestations of and reactions to CMT. Secondly, the participants are all white women living in southern England at a particular time in history. And thirdly, there is the researcher: As a white British heterosexual male, I carry the “invisible rucksack” of privilege (Tuckwell, 2006: 208). Historic patriarchal power relations between men and women inevitably form part of the set

decoration to this research. There will inevitably have been some aspects of their experience that I was biased towards; and others against. Clearly there are gender differences with regard to disability (eg. Coleman, Brunell and Haugen, 2015). It would be wrong to assume the experience of CMT would be similar within and between other people, cultures, places, times. In so much research whiteness in particular is often taken for granted—“a veil, a norm, a neutral zone in which all is apparently possible” (Lago, 2006: 202).

Given these caveats, and the parameters of this piece of research, I nevertheless offer some “truths” about CMT, starting with my fictional CMT archetype.

A person with CMT:

- Might initially have only mild symptoms which become highlighted at school, especially in sports. She might feel different, suffer embarrassing and humiliating experiences, and she may be bullied.
- As an adult it may have taken a long time to be diagnosed, and the diagnosis might have been delivered abruptly, with a lack of care for her feelings. She might have struggled to find much useful ongoing support.
- There might be a climate of shame, guilt and embarrassment around CMT at home. It isn't talked about. She might have just a few close confidants that she can talk to.
- She is conflicted about her symptoms. Sometimes she thinks of herself as disabled and wants help and special consideration. Other times she tries to be “normal” and wants to be treated like everyone else.
- Her symptoms might affect her in all sorts of ways, impacting her work, social life, romantic relationships and sense of self. She has to give up something she used to love doing, or lots of things.
- She finds that life can be hard, and people can be cruel, unempathic or just thoughtless. Sometimes she just wants to withdraw from the world. She needs to protect herself.
- She might feel conflicted about having children, and if she does, she may sometimes feel guilty if they too have CMT.

- As the symptoms progress into midlife, she might develop moderate to serious mobility and dexterity issues. Just when she feels she has adjusted to a new normal, another new problem rears its head, another piece of functionality is lost. She is sometimes despairing, or angry, or sad, but thinks she shouldn't grumble because there are people with far worse things.
- She values simple acts of kindness.
- She thinks there are some benefits to having CMT. It has made her resilient, self-reliant, patient, inventive. She is proud of the way she has coped. She thinks it has made her a nicer person.

## **THE FOUR THEMES REVISITED**

### **Loss**

CMT has had a significant impact on the lives of the six participants. The losses have been heavy: careers, relationships, beloved activities, the image of the kind of life they hoped to live—all gone. And they never know what is coming next: CMT is progressive, with an inexorable, gradual, linear degeneration of nerve and muscle. But loss of functionality often happens in discrete, quantum stages. Someone with CMT might one day wake up to discover that buttons or keys or signing their name are suddenly a problem, or the seemingly simple act of standing still is now impossible. The CMT journey includes many such landmark moments along the way. At each stage, a process of adjustment takes place, parameters are revised, and the sense of one's self and one's life shifts once again. The fresh losses are mourned anew. The losses accumulate: People with CMT experience a never-ending cycle of loss, grief, adaptation, acceptance, along with an ever-present anxiety over what the future holds.

Thomas and Siller (1999) liken the effects of disability to the mourning that Freud described as resulting from object loss (1917): a gradual withdrawal of libidinal energy from what has gone, the integration of the loss with reality such that life can go on, and the resulting continued survival of the ego—an ego that, as Freud stated, “is first and foremost a bodily ego” (1923: 25). CMT thus carries with it the possibility of an ongoing, never-ending series of mourning processes as function continues to decrease throughout the

lifespan, and for some such mourning may slide into pathology, what Freud called melancholia which “behaves like an open wound” (*ibid*), or perhaps, to borrow a phrase from the literature on parents with disabled children, “chronic sorrow” (Olshansky, 1962). Psychological support therefore needs to be tailored to facilitating this mourning process, for which “progress is long-drawn-out and gradual” (Freud, 1917: 255). For many people with progressive disabilities, this is a lifelong process of “working through.”

Livneh (1984) proposed a five-stage model that consolidated prior models of adaptation to disability. The first stage, “initial impact,” consists of two substages, shock, and anxiety. The second stage is “defense mobilization,” which consists of bargaining, and denial. The third stage, “initial realization” or “recognition,” consists of mourning and/or depression and internalizing anger. The fourth stage, “retaliation” or “rebellion,” includes both direct and indirect methods of externalizing anger and aggressiveness. The fifth and final stage, “reintegration” or “reorganization,” is composed of a cognitive substage of acknowledgment, an affective substage of acceptance or assimilation, and a behavioural substage of adjustment, adaptation, or reconstruction.

Livneh’s model bears a striking similarity to Kübler-Ross’ “five stages of grief” in her seminal book “On Death and Dying” (1969), based on her psychiatric work and interviews with terminally ill patients. You start with *denial* (“if I pretend it’s not there it will go away”), move into *anger* (“it’s not fair—why me?”), *bargaining* (“OK fine, I’ll exercise, take my meds, live a good life and then maybe it won’t be too bad”), *depression* (“this is terrible, what’s the point of living?”) and finally arrive at *acceptance* (“this is part of my life, I can cope, it will be OK”).

The book became a roadmap of mourning. An orderly procession from stage to stage, arriving at the final destination, a cheerful accommodation, much to the relief of family and friends, who might have tried to usher you along on your journey as expeditiously as possible. The model does provide a useful lens for research into how people respond to progressive physical disability. The six participants in my research have experienced all of these “stages” at

different times and with different intensities. While the experiences in their stories are all unique, anger and denial in particular were common reactions. All of the participants have had periods of depression or low mood but there is no way of knowing to what extent this is attributable to CMT. As we have seen, a common response to CMT is withdrawal. It's an awkward condition, embarrassing, hard to explain. You don't want the parent who gave it to you to feel bad. The world out there is a minefield. Better not to talk about it. Better to stay home.

The notion of "adjustment" to disability is contested as it puts all the onus on the person with a disability to change—in a manner that is acceptable to the able-bodied—rather than on an environment or able-bodied attitudes that fail to accommodate them (eg. Wright, 1983; Olkin, 1999: 44; Dunn, 2015: 28).

Further, grief is an idiosyncratic process that does not follow a predictable pattern. Each person's response to a loss is their own, and no-one has any right to question that. Certainly I do not want to live in a world where people with disabilities are pathologised unless or until they are able to demonstrate a sufficient level of cheerful, meek acceptance. This "requirement of mourning"—that a person's reaction to their disability must conform to the able-bodied person's assumptions and expectations—is oppressive (Wright, 1983). I have had people tell me they would kill themselves if they had Parkinson's; congratulate me "for not giving up"; praise me "for doing so well in the circumstances"; inform me that if I'm not really angry at having two neurological conditions, then clearly I must be "in denial." Others have demanded the opposite extreme: that I be "positive" or "brave" or "fight" the onset of symptoms.

In a later review, Livneh and Parker (2005) identified further models for adjustment to disability, beyond linear, orderly "stage" models—"linear-like models" (Livneh, 2001: 153), "pendular models" (Charmaz, 1995), "interactive models"—and also proposed a "chaos and complexity model," in which adaptation to disability is "nonlinear, unpredictable, and discontinuous." The clinical implications for this model are that it "suggests the supremacy of an

eclectic approach that incorporates multifaceted, yet nonrigid, views of the human experience ... Such an approach recognizes the complexity, uncertainty, transformation, and ever evolving dynamics of the human spirit, especially as it seeks to transcend the constraining barriers imposed by chronic illness and disability” (2005: 26).

This postmodern approach is in accord with the integrative, nondogmatic philosophy of counselling psychology. It is a reminder not to make any assumptions or generalisations about the phenomenology of people with CMT, and always to be open to the possibility of being surprised. As is clear from the six participant testimonies, the life of each person with CMT is unique.

### ***Discrimination***

All six participants have a sorry abundance of experiences of being excluded, denied, ridiculed and even attacked for having CMT. Instances of discrimination can be ever-present or intermittent, large or small, active or passive, conscious or unconscious, subtle or unsubtle (Deal, 2007; Ostrove, and Crawford, 2006). Sometimes it's the physical environment that presents the obstacles. Very often it's other people.

Human beings like to regard themselves as rational and logical and good but our motives, instincts and behaviours are not always noble. Allport (1954) said prejudice was not some rare evil but in fact a part of being human. Our survival has depended on a certain level of anxiety, vigilance and distrust towards the unknown, and an affiliation with the safety of the known—this has been our evolutionary process (Schaller *et al*, 2010). We navigate through life with the help of “thin-slicing” (Gladwell, 2006) in which we use our senses, our experience and our beliefs to process a given situation very quickly, largely unconsciously, and take action. Sometimes the red warning light can flash completely unnecessarily. We have an immediate physiological reaction to each other (Macrae and Quadflieg, 2010); White (2011) believes able-bodied people experience disgust and “dis smell” when they see her in her

wheelchair. The results of such bad intelligence can be devastating, especially when poor light and police firearms are involved.

This is not to say we are inherently prejudiced. One review of research into attitudes towards people with disabilities found them to be ambivalent rather than uniformly negative (Söder, 1990). But discrimination is an undeniable fact. And it can be contagious, too—thin-slicing draws heavily on groupthink. Tajfel's Social Identity Theory (1969) suggests that we categorize members of a group as being all the same. Such prejudice "creates or maintains hierarchical status relations between groups" (Dovidio *et al*, 2010: 7).

A number of studies have shown just how easy it is to create "in-groups" and "out-groups" based on the most meaningless of differences, and the hostility towards the out group can escalate with depressing ease. Examples are the "Lord of the Flies"-like Robbers Cave experiment with two arbitrary groups of 12-year-old boys (Sherif, Harvey, White *et al*, 1961), Jane Elliott's classic schoolroom blue eye brown eye exercise (Peters, 1971), Zimbardo *et al*'s Stanford prison experiment (1971) or tribal violence between people who support different football teams.

Using the power of projection, the out-group is demonised: "we" are good; "they" are bad—deviant, dangerous, dirty, lazy (and any number of other aspersions). The more unknown "they" are, the easier it is to imagine them as devils.

We are suggestible—we are hardwired to be on the alert for danger; to be full of doubt about "the other." We are Othello, and there is no shortage of lagsos whispering in our ear, casting aspersions, pointing the finger of blame. In this way, discrimination becomes political. The crude scapegoating of people from foreign fields, or "othering," is vigorously and cynically exploited by poisonous politicians, xenophobic newspapers, Brexit cheerleaders, apartheid regimes, dictators inciting genocide, or western governments seeking to justify punitive domestic budget cuts or illegal overseas interventions.

Said called this “Orientalism”—a process by which dominant cultural, professional, national, political, and economic powers establish versions of “knowledge” and “truth” about both themselves and those over whom they wish to exert power (2003: 273).

People who are physically impaired are at the bottom of the ladder; polar opposites of the “beauty-is-good” stereotype (Dion, Berscheid and Walster, 1972). They are looked down upon by everyone else on Fiske’s vertical hierarchy of power (2011). They are not regarded as whole people but damaged goods. Typically, disabled people are perceived as warm, but incompetent, eliciting pity from others, help (whether wanted or not), but also neglect (Fiske, Cuddy and Glick, 2007).

The medical model dictates that only the defective body part is seen, and it is assumed to be an enormous burden. This “correspondence bias” or “attribution error” (Pettigrew, 1979; Gilbert and Malone, 1995) is commonly applied to whole groups—wheelchair users, for example. Foucault’s “medical gaze” (1963) is not confined to doctors.

People with disabilities often harbour prejudices against the able-bodied (Monteith and Spicer, 2000; Johnson and Lecci, 2003). But they also typically internalize the negative social biases and stereotypes of others (Johnson, Trawalter and Dovidio, 2000; Ellemers, Spears and Doosje, 2002; Morris, 2014). This can manifest as feelings of shame, which Gilbert describes as “an agonising experience of feeling judged by another person or the eyes of the world and experiencing deep within the core self, an essentially bad, rejected feeling” (Gilbert, 2009). Guilt over something you’ve done is bad enough, but shame over who you are is far more pernicious. It is an unchanging message that runs to the very core of your being; “an inner wounding” (Wurmser, 1994) to accompany the physical deficits and impairments that you and society find so unacceptable. Shame makes us want to hide. Jung described it as a “soul-eating emotion” (1957: 23). The shamed live in “silence and secrecy” (Sanderson, 2015: 25). I believe this is true of many people with CMT.



## ***Identity***

Whenever someone with a medical concern accesses healthcare services, some kind of drama ensues. If you're on the list for a hernia operation or an NHS counsellor it's like "Waiting for Godot." A trip to A&E becomes "Long Day's Journey Into Night." All those tests you had when you were stressed and thought your heart was giving out? "Much Ado About Nothing."

Every medical room is a kind of theatre. There is often suspense, tragedy, mystery. There is rich dialogue; there are some fine soliloquies. There is comedy. Everyone knows their place, their lines, their props; everyone seems to be playing a role in keeping with NHS dramaturgical guidelines.

In general these roles polarise the cast into us-and-them: the well and the unwell, the sane and the insane, the OK and the not OK, the glad and the mad. In a sense, the staff have a vested interest in keeping the patients as far away from them as possible. It's hard for the two camps to reach each other across the great divide, within which lies a welter of fear and despair, with death never far away.

Goffman (1959) says this is how identity works. We each have a sense of ourselves from how we perform—and how we are expected to perform—in various social settings. We are aware of how our performance is received by others and we are alert to the reciprocal and interdependent performances of others, too. Erikson's theory of psychosocial development (1968) similarly says we learn a sense of ourselves through our interactions with others. This process takes place especially during adolescence, when someone with CMT might typically be experiencing bullying at school.

As outlined in the previous section, Social Identity Theory (Tajfel, 1969; Tajfel and Turner, 1986) suggests that we derive a lot of our personal sense of identity from our roles within social groups, and that perceived group identities lie at the heart of discrimination.

Identities can be seen to play a key role in creating and sustaining social

interactions and cultural practices. They are generally adopted unconsciously within social structures and accepted as part of the natural order, as a given. But they are not fixed. Sometimes we act as members of a particular social group, but we can also make choices to do things differently. Indeed it is in the dissonance between personal identities and different group identities that individual, social and cultural changes can happen (Giddens, 1991; Jenkins, 2008).

Acting as an individual, in defiance of your assigned or expected group identity—going against traditions, institutions, moral codes, and established ways of doing things—is not always easy. You might find opposition from hegemonic power networks, discourse and ideologies at family, community or state level (Althusser, 1971; Foucault, 1988; Butler, 1990; Brewer, 1991; Stangor, 2013).

When you get ill, you join a social group no one wants to belong to. Along with your diagnosis, you are given a new preconceived, prepackaged, approved identity too. Perhaps up to now you have told yourself a certain story about your life, one that integrates past and present selves and considers possible future ones, too. Such a narrative identity (Ricoeur, 1984; Markus and Nurius, 1986; Bruner, 1987) is, however, profoundly impacted by ill-health. In “The Wounded Storyteller” (1995), Frank describes how as patients we must surrender our own narrative of our “dis-ease” and submit to the narrative provided by the expert. Parkinson’s? OK, you’re a patient now, an ill person. You are that little old bent-over man, the one in the illustration that’s in every textbook and encyclopedia (he seriously needs a makeover—the illustration was first published 1886: see Appendix VIII). Take your pills, don’t make a fuss. Nothing more is expected of you. Shuffle off home and sink into the warm embrace of the sofa, or under the duvet of depression. One of my mum’s old nursing books states categorically that mental changes from Parkinson’s will include “resentful attitude with emotional lability, depression, lack of concentration, intellectual changes which may lead to dementia and paranoid delusion. Becomes miserable and over-sensitive” (Koshy, 1977: 169). Such a bleak, oppressive discourse creates and sustains what Foucault

calls a “regime of truth” (1980: 131), one that removes any agency or power or hope from the patient while reaffirming the authority and power of the medical system.

A diagnosis is not the end of the story however, though I have met people who have responded as though it were. But how is something like CMT to be integrated into one’s narrative? How does one manage what Goffman calls a “spoiled identity” (1963)? You have a stigma now; you are “not quite human” (*ibid*: 15).

Whatever the new happenstances—a diagnosis, a death, a divorce, for example—they will change the whole story. The past is revisited in the light of the present and the present in the light of the past (Bakhtin, 1981; Ricoeur, 1984; Bruner, 1987); different “possible selves” are foreshadowed for the future (Markus and Nurius, 1986). We experience then interpret; we interpret then experience. The formation of a sense of self is a lifelong reflexive process of hermeneutic phenomenology.

The perceived group identity of people with a common illness is so pejorative—and constantly reinforced by the daily insult of prejudice and discrimination—that it’s no surprise group members are ambivalent about adopting it. Goffman says the afflicted man “can neither embrace his group nor let it go” (1963: 132). CMT generally has fairly mild symptoms in the early years, allowing other, healthier identities to be established first. As an unwelcome guest arriving late to the party, it’s understandable that the CMT identity will initially be turned away at the door—some studies suggest that early onset of disability leads to better adjustment (eg. Barker and Maralani, 1997); Charmaz’ longitudinal study suggests the opposite (1995). Then there is the fact that for many years, sometimes for a whole lifetime, CMT can be largely invisible. For many people with CMT, it is possible to travel among the well disguised as one of them; to “pass” for “normal” (Goffman, 1963: 92). Finally, CMT identity itself is ill-formed. It is a largely unknown condition, lacking role models, spokespersons or any kind of culture of its own. It is understandable that one’s CMTness is frequently denied or disavowed. The

six research participants are all members of the national charity CMT UK and all have thus reached some kind of accommodation of their condition, but even they were highly CMT-ambivalent at times. CMT is like a big heavy cloak that we wear: it can't be removed, but it is sometimes invisible, and we do sometimes completely forget we are wearing it.

I believe the cloak of disability is particularly challenging for men to wear. Any kind of weakness conflicts with traditional, stereotypical constructions of masculine identity around strength. According to Jung, "Eros" dominates the female psyche, while males are governed by "Logos" (1982: 65). Boys don't cry. They must "repudiate all that is soft, vulnerable, playful, maternal and 'feminine' " (Samuels, 1999: 167). This may explain why more than three-quarters of suicides are by men (ONS, 2017), why men are three times more likely than women to become alcohol dependent (NHS Digital, 2015), and why women are twice as likely as men to access psychological therapies (NHS Digital, 2019). Or why there was so little response from men to my solicitation for research participants, who consequently were all women.

Adler described men's fear of weakness and its resulting overcompensatory lurch towards stereotypically aggressive, competitive and triumphalist behaviours as the "masculine protest"—the source of fascism and "the arch evil of our culture" (in Connell, 2005: 16). Or, as bell hooks puts it: "The first act of violence that patriarchy demands of males is not violence toward women. Instead patriarchy demands of all males that they engage in acts of psychic self-mutilation, that they kill off the emotional parts of themselves. If an individual is not successful in emotionally crippling himself, he can count on patriarchal men to enact rituals of power that will assault his self-esteem" (2004, 66). I would very much like to see further research on men, disability and identity and discussion on how men can be better helped toward care and self-care. I believe in closing the gender pay gap, but the life gap is rarely discussed: men on average die four years sooner than women (ONS, 2018).

Regardless, we should all wear our cloaks proudly. We should not deny, hide, feel ashamed by or apologise for an essential part of us. Ill or not, we all hold

the transformative power of being able to choose our own story, which in turn can then disrupt the accepted discursive and cultural norms. We can dance to the anthem provided, or we can write our own music and in so doing change the anthem. In this way, a society's narratives can be mediated by the "small stories" of individuals (Bamberg, 2006, 2011; Georgakopoulou, 2006).

How we wear our cloaks matters. Writing about gender, Butler (1990; 1993), sees identity is a performance, one that reflects the interplay between who you are and what you do. Individual performance is a choice; it can challenge and confront societal norms and expectations and thereby alter them. Butler named these "queer" performances: "Queer is by definition whatever is at odds with the normal, the legitimate, the dominant" (Halperin, 1995: 62).

If you have CMT, or Parkinson's for that matter, your assigned role now is perhaps to be somewhat helpless, benign, a bit dim, but also noble in your quiet suffering, and brave. While queer theory and disability studies have their differences (Sherry, 2004), a "queering" of disease and disability might be to refuse to accept all that and simply do it your way—there is a subversive thrill in defying expectations. These are not even diseases—they are conditions. And they need not diminish the appetite for and engagement with living. Quite the contrary.

### ***Growth***

Of the four themes, the participants had the least to say about this, but it is included because for me it is the most important, as the literature cited in this section reveals. To deny the potential for growth is to deny the potential for life. What might appear on the surface—or to others—as bad news can turn out to be good.

If you give small doses of poison to mice, they live longer than a control group of clean-living mice who are kept poison-free—this is the principle of hormesis (Mattson, 2008): Something that produces harmful effects at moderate to high doses may produce beneficial effects at low doses. More than a third of entrepreneurs in America are dyslexic (Logan, 2008); they regard their

disability as an “advantageous disadvantage” or a “desirable difficulty” (Bjork, 1994). Many successful people faced huge obstacles or traumas in their youth, such as the early loss of a parent (Gladwell, 2013); many go on to use their wounds to heal others by becoming brilliant therapists (Farber, 2017).

Maya Angelou grew up in the Great Depression. When she was eight, her mother’s boyfriend raped her. He was found guilty, served all of one day in jail, and was murdered four days later. Angelou, deeply traumatised, fell silent. She was mute for almost five years. She was tested, tormented, but from that place, somehow, she triumphed: She rose to become a poet, singer, filmmaker, groundbreaking writer and civil rights activist.

This verse is from her famous poem, “Still I Rise” (Angelou, 1986):

*You may shoot me with your words,  
You may cut me with your eyes,  
You may kill me with your hatefulness,  
But still, like air, I’ll rise*

Everyone falls or is felled to some extent, but it is in the rising that growth happens. Similarly, Wright (1983) argues that disability does not have to equate to suffering—successful adaptation to loss, she says, can sometimes facilitate the development of greater individuation, integration and mental health than the person experienced when able-bodied. Marinelli writes: “Disability is increasingly viewed as an enabling experience. This has allowed for the development of personal growth in life domains and contributions to the lives of others that were previously unavailable” (2007: xxii). Says Tannenbaum: “CMT can accelerate emotional maturity and a shift toward a more spiritual approach to life. A healthy life is not about having healthy legs” (personal communication).

Constraints can spur vitality rather than hinder it. I believe this can be true of conditions like CMT or Parkinson’s. They are not in any sense desirable, but they can be an invitation to respond, and in your response you may, if you’re

lucky, access and activate the best parts of you, parts you didn't know existed. These conditions are like a shot of penicillin; a little dose of death that reactivates and revitalises your life.

For the research participants, there have been times when the “dose” seems too high, the suffering too great, and positive healthy psychological growth a fantasy. But the potential is always there. There is always hope.

Relatedly, the literature on post-traumatic growth explores the remarkable irrepressibility of the human spirit. Tedeschi and Calhoun describe post-traumatic growth as “a change in people that goes beyond an ability to resist and not be damaged by highly stressful circumstances; it involves a movement beyond pre-trauma levels of adaptation ... it has a quality of transformation” (2004: 4). Typically, post-traumatic growth takes place in three areas: in improved relationships, from reaching out for help (Tedeschi and Calhoun, 1996); in an improved sense of self from trusting that you can survive and in an improved appreciation and philosophy of life (Tedeschi and Calhoun, 2004). In a qualitative study of people with disabilities, Boswell *et al* (2007) found spirituality played an important role in their lives, in five overlapping areas: purpose, awareness, connections, creativity and acceptance.

One model of post-traumatic growth that is easily applicable to the arrival of disease or disability is the shattered assumptions theory (Jannoff-Bulman, 1992). Everything you held true about your life, the “certainties” that you relied upon for your sense of security and wellbeing, are gone. From the wreckage you pick up the pieces and build a new life that—like the Japanese broken vase art form *kintsugi*—is stronger, more interesting and more beautiful than the original.

A useful image for me in coming to terms with CMT and Parkinson's is Jung's fantasy guru Philemon, who appeared to him in a dream, who “had a lame foot, but was winged in spirit” (Jung, 1961: 209); a perfect mind despite an imperfect body. There are countless other examples in fact and fiction, such

as “The Elephant Man,” “Children of a Lesser God,” “My Left Foot,” “The Diving Bell and the Butterfly,” “Wonder.”

For all the pain and suffering, sometimes disease can be healing.

In many such narratives however, the disabled person is cast in an heroic light, their suffering conferring upon them wisdom, heightened awareness and often supernatural powers, highlighting “our need to impose order and purposefulness on random events such as incurring a life-threatening illness” (Olkin, 1999: 25). This “halo effect” is the flip side of the moral model of disability: though the conception is a more positive one, it can be equally limiting and prejudicial as stereotypical negative depictions. The person with a disability is thus the reluctant recipient of projections of either sin or saintliness; both do a disservice to the person’s actual lived experience.

Similarly, one can regard the ageing process as either very bad, or very good; both things can be true. Old age can be a deterioration, a diminishment, a decay; “there’s no fool like an old fool,” my mum used to say. Or you can regard it as a distillation. It’s true things will be taken away from you during your life. But you will find other things, things you can do, and like a blind person, the things you can do become intensified, and you will do them better and enjoy them more, until they too must go. And you will join in the editing of your life too—you will declutter and get rid of useless, time- and energy-wasting baggage and people and activities and concerns that once bedeviled you. You will simplify, slow down and be still. Every day your soul matures and enlarges. It loses nothing. At the moment of death your body, often tired, broken and wasted, stops. But look at you. You’re quite something. All the grit was necessary to make such a beautiful pearl.

Increasingly I have come to think of growth as a choice. Viktor Frankl, the Austrian Jewish psychiatrist, a contemporary of Freud and Alfred Adler, was in 1944 sent with his wife to Auschwitz initially, then to other concentration camps. Frankl survived the Holocaust. His wife, mother and brother did not. All were murdered by the Nazis.



Unimaginable pain, suffering and loss. Yet Frankl chose to live well. After World War Two he wrote *“Trotzdem Ja Zum Leben Sagen: Ein Psychologe Erlebt das Konzentrationslager”* (“Saying Yes to Life in Spite of Everything: A Psychologist Experiences the Concentration Camp”). Today the slim volume, part-memoir, part-philosophy of life, part-inspirational self-help book, is called “Man’s Search for Meaning.” It is also a kind of manifesto for Frankl’s brand of existential psychotherapy that he developed after the war and called logotherapy.

Frankl argued that it is the absence of meaning that makes life unbearable—if you can find the “why” or your existence, he wrote, you will be able to bear almost any “how.” And even in the cruellest, most inhumane of circumstances, a person can find meaning. They can choose love.

Wrote Frankl: “Everything can be taken from a man but one thing: the last of the human freedoms—to choose one’s attitude in any given set of circumstances, to choose one’s own way” (2004 [1946]: 86).

Perhaps asking why we get ill—or why we got this body—is asking the wrong question. Better questions might be what and how. What are you going to do about it? How will you care for this body? What help do you need? What sense will you make of your body’s challenges? What are you going to learn? And above all, how are you going to live? As a victim? Or a wholehearted human? In the myth of Sisyphus, the gods punish the deposed king by making him see out his days pushing a boulder to the top of a hill, watching it roll all the way back down, then doing it all over, again and again. But he accepted his fate and therefore, writes Camus, “One must imagine Sisyphus happy” (2013 [1942]: 89).

I return again to the photograph of the lone, lame zebra in Botswana. And it hits me that what is so powerful about the moment is the silence, the stillness, the rich, illuminated calm. The zebra accepts, and waits. He stands tall. He is beautiful. Just before death, he is at last fully alive.

## THE “TWO WORLDS” MODEL

### *Disability apartheid*

The secret to happiness, according to Australian comedian Jim Jefferies, is to be good looking. Everyone is somewhere on a bell curve of attractiveness; he rates them from 1 to 10.

“1s are as rare as 10s,” says Jefferies in a live stage show in Nashville. “I’ve seen about five 1s in my life. 1s don’t really leave the house. They know they upset the rest of us. The only time you catch a 1 is they’re going to a doctor’s appointment or something. And it really is upsetting. You walk by, they’re normally being lifted out of a minivan with a special crane onto a special chair. And when you see a 1 it does ruin your day, doesn’t it? You walk by the 1 and you’re like, oh fuck me. Oh that’s a fucking 1 if ever I’ve seen one. You get to work and you can’t focus and your boss is like ‘what’s wrong with you?’ And your like, ‘Argh, I saw a fucking 1 didn’t I.’ ”

The audience laps it up. Jefferies has a good delivery; he is funny. But the segment reveals that it’s still culturally OK to target disability; it is perhaps the last acceptable prejudice. If Jefferies had denigrated a representative of any other minority group in this way, the result could well have been career-ending.

Joking aside, let us imagine life for the “1” in this sketch. He—in my imagination it’s a man—has a severe disability. Let’s say he acquired it in adulthood. This means he has experienced great loss in what he is able to do, impacting his ability to work, create, recreate and relate. Now he is being treated as “the ugliest person earth”—Jefferies literally can’t stand the sight of him. Illness or accident took away some of his functionality; now Jefferies is robbing him of his attractiveness, dignity and even right to appear in public.

The man essentially is excluded from everyday life. As are my participants. The themes from my research converge into an overriding picture of isolation, secrecy and invisibility for people with CMT. A kind of grand dissociation. The physical losses and impairments relegate people to disabled world, while

discrimination and the way identities are formed serve to keep them there. They are denied the opportunity to participate, to have their unique skills, knowledge and utilised, appreciated and rewarded. Their opportunities for growth are now circumscribed.

The West thus operates largely under a system of disability apartheid. “Good societies enable people to cope ... by removing barriers, providing supports, and by treating disability as part of normal human variation, rather than an abnormality to be discarded” (Shakespeare, 2018: 22).

The six disabled participants in this research all have experienced great losses which they have mourned and continue to mourn. They have faced all manner of discriminations, exclusions, rejections, shamings. They have struggled to integrate their physical condition into their identity, their sense of self. These hardships have to an extent facilitated growth but they have also stifled it. Rogers’ famous “actualising tendency” runs on the fuel of human kindness and self-belief (Rogers, 1961). For people with disabilities, actualising or becoming a person or developing a sense of self is so very often thwarted.

Taking these ideas, the participant interviews, my own experience, plus the quotation from Susan Sontag that starts this dissertation, I have created an overarching “two worlds” model of disability.

At its simplest, it depicts a world where anyone deemed “disabled” is largely invisible, unwelcome in the able-bodied world, unless they can “pass” for normal (Goffman, 1963). There is a hard border and a soft border between the two. Both borders are porous; lots of movement does happen. The hard border is physical (and political). It has a red light of segregation, and a green light of integration. The soft border is psychological, with a red light of shame and a green light of acceptance.

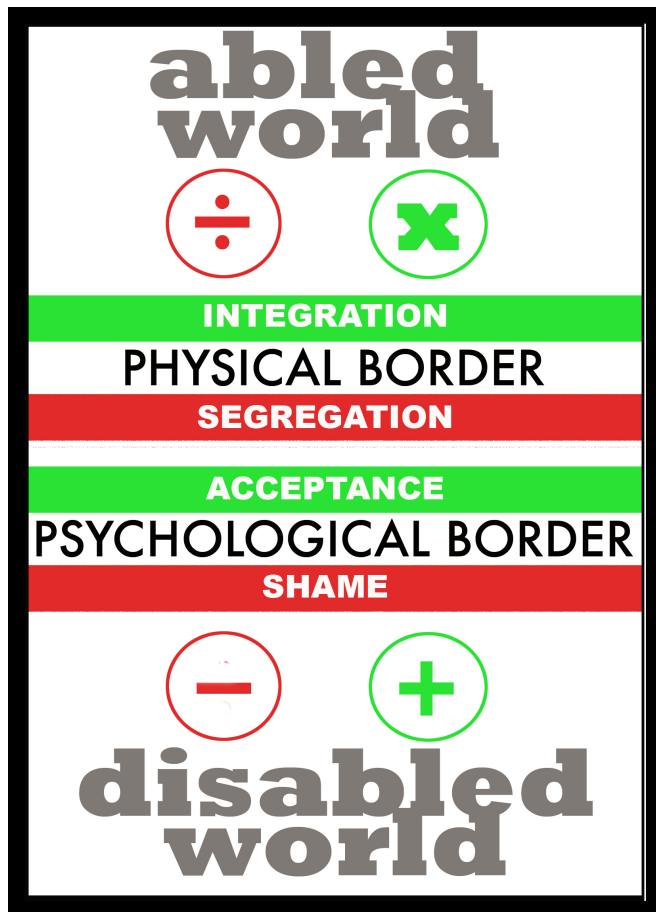


Fig 13: The “two worlds” model of disability

I have classified the population of the two worlds into four broad archetypes. The able-bodied I am calling either dividers or multipliers. The dividers (red light) like the apartheid system. They might be prejudiced a little or a lot, consciously or unconsciously. They judge, criticise, moralise and laugh at jokes about the disabled. They are part of the problem. Multipliers (green light) on the other hand are part of the solution. They have respect for difference, empathy, tolerance, open-mindedness and an appreciation of diversity.

The people with disabilities I have characterised as either subtractors or adders. Subtractors (red light) take themselves out of the game. They can be self-critical, sliding into self-pity, victimhood and depression. The adders (green light) by contrast have accepted the givens of their situation and choose to take responsibility for their life and live it. With vitality and confidence they go out into the world.

Of course these characterisations are highly simplistic. Sometimes people can speak or act in a way that supports apartheid; at other times—sometimes in the same breath—the exact opposite can be true.

**The physical border**

This is the nexus of activism; chipping away at dismantling the border wall with improved disability rights and legislation, better wheelchair access, Universal Design, integrated schools, inclusionary workplace hiring practices, public transport for all, a fair system of benefits. Kleinman states that images of chronic illness and disability are bad for PR: capitalist ideologies





	TWO WORLDS	ONE WORLD
ABLED	 <p><b>DIVISION</b> projections, fear, disgust, assumptions, patronise, deficits, othering, moralise, avoid, criticise</p>	 <p><b>MULTIPLICATION</b> empathy, flexibility, tolerance, open-mindedness, diversity, curiosity, inclusivity, assets, encourage</p>
(DIS)ABLED	 <p><b>SUBTRACTION</b> shame, invisibility, safety, victimhood, self-denial, fear, stagnation, depression, despair, self-criticism, guilt</p>	 <p><b>ADDITION</b> acceptance, pride, vitality, empowerment, growth, participation, capability, confidence, respect-ability</p>

Fig 14: The four archetypes

want to represent health and success as they try to encourage consumption or mobilize enthusiasm for governmental campaigns (1988: 47). The UK government was roundly condemned by the UN in 2017 for the way it has treated people with disabilities in the age of austerity (Butler, 2017).

Disability rights activists and the social/minority model of disability have successfully highlighted the way individuals and governments treat the most vulnerable members of society. A great many gains have been achieved over the past several decades, transforming the lives of millions.

Disability is an atypical demographic for a minority group. For one thing the nature of the disabilities themselves—and their attendant challenges—are extremely diverse. Even within one family affected by a single condition like CMT, such as my own, there is a variety of presentations. Within the world of disability at large, however, the quality and quantity of differences are so broad in scope as to render the catch-all term almost meaningless. I have enormous empathy for, say, someone who is blind, or deaf, or intellectually challenged, or in a wheelchair, or in unending pain. But other than our shared humanity and vulnerability, I don't feel I have much in common in particular with such a person, nor do I presume to know how they feel or what their challenges, abilities and needs might be.

Further, the social/minority model, like other minority liberation movements, has the potential to reinforce the barriers it seeks to abolish. It reinforces and draws attention to their negative group identity, which may induce victimhood, and it highlights difference in order to be treated just the same.

Fraser (2010) says identity politics can become inward-looking and sectarian, homogenising its members for the purposes of advocacy and political change. Fraser prefers an individual, “identitarian” approach. As discussed in Chapter 2, Owens favours a pluralistic approach based on the writings of Hannah Arendt (Owens, 2015). Levitt outlines his “active” model (2017), which focusses on the agency and actions of the person with disability—empowering the disablee rather than the targeting the disabling environment. Also of note is the human development model of disability (Mitra, 2018), based on economist Amartya Sen’s work on the role of human individual capability in poverty reduction. These post-social model ideas are abling in their foregrounding of the agency, capability and participation of the disabled.

Making political recommendations is beyond the realm of this paper. But what is true for individuals is true for society: both can disown their disability, or they can regard it as an “advantageous disadvantage”; they can learn from it, innovate, discover their best self and grow. I am optimistic that increasingly an integrative approach is adopted; that we are slowly but surely evolving from exclusion and segregation towards integration and, ultimately, inclusion—“one world” where all individual capabilities and limitations are respected and growth is permissible.

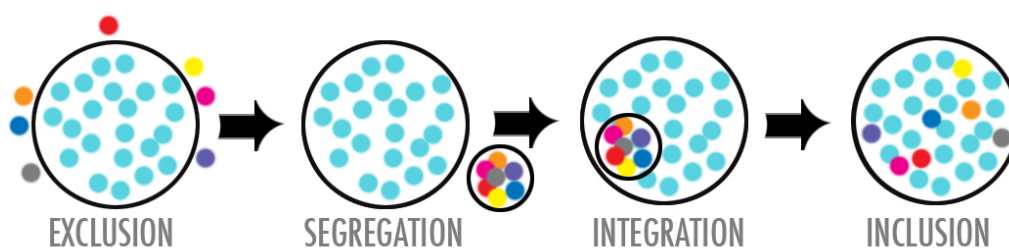


Fig 15: The road to inclusion

### ***The psychological border***

People with CMT have experienced losses that already take them out of the “normal” world. Often they have had to say goodbye to beloved careers, activities, places. Then there’s the problem of the psychological walls of the able-bodied—the subtle and the no-so-subtle aversion, hostility, bullying, prejudices and acts of discrimination that make the disabled feel unwelcome and unsafe in the abled world. Additionally, the unknown, unfashionable nature of CMT, a condition without a strong culture, a dearth of role models and commonly much intrafamilial blame and guilt, makes it hard for people to accept. It’s hard to be accepted if you don’t accept yourself. The psychological border has a red light of shame, and a green light of acceptance.

A well-known but uncited quote often attributed to Maslow: “In any given moment we have two options: to step forward into growth or to step back into safety.” We all of us live on that knife edge. For someone with a disability, safety is obviously enormously appealing, given how vulnerable we can feel in abled land. We all need to be subtractors, to retreat from the world, or to hang out and do things with other people with disabilities in disabled land. But we must not give up on growth. Feel the fear and do it anyway. Add ourselves to the party, despite the obstacles. We must not be victims.

I am interested in the internally disabling wall of victimhood. It’s all-too-easy to see oneself as a victim. Anyone who has ever lived at some time has probably been there, done that. I have. My mother has: One of her less shining moments was asking me not to talk about CMT (which she didn’t have) because, she said, “I’ve suffered so much with CMT.”

Chronic victims see their life as harder than anyone else’s, their suffering greater, their losses more significant. They are sponges of negativity. Seemingly minor events are mined for nuggets of bad feeling. If you ask them how they are, they will give you a lengthy exposition on all their aches and pains and doctors’ appointments.

The victim will find a way to insert themselves into events that have nothing to do with them, insisting on their right to feel personally victimised. The victim will often claim that if only all these terrible things hadn't happened, if only they weren't so unlucky, they would have achieved all sorts of amazing things, living lives full of courage, success and fun.

There are two kinds of victim. The first kind blame everyone else for their woes. They hold themselves as being completely blameless, innocent, beyond reproach. "All of these terrible things have happened to me," says the victim to anyone who will listen. "It's not fair. Why me?"

It's important to victims to surround themselves with people who will affirm their victim status, often kindly, sympathetic souls who can sit for hours listening to their litany of complaints. Until they inevitably experience compassion fatigue and give up, at which point, in the victim's eyes, they become part of the problem.

Any attempt at feedback or well-intentioned constructive criticism, however mild, is seen as an unforgivable attack—further evidence that the world is against them. People around such victims learn to walk on eggshells—or walk away.

The second kind of victim directs all the blame inwards. "I'm just a bad person," says one client. "I'm just such a disappointment," says another. "If I saw myself walking down the street, coming towards me, I'd cross the road," says a third.

These people are relentlessly self-critical. They exist under a brutal, tyrannical interior system of government. They have the worst boss in the world: themselves. And the boss is always there.

Being a victim is an enormously powerful position. In a way it offers a kind of defensive safety.



Victims will often go to therapy for years to prove that they can't be helped, that their problems are insurmountable, that they can't do anything and thus don't have to do anything.

Victims live as "misers and complainers," writes the poet David Whyte, "reluctant and fearful, always at the gates of existence, but never bravely and completely attempting to enter, never wanting to risk ourselves, never walking fully through the door" (2015: 234).

Nothing changes until, one way or another, a choice is made to live a different way; to get off the "drama triangle" (Karpman, 1968). This involves giving up the victim mentality, taking an honest look in the mirror, admitting your vulnerabilities, and accepting and loving oneself. And then, afraid but resolute, stepping through that door to life.

The most famous six words in literature: To be or not to be? That's the question Hamlet asked himself. Grief stricken over his father's death, unable to avenge his murder, incapacitated by indecision and fear—he chose to be, but as if he wasn't, a kind of living death, a walking shadow, until actual death chose him. The rest is silence.

If only Hamlet had found a good therapist. He might have chosen to live, to live perchance to dream.

The answer to Shakespeare's question is: be.

## CLINICAL RECOMMENDATIONS

When you are diagnosed with CMT—typically via a nerve conduction test and/or a genetic test—the NHS website says: “You may experience feelings of shock, denial, confusion or fear.” You might then be “taken on” by a neurologist for periodic check-ups and outpatient care. You might undergo a series of tests of your functionality. You might be offered



Fig 16: The therapy room

physiotherapy, occupational therapy, ankle-foot orthoses and other walking aids. Surgical options will likely be presented. A multidisciplinary team will be at your service. But it's most likely that at no stage will counselling, psychotherapy or any kind of emotional support be offered. The very last bullet-point item on the NHS' CMT page is “your emotional health” for which it provides a phone number and an email address to the charity CMT UK.

It is my view that the medical model that treats people like dysfunctional machines inevitably stigmatises people with health conditions like CMT and exacerbates the psychological challenge of coping. As shown in the participants' testimonies, particularly around diagnosis, there is sometimes an almost willful lack of empathy from some healthcare professionals that borders on cruelty—and which, anecdotally at least, can exacerbate symptoms. At the same time, the system does not care to offer any professional psychological care.

These 12 clinical recommendations come from the participants' experience—they are built around the four emergent themes of loss, discrimination, identity and growth—and from my own, too. They are intended for any counselling psychologists, psychotherapist or counsellor working with a client who has CMT, but they might prove helpful for a broader group of service providers including consultant neurologists, physiotherapists, GPs and researchers, and a broader group of service users, too, including anyone with a progressive condition or disability.

## **Loss**

1. Arm yourself with knowledge of disability culture, the medical and social models, and the client's condition. Read Rhoda Olkin's "What psychotherapists should know about disability" (1999). Find some disability-related CPD days. There's no excuse for ignorance, warns Olkin; it "can be expected to have the predictable problems inherent in cross-cultural counseling, such as premature termination, insufficient rapport, or negative outcomes" (*ibid*: 155).

At the same time, don't make any assumptions about the client's relationship with their condition, illness or disability. One of the worst things is dealing with other people's reactions. The assumption that it must be terrible, that life must surely be hardly worth living, is bad enough; the opposite—the demand to be relentlessly cheerful and upbeat—isn't much better. Two of the commonest countertransference issues with clients with disability revolve around pity, leading to unhelpful expressions of sympathy, and curiosity, leading to an unwanted, insensitive interrogation (Thomas and Schwarzbaum, 2011: 340). So don't do that. While there may be similarities in the problems they face in a disabling world, every client is (dis)abled in their own unique way. Each therapeutic dyad is unique, dictating a bottom-up psychology that emerges from the relationship rather than a modernist, top-down imposition of theories, techniques and methods from expert clinician to grateful client. Yalom suggests a new therapy is created for each client (2002: 33), an idea first floated by Jung (1995 [1961]: 152).

2. Consider where you are coming from. How have you and people close to you been impacted by health issues, and how might that impact the work? What are your attitudes and assumptions? Notice and reflect on your transference reactions, but try to keep things real—a good starting point is research participant Pam's excellent, down-to-earth approach on page 74. Your job is to be a solid, steady secure base. From that place you can offer emotional support and embark on a strong working alliance, a co-created venture, a joint exploration. The work may be all about the client's physical condition, or it may not be about that at all.

3. Invite the client to acknowledge what has been lost, to connect with all the emotion surrounding that; to mourn. There are no short cuts. People with health conditions or disabilities are often regarded as objects of shame; inevitably shame can be internalised, where, by definition, it often remains hidden ... because it's so shameful. Be alert to clues to shame and endeavour to cultivate a relationship in which it is safe for shame to be explored.

### ***Discrimination***

4. Introduce the client to the two-worlds model. What is their relationship to each of the two worlds? What do they believe, say or do that sustains the two-world status quo, and what do they do to subvert the mainstream and promote “one world”?

5. Take a systemic approach. Who is around—family, friends, colleagues, carers, service providers? Explore with the client what support they have in their life, and what they need. Respect boundaries; be on the side of client agency and autonomy. Are they good at asking for help? A life audit can be helpful: who are the people (and what are the activities, places and things) that are life affirming? And what brings them down? Who or what is discriminatory? And what can be changed? (Says the Serenity Prayer: May you find the serenity to accept the things you cannot change, the courage to change the things you can, and the wisdom to know the difference between the two.)

6. Join the client in solidarity in understanding and empathising with the daily insult of hassles, discriminations and challenges they may face as a disabled person. Become an advocate for disability rights. Utsey, Bolden and Brown (2001: 334) suggest that counsellors should become activists, seeking to deconstruct the oppressive social order in their own worlds. In this way, “the psychologist is invited to conjoin the personal, the professional and the political” (Gergen, 1992: 27). Both the therapist and client thus strive for emancipation. Olkin: “There is no such thing as an unpolitical therapy” (1999: 307).

## ***Identity***

7. On an ongoing basis but especially around diagnosis, explore with the client their relationship with their physical self. How do they see their identity as a diseased or disabled person—and where do those ideas come from? What is introjected; what is projected? Take a “community of selves” approach: How do they conceptualise all their other identities—and how do they all integrate and work together? The victim, the angry self, the withdrawn self, the rapturous, the suicidal—all are welcome in the consulting room. There are no bad selfies here.

8. Invite the client to tell their whole story (see Frank’s “The Wounded Storyteller” 1995). How does being ill or disabled fit in their life story and their sense of self? What sense or meaning is to be made? What is their narrative identity? The therapist is not obligated to collude in the client’s self-blaming or self-critical moralistic interpretations.

9. Introduce Judith Butler’s idea of “queering”—rejecting the bleak identity assigned to you by the medical establishment, friends and family and instead wearing your cloak of disease and disability in your own unique way. Role models can help the client see what is possible; they in turn can become role models to others.

## ***Growth***

10. As the therapeutic relationship develops, you might like to invite the client to explore whether there are any good things to come from their condition or disability. What are they grateful for? Where is the growth—what are their progressive abilities? Where is the love? Introduce the concepts of hormesis, advantageous disadvantage and post-traumatic growth.

11. Health conditions can be an opportunity to care for yourself, finally, after perhaps years of neglect. And I believe caring for yourself slows the progression of symptoms. I have found it useful to be reminded about the importance of the basics: healthy eating, drinking, sleeping, exercising. In a very direct, CBT way, the therapist may take on the role of a coach. Or parent.

**12.** In searching for meaning in disease and disability, a way to live, a purpose, *ikigai*, the client may be supported in accessing and developing greater meditative, spiritual, numinous, religious or transcendent aspects of themselves and life.

## 8. CONCLUSION

### *Findings*

In summary, this paper identifies and explores four fundamental pillars that create and shape the psychological experience of living with CMT (and by extension any progressive health condition): loss, discrimination, identity, growth. The nature of the response to the first three dictates the extent to which the fourth can happen—it can inhibit growth or sometimes accelerate it. However painful and



Fig 17: “Trees of Life”

traumatic the loss, however acute the level of discrimination, however impacted the identity, there is always the possibility of choice—of choosing growth over safety; of choosing life over a kind of death. Of choosing ability over disability.

In seeking to integrate the four main themes, this paper also offers a “two worlds” model as a way of looking at the current situation with regards to disability, which may be described as a kind of social apartheid. The able-bodied live in “abled world,” a land of growth, a land of potential hope and glory. The disabled by contrast inhabit “disabled world,” which can be a place of solidarity, support and political activism, but also a place of lack, victimhood and powerlessness. This paper supports the ideal of “one world” but currently the two worlds are separated by two porous yet enduring borders: a hard political border, and a soft psychological border. Much progress has been made in dismantling the former—the work of the social model of disability in demanding a less disabling environment with improved access, opportunity, representation and power. But we will never all live together in one world, where individual strengths are valued and vulnerabilities are supported and catered for, until the disabling internal psychological barriers are removed.

Both disabled and able-bodied people can be guilty of two-world thinking, the former choosing “subtraction” over “addition”; the latter “division” over “multiplication.” This only changes when we meet, greet, and get to know each other.

Lastly, this paper advocates ongoing psychological support for people with CMT and other disabling conditions. Too often the medical model-informed healthcare systems in the west are literally soulless, tending to focus only on the mechanical body and splitting off everything else. This paper offers 12 clinical recommendations, built around the four themes identified in the research. People with progressive conditions need help: To mourn and accept the losses; to contend with the daily discriminations; to build an authentic, cohesive, integrated and unconflicted identity; to discover, believe in and nurture the potential for growth within. These processes require or at least can certainly benefit from ongoing psychological support.

### ***Failings***

This piece of research is, like the researcher, unavoidably biased, compromised and constrained by its own parameters.

I have CMT, the phenomenon being researched, and included my testimony alongside those of my participants. I am male; they are female. I conducted this research during a midlife period of immense personal change, yet also, following a successful career, from a position of relative socioeconomic stability. We are all white, living in a particular place at a particular time in history. We each come from and exist in particular family constellations and each brought to this project our own unique, peculiar and complicated psychobiographies. How all these realities impacted the research and in what ways, both positive and negative, is for you to decide.

I make no claim that there are any “Truths” in these pages—universal, eternal absolutes. Anyone who encounters this research can decide what “truths” are resonant for them.



## ***Future***

Psychology should be part of the solution to disability apartheid, yet too often it is part of the problem. Building wheelchair ramps to provide better access to buildings is commendable, but they do not extend into the minds of therapists, course planners at training institutes, or researchers. These decisionmakers might better consider the perspectives of the most vulnerable members of society not just because it's the right thing to do, but because it leads to better decisions. This is the point of the diversity. Even though society at large might operate on a two-world system, psychology and psychotherapy can operate as one world, open and welcoming to all.

I would like to see more one-world, Paradigm II research. I personally intend to continue to explore the psychology of disease, disability and death and communicate the fruits of those explorations with words, images and video on a variety of outlets and platforms. I particularly would like to see and be involved in more research into the psychological barriers between the abled world and the disabled world that reinforce the regressive tendency towards disability apartheid. When we get to know each other, the world will live as one.

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## APPENDIX I: Recruitment notice

METANOIA INSTITUTE & MIDDLESEX UNIVERSITY

# Research into the psychology of Charcot-Marie-Tooth disease

## PARTICIPANT RECRUITMENT NOTICE

### GREETINGS!

Have you ever wondered about the psychology of CMT? I am carrying out some research and am interested in hearing from people with CMT about their personal experience—in their own words—of living with the condition and how it affects them. This study will explore in depth the testimonies of a small number of participants with the goal of identifying the essential themes around what it means to have CMT. This project is the research portion of my professional doctorate in Counselling Psychology and Psychotherapy (DCPsych) at the Metanoia Institute in London.

Please consider these questions:

- Were you diagnosed with CMT at least 10 years ago?
- Do you feel that your CMT has had a significant effect on you and your life?
- Do you live within 100 miles of London?
- Are you interested in talking about your experience of CMT and struggles with it, how it has impacted you and your life and those around you?

If you answered yes to all four questions, please contact me at [bartonjohn@hotmail.com](mailto:bartonjohn@hotmail.com). I will send you an Information Sheet and we'll take it from there.

Many thanks for your consideration.

Best wishes,  
John Barton



## **APPENDIX II: Participant information sheet**

**METANOIA INSTITUTE & MIDDLESEX UNIVERSITY**

# **Research into the psychology of Charcot-Marie-Tooth disease**

## **PARTICIPANT INFORMATION SHEET**

### **“Living with progressive disability: giving voice to people with Charcot-Marie-Tooth disease”**

You are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is the purpose of the study?**

I am carrying out some research into the psychology of CMT and am interested in hearing from people with CMT about their personal experience—in their own words—of living with the condition and how it affects them. This study that will explore in depth the testimonies of a small number of participants with the goal of identifying the essential themes around what it means to have CMT. Virtually no research into CMT of this kind has ever been done before.

This project is the research portion of my professional doctorate in Counselling Psychology and Psychotherapy (DCPsych) at the Metanoia Institute in London. The research will take place between autumn 2014 and autumn 2015. My personal interest in this topic is that I, too, have CMT (type 1a).

#### **Why have I been chosen?**

I am looking for 5 participants who can answer “yes” to all of these 4 questions:

- Were you diagnosed with CMT at least 10 years ago?
- Do you feel that your CMT has had a significant effect on you and your life?
- Do you live within 100 miles of London?
- Are you interested in talking about your experience of CMT and struggles with it, how it has impacted you and your life and those around you?

I will select 5 applicants who meet the criteria.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this Information Sheet to keep and you will be asked to sign a Consent Form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**What will happen to me if I take part?**

Your participation will involve being interviewed by me—an initial interview and possibly a follow-up interview, too—at times, dates and locations that are convenient to you. The interviews will each last approximately 60-90 minutes. The interviews will be semi-structured—I'll be encouraging each participant to talk freely, openly, honestly and deeply about their own personal experiences, challenges, thoughts and feelings associated with their CMT. The interviews will be tape recorded. Anonymity and data protection will be assured throughout, in accordance with the Data Protection Act. The recordings will be destroyed on completion of the research. Please note that in order to ensure quality assurance and equity this project may be selected for audit by a designated member of the committee. This means that the designated member can request to see signed Consent Forms. However, if this is the case your signed Consent Form will only be accessed by the designated auditor or member of the audit team.

**What are the possible benefits of taking part?**

Many people with CMT keep it to themselves and aren't able to discuss it. This is a unique opportunity to think about, talk about and share your experiences and in the process assist others with CMT. I hope that my research will: 1. Educate counselling psychologists and psychotherapists about CMT and the needs of people who have it; 2. Improve the nature and availability of psychological support around CMT; 3. Foster a great sense of community, voice and visibility for people with the condition and also raise awareness about it. By participating in my research you will be making a vital contribution to these things. And I hope that participating in the study will help you, too.

**What are the possible disadvantages and risks of taking part?**

You might find talking about your CMT to be a difficult experience. In the interviews, there is the potential of distressing thoughts, feelings or images being evoked in the course of our discussion. If this does happen, you might decide to pause, postpone or terminate the interview. I will be there to offer help and support and suggest resources you might access for further support. I will be available to you throughout the research process to assist you in the practicalities of finding access to any help that you may need.

**Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you which is used in the research will have your name, address and any identifying details removed so that you cannot be recognized from it. All data will be stored, analysed and reported in compliance with the Data Protection Act.

**What will happen to the results of the research study?**

I will write up my research and submit it to the Metanoia Institute/Middlesex University in late 2015 as part of my professional doctorate in counselling psychology and psychotherapy (DCPsych). In 2016 and beyond, shorter versions of the research may be published in peer-reviewed journals, presented at conferences/talks, and shared with the CMT community. You will not be identified in any report/publication.

**Who has reviewed the study?**

This research has been reviewed and approved by the Metanoia Research Ethics Committee.

**Who do I contact if I want to take part, or for further information?**

Please contact me, John Barton, by sending an email to: [bartonjohn@hotmail.com](mailto:bartonjohn@hotmail.com).  
You may also contact my research supervisor, Dr Lucia Swanepoel, at:  
Metanoia Institute  
13 North Common Road  
London W5 2QB  
Phone: 0208-579-2505

Thank you for your interest in this study!

## APPENDIX III: Resources for participants

# Research into the psychology of Charcot-Marie-Tooth disease

## RESOURCES FOR PARTICIPANTS

### CMT AND DISABILITY ORGANISATIONS

**CMT United Kingdom:** [www.cmt.org.uk](http://www.cmt.org.uk). The UK's principal support, information source and fundraising organisation for Charcot-Marie-Tooth disease. Find a support group in your area—or start one.

**CMT Association:** [www.cmtausa.org](http://www.cmtausa.org). The American CMT charity is also a rich source of information, research news and support—it hosts online communities including an “Emotional Support For CMT” forum.

**Office for Disability Issues:** [odi.dwp.gov.uk](http://odi.dwp.gov.uk)

**UK Disabled People's Council:** [www.ukdpc.net](http://www.ukdpc.net)

**Disability Rights UK:** [disabilityrightsuk.org](http://disabilityrightsuk.org)

### COUNSELLORS AND PSYCHOTHERAPISTS

**British Association for Counselling & Psychotherapy (BACP):** [www.bacp.co.uk](http://www.bacp.co.uk)

**UK Council for Psychotherapy (UKCP):** [www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)

**British Psychotherapy Foundation (BPF):**  
[www.britishpsychotherapyfoundation.org.uk](http://www.britishpsychotherapyfoundation.org.uk)

**British Psychoanalytic Council (BPC):** [www.pschoanalytic-council.org](http://www.pschoanalytic-council.org)

**British Association for Behavioural & Cognitive Psychotherapies (BABCP):**  
[www.babcp.com](http://www.babcp.com)

**British Psychological Society (BPS):** [www.bps.org.uk](http://www.bps.org.uk)

**Royal College of Psychiatrists:** [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

**Counselling Directory:** [www.counselling-directory.org.uk](http://www.counselling-directory.org.uk)

## **GENERAL RESOURCES**

**Mental Health Foundation:** [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

**Mind:** [www.mind.org.uk](http://www.mind.org.uk)

**NHS Direct:** Tel: 111 (this number has replaced the previous 0845 4647 service)

**Online support/meditation/mindfulness:** [www.bigwhitewall.com](http://www.bigwhitewall.com);  
[www.getsomeheadspace.com](http://www.getsomeheadspace.com); [www.bemindful.co.uk](http://www.bemindful.co.uk); [welldoing.org](http://welldoing.org)

**Samaritans:** Tel: 08457 90 90 90: [www.samaritans.org](http://www.samaritans.org)

**Sane:** [www.sane.org.uk](http://www.sane.org.uk)

## APPENDIX IV: Consent form

METANOIA INSTITUTE & MIDDLESEX UNIVERSITY

# Research into the psychology of Charcot-Marie-Tooth disease

### CONSENT FORM

**Title of Project:**

"Living with progressive disability: giving voice to people with Charcot-Marie-Tooth disease"

**Name of Researcher:** John Barton

**Participant Identification Number:**

**Please initial box**

1. I confirm that I have read and understand the Information Sheet that is dated ..... for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. If I choose to withdraw, I can decide what happens to any data I have provided.
3. I understand that my interview will be taped and subsequently transcribed.
4. I agree to take part in the above study.
5. I agree that this form that bears my name and signature may be seen by a designated auditor.

Name of participant	Date	Signature
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Name of person taking consent (if different from researcher)	Date	Signature
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Researcher	Date	Signature
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1 copy for participant; 1 copy for researcher

## APPENDIX V: Interview questions

# Research into the psychology of Charcot-Marie-Tooth disease

### INTERVIEW SCHEDULE

1. Tell me about your CMT?

*Prompts:*

- Family history, diagnosis, living situation etc
- What's it like to have CMT?
- How does your CMT affect your everyday life?

2. What has been your experience of your CMT in different areas of your life?

*Prompts:*

- At school?
- In career/work life?
- In leisure activities?
- In medical settings?
- In your family?
- Socially? In relationships?
- How have other people responded to your CMT?

3. What has been your experience of the progression of the disease?

*Prompts:*

- Any key moments that stand out in your CMT history?
- First experience of symptoms?
- Diagnosis?
- Progression milestones/plateaus/significant losses of function?
- Future projections, fears?

4. How have you coped with CMT?

*Prompts:*

- Self-management/resilience/coping strategies?
- Medical help?
- Practical and emotional support from others?

5. How does your CMT affect you?

*Prompts:*

- Emotional impacts and reactions?
- Effect on sense of identity, self-image, body, mental health, wellbeing?
- What sense do you make of having CMT?
- Do any words or images come to mind when you think about having CMT?
- What kinds of things do you say to yourself about having CMT? Do you feel like your CMT has changed you? If so, how?
- How would you be different if you didn't have CMT?
- Any good things arising from having CMT?

6. Is there anything else that feels important that you'd like to say?

## APPENDIX VI: Four themes and subthemes

*(subthemes pursued are in boldface)*

### LOSS

activities  
**adaptation and adjustment**  
anger  
challenge  
children  
coping  
denial  
depression  
**diagnosis**  
doctors  
**emotional reactions**  
family and friends  
fear  
frustration  
**help**  
**impact on life**  
independence  
loneliness  
resilience  
schools  
shock  
slowness  
uncertainty  
walking  
withdrawal  
work

### DISCRIMINATION

abuse  
awkwardness  
bodyimage  
bullying  
embarrassment  
guilt  
humiliation  
**NHS**  
**relationships**  
**school**  
**shame**  
slowness  
**social situations**  
strength  
uncertainty

understanding  
vulnerability  
walking  
**work**

### IDENTITY

**ambivalence**  
difference  
envy  
exclusion  
**family and friends**  
**help/helplessness**  
**intergenerational**  
invisibility  
isolation  
jealousy  
othering  
patronised  
powerless  
projection  
**relationships**  
resentment  
secret  
self criticism  
self esteem  
self-pity  
story

### GROWTH

acceptance  
advantages  
autonomy  
change  
death  
empathy  
future  
individuation  
strength  
transcendence  
understanding  
vulnerability



## APPENDIX VII: Role models

The six participants in this research are all my heroes. They have helped me and shown me how to be ill, how to be disabled. As have the following people. Thank you.

- My oldest sister **Diana Turner** has encouraged and supported and taught me—all my siblings have—but especially in showing me how to live with CMT with cheer and confidence. She was misdiagnosed at the age of 22 with Friedreich's ataxia. She went to the library and read that the life expectancy was 32. So she thought she had 10 years to live. And she had no support. She was thrilled to get the correct diagnosis a few years later: CMT.

- At 21, in his final year at Oxford, **Stephen Hawking** was diagnosed with motor neurone disease, also known as amyotrophic lateral sclerosis or ALS. He was told he had two years to live. But Hawking's was a rare early-onset and slowly progressing form of the disease. He was gradually paralysed over his lifetime. He lost the use of his legs, his body, his voice. But how his mind soared. He became a brilliant physicist, cosmologist and writer. He lived a full, rich life with his disability.

"Don't be disabled in spirit as well," he said (in Dreifus, 2011).

- My friend **Doug Sager** had a rough start in life but went on to become a tireless advocate and campaigner for social justice, filmmaker, poet, dancer and always a stylish, snappy dresser. Doug would dazzle the dancefloor with his fancy footwork for hours, still jumping and jiving long after men half his age had retired to the bar. The dancing days are over now because of late-onset CMT, plus more recently a stroke, but the passion, style and lust for life remain.

*FLYING STILL*

*Wake and push out of slumbers*

*I drag my weary body*

*Across the rumpled bed*

*Dancing days*

*Fondly remembered*

*And left in dreams*

*Grab bars and walls*

*My partners now*

*Wobbling not jiving*

*A different style*

*Movement not sublime*



*But graceful still*

*On a broken treadmill*

*Shaking not stirred*

*And to a different tune*

—Doug Sager

- ALS is also known as **Lou Gehrig's** disease after the American baseball player for the New York Yankees. ALS forced Gehrig to retire at 36 and killed him two years later. He said farewell to baseball and the world in a legendary speech on Independence Day, 1939, in which he listed the things he was grateful for in a life well lived: "For the past two weeks you've been reading about a bad break," he told a packed Yankee Stadium. "Today I consider myself the luckiest man on the face of the earth."

- When I worked at *Golf Digest* in America, I was privileged to have **Pete Farricker** as a fellow office colleague, writer and editor and friend. Pete was an ever-genial gentle giant who always greeted the world with a smile, a quip and a radiant attitude. After his diagnosis of ALS, Pete continued to grace the office, going to work every day until 5 days before he died. He wrote his own eulogy and had his wife read it out at the funeral. It began: "I have started writing this the day after the Giants lost the Super Bowl so if I still owe anyone money for a bet, good luck trying to collect."

- **Franklin Delano Roosevelt** contracted polio at 39 and lost the use of his

legs. He thought his political career was over; instead he became one of America's greatest presidents, steering his nation through the Great Depression and World War II.

- For most of her short life, **Vanessa Moss** was a cancer patient, yet she never stopped smiling, singing, dancing and having fun. She charmed everyone. She was eight when she died in 2017—after countless rounds of chemo, radiation, operations, transfusions—but hers was a rich, full life of joy. Vanessa's father, Parker Moss, a neighbourhood friend who is focusing his extraordinary talents on cancer research, writes: "So many people would ask us: how is it possible that Vanessa always smiles, that she always looks hopeful, is always excited by small gifts, is constantly besotted by babies, never complains ... despite her life of constant pain, year after year surrounded by death in the narrow corridors of an oncology ward, and with each and every one of her childhood hopes, crushed one after another? In her darkest hour, Vanessa simply chose to sing. Vanessa had purpose from the very start. Vanessa knew who she was, she was confident and proud of her identity, and she chose happiness every day, in spite of her circumstances.

"The only message that we can extract from the futility and the outrage of the death of the innocent is that when all is stripped back, when there are no more words, when every last hope has been extinguished, the only thing that remains is a fragile yet certain revelation that there is pure goodness, a profound and resilient thirst for happiness, at the core of our children. As adults, we need not aspire to attain these things. They are already within us. We just have to choose to reawaken them."

## APPENDIX VIII: Depiction of Parkinson's

Parkinson's? OK, you're a patient now, an ill person. You are that little old bent-over man, the one in the illustration that's in every textbook and encyclopedia (he seriously needs a makeover—the illustration was first published 1886). Take your pills, don't make a fuss. Nothing more is expected of you. Shuffle off home and sink into the warm embrace of the sofa, or under the duvet of depression.



By William Richard Gowers (1845–1915) after St. Leger (unknown dates) - Herter, Christian Archibald (1907) [1892]. "Fig 66 — Paralysis agitans. (After St. Leger.) (Gowers)". *Diagnosis of Organic Nervous Diseases* (2nd ed.). New York and London: G. P. Putnam's Sons. p. 589.