

# To disclose or not to disclose:

*A phenomenological and  
autoethnographic account  
of teaching while living  
with a hidden illness*

Kit Wyatt Perona-Wright

Oxford Brookes University

*This thesis is submitted in partial fulfilment  
of the requirement of the award of Doctor of  
Education (EdD)*

June 2023

# Table of Contents

|                                                                                   |       |
|-----------------------------------------------------------------------------------|-------|
| Acknowledgements                                                                  | p. 4  |
| Abstract                                                                          | p. 5  |
| 1. Introduction                                                                   | p. 7  |
| 1.1 Prologue                                                                      | p. 7  |
| 1.2 Research Questions                                                            | p. 7  |
| 1.3 Summary of thesis                                                             | p. 8  |
| 1.4 Who am I                                                                      | p. 9  |
| 1.5 Insider research                                                              | p. 9  |
| 2. Literature Review                                                              | p. 12 |
| 2.1 Introduction                                                                  | p. 12 |
| 2.2 The nature of teaching                                                        | p. 13 |
| 2.2.1 Being a teacher                                                             | p. 13 |
| 2.2.2 Perceptions of teachers and teaching                                        | p. 15 |
| 2.2.3 Teaching as a vocation                                                      | p. 17 |
| 2.3 Multiple Sclerosis (MS)                                                       | p. 19 |
| 2.4 Teaching with MS                                                              | p. 24 |
| 2.5 Disclosure                                                                    | p. 30 |
| 2.6 Disclosure in education                                                       | p. 35 |
| 2.7 Summary                                                                       | p. 36 |
| 3. Methodology and Methods                                                        | p. 38 |
| 3.1 Introduction                                                                  | p. 38 |
| 3.2 Personal assumptions/beliefs                                                  | p. 38 |
| 3.3 Qualitative inquiry                                                           | p. 43 |
| 3.4 Methodology                                                                   | p. 43 |
| 3.4.1 Phenomenology                                                               | p. 43 |
| 3.4.2 Autoethnography                                                             | p. 48 |
| 3.4.3 Bringing together Phenomenology and Autoethnography                         | p. 52 |
| 3.4.4 Considering alternative approaches                                          | p. 55 |
| 3.5 Methods                                                                       | p. 56 |
| 3.5.1 Choosing participants                                                       | p. 56 |
| 3.5.2 Data gathering (interviews)                                                 | p. 59 |
| 3.5.3 Data analysis and interpretation (Interpretative Phenomenological Analysis) | p. 60 |
| 3.6 Methodological issues                                                         | p. 64 |
| 3.6.1 Trustworthiness and validity                                                | p. 64 |
| 3.6.2 Ethics                                                                      | p. 67 |
| 3.7 Summary                                                                       | p. 71 |
| 4. The Past (Learning to live with MS)                                            | p. 72 |
| 4.1 Introduction                                                                  | p. 72 |
| 4.2 Themes                                                                        | p. 73 |
| 4.3 Participant Profiles                                                          | p. 75 |
| 4.3.1 Sally                                                                       | p. 75 |
| 4.3.2 Lucy                                                                        | p. 75 |
| 4.3.3 Emily                                                                       | p. 76 |
| 4.4 Initial symptoms                                                              | p. 76 |
| 4.5 Autoethnographic Analysis (Hidden symptoms)                                   | p. 81 |
| 4.6 Impact of diagnosis                                                           | p. 83 |

|                                                        |        |
|--------------------------------------------------------|--------|
| 4.7 Autoethnographic Analysis (Diagnosis)              | p. 86  |
| 4.8 Living with MS                                     | p. 90  |
| 4.9 Autoethnographic Analysis (Fatigue)                | p. 99  |
| 4.10 Summary                                           | p. 103 |
| 5. The Present (Learning my place in the world)        | p. 105 |
| 5.1 Disclosure issues                                  | p. 105 |
| 5.2 Autoethnographic Analysis (Disclosure/credibility) | p. 111 |
| 5.3 Relationships                                      | p. 113 |
| 5.4 Autoethnographic Analysis (Relationships and fear) | p. 122 |
| 5.5 Perception                                         | p. 124 |
| 5.6 Summary                                            | p. 132 |
| 6. The Future (Learning who I am to become)            | p. 134 |
| 6.1 Choice                                             | p. 134 |
| 6.2 Autoethnographic Analysis (Control/Choice)         | p. 140 |
| 6.3 Identity                                           | p. 142 |
| 6.4 Autoethnographic Analysis (Identity)               | p. 147 |
| 6.5 Compatibility of MS with teaching                  | p. 149 |
| 6.6 Autoethnographic Analysis (Career and future)      | p. 154 |
| 6.7 Summary                                            | p. 156 |
| 7. Conclusions                                         | p. 158 |
| 7.1 Reasons to disclose                                | p. 158 |
| 7.2 Who to disclose to                                 | p. 161 |
| 7.3 Reasons not to disclose                            | p. 165 |
| 7.4 Compatibility of teaching for a person with MS     | p. 168 |
| 7.5 Conclusions                                        | p. 171 |
| 7.6 Reflections on this study                          | p. 173 |
| 7.7 Limitations                                        | p. 174 |
| 7.8 Further work                                       | p. 175 |
| 7.9 Implications and practical meaning                 | p. 177 |
| Epilogue                                               | p. 179 |
| References                                             | p. 180 |
| Appendix 1: Phenomenology                              | p. 210 |
| Appendix 2: Participant Information Sheet              | p. 214 |
| Appendix 3: GDPR Privacy Consent Form                  | p. 216 |
| Appendix 4: Consent Form                               | p. 217 |
| Appendix 5: Example Transcript Extract                 | p. 218 |
| Appendix 6: Journal Entry (Hidden Symptoms)            | p. 219 |
| Appendix 7: Journal Entry (Diagnosis)                  | p. 221 |
| Appendix 8: Journal Entry (Fatigue)                    | p. 230 |
| Appendix 9: Journal Entry (Disclosure & Credibility)   | p. 233 |
| Appendix 10: Journal Entry (Relationships & Fear)      | p. 237 |
| Appendix 11: Journal Entry (Control/Choice)            | p. 239 |
| Appendix 12: Journal Entry (Identity)                  | p. 242 |
| Appendix 13: Journal Entry (Career & Future)           | p. 244 |

# Acknowledgements

I would like to express my grateful thanks and appreciation to a number of people, without whom this project would not have been realised.

First and foremost, the support, wisdom and patience from my supervision team of Dr Susannah Wright and Dr Patrick Alexander cannot be overstated enough. I am grateful to them both beyond measure. Mention should also go to Dr Ian Summerscales who, before starting his well-earned retirement, was also an integral part of the beginning of my doctoral journey, and he played a significant role in the direction this project has ultimately taken.

I was lucky to be in an EdD cohort of fellow students who have all shown great kindness, friendship and support to each other, and that network has provided endless support during the years of completion, including through COVID.

I am grateful to the research participants who gave of their time so generously and who saw the value in what I was trying to do with this deeply personal subject matter for us all.

I am also indebted to a number of friends and family members who have supported me throughout this doctorate in various ways: practical, financial and emotional.

Finally, I thank my wife and children for their patience and understanding during the significant period of all our lives that I have devoted to both study and writing. This is a project personal to all of us, not just me, and they are all entwined in every aspect of what is contained herein. Completing this project over these past few years has been time spent away from them all, and I hope that the finished product is worthy of their unfailing love and support.

# Abstract

Multiple Sclerosis (MS) affects more than 130,000 people in the UK (PHE, 2020). It is a degenerative disease of the central nervous system, currently without a cure, which can affect a wide range of physical and cognitive functions. Whilst there are many studies that explore the impact of the disease for those who have been diagnosed with MS, including the potential effect in the workplace and surrounding the issue of disclosure, there is a significant dearth of literature relating to how MS affects people specifically in the teaching profession.

The aim of this study is to explore teaching with a hidden illness – namely MS, and this was broken down into two main areas of focus: firstly, how compatible is having MS with being a member of the teaching profession, and secondly, what factors are considered when contemplating whether to disclose (or not).

The research was underpinned by combining a phenomenological mode of inquiry as outlined by Carel (2016) for semi-structured interviews with three teachers who have MS, and incorporating analytic autoethnography to draw upon my first-person narrative account of living and working as a teacher with MS, drawing on the work of Anderson (2006). The data from the participants was analysed using interpretative phenomenological analysis. By drawing upon my own first-person account of my lived experience alongside those of the participants, I make visible and analyse some of the invisible effects of living and working as a teacher with a chronic illness, such as MS.

Key themes were identified using a temporal lens of past, present, and future, and these cover initial symptoms, the impact of diagnosis and learning to live with MS, through to disclosure issues, relationships and perception, finishing with themes of choice, control and identity. The discussion surrounding these themes and influences highlighted potential issues with compatibility of MS for teachers, reasons for a teacher with MS to disclose, which include visibility of symptoms, the need for accommodations at work and the inability to maintain a current teaching role due to MS. There is a reluctance to disclose MS when the symptoms are (largely) hidden due to perceived negative reactions from colleagues or employers,

although it should be noted that this was not based on any actual experience of the participants nor myself. However, a sense of security is felt with selective disclosure of MS to close colleagues who are regarded as friends, even if employers are not informed, so that somebody is aware in the workplace should assistance or support be needed. A significant issue surrounding the reluctance to disclose is associated with the desire to maintain professional identity combined with the lack of awareness and understanding of the scope of MS by employers on the person diagnosed.

This study contributes to types of research that are purposefully transformational, in that it seeks to challenge both theory and practice, and contributes to the development of qualitative research methods using both phenomenology and autoethnography as different - but complementary - approaches. It has implications for people, like me, who are teaching with MS regarding considering disclosure, and for employers in the education sector regarding improving awareness and understanding of MS as an illness to be able to support staff who do choose to disclose.

# Chapter 1 | *Introduction*

## 1.1– Prologue

“I have MS and I didn’t tell anybody,” President Josiah Bartlet announced in the finale of Season 2 of the critically acclaimed NBC show *The West Wing*. Martin Sheen, playing the character of the fictional US President, must face a flood of questions from various quarters. His attorney is, understandably, deeply concerned that the President (as well as all the advisors, close aides and family members who knew) will ultimately be charged with fraud. There are then other staff members who were not party to the information about his condition who are feeling marginalised, misled and very uncertain. Everyone, including the President himself, is questioning his ability to be re-elected, and this is confirmed by a confidential poll taken stating that - had he initially disclosed his MS (multiple sclerosis) whilst running for office – he would not have been elected in the first place. Whilst this is a scenario from a fictional TV programme, albeit a very compelling one to watch, the issues are very real...

## 1.2– Research Questions

This research set out to examine the issues faced by teachers who have multiple sclerosis (MS) when deciding whether to disclose their illness or not. I have investigated the lived experience of three different teachers, all of whom live with a diagnosis of MS. I hoped to elicit responses regarding how having MS affects one’s ability to be an effective teacher, the reasons given as to why they have chosen to disclose (or not) their illness and – if it has occurred – what impact disclosure has had on their professional lives and careers. The two research questions I have explored are:

- How compatible is having MS with being a member of the teaching profession?
- What factors are considered when contemplating whether to disclose (or not)?

By utilising interviews with the participants discussing their MS and its compatibility with their role as a teacher, I sought to enrich and deepen my own understanding of what it is like for others to teach, and live with, this illness. I also hoped this research would be of value both to the participants as well as those who would read it. I encouraged sharing and allowing personal expression between the participants and myself in a mutually supportive context in the hope that meaning and value would be the outcome from this project. By working together, as researcher and the researched, the contribution of the participants and I can positively contribute to the lives and careers of other teachers who live and work with MS. Through use of autoethnography, my own personal voice will also strengthen the understanding of others in a similar situation.

### **1.3 – Summary of thesis**

Following this introductory chapter, there are six further chapters. In the literature review (Chapter 2), existing studies examining the nature of teaching, MS as an illness, and the compatibility of MS with teaching and employment are all explored. The following chapter (Chapter 3) outlines both the methodologies and methods employed in this project alongside the use of Interpretative Phenomenological Analysis as the means to explore the data. It also includes the argument for utilising and combining both phenomenology and autoethnography in the research design. The findings are then divided up into three separate chapters (Chapters 4, 5 and 6) based on temporal themes of past, present and future. Chapter 4 discusses the initial symptoms experienced by the participants, along with the impact of diagnosis and the experience of living with MS. Chapter 5 focuses on the issues of disclosure, relationships and perception, and Chapter 6 explores identity, choice and the compatibility of MS with teaching. The final chapter (Chapter 7) concludes this thesis by discussing the findings in relation to the research questions posed above and considers implications, next steps and a reflection on this study.

## 1.4– Who am I?

*“Once again I stand at the gate that is ajar. Now that my life has followed the course of the winding arabesque, I find myself once more at the place where I started.”*

(Shammas, 1988, p.226)

In the biographical narrative ‘Arabesque’ Shammas (1988) finds himself back to the place where his journey began. The story tells of his travels and the people he meets along the way. I, too, use the journey metaphor often. I use it naturally, but often unintentionally, to reflect the story and ongoing narrative of my life; whether in my career (as a senior leader in a leading UK private school, a Chair of Governors at a local primary school, a Fellow of the Chartered College of Teaching or a School Inspector), in my personal life (as a husband and father of two) or in my wider professional life (a researcher studying for a part-time Doctorate in Education). My life is undoubtedly following ‘the course of the winding arabesque’ with its intricate and complex patterns of vines and leaves, and yet as a researcher standing on the brink of completing my thesis, I also feel that I have not gone very far from ‘the place where I started’. There is no easy route. No obvious path to follow. The idea of a life journey taking place throughout temporal realms is one that I have used within this project to frame the analysis of the data to help provide a degree of clarity for myself and the reader. However, Van Manen (1990) writes of the entire process of research that “things turn very fuzzy just when they seem to become so clear” (p.41). This is also true for me since in the midst of studying for my doctorate, of negotiating a busy and demanding career, in pursuing professional ambitions and goals and of attempting to be a good husband and father, I am also consigned to living with an illness. Not just any illness, but a chronic, hidden, degenerative illness: multiple sclerosis (MS).

## 1.5 – Insider Research

As to why I, personally, chose to enter the world of education and this profession called teaching, it is the possibility for personal transformation that excites me, “the prospect that I will find another way to see into the world, glimpse its beauty,

reconstruct it in a way not yet known to me” (Liston, 2004, p.469). A cliché it may well be, but I feel so privileged to be able to teach young people. Whilst I also feel that it is an awesome responsibility, I personally feel there is no greater honour than to be entrusted to attempt to inspire and impart knowledge and wisdom to the next generation. In an interview for Headship recently, I was asked by a group of pupils on their School Council what my personal educational philosophy was. My reply was taken from Paulo Friere in his *Pedagogy of Hope* (1992), and I said that ‘the highest goal of education is to teach people to “read and write the word” so that they can eventually “re-read and re-write the world”’. Ultimately, if I do my job correctly, then the generation that follows will have the capacity to change the world for the better. This echoes Dewey’s statement some decades earlier that education “*has the power to modify the social order*” (Dewey, 1909, p.7). That is what excites me. That is what gives me passion for my profession despite all the demands and challenges that come with it. Whether that desire is compatible with living with MS, I am genuinely not sure. It is that which I explored after being introduced to the works of Havi Carel (2008 and 2016), an author who writes about illness and illness through a phenomenological lens, which both resonated with me and fuelled my interest in this project and the methodological framework behind it.

I am an aspirant Headteacher. Whilst I am under no legal obligation to disclose my MS to anyone at any time if it does not affect my ability to do my job, least of all an employer (or potential employer), I often question whether it is incumbent upon me to let someone know at some point. I do not yet have an answer to this. This is not an illness that I am yet to receive a diagnosis for (like someone discovering they have cancer), but one that I already know I have. It is one that is degenerative by its very nature, and I do not know how it will affect me in the future or when symptoms may progressively worsen. Is it only right and fair that I inform a future, or potential, employer of this fact when I apply for a job? It is this issue, and those surrounding my experience (current and ongoing) as a teacher with MS, that has driven my interest in researching the topic. As outlined in Chapter 2, existing research examines MS as an illness (including symptoms, diagnosis, living with the condition, MS in the workplace) by authors such as Vickers (1997), Grytten & Maseide (2005) and Cosh & Carslaw (2014), and also disclosure of illness (such as

the effect in the workplace and on employment) by authors such as Rao et al. (1991), Benedict et al. (2005) and Frndak et al. (2015). However, there is no significant body of research that marries the two issues together specifically for teachers. I cannot locate research that shines a light on the issue of MS within the teaching profession, beyond a Canadian doctoral thesis by Katie Flockhart (2001) discussing how teachers with MS can improve their wellbeing and remain in the profession, or any research regarding what the impact is for those living with the illness and why they chose to disclose (or not). This significant gap in knowledge and research has afforded me the opportunity to make an original contribution to an area of research that is valuable for academics and professionals alike. I acknowledge that the challenges of MS are not unique to education and a school environment. However, as I explore in the project, the conditions for teachers and school leaders are particularly acute due to the physical and cognitive nature of the profession, and this research will add to the existing literature by focusing on how these aspects of MS contribute towards the decision to disclose (or not).

## Chapter 2 | *Literature Review*

### 2.1 – Introduction

This chapter contextualises the study by examining the relevant literature surrounding the topics of teaching, multiple sclerosis (MS), employment and disclosure using a multidisciplinary approach. Firstly, I explore existing research about the nature of teaching and what it means to be a part of the teaching profession on a practical level, which provides the opportunity for reflection on teaching with an illness later in the chapter. Secondly, I outline the facts and features of MS as a chronic disease, noting the challenges associated with this condition. Thirdly, I reflect on the compatibility of living with MS for those in the teaching profession. Finally, I look at the issue of disclosure of illness, noting that whilst there has been considerable sociological research into living with chronic illnesses (including MS), research into disclosure in the context of teaching is arguably limited in comparison. Drawing these various aspects of the literature together in the final section, the argument is presented for further research into how disclosure is managed by those teachers who live and work with MS.

It is worth noting at this stage that there is a significant gap in the literature surrounding the specific issue of illness disclosure for those who work in the teaching profession in addition to gaps with the subject of ableism (Williams 2000, Ball 2021, Lyn 2021) in education. For example, much of the literature is focused on student experiences rather than the experience of teachers (Hehir, 2002), and certainly not on the experience of those with chronic illness. I have included older, established texts alongside more recent research to supplement the sparse literature in some areas of the review. My hope is that this research project will provide a much needed, valuable contribution to the literature.

## **2.2 – The nature of teaching**

In this section of the literature review I seek to critique the practical role that a teacher in a school environment plays in terms of tasks and workload, alongside examining broader perspectives on the nature of teaching in cultural, public and political discourse. This gives an insight into the perception of teaching held by the participants and me. This is important to attempt to define in relation to how compatible the role is with a disease, such as MS, aspects of which may restrict the ability to fulfil those very tasks and workload. These restrictions may, in turn, lead to disclosure out of necessity. Because the role of the teacher has evolved over time with ever-increasing pressures on those in the teaching profession from government and policy makers (Coe et al. 2014, Towers et al. 2022), I am purposefully reviewing a variety of literature which contains historical and philosophical perspectives about the nature of teaching.

### **2.2.1 - Being a teacher**

A teacher's own expectation about what it means to be a teacher is influenced by their own experience (Samuel and Stephens, 2000). This will include their own time spent in education as well as time spent training to be a teacher, and all of this contributes to building their own sense of professional identity (Rodrigues et al. 2018). Fullan (1993) outlines that any teacher is required to have soft skills such as a developed personal vision, to be mature and to be able to collaborate with others, whereas Day et al. (2006) suggest that the perception of the teaching role is usually associated with the tasks they undertake. In my personal experience, it is a combination of both, as collaboration and maturity of thought are important for a teacher whether in their own classroom, department or school community, whereas task-specific activities will clearly shape their perception of a particular role. A widely accepted view of the starting point for any teacher role is the requirement of the strength of their subject knowledge (Day et al. 2007). Radovan (2011) adds to this the need for teachers to have a competence in the use of information technology (IT) so they can create a learning environment in the classroom that supports pupils through visual displays and the use of technology. The knowledge needed by a teacher is wide-ranging, and according to Lachner et

al. (2016) can be broken down into three separate spheres. The first is, as referenced above, a deep knowledge of their subject, understanding the various concepts and principles that form that particular discipline. This might refer to a single, specific subject at secondary school level as is the case for me, or the broader, general subject teaching expected at primary school level as is the case for the three participants. The second is a more general, pedagogical knowledge about learning itself. This will include teaching methods and strategies and understanding how learners learn. The final sphere is more to do with the context of transmitting knowledge to the pupils and the art of explaining content to a varied group of young people of mixed ability. Korthagan (2004) adds to these requirements about knowledge by outlining the core personal traits that are also important for a teacher, namely creativity, trust, care, courage, sensitivity, decisiveness, spontaneity, commitment, and flexibility.

There is a long-standing debate about teaching as a technical or practical skill, but also as a process of phronesis or wisdom borne out of experience (Biesta, 2013). For example, Stenhouse (1983) advocated teachers utilising educational research to develop thoughtful reflection in order to strengthen their professional judgement (p.192), and this is seen in the creation of modern-day organisations to support the profession such as the Chartered College of Teaching, which makes current educational research available to all its members. However, Oancea & Furlong (2007) warn about a lack of clear criteria for assessing practitioner research in education and go on to present a framework of four dimensions through which meaningful evaluation of research can take place. More recently, Burn et al. (2022) outline the recent tensions created by a performative culture that pervades the UK education system, but they suggest that engaging with research through practical theorising and investigating a range of tools developed by other educators could aid beginner teachers.

However, some authors (Au, 2010, White, 2011) argue that critical thinking is not a desirable trait within the teaching profession. They argue that the job of a teacher is to be a skilled technician, able to deliver a prescribed curriculum that has been drawn up by others, and that there is little – if any – autonomy to be found in the classroom for the teacher at all as a result. However, when one reads the following

*“range of actions”* that make up the nature of teaching as suggested by Ayres (2011), it seems impossible to imagine that criticality is not deeply embedded within all members of the teaching profession: *“questioning, instructing, advising, counselling, organising, assessing, guiding, goading, showing, managing, modelling, coaching, disciplining, prodding, preaching, persuading, proselytizing, listening, interacting, nursing, doing and making, discovering and inspiring”* (p.17). To do all these things, a teacher would need to be what Labaree (2010) terms *“the expert ecologist of her classroom”* (p.157). Knowledge has to be gained and understood by a teacher to be able to transmit back to the pupils, but a teacher can only learn so much from reading books about teaching. Teachers need judgement, which mainly comes from experience, as well as technical skill (Field and Latta, 2001). A teacher is more than the thing they do (Coe et al. 2014). They are the teaching (Aoki, 1992, p.30).

### **2.2.2 - Perception of teachers and teaching**

Public debate and news sources suggest that the demands and complexities of the role are not always recognised. In Mockler’s (2022) exploration of print media discourses surrounding teachers and their work, one example extract from a journalist writing in 2020 cites the quality of teachers as the problem in education: *“It’s not that our schools are under-staffed or under-funded or under-equipped...yet despite the record billions being thrown at the problem, we are going backwards on almost every measure against our international competitors. And it is hardly surprising when you consider who is teaching our children ...academically deficient teachers lead to inadequately educated young adults.”* (p.16)

The nature of discussions surrounding teachers and teaching in the public arena clearly has an impact on the way that the wider public views teachers and shapes opinions of what they do and why they do it (Mockler, 2022). Teachers are often confronted with numerous changes to, and a variety of external influences within, their profession. These forces, political or public, can often prove a source of stress and anxiety for all educators, whether in leadership or the classroom. According to Fullan (1991, p.117), *“The conditions of teaching appear to have deteriorated over*

*the past two decades; it is a fact that teachers have become devalued by the community; teacher stress and alienation from the profession are at an all-time high”.*

It is ironic, and perhaps a little saddening, to read that analysis from Fullan written 30 years ago, since only a cursory search on the internet seeking clarification of current teacher satisfaction in the UK brings a large number of results all stating worryingly similar sentiments. For example, one article from The Guardian newspaper referred to the OECD (Organisation for Economic Co-operation and Development) survey in 2019 which is carried out every six years collecting data from teachers in 48 different countries around the world about all aspects of the profession. The headline read ‘*Teachers in England have an ‘unmanageable’ job*’ (Adams, 2019), with Mary Bousted, Joint General Secretary of the National Education Union, also saying the survey of 4,300 teachers at 300 schools revealed a demoralised workforce: “The findings should act as a wake-up call for any future prime minister. The government must end teachers’ unsustainable workload by tackling the high-stakes school accountability system which is fuelling the long hours culture and driving teachers out of the profession,” ([www.theguardian.com](http://www.theguardian.com) 19/06/19). What is interesting to note, looking at the data from the survey, is that the amount of time given to teacher training in the UK is high compared to many other participating countries. However, the amount of time expected to complete various aspects of the job and development once in post is comparatively low. Thus the initial training is not matched with sufficient time or continuous development once a teacher starts in their career in the UK, contributing to job dissatisfaction and poor retention.

Due to an issue of time poverty in the professional lives of most teachers, Campbell and Neill (1994) carried out research into the nature of primary teachers’ work, and this included breaking down the amount of time spent on various activities. Whilst their research is now a little dated, their findings detailing time spent on enactive teaching, preparation, marking, administration, and professional development gave rise to the view that primary teaching was not just a ‘9am-3.30pm’ profession. Gicheva (2022) also highlights the disparity of what is and is not ‘seen’ by the public of tasks undertaken by teachers, in her study of the burnout caused by the long

hours required to fulfil the role of a classroom teacher. The reality is, therefore, very different to the perception, with long days necessary to complete all the marking and preparation, and time spent during holiday periods planning for the following term in school. In a recent study by Allen (2019), it was found that one in four teachers are working at least a 60-hour week. Stamina is clearly an unspoken requirement as evidenced in the Government's own OFSTED (Office for Standards in Education and Children's Services) research report into teacher well-being in 2019, which noted that: "...despite the positive feelings towards teaching as a vocation and towards their workplace, many teachers believe that the advantages of their profession do not outweigh the disadvantages....teachers are suffering from high workloads, lack of work-life balance...they sometimes feel the profession does not receive the respect it deserves. All these negative feelings in turn may lead to higher levels of sickness absence." (p.5)

### **2.2.3 - Teaching as a vocation**

Yet despite the challenges outlined above, people are drawn to the profession of teaching and the world of education. *Primary Teachers Talking* (1989) was a study undertaken by Jennifer Nias in the UK which identified various positive aspects of teaching. Support given by colleagues, whether via advice, assistance or guidance was seen to be a significant feature of the work life of a teacher on both a practical and an emotional level (p.135). It also suggested that people who entered the teaching profession were often provided with a sense of achievement, fulfilment, and purpose: "*The resulting sense of equilibrium may account for why they feel 'whole' and 'in control'*" (p.199). As outlined by Schwehn (2001), teaching is more of a vocation than a profession due to being recognised as an activity which enriches all human lives. Teachers are expected to educate "*the whole child*" (p.397), and it is this holistic overview which requires such a wide-ranging set of skills and knowledge from a teacher as well as a sense of dedication and virtue in the role they are fulfilling (Metcalf, 2013). These suggestions about motivation to join and remain in the teaching profession due to it being considered more of a vocation are reinforced by a recent study by Onyefulu et al. (2022) which found that throughout all phases of a teaching career, teachers felt a strong sense of vocation and a passion for teaching, with a deep desire to make a positive difference in students' lives.

There are those, such as Muijs and Reynolds (2001) who consider the subject of teaching to be a science – a technical approach to learning that you can essentially measure (through outcomes for children) and therefore analyse which teaching methods are the most effective. This view would concur with the current UK government's utilisation of, and reliance on, standardised testing through National Curriculum (SATs) tests during primary school from the age of 4 years old. Others, such as Marland (1975), Labaree (2000) and Goodwin et al. (2014) would describe teaching as much more of a craft than a science. They view the craft of teaching as a set of skills that can be taught, learnt and honed over a period of time. Biesta (2007) takes this further by arguing that restrictions are placed on the development of teaching as a research-informed profession through over-reliance on politically motivated, scientific control. Biesta (2013) goes on to argue that teaching should not be reduced just to a technical process of delivering predetermined content and skills. Rather, he suggests that teaching is fundamentally an ethical and relational practice, which involves the formation of human beings through a process of "qualification, socialisation, and subjectification" (p.25). Qualification, for Biesta, refers to the development of knowledge and skills, socialisation involves the incorporation of individuals into social and cultural practices, and subjectification relates to the process of becoming a subject who is capable of independent thought and action. These three dimensions of teaching are intertwined and should be considered together in order to fully appreciate the nature and purpose of teaching.

There are others yet still that view teaching as more of an art form. Eisner (1979) describes teaching as an activity which is both creative and complex. He comments that we need to "recognise the contingent nature of educational practice, to savour its complexity, and to be unafraid to use whatever artistry we can master to deal with its problems" (p.33). In the Government's own words; "Teaching involves a lot more than care, mutual respect and well-placed optimism. It demands knowledge and practical skills; the ability to make informed judgements, and to balance pressures and challenges; practice and creativity; interest and effort, as well as an understanding of how children learn and develop." (Department for Education, 2002: p.4).

In order to elicit the view of children themselves regarding what they seek in teachers, the Cambridge Review (2010) asked pupils that exact question, and good teachers were described in the following terms:

- *Make learning fun*
- *Know everyone's names*
- *Explain things clearly so that you understand*
- *Know their 'stuff'*
- *Give you a record of what you learn*
- *Have lots of energy and enthusiasm*

(Alexander, 2010. p.148)

It is that final bullet point that is often cited by children and staff themselves that I will return to during this thesis. A number of research studies have examined this particular teaching trait, although they vary in the terminology used. Patrick et al. (2000) along with Kunter & Holzberger (2014) describe it as 'enthusiasm'. Serin (2017) uses the word 'passion', and Holley-Boen (2018) says it is 'stamina' that is required. As outlined earlier in this section, teachers work long hours and are often physically on their feet all day (either in front of a classroom of children directing their learning or moving around the space supporting on a more individual level). Is the perception of this aspect of the nature of teaching, in fact, a reality? Is it central to the identity or efficacy of a teacher? Does that make a career as a teacher compatible with having an illness such as MS? This thesis intends to interrogate these assumptions by examining the perspectives of teachers themselves, and lend an original contribution to our understanding of how expectations of teacher identity and practice are affected by living and working with MS.

## **2.3 – Multiple Sclerosis (MS)**

It is important to offer a detailed overview of MS as an illness, so that the context of teachers living and working with it can be better understood. Chronic illnesses are prolonged, do not resolve easily or by themselves, and they are rarely completely cured (Dowrick et al. 2005). The most common amongst them are forms of cardiovascular disease, forms of arthritis, respiratory problems, diabetes,

epilepsy, some forms of cancer and multiple sclerosis. Misconceptions surrounding multiple sclerosis (MS) are frequently fuelled by high-profile cases in the media. An internet search for 'MS' comes up with listings such as *"James Catmer on why he wants to take control if he faces a prolonged death from MS"*, *"It was a death that came as a relief to 65-year old Andrew, who suffered from 25 years of MS"* and *"Bury mum-of-three battling MS takes own life at Dignitas"* (Google search completed on 10/7/22). It is widely seen as a death sentence and is associated with pain, disfunction and misery. Perception portrayed in the public eye, as outlined above, is severe disability and the prognosis of someone most likely in a wheelchair. Whilst this is most certainly true for some, for the majority that is not actually the case.

MS affects in the region of 130,000 people in the UK ([www.mssociety.org.uk](http://www.mssociety.org.uk)), and is a chronic, progressive, autoimmune disease which impacts the neurological system. According to Cosh et al. (2014), in the UK most people are diagnosed between the age of 30 and 50 but they will experience symptoms years earlier. It also affects three times as many women as men (Mackenzie et al. 2013). The condition involves the myelin sheath, a coating surrounding and protecting the nerve fibres in the central nervous system, becoming damaged. For people with MS, it is believed that the body's own immune system attacks the myelin and when it heals it leaves lesions or scars (*sclerosis*). These damaged areas (lesions) of the myelin can be found anywhere on the central nervous system, including the brain and the spinal cord. Because the scope of physiological, functional, and psychological symptoms connected to the central nervous system is so wide, diagnosis can take months and even years (Fleming et al. 2010). A variety of tests are completed to rule out other likely causes for any initial symptoms (Solomon et al. 2012), and these will include blood tests (checking for various antibodies), inner ear checking (if balance problems are a symptom), Evoked Potential Tests (small electrodes placed on the head to see how the brain responds to sensations around the body, sight and sound), lumbar puncture/spinal tap (to extract fluid from your spinal cord to test for a particular antibody associated with MS) and MRI (magnetic resonance imaging) scans.

Any part of the central nervous system can be affected by the lesions caused by MS, and given the control this has over the vast majority of functions within our body and brain, the symptoms can be very varied from one person with MS to the next (Hutchinson, 2012). Common symptoms include loss of feeling in limbs, muscle weakness, fatigue, muscle pain, problems with mobility, bladder and bowel problems, visual impairment, tremors, loss of cognitive function (problems with memory and the ability to think clearly) and sexual dysfunction. There are four main types of MS: benign, relapsing-remitting, secondary progressive and primary progressive. People with benign MS often experience few or no symptoms or impairment from the disease at all. According to the MS Society (all figures from [www.mssociety.org.uk](http://www.mssociety.org.uk)), somewhere in the region of 85% of people with MS in the UK are diagnosed with the next category: relapsing-remitting MS. This is characterised by 'episodes' or 'relapses' where patients experience a period of symptom appearance which is then followed by partial or full recovery. These relapses can last a few days, weeks or even months. MS is a degenerative illness and, as a result, 65% of people with relapsing-remitting MS go on to develop the next stage of the disease – secondary progressive. Anyone diagnosed with this type of MS will experience near constant impairment or disability to a varying degree. The final, most severe form of MS – primary progressive – only affects in the region of 10% of all MS sufferers and is most likely to be the category that the people from the internet search above fall into. This brings with it significant impairment and disability and is characterised by a gradual worsening of symptoms over time with no return to full functionality for the sufferer. The speed of any disease progression will vary significantly from one patient to another, and even if the same MS type is shared by separate people, it is highly unlikely that they will experience the same symptoms in the same way.

MS is not curable. Because of the many symptoms there are and the different effects they have on different people with MS (Alonso et al. 2008), there are several options for treatment. These various types of disease modifying therapies (DMTs) can both reduce the number and frequency of the relapses suffered and slow down the progression of the disease as well ([www.mssociety.org.uk](http://www.mssociety.org.uk)). They range from taking a course of daily tablets, to giving yourself a weekly injection, through to a new treatment (Ocrevus) that is given as an infusion once every six months.

According to Jick, et al (2014) who carried out a cohort study of MS patients in the UK primary care system, fatigue is the single biggest issue for all people suffering with MS and it affects over 90% of those diagnosed with the condition. It is such an issue due to the fact it is different from merely feeling tired, as can be the case for everybody depending on lifestyle choices. Fatigue caused by MS leaves a person completely devoid of any energy, tired all over and often with a feeling of general weakness. Its frequency, level of intensity and rapid nature of onset can be debilitating. Fundamental assessments of the symptoms and their triggers have not changed markedly for the last few decades, and Burnfield (2003) explains that fatigue as a symptom of MS can be triggered by a variety of environmental or psychological factors as well, and these include stress, heat, over-exertion and depression. As further outlined by Dyck & Jongbloed (2000) in their study of MS and employment issues, unless this type of fatigue is more widely understood in a professional setting by colleagues, then anyone suffering from MS may be deemed to be either lazy, demotivated or battling with psychological problems (p.342).

In addition to fatigue, vision and speech problems will affect approximately half of all those with MS at some point from being diagnosed. Schapiro (2006) states that common issues with vision include Optic Neuritis (inflammation of the optic nerve) and blurred or double vision, and issues with speech include Dysarthria. This condition impacts the clarity of vocal output to the point where it can sound to the listener like slurred, deliberate speech. Schapiro (2006) also outlines that, whilst pain is not necessarily a primary symptom of MS, most patients who suffer from MS will experience a degree of pain and up to 15% of people will have to live with chronic pain as one of their symptoms. The type of pain is often described by patients as a deep aching, or burning sensation, or extreme pressure on parts of their body.

Regarding cognitive issues caused by MS, Schulz et. al (2006), note that memory recall, or short-term memory problems are the most frequently reported issues of impairment by patients. They state that, whilst more research is being conducted all the time into adverse effects of MS, it is highly likely that a wider variety of cognitive issues are affected by having MS, and these include problem-solving ability, reasoning skills, verbal fluency, and the ability to process information

quickly. Rao et. al (1992) reveal that emotional reactions will be like those encountered by people that suffer from other chronic illnesses. These are likely to include depression, but also fear of the unknown (pain or worsening conditions), grief (through loss of function), a reduced sense of self-worth and guilt (through reduced ability to perform social or practical tasks).

Multiple studies highlight the commonality of negative emotional reactions for patients being diagnosed with MS (Dilorenzo, 2008, Lexwell, et al, 2011, McCabe, et al, 2004). A quantitative study by Pakenham (2007) which incorporated findings from over 500 participants suggested that a positive mental outlook in their situation for patients with MS allowed them to more easily live with the condition due to the psychological adjustment they had made for themselves. Having a positive mental outlook as a coping strategy for a person diagnosed with MS is affected by the extent to which physical symptoms affect a person's disability. Pakenham's (1999) earlier study suggested that a lower level of physical disability led to a patient's greater ability to psychologically adjust to living with their MS. McCabe, et al (2004) found gendered differences to the mental adaptation and outlook on life when living with MS. Women seemed more likely to seek support and to utilise emotional coping strategies than men, and the study went on to conclude that a balance between increased problem focused coping strategies more often employed by men with MS and the development of social support strategies more often employed by women with MS, would be of the greatest benefit to a patient with MS regardless of gender. My research project does not seek to explore the differences between gender when considering MS disclosure, but it may naturally feature as part of the findings in relation to actions taken by participants.

Along with all the symptoms outlined above, other symptoms include bowel and bladder issues (increasing the frequency of needing the toilet, or having to use a catheter), problems with sexual function and balance (Ratchford et al. 2008). Whilst the range of MS symptoms outlined above – including physical, emotional, and cognitive – will vary from person to person in terms of frequency and severity, the vast majority are often hidden symptoms. It is entirely possible, then, to have some or all of the symptoms to varying degrees, but so that no one other than the

person living with them would know. There are more severe symptoms involving tremors, coordination, limb function and paralysis which make the condition impossible to hide, but most of the symptoms are, and can be, hidden. My own symptoms certainly are, and people express surprise if I choose to disclose my condition to them because they have no idea. Why would they? However, whether they then choose to ask about its wider effects on me or not, I perceive a myriad of subconscious questions silently whizzing around in their heads about it and what it really means. As a result, with colleagues or others on a professional level, I personally find it easier simply not to disclose. This is the case with two out of the three research participants who also have hidden symptoms, whilst the third participant discloses due to being in a wheelchair.

## 2.4 – Teaching with MS

Long-term conditions, such as MS, are often extremely challenging in nature because of the fact they are not able to be ‘cured’. As a result, the illness will then continue to feature as part of a person’s existence (Gabe et al. 2004). As Holman and Lorig (2000) state; *“With chronic disease, the patient’s life is irreversibly changed”* (p.527), and so for a teacher with MS whether your symptoms are visible or hidden, the focus shifts away from attempting to ‘cure’ the illness to learning how to manage it on a day-to-day basis. The Equality Act (2010) provides protection for people in the UK who have been diagnosed with a variety of conditions, including MS, when seeking employment, going through an interview process or currently in employment. When diagnosed, a person is under no legal obligation to disclose they have MS to an employer – that choice is theirs ([www.mssociety.org.uk](http://www.mssociety.org.uk)). There are a few exceptions, however, and these include if you work in the Armed Forces, if you drive for a living, or if it will affect the health and safety of you (or others) at work. There may be an argument to question why teaching, with its emphasis in the teaching standards on the safeguarding and wellbeing of the pupils and young people in their care (DfE, 2011), is not included in that list requiring disclosure of MS from a health and safety perspective. However, as outlined by Day & Gu (2007) and Huberman (1993), the exact tasks required to be carried out by a teacher will vary depending on the role they fulfil. This may be as a class teacher, a cover teacher, it may be part or full-time, the

subject specific nature of their teaching may be more active and practically orientated than a different subject (Physical Education as opposed to teaching English, for example), and the school setting and phase may be different too (for example, Early Years, Primary, Secondary, Further Education and so on). Therefore, with so many variables to consider, the health and safety implications of disclosure arguably differ to the extent that they could not be governed by a requirement for all teachers with MS to disclose to their employer.

Despite this disability legislation existing to protect employees, the wide-ranging nature of the demands placed on those in the teaching profession (as outlined above at the start of this chapter) mean that the challenges faced by teachers living with a chronic disability are considerable. Teachers are often confronted with a huge variety of changes that they must learn to cope with within their profession. These can come from a variety of directions and sources, usually external through public or political interests (Hargreaves, 2000), but these are changes that often cannot be planned or legislated for on an individual level and which can be the cause of much stress and anxiety. As Ball and Goodson (1985) state: *“Any attempt to portray the contemporary situation of teachers’ work and teachers’ careers must inevitably recognize the changing context within which this work is undertaken, and careers constructed. Changes in the financing of education, in the degree of political intervention into school matters, and in the views of and general level of esteem for teachers held within the public at large, have, and are having profound effects upon the ways that teachers experience their jobs.”* (p.2). For a teacher also living (and working) with a disability like MS, these constant external changes that demand flexibility and adaptability from both individuals and the profession at large can often be more difficult to fulfil and cater for due to symptoms such as fatigue or cognitive impairment.

Reflecting on the breadth of skills needed and demands made on teachers in sections 2.2 - 2.2.3, it is no wonder that any teacher who enters the profession with MS or any chronic illness will have an even greater adjustment to make. Gerber (1992), outlines that any new teacher starts out in the profession with a *“plethora of items on their professional agenda, instructional and behaviour management systems to develop, pedagogical skills to refine, and accountability and evaluation*

*procedures to master*” (p.213). Therefore, on top of these significant demands for any new teacher, someone that is entering the profession with MS – hidden or otherwise – is likely to be continually wondering what impact their illness will have on them, and not just year to year, but from day to day and lesson to lesson. According to Craig et al. (2012) new staff feel under immense pressure to conform to what they perceive to be an effective teacher, utilising all the traits outlined in the section above that they have learned during their initial training. Also, as Reisner (1990) describes, it is often the attitudes amongst staff in the Common Room that do not always allow for, or accommodate, individual differences or underperformance. It is this innate vulnerability of a teacher with MS making the decision not to disclose their hidden MS, particularly in the potentially unforgiving environment of a staff common room that does not allow for differences (Reisner 1990), that leads to a fear of failure and the desire to avoid prejudice (Gerber, 1992). Ball (2018) has more recently reinforced this idea of potentially unhealthy competition between individual teachers, as well as schools, due to the embedded nature of our education testing systems, performance-related pay and league tables. In his 2021 article, Ball goes as far as arguing ‘against’ the traditional model of the European school as an institution due to the embedded nature of “*universal normalisation*” (p.985) which occurs. This, in turn, leads to an “*unhealthy production of inequalities and isolated individuals*” (p.985) in a non-inclusive environment. Where I agree with his view is that, through a neoliberal lens, teaching can certainly be seen as a profession which encompasses competition and the labelling of success and failure for both teachers and students alike. Linked to this is what it means to be ‘normal’ through achievement, the reverse being deviation from that normality for those who do not achieve. Lyn (2021) in his doctoral thesis studying the discourse encountered by disabled teachers within schools argues that “*schools as disciplinary institutions are constrained to operate through normalising discourses*” (p.3) which constrain all teachers (especially those that are disabled).

However, there is an argument to be made that, particularly as equality, diversity and inclusion assume ever-increasing importance in the general workplace (Rao et al. 2016, Katmon et al. 2019, Peng et al. 2022) teachers within the education workforce who have a chronic illness will become a valuable role model for their

students. According to Weimer et al. (2022), it is these individuals who are most likely to add a unique perspective of diversity, providing an example to students of how to integrate themselves fully into society despite their illness. Recent studies have highlighted the importance of incorporating diverse perspectives into teacher training, including culturally responsive and inclusive practices, to help teachers develop a strong professional identity that fosters equitable and inclusive classrooms. For example, in a study by Smith & Lambeth (2016), findings indicate that American student teachers who participated in coursework focused on culturally responsive pedagogy demonstrated increased self-efficacy and a deeper understanding of their role in promoting social justice in education.

Whilst it does not specifically outline the issue of teaching whilst having MS, there is literature available which focuses on teachers' professional identity which outlines the inextricable relationship between the lives of teachers and their teaching experiences (Meijer et al. 2009, Kissling, 2014). Kissling (2014) describes these experiences of teachers as *"themes across a subset of the experiences of a person's life"* (p.83), and these themes shape future learning and teaching. Overcoming the adversity of living and working with MS as a teacher is potentially one such experience and the more teachers there are who live and work with a chronic illness, the more their colleagues, as well as students, will have an understanding of any limitations that exist as a result of the condition, and whether they really matter or not. According to Munir et al. (2005): *"disclosing an illness may elicit social support from colleagues and line managers by increasing their understanding of the effects of the illness"* (p.1398), but that – of course – relies on disclosure occurring in the first place.

Kolleck et al. (2021) researched teacher collaboration and trust relationships between teacher teams. The results outlined that teachers that involve themselves to a greater degree in collaborative working with colleagues were perceived as more trustworthy and others related more positively to them as a result. In my own experience, a teacher with MS that has chosen not to disclose yet may isolate themselves as a protective measure which could affect ongoing relationships with colleagues. It is the interpersonal nature of teaching – the relationships that are built between teacher and pupil, and between teaching colleagues – that is also

affected by having a chronic illness such as MS. Teaching itself requires an emotional involvement with others (pupils and staff) due to this relationality (Loh and Liew, 2016), and given that teachers are often expected to manage their own personal emotions while also having the ability to influence the emotions of others (Kinman et al. 2016), negotiating additional emotions caused by managing chronic illness is a significant added burden. It is this social aspect of living and working with MS that is just as important to consider as with the medical challenges (Strauss, 1975), and the issue of personal and professional relationships of the participants is discussed in Chapter 5.

Multiple studies have illustrated the impact of living with a chronic illness that affects a person's ability to partake in normal, day-to-day activities which often contributes to also having a negative effect on their overall sense of identity (Charmaz, 1991, Bury, 1991). The inherent unpredictability surrounding the often-changing symptoms for a person with MS, both the nature of the symptoms and how long they may last and have an effect, inevitably limits the activities that individual may want or need to undertake. This, in turn, has the potential to influence the relationships in their personal and professional lives if the inability to partake in any expected activities is misunderstood (or not even known, due to hidden symptoms) by colleagues, family or friends. Radley (1989) describes this as *"the unpredictable yet pressing demands of the body which dictate the terms in which that day shall be lived and personal relationships engaged in"* (p.232). In other words, it means as a teacher you are required to do practical and often, physical, tasks as part of your job. Therefore, your ability to fulfil these tasks will have an impact on the personal and professional relationships with those around you about how you are viewed and regarded.

As explained in two seminal works examining the role of chronic illness and identity from the 1980s, it is these limitations placed on a person with MS which can lead to a change in how they view themselves and their efficacy in their chosen profession. According to Charmaz (1983), it is living with pain and uncertainty, and the impact it has on a person's ability to fully participate in day-to-day activities expected of them, that creates a type of "suffering" and a sense of "being a burden" to others around them. Having a chronic condition such as MS, changes the whole

context of a person's life, not just from a medical point of view, something Bury (1982) describes as "biographical disruption". How that person views themselves and, perhaps more importantly, how they are viewed by others is disrupted from what is traditionally viewed as "normal" (Williams 2000, Ball 2021, Lyn 2021). This concept resonates strongly with my data and has proven useful for framing the nature of their experience as I go on to show in Chapter 6, section 6.5.

Having the ability to share and interact with others about illness in the workplace can often be beneficial to an employee with a long-term illness such as MS (Davison et al. 2000). Where hiding the condition is not an option (due to visible symptoms or accommodations required to fulfil their work), this can provide an important role in their emotional health at work. However, due to the limited numbers of teaching staff disclosing any long-term, disabling condition such as MS, the opportunities to receive or provide social support are vastly reduced. Outside of the workplace for any person with MS (not just teaching staff), the access to any kind of social support may be limited too depending on a variety of factors. These are likely to include gender, earnings, access to technology and level of education (Magliano et al. 2006). However, the emergence of online forums and support groups allow people with a variety of illnesses, MS included, to interact with others in a similar position. According to White and Dorman (2001), one strength of this approach is that there is always ready access and from most locations. A teacher with MS can engage and discuss issues and concerns with others that they connect with via a forum provided by a teaching union or other education association (such as the National Education Union, the NEU, which has specific representation for disabled teachers).

For those teachers with MS that have visible symptoms or have chosen to disclose to colleagues or their employer, then the Equality Act 2010 provides a degree of protection from a legal point of view, and help and support can be sought from Occupational Health by the teacher and the school to see what accommodations need to be made. This may take the form of mobility aids (motorised scooters), ramps for wheelchairs, changing location (ground floor classrooms), amending classroom layouts to create more physical space to move around freely, job-sharing or going part-time or changing roles within the school (to provide support for other staff, rather than having a class of their own). For anyone with MS entering the

teaching profession, these aspects of support will be actioned as part of employment (Knight et al. 1996). However, as Keller et al. (1998) state, it is people within the teaching profession generally - including those in positions of responsibility - that need to adjust their perceptions of the role that any disability plays in a person's life to individual circumstances, because being afforded these accommodations will rely on first being able to satisfy your potential employer that you are able to fulfil the role of a teacher. And, as Reiser (1990) warns, it is yet another added cost for the school to budget if accommodations need to be made, and this is in the current climate of ever-decreasing school budgets (Weale, 2019).

However, as stated previously, not all symptoms are visible, and many people with MS are concerned about what may happen if they inform their place of work about their condition. Chan et al. (2022) in a study of accommodations required by American teachers with disabilities acknowledge that the teaching profession is a demanding one which presents a particularly challenging context for accommodations to be made. This includes physical accommodations to school buildings, as well as the role that a person fulfils. As a result, several legal claims were highlighted relating to dismissal surrounding the failure of a teacher to meet the essential functions of the position. All of this leads onto the ever-present question regarding whether to disclose MS or not to an employer.

## **2.5 - Disclosure**

In an increasingly marketised and managerial state education sector, perception arguably matters just as much, if not more, in the private school sector. The traditional ideal of a leader in any walk of life is deemed to have 'strength' as a key characteristic, whether a Military General commanding troops on the battlefield or the Headteacher of a school, particularly one where the parents pay significant sums of money to send their children. There is no guarantee that parents will choose to send their children (and hard-earned money) to any school, and competition is immense. As outlined by Gupta (2022), parents' perception of what private schools offer is everything - from the facilities on offer through to the number of scholarships awarded to future schools, or Oxbridge entries gained. If you look on any website for a UK private school, often you will see a picture of the

Head standing (smiling) in front of the impressive buildings of their school (for example, Eton College, Cheltenham College, Westminster School). You may even see the Head sitting on a bench with their spouse, two children and the dutiful family dog sat at their feet. These images are used for a reason, and not ever do you see a photo of a Head using a walking stick to aid their mobility, or of one sat in a wheelchair because they cannot stand at all. This all relates back to the notion of normality embedded within the education sector as outlined by Ball (2021) in section 2.4. The importance of perception is evidenced across education sectors beyond the UK private school sector, as a recent study into state schools from the US has highlighted. According to Schock et al. (2022), Headteachers now see marketing as “a key component of school leadership” (p.1). Tah et al. (2022), in a study of private schools in Stockholm, similarly found marketing of “goals, values, studentship, methods and programmes, services and facilities” (p.681), but that generic marketing “may not appeal to students in need of special support, including disabilities” (p.681) due to a lack of specific reference to inclusivity. This idea of the perception of health being important across all workspaces in addition to private schools is echoed by Margaret Vickers (2001), who concludes in her study of invisible, chronic illness in the workplace that: “Capitalism is central to the western notion of success. Underpinning the essence of capitalism is the need for fully functioning individuals to provide utility to organisations. The problem of health is intimately involved in the functioning prerequisites of the social system – any level of illness that takes the individual below optimal capacity becomes a problem for a functionalist society. Health is regarded as a commodity, a resource, in a capitalist structure.” (p.3).

Queer theorist, Max Kirsch, suggests that for queer people ‘coming out’ in an area of their life that is traumatic or dangerous, the normal behaviour is to give the impression of, or mimic, being in a heterosexual relationship (Kirsch, 2000). Just like homosexual people, those living with a chronic, hidden illness live “with a foot in two different worlds – a straight [or healthy] world and a gay world [or a world of illness]” (Rhoads, 1994, p.66). Even though I suffer from MS relatively mildly, attempting to maintain a separation of these two worlds occasionally threatens to overwhelm and is, at the very least, a considerable challenge. The negotiating of my demanding, daily life (both personal and professional) alongside my MS

symptoms and treatment takes its toll. Following Butler's (1990) notion of gender performativity where nobody can be a gender before performing gendered acts, then I would argue that any ongoing non-disclosure of disability in my case stems from my desire to avoid being labelled as someone that is disabled. Being able, in my view, rather than disabled, is a performative act and one that has distinct values associated with it in an ableist society and ableist institution like a school (Hehir, 2002).

Fatigue is also an issue to factor in for most sufferers of MS, including me, and Vickers' (2001) comments speak to the experience of many with MS: "Fatigue for those with chronic illnesses can actually be disabling. This fatigue is relentless. Over-exercise or overwork does not cause it, and bed rest frequently fails to relieve it. It appears regardless of activity or inactivity, happiness or sadness. It simply exists in and of itself, and no medication, positive thought, or rest can relieve it" (p.241). If, or possibly when, my MS were to significantly change for the worse, I would no longer have the luxury of being able to conceal and choose not to disclose. This presents the biggest dilemma and is a 'catch-22' situation: I either decide to 'come out' in a manner and time of my choosing, or I risk being essentially 'outed' by the potentially cruel and unpredictable nature of my degenerative illness that follows no set time frame. For some, 'coming out' with an illness can ultimately prove liberating. It means a move from a 'resistance identity' (an identity of seeming defensiveness due to a devalued sense of self), through to a 'project identity' (an identity where a person actively constructs a new identity for themselves that redefines their position in society). It becomes a form of empowerment for oneself and, potentially, others as outlined in various studies (Castells, 1997, Gabe et al. 2004, Quinn et al. 2009).

Stigma has often been associated with chronic illness and disability due to the negative impact that it has on the identity of the individual concerned. You are often viewed as 'less than' or 'different' (Goffman, 1963, Charmaz, 1983, Gabe et al. 2004). Erving Goffman (1963) in an early research study into stigma labelled it as "an attribute that is deeply discrediting within a particular social interaction" (p.3). As Margaret Vickers (2001) outlined above regarding health being viewed as a commodity in Western culture, Goffman (1963) also describes an affinity with

that idea stating that “by definition, of course, we believe the person with a stigma is not quite human” (p.15). In his words, Goffman (1963) describes ‘the discredited and the discreditable’. The distinction being that ‘the discredited’ are those with stigma (who have an illness and have disclosed, or who do not have the ability to hide it) and everyone is aware of their limitation. However, ‘the discreditable’ are those for whom their illness is hidden and who choose the people they wish to inform of their condition. He refers to ‘covering’ as the process by which the discreditable attempt to conceal or minimise the importance of their illness. Whilst this important piece of research is quite dated now, it does still resonate with the questions that were asked about the issue of disclosure: “To display or not to display; to tell or not to tell, to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where” (p.57), and it is this exact sentiment which drives the research question of this project as a teacher with MS.

Some see the worst part of ‘covering’ (non-disclosure) of a chronic illness as the fact that it can potentially worsen the impact of the disease, both physically and psychologically (Frank, 1991). This is because disclosing is often viewed as a double-edged sword (Williams and Healy, 2001) due to the fact that it may well generate the hoped-for additional support, but it also runs the risk of resulting in being stigmatised. Many individuals fear the social reaction they will be faced with if they choose to disclose. It is a combination of misunderstanding of the illness being disclosed on the part of others as well as perception of what that might mean for the person with the disease that often prevents the disclosure (Williams and Healy, 2001). Numerous studies outline that the choice to disclose is both a difficult and complex decision (Joachim and Acorn, 2000, Fesko, 2001). For example, Fesko (2001) states that many individuals describe fear of disclosure due to uncertainty surrounding future employment prospects, loss of employment, impact on their salary and entitlements and general fear of discrimination. Whereas Joachim and Acorn (2000) outline that coping with a condition such as MS, which potentially has both visible and invisible symptoms, causes the person with the disease to struggle with the decision to either disclose and suffer possible stigma, or conceal and attempt to pass for normal.

Whether to disclose an illness due to potential stigma being carried by an individual is an ongoing issue, but not a new one. Foucault (1988) argued that in the 18<sup>th</sup> century there was an attempt to enact social control by creating colonies for the ill on the outskirts of a community because they were perceived to be deviant in some capacity. This treatment of members of society who are seen as different or less-than was, as Foucault (1988) described, a “great confinement” by the wealthy and powerful who viewed them as being an “ulcer on the body politic” (p.38). Why someone would choose to continue hiding (or, at least, not openly disclose) is often, as outlined by Goffman (1987), due to how individuals begin to internalise the stigma felt more broadly from a community or society. This internalised way that someone views themselves and their illness manifests itself for many as both shame and a sense of ‘other’. Robinson, Kendrick and Brown (2003, p.66) argue that a sense of self-worth for any individual is developed from relationships that they seek to forge and maintain. The strength of any relationship that occurs for a person that has MS with others, has the potential to inform their decision of whether to disclose or not. Empathy from others is a significant boost to a person’s confidence and sense of dignity. Therefore, understanding and empathy from other people can allow someone with MS to accept that their illness does not automatically make them “a stranger or an alien, totally different from the other” (p.66). This is often the case with members of a person’s family or their friends. However, disclosure to colleagues with whom a professional relationship is not a guarantee of understanding or empathy can risk being viewed and labelled as inadequate or less-than. Rusch et al. (2006, in Rusch and Corrigan, 2013) argue that the standard, emotional response to stigma from an individual is that of shame. Gonzales et al. (2015) undertook a study into microaggressions received by people with hidden mental illness, and they found that negative responses from others following disclosure led to internalised stigma. This, in turn, leaves the individual suffering from the illness feeling both inferior and invalidated. Richards (2008, p.1717) outlines the danger of this occurring by stating “the rendering of people as other (not like the norm) comes at a cost to humanity”.

A significant consideration for people with MS regarding whether to disclose their condition is due to the nature of many of the symptoms being ‘visible’ or ‘invisible’ (Joachim and Acorn, 2000). People with visible symptoms simply do not have the

choice and it is often, as accurately described by Goffman (1963); “the special indignity of knowing that they wear their situation on their sleeve” (p.152). Joachim and Acorn (2000) found that people with ‘invisible’ symptoms have a choice whether to disclose or not because of their seemingly ‘normal’ appearance to other people. As a result, the choice is often made not to disclose because of stigmatisation and the desire to be perceived as ‘normal’. However, the study also indicated that this strategy of non-disclosure carries with it risks that may affect the person’s ability to cope with the disease in the longer term if they choose to hide it. This concealment has been found to play a particularly significant role in the general mental health of a person with chronic illness (Fesko, 2001). Whilst the choice to hide their condition may have been a result of “concern for their own safety and protection” (p.239), the negative result was that they also felt socially isolated and lacked support for the illness. Some of the detrimental mental health issues faced by people concealing their condition included anxiety, guilt, and depression through feeling unable to explain to others why they were not having a very productive day at work (Fesko, 2001). For example. Van Manen and Levering (1996, p.142) outline a connection between any individual keeping a secret such as the non-disclosure of illness with the “splitting of inner and outer self”. These twin identities, according to Smith (1990), create an ongoing burden for the individual and contribute to feelings of both shame and guilt (p.25). As I explore in more detail in Chapter 4, I personally live with a tremendous amount of guilt because of my MS. Guilt that, through disclosure, I have burdened some with the knowledge that I have the illness. Guilt that I have not disclosed to many others. Guilt that I know there are many others worse off than me and that I ‘have no right’ to expect sympathy or accommodations. Even the most rational person (like, I hope, myself) who lives with a chronic illness can feel substantial guilt at not being able to continue with what they perceive to be normal professional activities (Myers, 2004).

## **2.6 – Disclosure in education**

Whilst there are several studies examining the broader issue of disclosure, the majority seem to have been carried out in the USA and may possibly contain nuanced cultural differences (Fesko, 2001, Beatty, 2004), particularly in relation to

employment law and rights. In the USA teachers, along with other workers, are protected by the Americans with Disabilities Act (ADA) enacted in 1990 rather than the Equalities Act (2010) protecting workers in the UK. In addition, other studies follow a more quantitative approach when exploring the factors behind the decision to disclose or conceal illness (Munir et al. 2005, Beatty, 2004). It is possible to generalise from a large-scale study such as that carried out by Munir et al. (2005) who surveyed 610 employees at a UK university. However, it is impossible in a study like this to elicit the detail of unique, nuanced, lived-experience which is derived from a smaller-scale, qualitative study. Other studies focus more readily on disclosure of illness that is more conventionally associated with stigma, such as HIV or mental health issues (Williams and Healy, 2001, Fesko, 2001). The grounded theory study into the role of disclosure of chronic illnesses in general and who needs to know by Henderson (2009) is much closer to extrapolating the type of detailed, personal information from participants that I am seeking to explore in my project. However my concern surrounds the fact that my exhaustive search of the literature reveals no readily available research that focuses on the disclosure (or not) of MS by those living and working in the teaching profession in the UK. The one project that is like my own is the Canada-based study by Katie Flockhart (2001), who researched the experience of teaching with MS. However, the focus does not examine the compatibility of teaching with MS or disclosure, but rather it focuses on the ability to stay in the teaching profession whilst maintaining a sense of well-being. The teachers interviewed have all disclosed already and the study details the accommodations made to enable them to stay in the profession following disclosure. Disclosure for MS, therefore, is an area in the literature which is bereft of evidence and studies that illustrate how those with MS have felt about disclosure or, indeed, have been motivated to remain discreet about their medical situation, which influenced my desire to explore the topic in this research project.

## **2.7 - Summary**

In this chapter, I have examined and critiqued the available literature in the professional and personal areas connected with my research project, notably that of the nature of teaching (what it means to be a teacher and what is involved in teaching), the nature of MS as a chronic disease, teaching whilst having MS and

disclosure of chronic illness. Through reading and my own personal experience of teaching with MS, I have become aware of the perception and reality of both aspects – that of the profession and the illness. The examination of the literature outlines that there is an enduring and under-researched tension between all of the various contexts explored in this thesis. These contexts include the popular framings of the role of the teacher (Fullan 1993, Day et al. 2006, Radovan, 2011, Biesta 2013, Lachner et al. 2016), accepted imaginings of MS (Rao et al. 1992, Burnfield 2003, Fleming et al. 2010, Cosh et al. 2014), and academic research into the process of disclosure (Butler 1990, Williams & Healy 2001, Rusch et al. 2006, Henderson 2009), considering what all this combined reveals about the broader social processes at play in terms of establishing exclusionary social norms (Vickers 2001, Ball 2021, Lyn 2021) and constructing notions of stigma (Goffman 1963, Bury 1982 & 1991, Charmaz 1983 & 1991, Richards 2008). This has led me to question the compatibility of working as a teacher whilst living with a chronic condition such as MS, given the tension between choice of profession and burden of disease. It is that synthesis that I am driven to explore in detail in this project, both for myself and for others, and to look at what drives people to disclose or not. The broader issues of MS, including symptoms and diagnosis are discussed in Chapter 4. Concepts surrounding disclosure, the importance of relationships and perception of self and others are explored in Chapter 5, and then the other key points of identity, choice and compatibility of MS and teaching are examined in Chapter 6. The literature linking all of these areas is sparse at best, and my study will set out to fill the research gap by exploring the issues inherent for teachers who live and work with MS regarding compatibility of profession and illness, and the selection of an appropriate research methodology is set out in Chapter 3.

# Chapter 3 | Methodology and Methods

## 3.1 – Introduction

The purpose of this chapter is to set out both the methodology and the methods which I have used in this study. Due to the nature of the issue being studied in my project, and the resulting utilisation of both phenomenology and autoethnography (both of which can be argued as methods and methodologies in their own right) it made sense to combine it into one, large, chapter. I outline my rationale for the methodologies and methods used in this project, explore their compatibility, and describe in detail the methods I used to collect and analyse the data. This includes interviewing three participants individually for a single interview of approximately two hours in length which took place in 2020, incorporating eight of my own personal journal entries into the project for the autographic element, and using Interpretative Phenomenological Analysis as the means to explore meaning behind all of the data. Discussion of the issues surrounding trustworthiness and ethics conclude the chapter.

## 3.2 – Personal assumptions/beliefs

When considering this research project and the direction it was likely to take, namely that of interviewing fellow education professionals as part of the data collection, I was acutely aware that – being a teacher myself – any research had to be done alongside, or with, the other participants and not on them. For the type of research I was planning to do, Hatch's (2002) suggestion applied; that treating pupils or teaching staff merely as subjects on whom experiments can be carried out is not appealing for a researcher of research participants. Given the personal, sensitive nature of the research topic I was looking to explore, I knew it was important to incorporate research participants intrinsically in the work through a suitable, methodological approach such as phenomenology, rather than simply seeking out subjects that might become objects to be researched.

The issue of whether it is appropriate for research in the social sciences to borrow methodology from the physical sciences has been debated since the 19<sup>th</sup> century

(Smith, 1983, Biesta, 2020). There were, and have been countless times since, concerns surrounding the ability of the methodology of physics to delve into or understand the social and human world. It was in the 1980s that this rejection of positivism spawned a much increased participatory, reflexive approach to social science research using a variety of qualitative methodologies (Guba and Lincoln, 1994). Certainly, as someone new to research that chose to step tentatively into the world of academia whilst maintaining my day to day professional teaching role, it might have been easy to be convinced by the perceived reliability and acceptability of a positivist approach:- *“Scientific maturity is commonly believed to emerge as the degree of quantification within a given field increases”* (Guba and Lincoln, 1994, p.106). It is concerning for the purposes of academic credibility to read:- *“[academics aiming]...to gain employment in the world of academia or research are left with the impression that they have to pledge allegiance to one research school of thought or the other.”* (Onwuegbuzie, 2005, p.376).

My research attempts to gain an insight into the issues faced by teachers who live and work with a chronic illness. I wanted to explore the connection between their illness, its compatibility with their career and how and when (or if) they have disclosed. The research seeks to understand the lived experience for the participants, to see how they make sense of it and how they respond to it. If I were to follow a quantitative methodological approach for this research, I would potentially be incorporating a hypothesis-driven paradigm that essentially supports the view that there is only one reality (Kaushik et al. 2019). I would therefore have attempted to, in some way, measure that reality. I do not share that view and have not tried to measure the participants’ reality. My own, personal view most appropriate for the aims of this study is one of a social constructionist epistemology, as outlined by Charmaz (2000, 2006). Knowledge relevant to my aims is not the discovery of some ultimate truth by a neutral observer (Dick, 2018). It must be constructed by human interaction and inter-subjectivity. Willig (2008) describes this view as: - *“identifying the various ways of constructing social reality that are available in a culture, to explore the conditions of their use and to trace their implications for human experience and social practice.”* (p.7). It is that view, allied with my own, which renders social constructionism a suitable perspective from which to have completed this research project.

As mentioned in the introduction and discussed in later sections of this thesis, my own involvement in the research is key for various reasons. First and foremost, I am in the same position as the other participants. I am a teacher living and working with a chronic hidden illness, trying to make sense of the connections between my illness and career. Secondly, I was the constructor of the research and the findings that came as a result. However, and just as importantly, I was also a part of the findings, having played a part in sharing some of the experience with the participants. This position left me as a *“co-creator of the research findings rather than just a witness to them”* (Willig, 2008, p.274). Some branches of phenomenology suggest that a researcher should put to one side (or attempt to ‘bracket’) their own personal, taken for granted world views so that they may solely focus on the important process of reflection (Smith, Larkin & Flowers, 2009). However, my own voice has inevitably featured as part of the autoethnographic element of the research.

The ontological supposition surrounding this research is my attempt to explore and understand the reality that is constituted in the perception of the individual participants and in their articulation of these perceptions, compared with my own. It is also an attempt to examine how they differ, if at all, from each other as well as me. All the data, whether my own or that of the participants, is a version of reality. It is the internal reality of personal, subjective experience, or an ontologically interpretative position (Nel, 2007). This interpretative stance, or ‘out-there-ness’ as described by Willig (2008, p.275), goes some way to explain the multitude of ways that the research can be construed. Willig goes on to suggest that qualitative methods used in research cover a continuum of different epistemological stances. This spectrum can be seen as stretching from an almost naïve realism at one end, through to a radical relativism at the other (Willig, 2008). I feel that my research project should be placed, from an epistemological point of view, at some mid-range on the continuum described above given the experiences of the participants are very real to them on the one hand, and yet those individual constructions are then taken and interpreted by me. This suggests a greater lean towards a relativist position than a realist one.

As an educator, senior leader, and researcher with the lived experience of navigating all the above whilst having MS myself, I am positioning myself in this project as both an outsider and an insider. Depending on the findings, I have therefore potentially positioned myself against, whilst also within, my own profession. That potential tension could well cause the division between my personal and professional life to significantly weaken, bringing the two ever closer together and entwined, whilst also creating more of a divide between myself and others who do not share the same experiences (Reed-Danahay, 1997). Through participation, I have found myself closer to the participants because of connecting through shared experiences. Conversely, I am aware that my reluctance to attempt to share personal experiences relating to my MS with those who do not have it themselves, has become further entrenched. This relational aspect of the research is important. The connections made between me and the participants is key to the success of the outcome. Malidoma Some (1994) has suggested that: "You cannot be who you truly are until you can put what you remember into action in your life" (p.309). My research, taking place within my own memory and that of the participants is, in itself, an ontological way of being in the world. It is both a process of potential, personal transformation as well as an emerging understanding of the nature of reality. It is an act of togetherness. One that appreciates the synergy of knowing and unknowing in a shared exercise, expressing hope, loss, the expected and unexpected, and all this experience lived by us all over and over again. This interpersonal construction of knowledge exists due to the shared experience, or rather the embodiment of knowing and unknowing the life of a teacher with (and without) MS, and it moves us as individuals beyond one's sense of self (Hadot, 1995). Our individual way of being resonates both inwards and outwards, and by exploring that space between us during this research project, I argue that we have discovered personal truths about ourselves and the world around us (Corlett & Marvin, 2018). Truths about our place in the world and about our place in this moment in time. The power of 'community' in this project can, I hope, enable this research to become something bigger than any one of us individually and, as discussed in Chapter 7, the discovery of these truths can have an impact on the professional lives of participants.

As I discuss in section 3.3 in this chapter, it was a growing interest in and awareness of phenomenology that helped start the process of self-discovery and an attempt to find meaning in the juxtaposition of being a teacher with a hidden illness for myself and others. This deepening ontological development was (and is) part of my ongoing journey into human existence and of 'being' in the world. This sense of time and temporality is important to me and goes back to my continual reference of being on a journey. In Heidegger's *Being and Time* (1927), he presents his view essentially as phenomenological ontology. A way of being that is defined by temporality and also viewing time as a way to understand the sense of being. His view of Da-sein (there-being) is one of always being in the world, and this resonates so much for me when thinking about how and where I fit in to my existence and when thinking about the notions of my being. About my body. About my very presence. MS is a part of me. It is present all the time. My body that contains MS is part of the self that makes me who I am and is undergoing constant change throughout time.

Deleuze (1994) rejects the traditional idea of past, present, and future, and instead argues that temporal realms are actually based on memory, habit and what he refers to as 'the new'. As discussed during the analysis of one of my journal entries in Chapter 4, I personally remember (vividly) sitting in the hospital consultation room with my wife by my side being given the diagnosis of MS when we had absolutely no idea it was coming. I remember thinking that I had no idea what it meant for me moving forward on my life journey. What it might mean for my family, friends, or what it would mean for my ability to work in the future. Those moments of thinking, feeling and emotion are temporally situated in my past, prior memories, but continue to affect both my present habits and potentially new future. It is this that I explore with my participants, and within my own personal experience as part of this research. Through our own, personal life journeys, we experience and live many things. I now move on to outline the methodological ways in which I seek to explore these issues.

### **3.3 – Qualitative inquiry**

My research sits within a qualitative paradigm due to the concern it has for the subjective experience, the individual feelings and personal thoughts had by people about a specific occasion, situation, or phenomenon. Moreover, it is concerned with the meaning that they, as individuals, attribute to this, whilst retaining recognition of the highly subjective nature and wider contextual influences surrounding the meaning. According to Denzin and Lincoln (2011), qualitative research is “a set of interpretative material practices that make the world visible” (p.3) and uses a wide range of methods for data collection. These might include methods ranging from narratives, ethnographic observation, life histories, personal accounts and much more. It considers experiences, albeit remembered or reported experiences. Not only individual or group experiences themselves but, perhaps more importantly, the cultural, situational, or social intricacies of those experiences. These contextual influences which shape our experiences might include cultural beliefs, religion, values (personal or moral) or past experiences (Thorne, 2000).

The social history of the person completing the research is also intrinsically embedded in any qualitative research. My journey, both as a teacher living with a chronic hidden illness as well as someone completing research, has been chronicled in a reflexive journal. This is not merely referred to in the research but forms an integral part of it via the autoethnographic methodology outlined later in this section. That is to make explicitly clear the influence and role I have played in the research, and to encourage this to be integrated and understood by the reader. This also adds to the credibility of the thesis and enhances the trustworthiness of my conduct as a researcher throughout the study.

### **3.4 - Methodology**

#### **3.4.1 – Phenomenology**

It is important to give a full description of phenomenology to fully outline the relevance of its use in this project. However, due to the limitations of word count,

I have placed the more comprehensive description of it into the appendices (Appendix 1), which should be read alongside this section of the chapter.

As a teacher that suffers with a chronic illness, I have increasingly found myself longing for a greater dialogue with the medical professionals that I interact with regarding their understanding of how the illness is affecting me physically, but also mentally and emotionally. The concept of illness has been debated, discussed, and argued over by philosophers and medical staff throughout history (Cohen, 1955, Porter, 1985, Boyd, 2000). There have been two overriding approaches to the concept of illness, one being a naturalistic view (most prevalent in the medical profession), and the other being a normativist view (Bishop, 2011). With the former, a medical professional will view illness as a disease. Something objective. A biological dysfunction. For example, if you were to visit your local doctor with an illness such as the flu, you would display symptoms such as a sore throat, temperature fluctuations and a runny nose. A medical professional, the doctor in this case, can view these symptoms in an objective way. They can be measured (temperature can be checked, throat and runny nose observed), diagnosed and treated. It was Foucault (1976) who suggested this notion of the 'clinical gaze', a new relationship, if you like, set apart from one where two people interact equally into one where a medical professional simply looks at (or inside) the body without any active participation of the patient themselves.

With the proponents of the normativist view of illness, disease is value-laden, and we need to focus on the way that society views the ill person. The normativist view looks to the social conception of the illness and the ways that such a disease could potentially socially impair the sufferer. Rachel Cooper in her study of illness writes: *"no biological account of disease can be provided because this class of conditions is by its nature anthropocentric and corresponds to no natural class of conditions in the world."* (2002: p.271).

In both common views of illness, nowhere is the voice of the person suffering from the illness to be found. The first-person perspective is missing, and that is something which has led to my desire to pursue this research project. Take MS, for example. A physiological description, such as outlined in Chapter 2, would include

a factual report of localised failure of the central nervous system due to demyelination. It does not, however, tell of fatigue, the sufferer's fear for their future and career, a growing dependency on others and the development of a multitude of other frightening symptoms (many of which are hidden from view). Chronic illness such as MS and not just a common cold, deals with the transformation of one's life (Carel, 2016). There is a disruption of habits, expectations and abilities, and there is a destabilisation of meaning structures, so there is an overall breakdown of meaning in the ill person's life. If my research project aims to examine the subjective, lived experience of teachers suffering with MS and not merely describe symptoms and their severity, then a qualitative methodology such as phenomenology - which places the lived experience of participants at the centre of the research - is essential for exploring perspectives.

Phenomenology is, therefore, an incredibly useful tool to help us understand how illness impacts one's life, how it changes experience and shapes the life of the ill person, and how it ultimately forms a "*complete way of being*" (Merleau-Ponty 2012, p.110). Phenomenology provides a method for discerning and describing human experience. It understands perceptual experience as embedded in a particular culture and as having a particular meaning based on the concepts and values of that culture (Carel, 2016). Many of the early phenomenologists did not write explicitly about illness. However, there is much that can be drawn from the literature to provide a framework for understanding human experience and, ultimately, illness.

For example, I have found Heidegger's tool analysis in his *Being and time* (1962) a useful way to consider illness such as MS. In his view, an object is not just a 'thing'. It is a tool that we use in our everyday lives (such as a pen, or a hammer) and, as such, it is characterised by an inconspicuous presence (Carel, 2008). There are three types of disfunction that Heidegger has distinguished: *conspicuousness* where the required tool has stopped working (my pen has run out of ink); *obtrusiveness* where the necessary tool is missing (I have lost my pen); and *obstinacy* where the tool is not suitable (I only have a thick marker pen to write a letter with, not my fountain pen) (Heidegger, 1962). As Carel (2016) goes on to outline, the analogy to the body is clear. When my left hand is working normally, I do not think twice about my

ability as a teacher or performer to play a complicated piece on the piano, or the physical mechanisms involved. I experience the world through my body but when it is working my attention is directed away from it to the task in hand. So, when I play the piano to pupils or an audience, I am concentrating on the music I am playing and the sound I am trying to create. However, if the dexterity of my left hand is affected (as described above) or my left index finger and thumb go numb due to my MS, then I am also experiencing a failure of a tool. It just happens to be a tool that is part of my body. The difference is, of course, that I cannot use a different computer or piano as the failure is in my hand (rather than the object used by my hand). Any bodily dysfunction is experienced in a personal, deep and subjective way, and the different tools that I use as a teacher on a daily basis can be (and are at times) affected by my hidden illness. Motor function, sight, speech, memory, cognitive function, mobility, stamina - these are all things we take for granted. Yet they are also the tools that an MS sufferer may experience a breakdown of at varying points in their lives. Whilst I have referred here to a specific example related to my own MS, the effect of MS on bodily function (or 'tools') for the participants in relation to their work as teachers is explored in Chapter 4 as part of the narrative surrounding initial MS symptoms being experienced.

I also find Merleau-Ponty's focus on perception and of the human body being central to existence (2012) offers valuable insights into the experience of illness. For him, the body is a body-subject, engaged in a dialogue with the world. It is, of course, a physical 'thing', but one that is the source of intensely subjective feelings, emotions, sensations, and perceptions. It is something that can be experienced both from a third person and first-person view (other people can see me sat here typing, they can measure my size or observe my hair colour, but I am the one that can feel my arms resting on the table whilst typing, needing to stretch my legs and experience the ache in my muscles). As a person with a chronic, degenerative illness, Merleau-Ponty's notion of bodily intentionality (2012) certainly resonates strongly. The intentional arc, linking my body to the world around me, is interfered with through illness and particularly with a condition like MS. The idea of bodily intentionality is that the body does not just wait for mental commands but partakes in many activities because they have become habitual. However, due to the

demyelination of the central nervous system in MS, the signals sent round the body via the nerves are sometimes interfered with.

As an organist and pianist of some considerable ability (I am a Fellow of the London College of Music, a Fellow of the Royal Schools of Music, and an Associate of the Royal College of Organists), it was rather disconcerting in 2012 to discover that the dexterity of my left hand was being affected by an attack of MS. I am right-handed, so writing or using my right hand for everyday function was not an issue. Attempting to play the piano at school in front of a class was suddenly a very real (and alarming) challenge. Because of my advanced musical ability, I was able to hide it. However, had I been required to perform a recital of professional standard I might have had to cancel. What I thought I was telling my left hand to do was not manifesting itself in the physical action. Any intentional, planned, goal-directed movements that used to form part of my bodily intentionality when playing the piano (or, indeed, just using my left hand 'normally') were suddenly no longer within my control. *"For us the body is much more than an instrument or a means; it is our expression in the world, the visible form of our intentions"* (Merleau-Ponty, 1964, p.5). If, in Merleau-Ponty's view, the body is the core of our existence and the basis for any interaction with the world (Carel, 2008), then by having an illness like MS, my habits, my ongoing existence as a teacher (as well as a husband, father, musician, friend and human) is inextricably altered. This unique view of subjective, lived experience highlights the benefit and suitability of phenomenology as a methodology for my research.

Phenomenologist S. Kay Toombs has written extensively about her own experience living with MS. The experience of illness for one person will be very different to the next (whether emotionally or physically) and this makes any detailed, subjective analysis of a group of people with the same illness challenging. However, Toombs argues that being 'ill' still manifests itself for the individual as a 'way of being' (Toombs 1987, p.228). She argues that there are certain features of illness inherent for everyone, regardless of the specific version of a particular disease (Toombs, 1987). These essential features of illness are narrowed down to five 'losses': the loss of wholeness, loss of certainty, loss of control, loss of freedom to act and loss of the familiar world. Any loss of bodily function through bodily impairment, such

as I described above with MS affecting the dexterity of my left hand, can lead to a profound sense of general loss for anyone suffering illness. If your actions or choices have been impeded by illness, then you can no longer take your own body for granted (Toombs, 1987). For Toombs, this model of illness as outlined in these five losses brings the subjectivity of the person explicitly to the fore, and not merely secondary to the naturalistic or normativist view that objectively views illness as a disease that can be labelled, studied and treated.

If, as Van Manen (1990) states *"The method one chooses ought to maintain a certain harmony with the deep interest that makes one an educator (a parent or a teacher) in the first place"* (p.2), then phenomenology strongly speaks to me as a researcher. It also speaks to me as a teacher living with MS as a way of revealing the quality of that experience, and of that of my participants, in its deepest, fullest, and richest form.

### **3.4.2 – Autoethnography**

I believe that we are on a journey and that we live 'storied lives' (Polkinghorne, 2005, Bruner, 1990). People are natural storytellers: their stories give understanding, continuity, and coherence to their existence (Lieblich et al. 1988). Others, such as Polkinghorne (1998) go even further and argue that narratives are people's identities; the stories people tell shape and construct the narrator's personality and reality as the story is retold and reconstructed throughout that individual's life. To Clandinin and Connelly (2000) narrative is a way of understanding lived experiences and they often refer to their work as *"stories of experience"*. In selecting a suitable research tool/instrument for this project, using narrative is inherently intertwined with both phenomenology and ethnography.

The point of phenomenological research is to document other people's experiences and their reflections on their experiences to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience (Van Manen, 1997). Autoethnography gives an insight into the author's own personal systems of meaning, framed by their culture and social world (Lieblich et al. 1988), which includes interaction with others. As I reflect on my ongoing journey researching this

project, I am drawn to the explanation of the nature of our experiences given by Dewey (1916) in his *Democracy and Education*. He elaborates that experience involves change, but unless this change is connected to a consequence (positive or negative), then it is a “*meaningless transition*” with little or nothing learned (p.133). Experience will simply not occur unless one has an interaction within another context (this can be another person, with an idea, an object, or the world around us). My interaction with others through this research project, particularly those in the same situation as me living with a hidden illness, will strengthen and give consequence to the experience for all of us, and add integrity and authenticity to my research as a result.

Autoethnography is a research method that uses deep and considered self-reflection (often referred to in academic circles as ‘reflexivity’) to question and analyse the various intersections between oneself and society, the particular and the general, the personal and the political (Berry et al. 2011). It had its genesis in what some people within the academic community have referred to as the ‘crisis in representation’, “*a quiet methodological revolution has been occurring in the social sciences; a blurring of disciplinary boundaries has occurred*” (Denzin and Lincoln, 2011, p.9). It balances creativity and emotion with intellectual and methodological rigour, and it strives for social justice and to make life better (Bochner et al. 1999). It does not espouse any single, objective truth, rather just the lived experience of the author’s own construction of their reality (Turner, 2013).

Ellis (2004, 2009) states that, in autoethnography, using “I” creates a situated story. It means the author is the one that both describes and experiences, observing and creating at the same time. Ellis (2009) outlines how autoethnographic approaches are both reflective and reflexive of our lives as lived. There is no set rule(s) regarding the procedure to follow. The goal is simply to develop a greater awareness about the constantly changing account of our lives. It is now the case that many academics have turned to autoethnography to write about some of the more complex aspects of human life by incorporating self into the personal narrative. By being personally, aesthetically, emotionally, and also narratively connected to a cultural group or experience (other teachers navigating a career in teaching with a hidden illness in the case of my own project here), autoethnographers like me may take more

responsibility for and greater care in representing themselves and others (Adams et al. 2015).

Ellis and Bochner (2000) have highlighted this growing trend of provocative research grounded in the personal experience of the authors which aims to connect with the reader about topics such as identity, racial inequality, disability, social justice, and stigma. It may well be that the text written and included as part of this project invokes some kind of evocative response from the audience too. This additional potential connection with people reading the text can both provide space and give voice to those previously silenced (Denzin, 2005). I want to give a voice, a personal voice, through sharing my story which will contribute an alternative to the multitude of more scientifically based inquiries of living with MS (whether as a teacher or not). Ellis et al. (2011) says that utilising autoethnography provides a variety of different forms for a researcher to make their personal experience meaningful in ways that, perhaps, more traditional methods usually disregard. This might mean incorporating music, drama, dance, art, photography, or other creative methods alongside the written word. I actually composed various pieces of music as an emotional response to extracts from my journal during the course of this project, but the word count and type of thesis did not allow for inclusion on this occasion. Ellis (2004) goes on to say that autoethnography is research, writing and method that connects both the personal, lived experience and the autobiographical to the wider cultural and social. That is what I am hoping to achieve through incorporating my story alongside those of my participants in this project.

The goal of my research is to improve understanding of broader social phenomena. Anderson (2006) outlines that one style of autoethnography, known as analytic autoethnography, has the features to enable this. They are when the researcher; 1) is a full member of the research setting, 2) has a visible narrative presence in the text, and 3) engages in dialogue with informants beyond the self. This style of autoethnography is the one that I selected as most appropriate for use in my project.

Autoethnography has many benefits for research seeking to explore human action, relationships, and personal experience. Chang (2008, p.52) suggests these benefits can essentially be found in three main areas. Firstly, autoethnography is a research friendly method for both researchers and readers. Secondly, it enhances understanding of self and of others. Lastly, and most importantly, it has the potential to transform both self and others. Chang (2008) goes on to add that autoethnography is an excellent means by which researchers can come to understand themselves and others, and this element of self-reflection and reflexivity is a clear benefit to this project.

Ellis et al. (2011) argue that writing personal text via the method of autoethnography can have therapeutic outcomes for both the participant and readers, and through this, self-transformation is often seen as a benefit. Whilst some academics might take exception to the notion of personal therapy benefitting the researcher or researched (Holt, 2003), it should be noted that this is often an unintended consequence through the process of deep self-examination (Ellis et al. 2011). This connection between the author and the reader is often seen as a significant potential of autoethnography. Chang (2008, p.54) suggests that the link between increased self-reflection, the use of a culturally relevant pedagogy and a strong desire to explore the wider community setting creates a self-transformative outcome that is often a benefit to those who live and work in diverse backgrounds. As MS is classed as a disability, then for someone with MS to write about what it means to them and the effect that it has on various aspects of their life can only be of benefit to them and – crucially – to others that read about it.

However, this is the strongly contested point within the world of academia. Even as my own burgeoning interest in autoethnography grew during my doctoral studies, one of my professors questioned the interest in the method. Was it, he asked, 'research', or was it 'me-search'? My answer was that whilst attempting to do the first, the second may well end up being another potential outcome despite not necessarily being the reason for utilising autoethnography in the first place. McIlveen (2008) emphasises that the reader plays an important role in establishing the value of autoethnography as research, and that is the case for both the autoethnographic and phenomenological lived-experience accounts offered by

myself and the participants. He argues that people reading research which has the inclusion of personal accounts enriched with both theory and rich descriptions of lived-experience may start to formulate new ideas or lessons for themselves individually or for their cultural sphere (personally or professionally). In the same way that people reading this thesis may develop new thoughts and actions about the topics discussed within, a central tenet of a professional doctorate is also to link knowledge to practice. As a researcher and a teacher living and working with MS, I am uniquely positioned to utilise knowledge gained through participation in this project to inform and guide the next steps in my career. The doing of autoethnography creates opportunity for *“catalytic and educative authenticity”* (Hayes and Fulton, 2015, p.12), and it is this sense of credibility as both a teacher and researcher that is enhanced by completing this doctorate.

Examples of similar autoethnographies that I have studied and speak to my own interest in the method, and which are also used to describe the first-person, lived-experience of chronic illness, include Nowakowski’s (2016) work about visible chronic illness. This research is engaging due to the descriptions of how she perceives others that treat visible illness as a type of deviance, thus creating stigma. Conversely, Moore’s 2012 study titled *“The Beast Within”* is about living with an invisible chronic illness. In this, she questions the sense of societal validity for those with an invisible illness and makes a strong connection between using autoethnography as a means of expression and helping to understand issues related to disclosure. Finally, Parke’s (2018) study, an autoethnographic work viewing a teacher’s experience with illness and the problems associated with identity that stem from it, resonates clearly with my own thesis. All of these examples have contributed to my engagement with autoethnography in this project.

### **3.4.3 – Bringing together Phenomenology and Autoethnography**

My desire to recognise the importance and usefulness of phenomenology to the success of my research project is then counterbalanced by my desire to place my own voice within the research as well using autoethnography. This struggle to find

the best, most suitable path to follow regarding the research process is by no means unique to me, and there seems to be an emerging repertoire of literature that recognises the need for a degree of flexibility surrounding research methodology (Kincheloe, 2001). Reassuringly, perhaps, for me, there is a growing discourse surrounding research method and research philosophy that favours a much more pragmatic approach (Warne & McAndrew, 2009). It suggests that one option for researchers is to look to draw from a wide and diverse range of theoretical methods and traditions to create the basis for the practical application of any research theory. This, in turn, will then encourage them to produce more rigorous project studies and outcomes, the goal of which is to then provide new insights into sociological experience and phenomena.

According to Moustakas (1994), the research approaches of phenomenology, hermeneutics, ethnography, and grounded research theory are all models that acknowledge the value of the study of human experience. Ellis (2004) argues that autoethnography is closely allied with these models as a result. They all attempt to investigate the fullness of an experience as opposed to merely its objects or parts. Moustakas (1994) also goes on to say that these various methodologies all seek to discover the meanings and the essence of lived, human experience. They do not, as per other quantitative paradigms, seek to measure or explain, but to obtain descriptions (narrative or otherwise) of experience through formal or informal conversations and interviews. He argues that there are significant commonalities between the various qualitative approaches outlined above, such as they formulate questions and problems that reflect the interest, involvement and passions of the researcher, that they regard the data of experience to be of central importance in understanding human behaviour and as evidence for scientific investigations, and lastly, that these methodologies focus on the wholeness of experience and human behaviour as an *"integrated and inseparable relationship of subject and object, and parts of a whole"* (Moustakas, 1994, p.12).

This is a discussion surrounding features that are reflected within qualitative research methodologies in quite broad, general terms. However, for me as someone starting out in research, I wanted to explore the synthesis of both phenomenology and autoethnography to achieve a unified goal at the end of the

process. Both of these aim to explore and uncover the true nature and meaning of a phenomenon or experience directly from those that have lived it. It does not matter whether that is from the perspective of participants giving the researcher their own subjective views, or the perspective of the researcher themselves. My desire to explore the experience of teachers living and working with MS also included myself, and I have gained insight into this both from the perspective of others who have encountered it as well as my own experience. I have also gained an increased level of self-awareness and self-understanding through my role as both a researcher and as a learner throughout this study (Moustakas, 1994), and given others self-awareness and understanding through the reading of my autoethnographic accounts.

So, having intended to understand and having attempted to describe the experience of living and working as a teacher with MS from the perspective of participants who have lived it, I have therefore chosen to draw upon those characteristics that are taken from a phenomenological research approach. Alongside this, I have then sought to enhance the richness of the description surrounding the lived experience of the participants by adding my own voice through utilising autoethnography. Using analytic autoethnography (Lofland 1995; Snow et al. 2003; Anderson 2006; Struthers 2014), I have based my contribution on similar works that have influenced me in this genre. These include an autoethnographic doctoral study by Allbon (2013) who writes about broad issues relating to identity when having MS, and two autoethnographic research articles about chronic illness; the first, by Nowakoski (2016) focuses on the difficulties of living with a visible chronic illness, whilst Moore's 2012 article *"The Beast Within"* is a study about invisible chronic illness.

The intention is to try to weave my personal narrative, or as Rath (2021, p.1) describes my *"narrative inheritance"*, alongside those of my participants to culturally situate the 'lived experience stories' of teachers living and working with MS. Reed-Danahay (1977, p.3) suggests that *"one of the main characteristics of an autoethnographic perspective is that the autoethnographer is a boundary crosser and the role can be characterised as that of dual identity"*. As Ellis (2004) describes, autoethnography is both a text and a method like that of ethnography. However,

the biggest difference is that 'self' is deeply embedded in both the social and the cultural context in autoethnography. Having a deep connection to the topic as a participant through my autoethnography, whilst also working alongside other participants using a phenomenological approach gives me that sense of "*dual identity*" as outlined above and adds value to the project as a result. Through my use of analytic autoethnography, I was able to select, analyse and incorporate relevant text detailing my own experience as a teacher with MS, alongside the data gained from participant interviews and analysed through phenomenological method. The synthesis of the two approaches is an important part of this project to gain the requisite experiential knowledge that is needed to achieve my research aim.

There are some purists, as well as others, who will question the efficacy of this mixed approach. For example, as a disadvantage of mixing approaches, Gorard (2005) cites confusion regarding evidence and how it is interpreted, particularly with qualitative, small-scale, social science projects in the field of educational research. However, as a researcher starting out with his first research project, I am drawn to both methodologies as I see a cohesiveness that is beneficial to my research. Not only about their compatibility, but also the practical usefulness of the overall outcome as a result. Merging of these various personal stories and accounts has added further layers of subjectivity to my project, making for an important increase in rich detail (Adams, Jones and Ellis, 2015).

### **3.4.4 – Considering alternative approaches**

As a novice researcher, I knew it was important to consider carefully which the most appropriate methodology would be for my proposed study. In this section, I outline some of the options which were considered for analysis but were not adopted, along with the reasons for not doing so. Glaser and Strauss's (1967) grounded theory aims to merge the process of collection of data with analysis of it and requires the researcher to return to participants to collect additional data once initial data has been analysed. It was not appropriate for this project due to the need for relatively large sampling sizes for sufficient data and the role of the researcher as a witness to the process rather than having their own voice within it.

Similarly, discourse analysis seeks to develop and understand naturally occurring text, and it looks at how these then construct versions of reality. Burr (1995) states that one major issue with discourse analysis is *“the identification of discourses has a tendency to become little more than the labelling of everyday common-sense categories”* (p.174). This is problematic in my view due to the requirement of this project to elicit subjective, nuanced data from the participants which ought not to be reduced down to unnecessary generalisations. Other critics, such as Willig (2008) also warn that discourse analysis can end up giving more validity to the role of language and text rather than mental state or subjectivity. The latter is clearly a concern for me regarding the personal viewpoint sought from my participants as well as myself and have discounted discourse analysis as a result.

## **3.5 – Methods**

### **3.5.1 – Choosing participants**

Due to the focused, small-scale nature of this research project, it was important to have a clear plan in place regarding my participants. I acknowledge that other types of qualitative researchers may well be more open to the way that their project naturally unfolds when it comes to participant identification and selection, such as those undertaking action research or some ethnographic projects. However, participants for phenomenological researchers are often those who will have had the actual experience(s) under investigation in the project, and who are able to provide detailed descriptions of it (Polkinghorne, 2005). To that end, I needed to identify at least three participants for my project to give adequate data for analysis and, like me, they needed to be a member of the teaching profession (current or previously) and to have been diagnosed with MS.

Because the project was going to generally explore the compatibility and experience of teaching whilst having MS, there was no set criteria regarding when the diagnosis of MS was made for the participants, and it therefore did not matter whether they had recently had the diagnosis or whether they had received it a significant period of time ago. Equally, it did not matter what specific role the participants had within the teaching profession, as that was potentially one of the

interesting issues to explore depending on the participants that agreed to take part (whether MS is compatible with particular teaching roles). Also in this regard, I was not selective about the nature/severity/type of MS that the participant(s) had been diagnosed with (relapsing-remitting, primary progressive, secondary progressive). Much of the reasoning behind that decision was expediency. I knew that it would potentially be challenging to locate suitable participants who fitted the more general criteria (members of the teaching profession diagnosed with MS who were willing to take part in my study) without then attempting to refine that search further by specifying any particular classification of MS for the participants.

As for the gender of the participants, I did not want to make that a specific feature of this project and was open to any gender taking part as a result. Whilst I was keen to encourage the individual participants to describe their own stories and experience of both living and working with MS, it would mean that this would naturally blur the lines for most (if not all) participants between the impact of MS on their professional and personal lives whether male or female. Any potential issue that arose due to gender roles within either the workplace or the home would be something to explore as part of the data collection. Lastly, MS affects almost twice as many women as it does men, so it was highly likely that some – if not all – of my participants would be female. This dynamic ended up being reflected in the snowballing approach to the recruitment with three female participants. Because I was also incorporating my own personal story and experience(s) through the autoethnography, it was inevitable that both genders would have some kind of input into the project.

Qualitative researchers often use a 'snowballing' (networking) technique to locate and identify participants for their projects (Seidman, 1991, p.58), and knowing how sensitive the topic of my research was going to be I felt strongly that having connections with the participants would engender trust and openness during the data collection process. Because I am a member of my local MS Society branch, I was already aware of several other teaching staff within my locality and initially made provisional contact with three of them that fitted the criteria above by e-mail to outline the project and to ask whether they would consider taking part. I described what the project would involve for them, and how important and

valuable it might be (Hunt, 1992). It so happened that one of the participants knew the other two that I had approached. Participants A and B worked together at the same school, and participants B and C had been friends at secondary school and had stayed in touch with each other (and both knew that they had MS). These additional connections may well have had a positive influence on all three participants being prepared to take part in my research project (as they may have felt a sense of security knowing others that they knew who were in the same position as them were also taking part), but that was good fortune rather than by design. All three participants were female, and more detail about them from a professional and personal perspective is given in Chapter 4.

Broader ethical considerations of this project are discussed at the end of this chapter. However, from a practical perspective I outline here the procedure undertaken following full ethical approval being sought and obtained from Oxford Brookes University Research Ethics Committee. All participants were given a Participant Information Sheet (Appendix 2), a GDPR Privacy Consent Form (Appendix 3) and a Consent Form (Appendix 4) to read, sign and return prior to taking part in the project. This all formed an important part of the process of recruitment, known as 'informed consent', which specifically relates to the ethical principle of autonomy. This all provided the participants with the following:

- The right to withdraw from the project at any time, and without explanation
- The provision by me (as the researcher) of adequate information about the project, which included an outline of both the benefits and potential risks
- The opportunity for the participant(s) to contact me, as the researcher, or one of my supervisors, to ask questions about the project

In addition to this written information being supplied to, and signed consent being obtained from, all three participants prior to the data collection starting, each participant was reminded of their right to withdraw at the start of each interview, along with a reminder that the data would be anonymised.

### 3.5.2 – Data gathering (*interviews*)

The most common method of collecting data for phenomenological research is the interview (Smith et al. 2009). This method allows for a connection between participant and researcher through which a narrative construction of the experience being studied is created (Darlston-Jones, 2007). As a result, several realities can be incorporated into the research by interviewing several participants who may have shared the experience under investigation. Darlston-Jones (2007) argues that interviews are strongly justified as a method for data collection in a project such as this (that deals with lived-experience) due to the natural alignment of social constructionism and biographical research brought together through ontological stance. Because of my desire to allow the participants freedom to express themselves and to describe events as they experienced them, I used semi-structured interviews. I drew up an interview guide outlining the main topics of interest I intended to cover, however it was important to allow flexibility for the participants to be able to speak freely and to direct the conversation as they wished.

The world-wide COVID pandemic of 2020 had an impact on my data collection on two fronts. Firstly, regarding the physical site of the data collection and, secondly, with regard to the number of interviews possible. The restrictions of social distancing and going through periods of national lockdown caused significant problems for my intended plan of data collection. I had gained ethical approval for one interview with each participant but with the possibility of a follow up interview with each, if it were deemed necessary or useful. It was fortunate, then, that all three participants were able and prepared to give significant time to their individual interviews (they were all between 90-120 minutes in length) conducted in 2020. As such, it was felt that I had sufficiently rich data from all participants not to warrant needing further interviews. However, the location of the data collection was affected. The issue of the possible imbalance of power in the relationship between participant and researcher can often be mitigated by allowing the participant to select a preferred venue for data collection in which they feel the most comfortable and relaxed (Esterburg, 2002). For the first two participants in my project, the interviews took place within their homes. This helped to shift the imbalance of

power, as it allowed the participants a degree of control over their surroundings and enabled them to be much more relaxed. However, because of COVID restrictions, the final participant had to be interviewed remotely using a live video call (Microsoft Teams). There was no noticeable difference in the quantity or quality of the data for the final participant, and that can perhaps be attributed to the fact they were still in their own home and comfortable with their surroundings (Fielding et al. 2017), and that they were at ease using video conferencing/calling due to its increased usage for the majority of adults since the start of the COVID pandemic in 2020. No mention was made by the participants in any of the interviews about pandemic conditions or influence regarding the subject being researched.

During the interviews with the first two participants (A and B), the data was audio recorded using a DAW (digital audio workstation) with recording software called 'Reaper' on the researcher's laptop. For the final, remote, video interview (for participant C) using Microsoft Teams, the video call was recorded and then the audio removed for usage. I purposely decided not to take any notes during the interview process for all three participants. I felt that it would be detrimental to the data collection process by not giving the participants my full attention throughout (Gillham, 2005). The three audio interviews were converted to mp3 audio files and transcribed using electronic software. The need for me, as the researcher, to carefully go through each transcription to check for errors and make amendments was a time-consuming – yet immensely valuable – process. It formed a significant part of the analytic process as outlined below and, as outlined by McMullin (2021), afforded me a deep connection to each data set by revisiting it in detail.

As highlighted by Koopman, et al. (2020), as an effective method of collecting and presenting reflexive data in autoethnography, the data used for the personal, autoethnographic aspect of this project is a handwritten journal that I have been keeping for several years in relation to my MS. Some years have several entries contained within the journal, others only one or two. Entries have usually been made following some aspect of my life that has been influenced in some way by my MS. That could be on a personal, or professional basis, or both. This journal provided rich, descriptive data to sit alongside that from the participants from which I analysed and incorporated where relevant.

### 3.5.3 – Data analysis and interpretation (*IPA*)

Interpretative Phenomenological Analysis (*IPA*) can be seen as the bringing together of phenomenology, hermeneutics and idiography. It is particularly appealing for projects such as mine due to its commitment to explore, describe, interpret, and situate the participants' sense-making of their experiences (Smith et al. 2009), which made it suitable for the autoethnographic element of the data too. *IPA* integrates the work of four major phenomenological philosophers: three of whom have been discussed above and uses it to place all strands of their phenomenology on a continuum, or as a singular endeavour. This is one of the reasons behind arguing against aligning with only one specific strand of the philosophy because they all have much to offer (whether in the guise of *IPA* or not), and do not have to be followed in a purist fashion to elicit valuable research. Researchers seek to explore and interpret personal lived experience. An *IPA* researcher is said to engage in 'double hermeneutic', in that the researcher is making sense of the participants' sense-making, but is also central to the analysis and interpretation of the participants' experiences (Smith et al. 2009). This constant flow back-and-forth of data interpretation and reflection is like that of the hermeneutic spiral model that deals with the 'part' and the 'whole' at various levels, giving a deep, overall analytical interpretation. With *IPA* the 'part' is the researcher's contact and interaction with the participant during a research project, and the 'whole' is the extraction and utilisation of knowledge and experience of the researcher themselves (Smith et al. 2009). It is fundamentally idiographic due to its detailed and nuanced analysis of a phenomenon under investigation (Eatough, 2006), and it values each case on its own merits before moving to the more general cross-case analysis (looking at convergence and divergence between cases). Part of its attraction for someone starting research (such as me) is that it provides practical and accessible guidelines in conducting research.

Like many qualitative research methodologies, such as autoethnography detailed above, *IPA* most certainly has its critics. Some would argue that it lacks standardisation (Giorgi, 2010) or that it is too descriptive and does not involve enough interpretation (Larkin et al. 2006). However, it has become established enough through research and publications to counter these claims (Smith et al. 2009). The biggest criticisms of *IPA* surround that of language (its use), perception

and the nature of experience, although the same is true of other forms of phenomenology and narrative methodologies (Henriksson et al. 2012). Phenomenology as a research approach relies on the experiences of the researcher, and the accounts of participants. Whilst the potential issue of elitism surrounding use of language in all phenomenological research does exist (Willig, 2008) due to the need for vivid description, that is mitigated to some extent in this project by the fact my participants will be educated to some standard by virtue of the fact they are teachers: a profession that requires a minimum standard of education. Some phenomenological research only focuses on understanding the lived experiences of participants and not the context in which it occurs (Willig, 2008). However, the purpose of my research project is specifically attempting to root itself in the wider conditions of the participants' – and my own - experience. As a result, it is not just about a person living with MS. It is what that also means as a teacher, in that profession, with those demands of the job and what it is about MS and teaching that people must think about when considering disclosure. My project explores the varied, wider conditions surrounding participants' experiences (whether located in past events, histories, or social-cultural domain).

Epistemologically, IPA is closely aligned with constructivism and critical realism given the connection they all make between discourse, social structures, and practices, but social constructionism is at the heart of this project. All the participants, and I include myself in that, actively engaged together in the creation of new knowledge and understanding relating to the localised field in which we are living and working. IPA enables the participants, through the extended data collection, as well as myself through analysing my autoethnographic material, to engage in a considerable amount of reflecting, thinking and feeling as we work through what it means to us.

As stated above, IPA advocates focusing on the individual nature of each participant's account and analysing that in detail prior to moving on to the next. I found this useful as it meant that I could concentrate on one data set at a time and attempt to explore some of the issues and themes raised within it in isolation. That also applied to the analysis of my personal journal and the extracts contained

therein. There is a helpful structure to the analytic process of IPA (helpful to inexperienced researchers, like me) which follows seven steps (Smith et. al. 2009).

They are:

- 1) Reading & re-reading
- 2) Initial noting
- 3) Developing emergent themes
- 4) Searching for connections across emergent themes
- 5) Moving to the next case
- 6) Looking for patterns across cases
- 7) Writing up

Once I had completed the three participant interviews, I began the process of transcribing them. This formed part of the first and second steps above and served to help immerse me in the data itself. According to Smith et al. (2009), there are no set rules to follow when starting to note initial thoughts, and for me it involved making comments on each transcript which then provided a series of descriptions to draw on when attempting to interpret the experience. An example of a transcript page can be found in Appendix 5. I often asked questions of the data, such as: *“Is it a case of forgetting, or are they purposely choosing to put it out of mind?”*, or *“How do they need to be prepared – mentally? Physically? Financially/practically?”*. Smith et al. (2009) also encourage researchers to take note of the text from a linguistic point of view, as this can often shed additional light on the meaning of an experience from the participant’s perspective. In this way, IPA has similarities to discourse analysis, and suggests analysis of discourse such as metaphor, use of pronoun (did the participant use ‘I’ to describe something, or ‘you’, which changes the emphasis?) and repetition, for example, if a participant keeps repeating a seemingly throwaway line such as “it is what it is”. This can be viewed as either a relaxed attitude to their experience or can be seen as a means of covering for uncertainty of what may befall them, and it is up to the researcher to explore the possible meaning behind this use of language.

In the third step, the development of thematic and conceptual codes can start to be grouped together into clusters. The patterns and connections made at this point mark the importance of the relationship between participant and researcher (Smith et al. 2009), and the interpretative outcome of the lived experience is a result of a joint perspective through this process. Step four involves mapping themes across the whole, overall data set for that participant, and looks for patterns, similarities, and connections. Once that has been completed, the entire process is then repeated for each participant data set (transcript). The idea of 'bracketing' is encouraged here by the authors, as they suggest that a researcher should attempt to bracket off the ideas from any previous data set. I knew this was a challenging thing to do throughout the IPA process, as not only would any researcher naturally continue to carry interpretations and internal biases with them throughout an entire research process, but that is magnified in my case due to my intrinsic involvement as a participant myself. However, I tried to ensure that sufficient time was left between the analysis of each participant data set to make sure the previous analysis was not current in the memory before starting the next. I attempted to enter each analysis mindful of the need to approach the analysis with a fresh pair of eyes with as little internal bias as possible, as much as I was able whilst acknowledging that I was unable to fully bracket off my own experience. Because of these measures, and the extended period taken to complete the analysis of each individual data set and the subsequent immersion with it as a result, I was confident regarding my attempt at interpreting each individual data set analysis. The sixth step then sees the researcher mapping connections and themes across the entire data set of all participant interviews and my journal entries. Through this process, I identified a series of themes and developed categories for intermediate themes and over-arching superordinate themes, and these are outlined in detail at the beginning of Chapter 4.

### **3.6 – Methodological issues**

#### **3.6.1 – Trustworthiness and Validity**

As a researcher at the beginning of his academic journey, I have concerns about voices within academic literature (O'Bryne, 2007) regarding the potentially

prohibitive need for a researcher to solely align themselves to a particular approach or method. There are those who argue that this drive for neatly defined research methods and/or methodologies is reminiscent of '*gendered dichotomies*' present within the discourse of the social sciences. As Burnier (2006) describes "*Personal, emotional, literary-poetic, and descriptive knowledge historically has been constructed as feminine, whereas scholarly, rational, analytical, and theoretical knowledge has been constructed as masculine*" (p.416). Whilst my choice of both phenomenology and autoethnography are different, distinct methodologies in their own right, I specifically chose them for a number of reasons. As outlined above in previous sections, they spoke to me in their own individual ways, they both offered something different, they complemented each other, and both contributed to the unique nature of my project. This synergy of two approaches is intended to provide a layered account (Ronai, 1995). The importance of the connection of self and others combined with a significant amount of personal reflexivity and analysis of participant data, will serve to strengthen the trustworthiness of the study.

There continue to be significant questions, whether within education or other disciplines, regarding the perceived legitimacy that is or is not granted to autoethnography and the general credibility of the genre as scholarly work. Critics seem to refuse to accept it as 'scholarly' on the narrow view that this type of highly personal, auto-biographic work simply cannot be assessed for its explanatory power, scholarly insight, or ability to cultivate social change (Holt, 2003; Muncey, 2005; Sparkes, 2000). However, the transferability and credibility (Lincoln & Guba, 1985) of my personal story contained within my thesis will be apparent to any reader (whether an academic assessing the work or someone merely reading it), and that they will see the "*use of narrative as a source of empowerment and a form of resistance to counter the domination and authority of canonical discourses*" (Ellis & Bochner, 2000, p.749). I use autoethnography to provide an insight into the social experience of being a teacher living with a chronic illness, and that simply cannot be observed directly (the experiences occur in their own time and in their own way). It cannot be recreated in an experiment or a laboratory, and the personal issues that are inherent in my thesis topic (such as illness and disclosure) are often too sensitive to discuss in formal interviews or survey research. However, as an

'insider', I have the unique ability to describe the nuance, emotion, and complexity of the experiences as I am living them (Adams et al. 2015).

This also applies to the participants who, like me, can give unique, first-hand accounts of what it is like to live and work as a teacher with MS as part of the phenomenological part of this project. Whilst there is difficulty for me realistically being able to 'bracket off' myself from the data and the process of collecting it from the participants, the fact I am acknowledging my central role in the meaning-making process as both an important and a valuable one strengthens the outcome of the project. Any interpretations I make of the data will be made alongside an ongoing alertness to my natural bias, and I will have had the ability to examine and consider my subjectivity throughout the entire project. Lincoln and Guba (1985) suggest using terms such as 'dependability' or 'consistency' when thinking about any interpretation gleaned from the data (rather than 'reliability') in a qualitative study. The aim should be, according to Merriman (1988), that any outsider will agree that the result of data gathered makes sense, is consistent and dependable. With any small-scale project (certainly in terms of participant numbers), any attempt at 'generalisability' is difficult. However, Eisner (1991) suggests that in a qualitative research project (such as this), the focus is more on the ability to learn from the experience of others, and that narrative provides an important and rich source for the reader to assess any degree of applicability to their own situation.

It is important to view both autoethnography and phenomenology through a different lens to that of traditional social scientific enquiry, particularly when using terms such as validity and generalisation. For both methods and methodologies, much is reliant on memory. Either the memory of the author (autoethnography) or that of any other participants (phenomenology). Memory is, to put it bluntly, fallible! Tullis (2013) suggests that it is not just difficult but impossible to describe phenomena, events or occasions in language that completely or exactly portrays for the reader how they were lived or felt by the author, and it is also important to recognize that people who share the same experience(s) will often describe things in very different, unique ways. The focus of generalisability in autoethnography is determined by whether the author of the work can shed light on unfamiliar cultural processes for the reader according to Ellis and Bochner (2000), and I suggest this

applies to phenomenology too. It is the reader that provides validation of any autoethnographic or phenomenological work by comparing their own lives to that being described, and by thinking about how and why they are similar or different (Flick, 2010). The stories or descriptions of lived-experience should inform the reader about unfamiliar people, lives, or experiences. As Ellis (2004, p.124) describes, autoethnography can be judged by whether it helps the reader to communicate with others different from themselves or offers a way to improve the lives of either the participants or reader, I would additionally apply this to phenomenology.

One of the reasons I was particularly drawn to autoethnography was the degree of flexibility surrounding the method and the approaches that I could potentially choose to adopt. However, this is one of the reasons that it maintains its critics. They cite this as reason for the genre lacking perceived academic rigour (Delamont, 2009). In contrast to this, Chang (2008) states that this flexibility and ability to adapt creates conditions that are best suited to projects or topics such as mine, and any insights that may arise as a result. The dual, complementary methodologies that I have chosen of phenomenology and autoethnography will strengthen the validity of my research project, rather than detract away from it, due to the addition of extra layers of data from my participants combined with my own. This layering of data should allow for greater academic rigour and enhance the trustworthiness of the research (Anderson, 2006). Ultimately, both phenomenology and autoethnography rely on a connection between what is being written about in the project and the person then reading it. The degree to which any of the issues discussed within my thesis are applicable to other teachers that are living with MS is something that will be decided on by those individuals. By paying attention to the context of the lived-experiences of the participants (including me, as author), anyone reading the thesis will be able to decide which elements of those experiences bear any relevance to their own lives.

### **3.6.2 – Ethics**

The issue of ethics was always going to feature heavily in a deeply personal research topic such as mine, particularly one that explores life changing illness for the participants as well as me as the researcher. There are numerous decisions to be

made throughout the entire process of a research project, regardless of any paradigm that has been chosen. Making ethical decisions (or decisions about ethics) will invariably involve tackling several dilemmas. Ellis et al. (2011) state that when we undertake or write research, we implicate others in it. The reason for that is simply that none of us exist in an isolated bubble. We have any number of connections surrounding us. Connections in our personal lives and our professional lives, and these communities are often intricately woven networks that span much further than any of us realise. According to Glesne and Peshkin (1992), qualitative researchers need to continuously define what it means to be 'ethical', given the process of developing relationships with participants. This relationship has respect at its core. Respect by the researcher for the researched, and for the privacy that needs to be protected. It is incumbent upon the researcher to ensure that any participants are not harmed, deceived, betrayed, or exploited (Burgess, 1989). The informed consent sought from the participants was an important first step in this regard, given the sensitive nature of the topics being discussed at interview, and I certainly did not want to place them at any risk of experiencing emotional stress additional to that which they may already be experiencing in their personal and professional lives.

There is a fine ethical line to be trodden during in-depth interviews when 'probing' for additional information from participants. Despite the driving goal to glean as much valuable data as possible, the issue of 'respect' comes to bear once more. The important need to respect the boundaries of participants during interview is outlined by multiple authors writing about the process of undertaking qualitative studies (Measor 1985; Cohen et al. 2000; Denzin & Lincoln, 2011). Cole (1991) says that *"Being careful not to overtake the interview, the interviewer at appropriate points, needs to ask clarifying questions, and both verbally and non-verbally demonstrate interest and provide encouragement for the informant to continue talking."* (p.201). It has been of the utmost importance that I maintain a high level of alertness during the interview process to each individual participant's comfort level whilst discussing sensitive aspects of their personal and professional life. It was a key part of each interview to give the participant the right to decide whether they wished to pursue certain elements of their experience or not, and to make sure they felt they had a level of control about the process and the stories they

wished to tell me. This was achieved partly using semi-structured interviews with only a limited number of pre-determined issues to discuss which allowed for the participants to go into greater depth on certain topics, but also through my sensitivity and awareness as an interviewer. I felt that all three participants were not only keen to share their experiences with me during the interviews, but that they appreciated the ability to discuss various issues surrounding their MS with someone that was able to relate to it, and this was reflected in the data by grateful remarks made by two of the participants in the interview data.

Allied to this aspect of ethical consideration, is the need for anonymity and confidentiality for the participants. Given the nature of the research topic and that the issue of illness disclosure by the participants was unknown prior to the interviews taking place, the use of pseudonyms and the replacement of names for places/employers was essential. It is also for this reason that full transcripts do not appear in the appendices, as I am not able to guarantee that the various transcripts (even with a degree of redaction) would not be identifiable back to the participants because of the personal detail about individuals, institutions and places included.

Autoethnography has its own unique ethical considerations, namely those relating to self as well as of others. As Chang (2008) questions, *"What of the safety of the researcher who is researched?"* (p.53). I am, as outlined in previous sections of this thesis, selective about who I choose to disclose my illness to, particularly from a professional perspective. By openly writing about it in this public, doctoral piece of academic work, I am choosing to potentially disclose to a much wider audience and one over which I have no control. However, I do this knowingly and after careful consideration, and I choose to do so because of the overall value I feel that my personal narrative brings to this project. That value exists in two main parts. Firstly, because of the illumination of the lived-experience that my own description can bring to the reader, and secondly, because of the increased connection between myself and the participants. This connection was, I would argue, of huge importance in eliciting rich, unguarded data from all the participants simply because they viewed me as 'one of them' and not an outsider. Despite this, Chang (2008) goes on to state that any individual's story is not made in a vacuum, and that others are always going to be a mixture of visible and invisible as part of that story.

Once I make myself visible (by writing about myself), it is then almost impossible to conceal the other people that are involved in my life story. Morse (2002) explains this issue by stating that other people are always present in self-narratives, either as active participants or as associates in the background.

Because of this, it was important for me to adopt Ellis's (2007) *Relational Ethics* when considering what to write about, or to include from my own previous (journal) writing. In my writing, I have taken care not to name many other people, be they friends, colleagues, or family. The two exceptions to this are extracts involving my wife, Emma, and one of my colleagues, Elly. The reason for including references to my wife is because of the effect that my illness has on thoughts, feelings and events to which she is inextricably linked. Accepting Ellis's contention (2009, p.308) that because I was already disclosing my own identity it would mean the identity of others connected to me would become transparent to the wider audience, I knew that Emma would be most easily identifiable even if I did not name her. I, therefore, had a discussion with her about the content of the extracts I proposed to include prior to their inclusion to gain her support to do so. The inclusion of events surrounding my colleague Elly are due to the close correlation of her battle with cancer that became a terminal diagnosis which saw her pass away in 2018, and for those living with a chronic, degenerative illness. Her attitude(s) to living with illness and how she viewed both life and death were inspiring to me and elicited a number of extracts in my journal when considering the effect of illness on the life of a person. Couser (2004) makes the important point that attention must be given to the ethics of writing about those who are unable to represent themselves in the text, or who are simply not able to give any kind of meaningful consent to their inclusion in the data by someone else. This is exacerbated if they are then being written about by someone they are involved with in a trust-based relationship. Because of this, I made sure to seek consent from another colleague (a friend of Elly) who had power of attorney for Elly at the end of her life, and from Elly's mother, to use any journal extracts that related to Elly. They were both very happy to grant permission and I feel that my personal story included in this thesis is all the richer for it.

### **3.7 - Summary**

In this chapter, I have outlined both the methodologies and the methods utilised within my research project, as well as my own personal assumptions and beliefs, namely the need for methodologies that are capable of eliciting large amounts of subjective, personal data from only a few participants (including myself as the researcher). I have made a case for the selection and use of both phenomenology and autoethnography within the qualitative paradigm, and I have also argued for their compatibility within the context of my research project. It has provided both justification and an acknowledgment of their strengths and limitations. I have described the analytic process employed for the participant data (Interpretative Phenomenological Analysis) and finished with a discussion surrounding trustworthiness, validity, and methodological considerations. The practical steps taken to address the significant ethical issues inherent in the project have been highlighted, and the following chapter will present the findings of the study which have emerged from the analytic process.

## Chapter 4 | *The Past (Learning to live with MS)*

### 4.1 – Introduction

In this chapter and the two that follow, I present the findings from my analysis of the interview data from the three participants, all of whom are teachers with a diagnosis of MS. In addition to presenting data from the three participants, I also incorporate analysis of my own personal journal to provide additional data through autoethnography. The journal extracts themselves are in the appendices due to the restriction of word count but are to be read in their entirety at the appropriate juncture of the chapter(s). Whilst combining my personal data with that from the participants might initially seem at odds, in Chapter 3 I made a clear argument that the use of both phenomenology for the participant data and autoethnography for my own allow for both. The intention is to strengthen the process of exploring lived experience, and the commonality of living and working with MS as a teacher gave rise to similar themes emerging from all participants, including myself.

As described in Chapter 3, I applied the principles of interpretative phenomenological analysis (IPA) to the data. Each of the three teachers who participated in the interview process did so knowing that they may relive some difficult memories or personal issues surrounding their health and careers. All of this provided me with rich data which enabled me to attempt to establish an understanding of their specific, personal experiences. In section 3.5.3 of Chapter 3 I outlined the process behind how each theme was conceptualised. That detail, combined with the findings contained in this chapter describe the decisions made during the various steps which led towards the construction of the themes. The iterative process of IPA necessitated a continual, active engagement with the data, and from this process I constructed and named the superordinate, main themes into which the other subordinate categories were put. The three main, temporal themes were:

- The Past | *learning to live with MS* (Chapter 4)
- The Present | *learning my place in the world* (Chapter 5)
- The Future | *learning who I am to become* (Chapter 6)

In Chapters 4 to 6 I present my interpretation of the interview data, and I present this with relevant extracts from the participant interviews to illustrate each theme. On occasion, I use individual quotes from a specific participant, but sometimes I group together several extracts from two or more of the participants where a particular point has been shared or identified by more than one. I also incorporate autoethnographic data into the themes to further strengthen the findings and outline the lived experience of another teacher with MS. I have utilised a different font for my journal extracts to mirror more closely the handwritten nature of my journal. Representing the handwritten aspects of my journal entries with a different font enhances the personal, autoethnographic nature of the writing, and more readily distinguishes it from the other data used in these chapters from the participants, as can be found in other thesis examples (Allbon, 2013). The language that appears in this chapter for labelling and analysing the various themes is mine and is a key factor in how I have conceptualised them. The subordinate categories do not appear in the order related to how the participant data was taken during interview or articulated in the autoethnographic extracts, but in a sequence that gives my analysis meaning relating to the different time periods in their lives spent managing MS and its impact, both personally and professionally. I have grouped the themes together to make sense of the various issues as they occur chronologically. As already mentioned in Chapter 3, section 3.6.2, all participants are de-identified and have been given a pseudonym to protect their anonymity.

## 4.2 – Themes

| Superordinate themes                | Subordinate themes                                        |
|-------------------------------------|-----------------------------------------------------------|
| Learning to live with MS (The Past) | Initial symptoms<br>Impact of diagnosis<br>Living with MS |

|                                              |                                                        |
|----------------------------------------------|--------------------------------------------------------|
| Learning my place in the world (The Present) | Disclosure issues<br>Relationships<br>Perception       |
| Learning who I am to become (The Future)     | Choice<br>Identity<br>Compatibility of MS and teaching |

The superordinate, over-arching themes were intrinsically embedded within the data to some extent for all three participants, as were the subordinate themes to some degree. The individual subordinate themes are discussed and outlined in this chapter, whilst also examining the commonality of the superordinate themes across them all. The idea of a person living their life echoing that of being on a journey is a discourse that has often influenced my own thinking. That naturally drew me to consider my own, personal journey, and how similar or otherwise it was to that of the participants. The iterative process as outlined in section 3.5.3 of Chapter 3 was instrumental in my formulating and constructing the themes above. It was a very gradual process undertaken on an individual participant level, with the common subordinate themes being those that were present across all three individual sets of data. These themes resonated with data from my own experience, and the overarching, superordinate themes based around temporality emerged from the participant data and my autoethnographic writing. Whilst I have attempted to group the subordinate themes into three, overarching, temporal, superordinate themes as part of utilising IPA, it should be acknowledged that there is inevitable overlap between these. I have grouped them in a way that makes sense of the data in a linear, chronological way.

However, as Deleuze (1994) argues in his *Difference and Repetition*, the notion of time as distinct and separate realms is false. These realms are inextricably linked, with the past and the future living presently in the here and now, and our past and present both informing the future as part of the “*eternal return*” (Deleuze, 1994, p.243). This idea of temporality is further interweaved into the research question surrounding disclosure of MS, due to disclosure – should it occur – featuring as an irreversible act along a linear, consequential timeline of a person’s life. The structure of ‘time’ is something imposed on all of us, and something we must

navigate and incorporate into our thinking surrounding actions such as disclosure. My intention when utilising these temporal realms, beyond honestly presenting themes that spoke to me as part of completing the IPA, was to attempt to provide a framework for the reader that allowed for a deeper understanding of the data and the issues at hand as experienced by the participants as they moved through their lived experience journeys, complexities of the temporal framing are returned to in the conclusion.

## **4.3 – Participant Profiles**

In Chapter 1, I outlined the personal and professional context behind this research project. Given the wider context of this study and the fact that it is examining the lived experience of a very limited number of individuals, it is of relevance to give a description of who they are to allow for a greater degree of context.

### **4.3.1 – Sally**

Sally is a 59-year-old mother of one adult son, teaching full-time in the preparatory school (aged 3-13) of an all-through aged 3-18, co-educational, independent school in South West England. She was diagnosed with MS when she was 38 and working in this same school. Sally is currently using Siponimod as the Disease Modifying treatment (DMT) for her MS, which is self-administered as a daily tablet. Sally currently has mild visible symptoms as her walking and balance are affected by her MS, but she does not currently use any kind of mobility aid (nor has she in the past).

### **4.3.2 – Lucy**

Lucy is a 43-year-old mother of two young boys, married, and working full-time as a class teacher in the preparatory school (aged 3-13) of an all-through aged 3-18, co-educational, independent school in South West England. She was diagnosed with MS when she was 34 years old when she was already working as a teacher in a Primary School. Lucy is currently using Avonex (Beta-Interferon) as the Disease Modifying treatment (DMT) for her MS, which is self-administered as a weekly injection, but is on a waiting list for a newer treatment called Ocrevus, which is

administered as an infusion every six months as an in-patient in a local hospital. Lucy does not currently have visible symptoms or use a mobility aid.

### **4.3.3 – Emily**

Emily is a 43-year-old mother of two young children, married, and teaching part-time in a state primary school (aged 4-11) in South West England. She was diagnosed with MS when she was 23 and applying to train to be a teacher via the PGCE (Post-Graduate Certificate of Education). Emily is currently using Avonex (Beta-Interferon) as the Disease Modifying treatment (DMT) for her MS, which is self-administered as a weekly injection, having previously used Copaxone, also a self-administered injection, which she had severe side-effect reactions to. Emily currently uses a wheelchair due to the impact of MS on her mobility and has been using one for over ten years.

## **4.4 – Initial symptoms**

Symptoms of MS are numerous and varied. Being a disease of the central nervous system (brain and/or spinal cord), it can affect speech, sight, memory, cognitive function, mobility, bowel functions and much more besides. As with any illness, serious or otherwise, one sufferer often deals with it in different ways to another. This includes at the initial stages of noticing symptoms. This can vary from periods of reflection and cognitive adjustment in relation to how the illness is affecting daily living (Courtenay, 2000) through to hoping for a better future if, or once, the symptoms subside (Nowakowski, 2016b). Much depends on the individual. However, through discussion with the participants in this study, there are several similarities which seemed to occur.

For example, Sally spoke about self-doubt creeping in when she started to suffer symptoms of MS, particularly regarding her safety and the safety of others, despite not knowing what was causing them:

*I had to stop driving because I couldn't work the clutch. I didn't have enough sensations to do it. I didn't trust myself because the kids were young. (Sally, p.3)*

Emily also referred to uncertainty when she first noticed symptoms whilst travelling in South America with friends:

*It was while I was travelling that I began to notice things weren't quite right, I didn't really know what it was. (Emily, p.4)*

Lucy described her initial symptoms coming and going, creating peaks of anxiety aligned with the ailment that would then dissipate with the subsidence of the symptom:

*I would lose sensation in a foot and I'd think 'that was weird'. Then just as I was starting to sort of worry about it, it would go away. (Lucy, p.8)*

This notion of hoping for the best amongst the “*emotional rollercoaster of illness management*” as outlined by Nowakowski (2016b, p.899) and, as a result, not wanting to or understanding how to deal with initial symptoms, is also something connecting all three participants in my study. Lucy and Sally were both in their 30s when they were diagnosed with MS, and Emily was in her 20s. As evidenced in the following statements by all three of the participants, they had taken their health for granted up to the point of experiencing unknown symptoms:

*I just thought 'oh, this is one of those things' and I just didn't really worry about it too much. (Lucy, p.6)*

*I had this weird sensation...on one side of my body...but I didn't really, sort of, worry about it. But with hindsight, yeah, that was probably all part of it [initial symptoms]. (Sally, p.2)*

*God, I was so naïve and I was young and, you know, you feel you're invincible, don't you? (Emily, p.6)*

As discussed above, the idea of distinct temporal realms of past, present, and future has its issues. One realm naturally informs another, and the discrete lines become

blurred (Williams, 2011). This is true for those with disconcerting symptoms of disease such as the participants in this study who have not been expecting to have to consider or cope with what those symptoms might mean to the next step on their life journey. It is what Bury (1982 and 1991) refers to as 'biological disruption', and what other authors such as Cardano (2010) and Bohlmeijer et al. (2011) go on to outline as a necessary part of life-long learning and meaning-making with regards to one's identity for people with illness. Both Lucy and Sally expressed a sense of uncertainty about the future when faced with their unknown symptoms because of how the past and present experiences of ill-health had informed their thinking:

*I was pretty scared because I thought it might have been that Motor Neurone one. So, when you don't know, you didn't know what it was. I was hoping it was nothing like that... obviously it was a worry. (Sally, p.3)*

*I think everybody had been looking at the symptoms individually, in isolation... and it was getting worse. And so then I started to get worried about it. (Lucy, p.9)*

As outlined in Chapter 2, the nature of teaching is such that a teacher is expected to work significant hours with the majority being on their feet resulting in the need for both physical stamina and energy (Alexander, 2010). Initial symptoms for all three participants included loss of sensation in one or more parts of their bodies, a breakdown of their bodily 'tools' as explored in Chapter 3, and for Sally it also included issues with balance and mobility when she was walking:

*My legs felt more weird to walk on. I don't know whether it was my balance as well that was affected or whether it was just because my legs felt funny. But people, you know, some people used to laugh at me. (Sally, p.2)*

For most MS sufferers, fatigue is an almost constant, underlying symptom (Green, et al. 2017) which is naturally juxtaposed with the physical demands of the teaching profession. Both Emily and Lucy spoke candidly about the effects of feeling this extreme tiredness as part of the journey towards discovering MS. For Emily, this was a gradual decline as part of various symptoms:

*I was just finding it too much. I was struggling to walk around the school. Really, really struggling to walk. And so I spoke to my Headteacher and, um, I just said 'I just can't do this. I can't do this anymore. It's too much'. (Emily, p.22)*

Whereas Lucy was enduring a difficult period in her personal life with her mother being seriously ill in hospital whilst she (Lucy) was also experiencing initial symptoms of MS without knowing what it was:

*In the summer of 2014, my mum got really ill. She was in hospital for three months. And so I was working full time and going straight from work to the hospital... staying with her in the hospital until they kicked you out at nine o'clock, whatever. Going home then trying to do some work for the next day. I went into a relapse because I was completely burnt out after about a month of doing that. I was exhausted. Not just... not just tired. Literally every time I sat down, I would fall asleep. I had no feeling in either of my legs. (Lucy, p.12)*

The road to diagnosis was different for Emily than it was for Sally and Lucy. The severity of her initial symptoms (loss of sensation in her legs, not being able to walk properly, eyesight becoming blurry) led to a relatively swift prognosis following a scan and other tests in hospital. However, in the case of Sally and Lucy, medical professionals seemed to focus on individual aspects of the disease in isolation. For example, Lucy was initially treated pathologically for an inner ear infection as the possible cause of her balance issues which resulted in an individual prognosis. This was rather than looking holistically at the various symptoms (including loss of sensation) that she was feeling to consider a more serious condition as the overall cause. As a result, diagnosis came much later for both of them, with the potential for unknown deterioration of disease severity due to no medication or treatment for MS being provided due to a lack of recognition and diagnosis of the illness.

This sense of uncertainty is commonly felt by many people when experiencing symptoms that may infer a more serious underlying problem, as Horlick-Jones (2011) noted in his study of cancer patients and their heightened sense of awareness of even mundane, every-day bodily sensations and fearing the worst. A

significant number of symptoms for a variety of serious illnesses (ranging from cancer through to MS) in isolation are not a cause for concern. Take feeling tired as an example. Because this is not something measurable or quantifiable in any objective way, it depends what any particular individual is either used to, prepared to live with, or to accept as normal (accepting that 'normal' is a subjective term anyway). Fatigue is often a constant underlying symptom that never really goes away for sufferers of MS (Green, et al. 2017). And by fatigue, I am referring to extreme tiredness. It is like having a battery that you can never fully recharge so that you are always running on some degree of empty, which creates tension with a profession like teaching that is widely accepted to demand energy and stamina (Patrick et al. 2000; Alexander, 2010; Kunter & Holzberger 2014; Holley-Boen, 2018).

Whilst this thesis explores the specific angle of compatibility with teaching, uncertainty and anxiety feature significantly for those awaiting diagnosis of serious illness as they contemplate the meaning of what may or may not lie ahead for them in all aspects of their lives, both personal and professional. MS disrupts an individual's lived experience, and the personal and professional are inextricably linked. An initial symptom being experienced by a teacher like Lucy or Emily outlined above, unaware they have MS, such as fatigue or dysfunction of one or more of their limbs, caused both a physical impairment to their ability to function as a teacher as well as creating mental anxiety about what may be the underlying cause and the impact it may have moving forward. The realms of past, present, and future are all linked. In the present moment of experiencing symptoms, there is anxiety and potential fear for the future and that is, in part, informed by experience from the past when dealing with other illnesses or through one's understanding of what these symptoms might mean obtained via external sources of information. I have situated this theme of initial symptoms in the past because it chronologically appears towards the start of the journey for the participants. They have discovered they have MS because of these various symptoms, and this is both worrying and disconcerting for the participants because symptoms of illness imply deviation from perceived normality (Foucault, 1976). Therefore, in experiencing a rupture with an anticipated narrative of their life course, the participants are compelled not only to

consider significant shifts in how they perceive the temporal realms of the self, but also of their professional identity as part of this process.

#### **4.5 - Autoethnographic analysis (*Hidden Symptoms*)**

In the extract in Appendix 6 from my personal journal, I am discussing the underlying MS symptom that I suffer from; fatigue and the effect it has on me as an individual, as well as the subsequent, wider effect that it has on my relationships with family at home. What this extract demonstrates is the inextricable links between experiences of chronic illness in the professional domain and experiences in other areas of life. In this case, family time is framed in relation to school term holidays and in relation to the high expectations for working long hours in my school setting. The extract has been taken from the start of a school holiday at the end of the Spring Term. The end of each school term is usually very busy for me with several school events taking place across a number of evenings adding to the already long school day. In addition, I have weekend commitments at school so there is very little respite away from school in the lead up to the end of a term. As a result, the overt sense of tiredness and fatigue that builds up culminating in a lack of physical ability or desire to do anything at all once term ends is significant.

In terms of analysis, I have used this extract as an example of the effect that hidden symptoms have on an individual with MS, both on themselves as well as those around them, including the enduring impact of fatigue. Hidden symptoms have, for me at least, created uncertainty as I reference in the extract: *"I simply don't know what I'm 'allowed' to feel, or think or say about my MS"*. Uncertainty for me as an individual not knowing what they mean or how best to handle them (Foucault, 1976), whilst at the same time having a desire to appear normal and healthy so as not to create undue worry or stress for my loved ones. Whilst this extract has been taken from a point in time after I had been diagnosed with MS rather than an initial symptom prior to diagnosis, it is an example of a common symptom – fatigue – experienced by many MS sufferers (Green et al. 2017) both before and after diagnosis. Fatigue is one of the symptoms most difficult to compare with another person. With a different symptom suffered by other participants like Lucy and Emily, such as visual impairment or weakness in a limb, there are comparative tests that can be completed formally or informally to evaluate the extent of any

dysfunctionality. That is much more challenging for a symptom such as fatigue. Therefore, it is very difficult to ascertain whether the level of tiredness for one individual is at a higher or lower level than another, and this is what makes it a phenomenologically rich aspect of the condition.

A critical analysis of my excerpt suggests resonances with the theme of visibility or otherwise of symptoms discussed in the literature review (Goffman 1963, Joachim & Acorn 2000, Fesko 2001). The lack of a visible symptom in this regard has affected me, as outlined previously in this section, on a practical level (physically struggling to function as I perceive I should be able to and making reference to *“feeling really tired”*) as well as a mental level (dealing with the subsequent feelings of frustration, anxiety, and guilt that I refer to at the end of the extract when I state *“And now, I have feelings of guilt, selfishness and embarrassment for even thinking that.”*). I acknowledge the fact that I have hidden symptoms in the extract, but also question whether visibility of symptoms might contribute to some positive outcomes on a personal level through increased understanding and acceptance from loved ones. It is not something that was articulated by any of the participants during their interviews. This might be the result of them either having more severe symptoms (despite still being hidden) than me already, or due to having communicated more frequently and openly about the symptoms with their family at the point of experiencing them as part of a pathological investigation to uncover the cause.

Through the iterative nature of IPA when examining my journal extracts, a further level of critical analysis in the coding of this data led me to focus on the fact that that I differ from the other participants regarding disclosure at home as well as in the work-place stems from my unconscious personal desire to conform to what society views as the masculine role in both environments (Butler 1990). Gender in this case overlaps with other aspects of symptoms explored thus far, inasmuch as symptoms such as fatigue, energy and visible/hidden symptoms are heavily gendered. I refer in the journal entry of wanting to be perceived by my children as a *“good dad”* and by my wife as a *“good husband”* at home, but that is also absolutely true of the role I want to fulfil at work as well. As Grytten (2005) outlined in her study of adults coping with the stigma of MS, one motive for concealing MS is *“to be associated with the ability to work which becomes the main symbol of*

*status... drawing attention to an identity as healthy, masculine and self-supportive.”* (p.237). The theoretical perspective from the literature (Goffman 1963, Butler 1990) reveals how this plays out in my accounting of this moment in my life, both at home and at work. However, the context of my home environment means that I feel a sense of security at allowing my MS to be ‘seen’, albeit gradually, whereas I do not feel that same sense of security at work, leading to greater concealment in that context at this time. It is through reflecting critically on the journal extract above that I can see with greater clarity how the desire to be normal and not be a burden on others is based on a normative discourse of the body and how it should relate to others (Bury, 1991). My ability to recognise this in turn denotes my sense of biographical rupture - the distance between what I had imagined and what I anticipate as a new reality because of the experience of chronic illness. This is similar to the experience of both Sally and Lucy, who were able to keep their MS hidden, whereas the situation was different for Emily who had visible symptoms very early on. As suggested by Foucault (1976), the power of normative discourses about the body are such that one may also feel, as in my case, emotions of self-blame or guilt, as the discourse works its way even into the self-perception of those most likely to see the limitations of the discourse or of the illness.

#### **4.6 – Impact of diagnosis**

Following on from, and related to, the sub-theme of initial symptoms felt by the participants, this next section explores the sub-theme of the impact of diagnosis on them. It was clear that receiving the diagnosis signified a turning point in the biographical discourse for each participant and, as such, has been situated in this temporal realm of ‘the past’. However, the extent of impact a diagnosis of any illness has psychologically or emotionally will very much depend on general outlook on life. Horlick-Jones, in his 2011 study of understanding fear of cancer recurrence in terms of damage to everyday health, outlines that *“coping with the impact of illness is an adaptive mode of cognitive reasoning”* (p.894). It is possible, for example, for someone diagnosed with terminal cancer to have a positive outlook on what remains of their life and to use the opportunity to live life to the fullest

degree they can, and I outline that exact mentality as observed by me in a colleague who was diagnosed with terminal cancer in Appendix 9 and 11.

Sally and Emily both considered having a positive outlook as important to be able to cope with a diagnosis of MS:

*I'm a very 'live in the day/moment' sort of person. I didn't really worry about it because, you know, you can't change things. (Sally, p.4)*

*It is what it is. You've just got to make the most of it [life] because, like you say, you could get run over by a bus! (Emily, p.41)*

However, in the actual moment of being diagnosed, all three participants felt a very real sense of fear and of the significance of the information being given to them. They were all working in schools at the time of their respective diagnoses and will have had to consider the impact that this new information about their health condition would have on their general ability to work, although only Lucy explicitly mentions 'work' as part of her reply:

*It's quite heart stopping, isn't it really? When they actually first say 'yes, you've actually got this disease'. It's quite...you know? Your heart goes doesn't it? You don't know what's actually coming. (Sally, p.6)*

*I did wonder whether I'd end up in a wheelchair because it was my legs that were the main culprit. (Sally, p.24)*

*I got the diagnosis and then I went to work the next day, but I was still... I was really shaken and it was still really playing on my mind, and I was quite upset. (Lucy, p.15)*

*They told me it was MS and I actually got confused and thought it was... well, they said Multiple Sclerosis and in the sort of haze of everything, I thought it was like Cystic Fibrosis. So, I was like, 'I'm going to die'. You know, that was my immediate thought, so that wasn't very nice. (Emily, p.7)*

As mentioned in the section above regarding initial symptoms, Emily had a greater severity of initial symptoms which seemed to result in a quicker diagnosis. However, she admits to not really having a deep understanding of the disease that she was being diagnosed with, and this will have been one of the causes of her anxiety about possible increased likelihood of reduced mortality:

*I just thought, hang on, something's not quite right here. Just my eyes, with my knee, my foot, and my balance was a bit dodgy in myself, so it's not right... and then within a week, I was diagnosed. I think they knew straight away what it was. But, you know, I don't think I'd heard of MS. I honestly don't think I had. (Emily, p.5)*

Lucy described how she also felt significant emotional impact at the moment of diagnosis, particularly in relation to possible future physical impairment and also possible reduced life-expectancy:

*I came out completely shocked that it was MS, and all I heard was 'reduced life-expectancy' and 'I could be in a wheel-chair in 10 to 15 years'. (Lucy, p.10)*

*I was completely devastated, because all I could think was how active I am, how much I love my sport....and how that was just going to ruin my life. (Lucy, p.11)*

Sally spoke several times about having a positive personal outlook, and this interaction between us during our interview outlines how the fact she viewed her diagnosis of MS in quite practical terms (rather than emotional) helped her subsequently with a diagnosis of cancer. This resonates with what Horlick-Jones (2011) outlines as 'adaptive reasoning' (p.894) due to the prior experience of learning to cope with MS having an impact on her subsequent cancer diagnosis. Here, she speaks of thinking through the various 'processes' of what she needs to do or is being advised to do following on from diagnosis, and I have included the full exchange between us due to the psychological link that was referenced connecting the diagnosis of MS and cancer:

Sally: *I used to say 'Oh well, I've got MS, that's fine'. You know, everyone has something, as least I've got it mildly and I haven't got cancer....and then I go and get cancer! [laughs]*

KPW: *And so, did you treat that, when that happened, with the same kind of positive mental outlook?*

Sally: *Because MS can't necessarily kill you....that was fine. Cancer can, and I was surprised by how calm I was about that.*

KPW: *Do you think having had a diagnosis of MS helped at all with dealing with the process of being diagnosed with something else?*

Sally: *Yeah. I mean, I just went through all of the processes. You know, you go 'you've got to do this'. Yeah. 'You've got to do that'. Yeah. I was surprised by my outlook I have to say, because that [cancer] is a different kettle of fish and it can kill you. But MS can't. So that was... that was in my mindset. OK, if you have to be in a wheel-chair, then you have to be in a wheel-chair! (Sally & KPW, p.19-20)*

The feeling of uncertainty about various aspects of the participants' lives following diagnosis, but particularly surrounding their professional futures, was summed up succinctly by Lucy as she spoke of her own lack of knowledge of MS and the impact it could have on her working life:

*I don't know legally if I'm supposed to disclose that or not... (Lucy, p.33)*

The descriptions of initial symptoms, the anxiety felt by the participants, and the subsequent diagnosis of MS with all the emotion associated with that impact, leads onto the section 4.8 which relates to how the participants have learned to live with their MS.

## **4.7 – Autoethnographic analysis (*Diagnosis*)**

The journal extract relating to my diagnosis of MS is long due to the profound impact that it has made on my life, and is found in Appendix 7. In the extract, I outline my memory of the day I was diagnosed with MS. It includes some of the initial symptoms that I had been experiencing as well as the exploratory testing I had to undertake which led to the diagnosis. The extract covers several of the

themes which have also been identified through participant interviews. These include symptoms, aspects of my identity, fear of the unknown, practical consequences of the diagnosis, emotions, and impact of receiving the diagnosis. Even though diagnosis is situated at the beginning of the chronic illness journey for me and therefore sits in the temporal realm of the past, in my extract I was concerned about what impact the diagnosis might have on the present and future. It contains descriptive, evocative language and, along with the analysis that follows here, forms part of my authentic, autoethnographic voice in this process. I vividly remember where I was, as you can read in the extract, and how I was temporally situated both physically and emotionally in the moment. My experience of this particular day receiving a diagnosis of MS is part of my 'being', my very existence. This temporally situated experience which radically changed my sense of 'self' that occurred in my past continues with me in the present and will also continue to do so into the future. As Deleuze (1990, p.162) outlines as he describes one portrayal of time, it is like that of 'chronos' – the idea that only the present fills time. The past and the future are two aspects of reality to the present, and my diagnosis of MS is now simply a part of who I am in every temporal realm. It took multiple iterations through the IPA process of my personal journey entry to come to this understanding of the complex temporal nature of diagnosis both as a punctuated moment in the past, and as a moment that resonates into all future moments. Analysing my entry in these terms also revealed resonances with both Sally and Emily who speak about temporality, and as Lucy suggests regarding her concern for the possibility of being in a wheelchair in *"10 or 15 years' time"*, the fear of the future because of diagnosis is real for us all. The implications of this finding for the professional context are that diagnosis is at once a fixed punctuation in the past, but also something that resonates through every moment of professional life in the present.

This extract outlines the significance that I felt being diagnosed with MS. In it, I reference the fact that I was unaware of the illness and what it meant on a practical level: *"Neither of us knew anything about MS. It was just one of those things you hear of when the hot-potato topic of assisted-suicide cropped up in the media, and there was usually an MS patient with no quality of life at all wanting to be allowed to go to Dignitas in Switzerland to die"*.

During the journey to diagnosis, I attended various medical appointments and, in similar ways to Lucy and Sally, the medical professionals spent time ruling out various other possible illnesses first. At no point had anyone mentioned MS to me as a possibility. Why not? Perhaps that is the default position of the medical profession to not hypothesise to prevent undue anxiety. However, potentially by an individual not being provided with the spectrum of diagnosis possibilities associated with their symptoms, they are likely to cause exactly that which they are seeking to avoid – anxiety. In this current age of instant information being accessible via the internet and mobile devices, it is common for individuals to self-diagnose, often incorrectly, leading to additional anxiety and stress (Ryan & Wilson, 2008). An explanation from medical professionals right from the start at the initial consultation to outline the various possible illnesses they are testing for might enable a patient to ask questions appropriate to their individual circumstance and symptoms, and lead to a greater degree of understanding and reduced anxiety. In addition, it could prevent the feeling that I describe in my extract of getting a significant diagnosis (of a chronic illness) unexpectedly.

I had convinced myself – incorrectly – that I was undertaking all these tests and attending appointments that were going to lead to nothing of any significance from a health perspective: *“It had all come from, well, nothing really. A strange sensation in my legs when I flexed my neck forward. It wasn’t particularly painful or disabling, just a little disconcerting, that’s all. Kind of a cross between pins and needles and a loss of sensation. Just enough to make me think ‘hmmm, that’s a bit odd’, but nothing else”*. When I received what I felt was a very sudden diagnosis completely unexpectedly, I did not know how to deal with that information.

That same sentiment was echoed by all three participants when they received their diagnoses too. A sense of shock and of not knowing what MS was or meant for them. All the participants articulated that they assumed they would end up in a wheelchair due to their limited knowledge of MS as an illness and the perception of its severity in relation to occurrences in the mainstream media. I can see, analysing this extract detailing my own journey to diagnosis, that various external forces – including various types of media – have potentially played a role in

encouraging me early in the process to anticipate normality despite undergoing tests for something out of the ordinary such as MS. This is similar when comparing my excerpt to the data from the three participants, who all equally cited initial fear of MS stemming from their limited knowledge gained from external forces. The discursive power of normative expectations about the body mean that even when confronted with the process of being positioned as 'abnormal', there is a tendency to resist this positioning or – alternatively – to experience the fear derived from this discourse (for example, that all illness must signal the worst case scenario).

The overwhelming sense of the unknown for what MS suddenly means to a newly diagnosed patient, allied with a limited, often incorrect, understanding of the potential or probable extent of disease progression, had led all the participants as well as me to assume the very worst. This has ranged from being in a wheelchair, to passing MS onto future children as a hereditary disease, through to reduced life-expectancy: *"So many things filled my head – am I going to die? Am I going to be able to carry on working? Can I still drive? How long am I going to have to live my current, normal life? Am I going to become one of the patients outside the door of this little room stuck in a wheelchair needing Emma to push me round? Even worse, is she going to be lumbered with taking care of my every need – clothing, washing, feeding? Going to the loo, even? Christ, this isn't what she signed up to when she married me. This doesn't just ruin my life, but all those of the people around me. What about my unborn daughter currently growing innocently in Emma's womb? What if I don't have the use of my body – arms or legs – to be able to hold her, hug her, play with her? Be a normal dad?"*.

The reality is actually very different. All those things are, of course, possible and one of the participants (Emily) is currently a wheelchair user. However, new treatments are being developed all the time and most people with MS manage to lead long lives with no shortening of life-expectancy because of the disease. Looking back and analysing my response to this whole process in the journal extract, it is clear that I would have valued greater communication throughout from the medical professionals, and that would have enabled me to start to consider the options available to me on a personal and professional level should I have been diagnosed with MS (which, of course, I was). Lucy, like me, was also uncertain about

what the diagnosis meant legally from an employment point of view, and that added to the sense of anxiety for us both.

The 'othering' (Charmaz, 1991 and 2002) impact of diagnosis of any chronic illness such as MS is significant, and the magnitude of this othering discourse is clear to me when I analyse this extract from my journal. Diagnosis includes a variety of emotions for the person and their families, as well as practical considerations for what it means moving forward (physically, and on a personal and professional level). However, I have concluded - from speaking to the participants in this project as well as analysing my own memories from my journal – that for most individuals being tested for MS, the impact only occurs at the end of a pathological process where other possible illnesses are gradually being ruled out. The way in which this process - in the cases explored here, whether short or lengthy - is handled by medical professionals, to consider the lived experience that the individual is going through at each step of the process and not just the final diagnosis, might be significantly improved with greater communication throughout.

## **4.8 – Living with MS**

Having situated the initial symptoms experienced by the participants and the impact of the subsequent diagnoses chronologically, I have also included this section on living with MS as the final part of this chapter. As outlined previously, one could argue that living with MS could also be situated in the present. However, I have focused on the way in which the participants have learnt to cope with some of their symptoms, the treatment of these and additional symptoms that have subsequently emerged. How the participants manage their chronic illness daily depends on two varying factors (Courtenay, 2000). Firstly, their mental attitude, and secondly, the severity of symptoms, and both of these factors are strongly linked to the participants' perception of their ability to function normally in the professional realm. As noted previously, Sally spoke several times about having a positive mental attitude to life which also stretched to her view of MS. For example, here she is describing initially being seen for tests and a likely prognosis of MS:

*It's all a bit 'matter of fact', sort of thing. You go [to a doctor or specialist] because you've got a problem. I mean, they send you there to see what it is. So, that's fine. Then I guess when they said it could be MS... it's a long time ago now. It's hard to remember your exact feeling about it at the time. At no time did I ever have a breakdown... have a cry about it. I know that much. (Sally, p.13)*

The impact of the news that Sally was likely to have MS has not left a lasting memory for her. She spoke very openly about wanting to continue as normal until something prevented that from happening. She recognised this lack of anxiety in herself during the interview process:

*Quite blasé aren't I?! I don't really care...[laughs]! (Sally, p.9)*

*I joked to the kids that I'm going to be one of those OAPs with incontinence...[laughs]! (Sally, p.21)*

Sally was careful to balance up this positive mental attitude with an acknowledgment that the future is still uncertain, but because of that uncertainty, she felt strongly that it was important to live in the moment:

*Yeah, I... there's no point in worrying about what might happen in the future, you know, because you're wasting your life. So I go out and do everything I want to do. I make the most of it really. You don't know when you won't be able to... (Sally, p.23)*

In terms of the potential impact of severity, Sally does not have severe ongoing symptoms and has had no new symptoms beyond those that caused the initial investigation and diagnosis earlier in her professional life. Here, she discusses how her positive attitude would potentially be rather different if her MS affected her more severely than it does:

*I just get on with it, because it hasn't actually affected my work. So, it hasn't actually been a problem and life is just always as normal. So, if it got to a stage where it affected my work... well, I think that is a different... mindset. And it might*

*affect me more because I'd probably be more frustrated by not being able to do something. In fact, very frustrated actually, thinking about it! Yeah, I would be if it was stopping me doing stuff. (Sally, p.20)*

That overt admission that Sally's relatively positive mental relationship with her MS would be significantly affected should any symptoms prevent her from living what she perceives to be a 'normal' life is echoed by Lucy. Here, she is first describing her symptoms:

*Every other step I trip [when running], and I have to really think hard about 'put the foot down, put the foot down'. I have to concentrate really hard on this leg, and if I'm quite far from home I just have to stop and walk, but there are quite a few times I've tripped and fallen in the road. I have to be quite careful about where I run now because, yeah, it's easy to lose control quite quickly. All of a sudden. Then I lose coordination, balance. Everything. (Lucy, p.13)*

These MS symptoms having a detrimental effect on Lucy's perceived 'normal' activities then proceeded to have a more significant emotional impact on her as a result:

*I used to come back from netball and just felt really down and really depressed and want to cry, because I could see my symptoms more obviously and I would feel really down that I couldn't play netball like I used to be able to do. (Lucy, p.14)*

She further articulated this sense of anxiety about what the future may hold regarding MS impacting on life for her when she was referencing another person that she knew with MS whose symptoms were more severe:

Lucy: *She's always just been really open... um... which I haven't. But actually, at some point, I think I will have to be.*

KPW: *If and when it affects you more severely?*

Lucy: *Yes. But not at the moment! Not yet, not yet, not yet...!*

KPW: *Not yet?*

Lucy: *We're not ready yet. (Lucy, p.41)*

This reference to 'we' was both Lucy as an individual, and also her and her family. She wants to continue living her life, albeit with MS, as normally as she possibly can for herself and for her husband and children. Whilst I discuss relationships in more detail in the next theme of 'the present', I refer to family and children now since in the early stages post-diagnosis Lucy lacked an awareness or understanding of what the potential impact of her MS diagnosis would be on them.

All the participants have children, but Sally's are older now whereas both Lucy and Emily have had young, school-aged children since suffering from MS symptoms in their early adult lives. Lucy described needing to consider carefully whether to try to be in the same work (school) environment as her teacher husband so that a ready-made support was on hand for her should MS issues arise:

*So, then I was like 'what do I do?'. Do I come with you or carve my own thing out [at a different school]? We went back and forth for ages, and then I eventually thought, 'well, if we're going to have children, then it makes sense if we were all in the same place'. (Lucy, p.19)*

For Emily, the early part of her adult life learning to live with MS was impacted by a lack of knowledge and awareness of the disease and the effect it could have over a wide variety of aspects of her life:

*I don't know that I did ask many questions [at the point of diagnosis]. I honestly didn't know what to expect. (Emily, p.8)*

Sally, on the other hand, had an awareness of the scope of the disease at the point of diagnosis and her description of the impact is noticeably different:

*Because MS can't necessarily kill you... that [accepting the diagnosis] was fine. (Sally, p.20)*

The varying degrees to which the participants had either existing knowledge of MS, or were made aware of the scope of MS with regard to possible symptoms over

time speaks of a potential inconsistency of approach by the medical profession in these cases. This may well be due to the unique nature of the illness and the fact that it can present significantly different symptoms from one person to the next. That, allied with the fact that the medical profession does not often like to deal in hypothetical situations (but just fact, as outlined earlier in this thesis as part of a 'normative' approach to healthcare), suggests a possible reluctance to give a newly diagnosed patient with MS the full picture of what might happen to them for fear of creating unnecessary anxiety over symptoms that may never occur (Ryan & Wilson, 2008). Here, Emily is explaining her current symptoms of MS, whilst referring to the fact they have all worsened due to the fact it is degenerative:

*Lots of other things that were there at the start have just progressively got worse. So, my balance is awful. My left leg is pretty much... doesn't work. My left arm, I can sort of lift up a bit. Dexterity isn't great. I had optic neuritis again one more time. (Emily, p.16)*

Several different physical symptoms affected by MS and experienced by the participants have already been outlined and quoted above. Some symptoms cause problems that some people find difficult or embarrassing to discuss, with one such example exemplified by Sally when discussing bladder issues caused by MS:

*Actually, one of the things [symptoms]... probably too much information... but I always want to go to the loo. When I want to go to the loo, I have to go to the loo! (Sally, p.21)*

The urgent desire to use the loo is a common symptom for many MS sufferers, and one that often progressively gets worse (Cosh & Carslaw, 2014). As a hidden symptom, it can provide a level of anxiety about suitable facilities that are readily accessible in the workplace as well as when trying to navigate day-to-day life (for example, working on a floor of a building without a toilet nearby, going shopping or travelling long distances in a car on a journey). This lack of forewarning about how and when any (or all) of your MS symptoms may affect you daily, is a part of the general anxiety felt by MS sufferers due to the unpredictability inherent with the disease.

Pain and fatigue are two more common symptoms negotiated by participants in this research, but both can very readily become debilitating to the point of a person's inability to continue to function in their normal daily lives. This idea of normality being subjective to each individual (Wood et al. 2007) is typified by a discussion with Emily surrounding living with pain as part of the MS medication she is on. If a seemingly healthy person (with no other underlying health condition) were to have a bout of flu, and with it the muscular aches and pains associated with that virus, the probability is that they would find the pain so debilitating that they needed to rest and certainly take pain relieving medication. Emily spoke of her MS treatment, Avonex (Beta-Inferon):

*Avonex gave me quite horrible flu-like symptoms. I can cope with that. It's once a week if I do it before I go to bed and just take some paracetamol. Flu-like symptoms in the grand scheme of things, aren't really that bad. (Emily, p.10-11)*

I also used to be on the very same MS treatment and describe the effects of taking the medication in the exact same way in the next journal extract following this section. Lucy is also currently on the same medication (Avonex), and further describes the flu-like symptoms that she experiences:

*Sometimes I take it [Avonex] and I get really cold, really shivery. Can't get warm. Feels like all my muscles ache. (Lucy, p.26)*

Avonex is a weekly injection, and these common side-effects are something you learn to accept. However, that – in itself – is an extraordinary burden that MS sufferers on this treatment have to bear. If having flu (and, therefore, flu-like symptoms) is a significant negative health event for those healthy people with no under-lying health conditions who get it, then - by extension - having to accept and learn to put up with these symptoms on a weekly basis for MS sufferers is a significantly more detrimental event, particularly when the side-effects impact on your ability to function effectively at work as well as home. However, Emily describes it above as not being 'really that bad' simply because of the advanced state of her MS and she is making comparison of flu-like symptoms to the severity

of her multiple other MS symptoms. So, not only are there the physical side-effects of medication to contend with on a regular basis, but there is the mental anxiety that comes with the anticipation of those very side-effects (Gottberg et al. 2000). Whether you are an inherently positive person or not can only temper all this to a certain extent. The physical pain of the flu-like symptoms is felt by all, even if some individuals try to use a more positive mental attitude as part of the daily (or regular) management of their MS so as not to allow fear or anxiety about potential pain (or other side-effects), however likely it might be. Emily spoke about her negative experience with a different MS treatment, Copaxone, also an injection (taken three times a week), and how this led to changing treatment back onto Avonex:

*I remember I sat there [points to an area of the kitchen], did it [took the injection], and then I just suddenly said [to my husband] 'Something's not right'. And literally, heat just came up my body slowly. I started sweating. I went red and I just had to shut my eyes and breathe. And then, sort of five, ten minutes later, I was sick. He said 'do you need me to call an ambulance?'. I was like, 'no, no, it's OK'. I had a dodgy stomach and then I went up to bed. It was ten o'clock, so I was going on the way up to bed just after I'd done it, as I usually would be. Got into bed and was shivering and... oh, it was horrible. Absolutely horrible. So, now I'm going back onto Avonex. (Emily, p.10 & 11)*

The impact of the side-effects of MS treatment seems to be significant, both in terms of the physical effect it has on the participants, but also because of the need for them to factor in how best to manage coping with it as part of their day-to-day existence, including at work. As she described above, Emily factored in her taking of MS treatment prior to going to bed to try to 'sleep off' some of the symptoms. It is both the illness and its treatment that impact significantly on teacher perceptions of their ability to do the job, and also the ways that they might feel they possibly need to mask both their symptoms and symptoms of treatment. For example, Lucy also referred to scheduling her injections around when her teaching timetable was lighter as it put her in a position to cope with the negative reaction more easily:

*I was taking it [Avonex injections] on a Monday night, because my Tuesday was quite an easy day. Yeah, so I had to, sort of, plan it around my easy day. (Lucy, p.26)*

So, it is not just the symptoms of MS that are a factor in the daily lives of the participants, but the management (treatment) of those symptoms, and the impact on learning to live with MS that that may have as a result.

Fatigue was highlighted earlier as a common initial symptom that often plays a part in an initial discovery or diagnosis of MS. I also highlighted it as a symptom I must also manage in one of my previous journal extracts. For some, this is a constant symptom, and for others it might be something that comes and goes along with other symptoms (Cosh & Carslaw, 2014). In a recent publication by the MS Society of their members' magazine, titled 'MS Matters', there was a double page spread of quotes from some members (with MS) that they use to describe aspects of their illness to others. This is how one lady, 'Danielle', described fatigue as an MS sufferer:

*I explain fatigue as like when your phone battery is low. You have to think about how to use it. When it's low, you can't waste it on things that will run it down quicker (usually the fun stuff!). (MS Matters, Spring 2022, Issue 140)*

Fatigue has a significant impact on all aspects of an MS sufferer's life. Clearly, the physical demands of professional work need negotiating to whatever extent they may exist. However, day to day life also demands a certain amount of physical exertion, particularly if, like Lucy, you have a young family, or, like Sally, you live on your own and must run your own household without help from friends, family or carers:

*Before having children, I would take it at the weekend [Avonex injections]. But now having two children all weekend is harder than working! (Lucy, p.26)*

*Yesterday, when I was hoovering and cleaning and everything, my legs were tired. It's like running a marathon [laughs]! I don't feel tired in myself, but my legs are tired. (Sally, p.14)*

Each participant has several physical symptoms that they have learned or must learn to live with as part of having MS. Alongside this, the various treatments they are on, or have been on in the past, come with a different set of physical side-effects that they must learn to factor into their daily lives. However, Lucy spoke of the motivation to keep persisting with taking her MS medication despite the significant side-effects, because of seeing the severity of MS symptoms affecting another MS patient she knows:

*It's a kind of... almost motivation to keep going with the injections because of what could happen. To try and stay as well as possible for as long as possible. Because, you know, she can't look after her boys, she can't teach anymore, and I can see what's in the future [for me] when I see her. (Lucy, p.41)*

This spectrum of severity of MS and how it affects different people, aligned with their own individual mental attitude to dealing with it was inherent during the discussion with the participants. On the one hand Sally, like me, has relatively mild symptoms and they are all currently hidden. She and I share a certain amount of guilt surrounding having MS because we are both aware there are others who are affected much more severely by it. Here, Sally describes this feeling despite the fact she had spoken to me at length about various symptoms that she lives with (as outlined in this chapter), such as fatigue, mobility issues and incontinence issues:

*I always feel a bit of a fraud... because I haven't really had any bad relapses, and you think 'oh, did they get it wrong' [being diagnosed with MS]? Yeah, I feel a fraud. (Sally, p.21)*

Whereas Emily, who is in a wheelchair due to the severity of her MS, spoke about the inherent difference between her visible and my invisible symptoms during our interview:

Emily: *You just don't know [how severely someone is affected by MS] ... because it's degenerative, but to what extent? How do you know? You've had it [MS] for 11 years and you wouldn't know it [to look at you]. I've had it for 17 years and I'm in a wheelchair. But then, for the first 10 years, you wouldn't have known I had it, so you just don't know.*

KPW: *It's so personal in terms of what it means and how it affects us. Because you could have identical symptoms to somebody else in a wheelchair and you probably do, but because of your positive outlook on life, the way you choose to live your life is a completely different thing to the next person.*

Emily: *Yeah. I'm... this is... I've been... as far as I'm concerned, I've been dealt a very crap hand and I'm not going to let that get in the way.* (Emily, p.41)

For the participants, there seems to be a feeling that they are expecting the degenerative nature of the disease to become apparent at some stage, almost like an inevitable destination stretching out ahead of you in the future. There always seems to be someone else that has more severe symptoms or disability than you. I perceive an enduring expectation after diagnosis that one should experience the authentic (or worst case) version of an illness rather than any variation on a broad spectrum. This might contribute to the power of discourse about normal health.

All three participants have described having a positive mental attitude towards their MS despite the spectrum of symptoms shared between them all, and this seems to enable a degree of accepting living within a 'new normal' (or learning to cope with living with their own individual MS symptoms), despite the looming nature of potential disease progression on the horizon.

## **4.9 - Autoethnographic analysis (Fatigue)**

In this extract from my journal, found in Appendix 8, I outline not only the symptom of fatigue which I have described previously, and which has also been highlighted as a challenging, debilitating symptom by both Sally and Lucy, but also the treatment that I was receiving (and self-administering) for the management of my MS. I outline some of the detrimental side-effects caused by the medication which contribute to a lack of physical and mental well-being all linked to taking the

medication. The phenomenological approach utilised through IPA in this thesis has been important to help understand the subjective qualities of symptoms (such as fatigue) experienced by individuals. This has been valuable since there was a clear link to perceived requirements of a “good teacher” of energy (Alexander, 2010), passion (Serin, 2017), stamina (Holley-Boen, 2018) and enthusiasm (Patrick et al. 2000; Kunter & Holzberger, 2014) in the review of literature in Chapter 2. It seems that all the participants have acknowledged they lack this requirement due to fatigue, along with myself in this extract.

The extract raises various issues to do with learning to live with MS. Namely that fatigue – a common symptom for most MS sufferers – is not measurable or comparable. It is not possible for me to know whether I am more or less tired than anyone else: *“Surely everyone is tired? Everyone who has taught all week is tired, right? All my colleagues on the EdD that have worked all week and now done a day of lectures must be really tired too, surely? Is what I’m feeling ‘normal’, or do I have it worse than others because of my MS? Am I ‘extra’ tired and have ‘the right’ to feel my cross is much larger to bear than others?”*.

Given that it is a hidden symptom and I choose not to widely disclose my MS to many people, am I focused so much on keeping symptoms hidden so as not to allow disclosure that I am doing this to the detriment of my own health? This would certainly seem to be in keeping with the literature referenced in Chapter 2 surrounding ableism (Butler, 1990), the importance of performance in the workplace (Ball, 2021) and not wanting to deviate from perceived societal norms (Williams, 2000, Lyn, 2021). Lucy and Sally both discussed fatigue taking hold of them to a physically debilitating level, but they have been more open with their family members about their MS than I have. I have not disclosed to my children because I do not want them to worry, but it means that I must constantly explain away my lack of desire to take part in various family activities because I feel tired. As a result, they do not understand why I seem tired all the time. So, my desire to protect them is potentially creating a different set of problems with them viewing me as ‘less than’ in a different way: *“I want to shield them from the unnecessary worry and burden of knowing I have MS (how would they possibly understand what*

*it is anyway...?), yet it perpetuates the feeling they will increasingly have that I am not as fun as other dads."*

Secondly, Lucy spoke in her interview about using the same (Avonex) injections for her MS medication that I was put on. She seemed to suffer from the same physically detrimental side-effects as I did, notably that of flu-like aches and pains combined with temperature fluctuations. As I outline in the extract, I used to dread taking this medication every week because of the way it made me feel: *"It hurt tonight, the injection. Don't know why, I guess it is luck of the draw as to the exact spot in your leg you do it - but it was a sharper pain than usual tonight, and more sore than usual afterwards too. This is exactly why I don't enjoy it and want to get it out the way. I also dread my existing physical tiredness and the aches in my body as a result being compounded by the forced additional aches and pains from the injection."*

I was (am) always so tired and often achy in my muscles, that the thought of having to inject myself knowing that it would compound these existing symptoms causing a lack of sleep and additional pain was genuinely quite depressing. I do not use that term lightly, I do mean depressing (as in causing me stress, anxiety and making me feel 'down'). It was so confusing that the medication supposed to be helping me seemed to be, at least on the face of it, causing more harm than good: *"It is so utterly frustrating. I crave sleep. My body and my mind both need to rest, and the thing causing that need is also the thing preventing me from actually being able to achieve it. It is so frustrating, and makes me feel so helpless."*

The discussion with Lucy hearing her similar experience with the medication was, in many ways, a relief. Having to learn to live with the experience of my symptoms and the medication that was prescribed for them by medical professionals was a lonely existence. I felt confused (not knowing how I was supposed, or allowed, to feel about it all) and very alone, despite being surrounded by family that love me. Discussing it with someone else that had experienced similar feelings, experiences and emotions gave both of us a sense of reassurance. As Kever et al. (2022) outline, loneliness is often experienced by people with MS, and felt more so by those who choose not to disclose. This is due to the unique nature of the symptoms, many of them hidden, and the concern that others may not understand the symptoms and

the ways they manifest in different individuals. Also concern surrounding the uncertainty and anxiety that is associated with experiencing these symptoms and that others might not understand the uncertainty or anxiety being felt. To be able to discuss it with someone that understood that similar lived experience was a positive outcome from my interview with Lucy for both of us. This reflects the ableist discourse (Goffman, 1963, Butler, 1990) inherent in our society, and the fact that this contributed to an emotion of loneliness and isolation for both me and Lucy before we were able to communicate openly about our shared experiences through the research interview.

Thirdly, I mention navigating work commitments during the extract. I outline the fact that it had been a 'usual busy week at school' with lots of extras such as concerts and other events to attend with the pupils: *"I'm exhausted. Not just tired, but exhausted and entirely 'spent'. It's been a usual busy week at school (lots of extras like taking various kids to the local performing arts festival and our summer serenade, etc), and I've just spent the day in Oxford for the EdD too."*

This is an important part of teaching. As outlined in Chapter 2, the expectation of teaching is not just what you do with pupils in a classroom. It is all the extra facets of education you provide for them with trips, clubs, activities, and other events to further enrich their learning that is an expected part of the profession (Gupta, 2022). Not every school is the same, and I teach in a private school where the extra-curricular life of the school (everything that is offered outside the classroom) is considered just as important as what is offered inside the classroom. My normal working hours are 7.30am through to at least 6pm when clubs and activities finish, and we have weekend commitments too. I fully expect that all my colleagues at school, as well as those working full-time and completing a doctorate like me, would also describe themselves as tired at the end of a week too. Chapter 2 outlined the expectation for teachers to have energy, stamina and enthusiasm (Patrick et al. 2000; Alexander, 2010; Kunter & Holzberger 2014; Holley-Boen, 2018). So, if feeling tired as a teacher (particularly a teacher at my specific school) is 'normal', then how am I supposed to know whether the MS makes it worse? And, if it does, how am I supposed to quantify how much worse it makes me feel? The answer is, of course, that I cannot. This normative societal culture (Charmaz, 1991;

Vickers, 2001; Ball, 2021) as identified in the literature review means that schools seemingly thrive on a discourse of tiredness and relentless pace. Ironically, the prevalence of discourses of both tiredness and energy in teaching take away the opportunity for those with chronic illness to claim 'tiredness' on their own terms (for example, they cannot articulate the additional challenges of extreme fatigue versus 'normal' tiredness). This, then, is doubly disempowering to those with chronic illness, and the idea of 'covering' (Joachim & Acorn, 2000) for a person with illness is linked to what Dyck & Jongbloed (2000) outlined in their study of MS in the workplace – namely that fatigue is often misunderstood and misinterpreted by colleagues, and often leads to negative workplace experiences. Therefore, I continue to not disclose my MS but without knowing whether that is ultimately to the detriment of my future health moving forward (because I am attempting to do and cope with what I perceive to be 'normal'; the same as all my colleagues).

#### **4.10 – Summary**

This first chapter of findings from the data has focused on initial symptoms experienced by the participants and myself which have led to a diagnosis of MS. There have been some shared symptoms, such as fatigue, as well as other physical dysfunction, such as numbness, loss of balance or foot-drop, which has differed for each of the participants. The severity of the symptoms has had an influence on the speed with which the participants have been diagnosed. Emily, for example, who suffered relatively acute initial symptoms, was diagnosed with MS quickly. However, both Sally and Lucy were tested for various illnesses before ultimately receiving their diagnosis. My own experience was like that of Sally and Lucy due to having mild symptoms initially. However, whether the diagnosis was quick or after a lengthy period, all the participants spoke of the significant mental impact of receiving their diagnosis of MS. The awareness of what the illness was and the extent to which it may affect an individual was misunderstood by all three participants, and by myself. A lack of communication throughout the medical process leading up to diagnosis, as well as at the point of diagnosis arguably led to greater anxiety and initial, unfounded, concern for well-being, life-expectancy and perceptions of future career. In the final part of this section, I have sought to outline the ways in which the participants have tried to learn to live with MS. This has

included their developing MS symptoms, examples being Emily in a wheelchair unable to use various limbs, Lucy experiencing debilitating fatigue, and Sally experiencing bowel and incontinence issues. They have also spoken of their experience of taking medication, with Emily and Lucy both describing significant negative side-effects with differing MS medication. I have included extracts from my own journal outlining my own experience of living with fatigue, detailing my journey to diagnosis of MS, and in two of the extracts discussing the effect of MS symptoms (fatigue in my case) on my wider life as a teacher, as well as my personal life.

All these themes I have situated in the past for the participants and myself, whilst acknowledging that aspects of the themes (such as any discussion of symptoms) will be both very present as well as potentially in the future. However, these are all issues related to MS for the participants and myself that we have had to learn to initially live with, to enable us to then be able to navigate further and learn our place in the present world. They are aspects of daily living that affect our professional and personal lives, and have required management by us all to be able to learn what our place is in the world, both as a teacher and as a person with MS. What this chapter shows is that the experience of chronic illness in the professional domain is profoundly impacted by how it is experienced or 'lived with' in other domains (for example, discourses outlined above about gender and masculinity, and about energy and fatigue). These embodied qualities of chronic illness exist with all of us (myself and the participants), and how they manifest themselves with influence over our relationships, perception of self and others, and disclosure, are all explored in the following chapter.

## Chapter 5 | *The Present (Learning my place in the world)*

Having explored how MS was discovered and subsequently diagnosed for each of the participants and myself, and discovering how each of us have learnt to live with MS in the past, this chapter of the thesis seeks to establish what MS means for us now in the present time (when the interviews took place). During the interviews with the participants it was clear that each of them had issues surrounding disclosure of their disease. Disclosure, and the illness itself, has an impact on relationships, and from a professional perspective the role of perception - both the participants' and my perception of ourselves, as well as others' perception of us - seemingly plays a significant role on how we view our MS, how we attempt to navigate the sphere of work and who we disclose to. Some aspects of these themes do not discretely fit inside this temporal realm of 'the present', for example some of the issues surrounding disclosure for the participants will have occurred nearer the point of diagnosis. However, I have included them in this section because they refer to issues of disclosure predominantly on a professional level and, as such, have formed part of the ongoing journey learning our current place in the world as teachers with MS.

### 5.1 – Disclosure issues

The in-depth interviews with the participants, and subsequent analysis, provided a valuable opportunity to ascertain the extent to which disclosure issues outlined in the literature were borne out in the experiences of the individuals involved. This includes the participants' desire to appear 'normal' (Kirsh, 2000), their own and others' perception of illness and how those influence both thoughts and actions (Vickers, 2001), and the type and strength of the participants' various relationships, particularly in a professional context where loyalty and support is not assumed in the same way as with personal relationships (Robinson et al. 2003).

In discussion with Sally, there were initial suggestions that she viewed her diagnosis as negative which had a bearing on the use of language surrounding disclosure. For example, she referenced that it was '*fortunate that it happened... over the Christmas holidays*' (Sally, p.3) rather than whilst at work, and went onto say that:

*Fortunately, I didn't have another bad one [attack] where everything was visible outside. A lot of the time it was just... the sensation... I felt it.* (Sally, p.6).

In these early episodes of the disease affecting her, Sally references feeling 'fortunate' that it was hidden and that she was not at work when it happened. This echoes the findings in Fesko's (2001) study which found employees feared to disclose chronic illness due to the uncertainty of their ongoing employment prospects and discrimination at work. However, it is the fact that the symptoms were hidden that meant that Sally was unsure how to feel psychologically, almost to the point of thinking she was being dishonest in some way:

*It just makes you feel a bit weird because you carry on as normal and no one knows... you know... that you're feeling weird. Feeling different. And it's not quite... things aren't as they should be.* (Sally, p.7)

Perhaps it is because of the unpredictable nature of the illness allied to the unknown course on which it may take you in the future, that people do not know how best to disclose, either personally or professionally. As outlined in Chapter 2, an individual's outlook on life – positive or otherwise – clearly has some impact on how they choose to live with the disease (Pakenham, 2007). Sally views herself as a positive person, as described in section 4.8, and so when she decided to disclose to her children (who were around the age of 10), she told them the bare minimum:

*I just told them I had MS... so I said that maybe now and then I'll be walking funny or whatever. But apart from that "everything's fine kids! Nothing to worry about!". So, yeah, I told them I'd got it, but I didn't go into detail.* (Sally, p.8)

It could have been their relatively young age that dictated perception on Sally's part of a potential lack of understanding from her children. What is not clear is whether

Sally's reluctance to openly disclose to her children is just due to their young age, or whether her reluctance is a commonality for all her relationships – personal or professional. For example, when Sally's MS was discovered by her employer through an accidental disclosure from her husband, not only had she chosen not to disclose up to that point but also her description of how she felt was candid:

*A bit embarrassed, I suppose. I probably wouldn't have mentioned anything yet. It's one thing telling friends and family, but people that you're not as close to in a work environment is a bit different. (Sally, p.10).*

She references two distinct groups of people when describing disclosure. Firstly, 'friends and family' as one group, and then people who you work with that you may not be as 'close to'. The strength of relationships for someone with a chronic illness plays a part in the decision to disclose (Robinson et al. 2003), as discussed in Chapter 2. For Sally, her partial disclosure to her children contrasts with her initial decision not to disclose at all to her professional work colleagues. The disclosure at work for Sally actually happened slightly by accident. Her employer had rung her home number to ask to see her in school about a work matter during the school holiday, and her husband had answered the phone. As she describes it:

*He wanted to see me and [my husband] was at home and he told him "oh, she's at [the hospital] having an MRI scan. I'll text her and she can call in after that". So obviously when I called in after, he knew I'd just been for an MRI scan. (Sally, p.9)*

This led onto a conversation where the employer asked Sally why she had been for an MRI scan, which then led to the disclosure about the symptoms she had been having and the likely diagnosis. That control over disclosure was removed for Sally, and not by her own volition. The decision to 'come out' in her own way and at a time of her choosing was taken away from Sally, thus causing her to lose a sense of empowerment and ownership of her personal situation (Castells, 1997). I would suggest- given the experience of Sally - that disclosure in the workplace is affected by complex power relations (Follmer, 2019) that traverse the private sphere of the family and the public sphere of the workplace. Early in our discussion, we talked

about her original feelings surrounding possible disclosure at work and how she had felt about it:

*You don't know them on a personal level... I don't know that I was worried... well... worried? Embarrassed? That's not quite the right word, but it's how to start the conversation at that time, because it was all new to me. (Sally, p.10-11)*

However, she later referenced the fact that, due to uncertainty surrounding the how, where, when of disclosure to others, it may have actually been of benefit to her that the disclosure to work (in part by her husband) had been accidental as it removed some of this potential anxiety;

*Yeah... because [my husband's] got a big mouth... (laughs)! Would I have told him [my employer]? Would I have been so open about it [my MS]? I don't know. Because it's about having that first conversation. I'm quite shy. I don't... I'd have found it quite hard to bring up, I think. So that fact that I didn't really have to made it a lot easier. (Sally, p.18)*

As Williams & Healy (2001) outlined in their study of the disclosure of health problems, a person with a chronic, hidden illness is often conflicted about whether to disclose or not. This is because the person suffering from the chronic, hidden illness may want or require the understanding of an employer due to accommodations being needed, whilst at the same time being concerned about the possible stigma that may be associated with it moving forward. Lucy felt ill-equipped to deal with disclosure professionally due to a lack of knowledge or awareness on her part:

*I don't think it's ever crossed my mind that I should tell people, that I should tell them [work]. I think "I've put it on the medical form... that's my bit done!" (Lucy, p.24)*

That sentiment was echoed later in our conversation when I asked Lucy about possibly choosing to disclose to a future employer:

*I know, I said I didn't think I would. I didn't think it would occur to me to tell them. I don't know legally if I'm supposed to disclose that or not....* (Lucy, p.33)

As outlined in section 4.8 examining my autoethnographic extract regarding diagnosis, both Lucy and I have articulated uncertainty surrounding the professional consequences of our MS diagnosis. Whilst I was told at the point of diagnosis that I was under no legal obligation to disclose my condition, that is only because I specifically asked that question of the medical staff. Lucy has not received the same clarity and, as evidenced in our interview a significant number of years after diagnosis, she is still describing a lack of knowledge and awareness regarding any obligation to disclose to a future employer. It seems that at the level of institutional policy, most schools do not seem to have planned or proactively articulated such provision to staff with chronic illness because it simply is not associated with teaching in our current, ableist society (Goffman, 1963, Butler, 1990).

Disclosure was not such an issue for Emily as part of her first job, as the Deputy Head was a family connection and already had prior knowledge of Emily's MS diagnosis, which is an interesting finding in so much as this provision was purely circumstantial and not planned or provided for. The particular nature of teaching as a profession makes the blurring of personal and professional domains more complex as they so often overlap - with colleagues becoming friends, for example. This notion of the strength of relationships, personal and professional, having an impact on a decision to disclose (Robinson et al. 2003) is echoed further by Flockhart (2001) in her study of the experience of teaching with MS. She states, "*for a teacher with MS, one's decision to disclose or withhold having this disease may take into account her own comfort level with the people involved*" (p.179). For Emily, already having someone on the senior leadership team of her school aware of her MS diagnosis, provided this sense of comfort and this contrasts with Sally, who had to rely on an accidental disclosure to force a conversation with her employer that she would not have otherwise chosen to have. However, Emily and I still discussed this issue of what to say, to whom and when as part of going for a job, and Emily – either through lack of knowledge of the disease herself, or hoping that the impact on her life would not be significant – chose not to ask for any

accommodations to begin with or offer up descriptions of how MS affected her, even though she had already had serious physical episodes leading up to diagnosis:

KPW: *[if the Deputy Head didn't already know] would you have disclosed in the same way as part of your application?*

Emily: *I remember having a chat once that they had offered me the job. I remember her asking me "so how does this affect you?", erm, "how would this affect you at school?", and I said "it won't at the moment".* (Emily, p.20)

It is interesting that Emily had the difficulty of having to disclose to an employer removed from the outset (as they already had prior knowledge of her medical situation), however she chose not to go into much detail. When I asked her about that and how she dealt with disclosure moving forward in the school post she was appointed to, she explained that disclosure happened gradually as her symptoms worsened:

*I think because things happened quite slowly, it's a gradual decline. I think I just spoke to people as and, you know, when it comes.* (Emily, p.28)

Emily described that she felt positive as a result of more of her colleagues knowing and that she had disclosed to them over time;

*I felt good actually. I felt really....it wasn't like a release, but it was just like "right, it's out there, everybody knows".* (Emily p.29)

That seems to typify the main issue surrounding disclosure for all of the participants - that of not wanting to hide their illness and making it 'visible' (Goffman, 1963; Joachim & Acorn, 2000; Fesko, 2001) but at the same time, not knowing how (or when, or to whom) to disclose. All three participants have made reference to wanting job security, or to be a known quantity to their managers or colleagues before making a disclosure:

*If I were going for a new job, I wouldn't mention it. Just because... if I'm going for a job, I haven't got it yet so they don't need to know. Once I got the job,*

*because of my circumstances when I don't relapse very often, I might not even tell them at all. (Sally, p.16)*

Lucy: *I remember saying [to my husband about whether to disclose MS to an employer] "do I tell them? They don't know me. They don't... nobody knows me."*

KPW: *What was your fear about that?*

Lucy: *I don't know. Just that they might think that I can't do things or that they might think "oh, I've given her this job. Oh no, she's damaged" that kind of thing. And maybe that they would regret employing me? (Lucy. p.20)*

*I don't want them to know straightaway... I don't want them to judge me straightaway. (Emily, p.18)*

The confidence or extent with which the participants have felt able to disclose to someone, personally or professionally, seems very much to depend on the strength and type of relationship that they hold with that person and the political or power dimensions of the relationship in a professional context. This is in line with the findings of Joachim & Acorn (2000) who outline the prevalence for a patient suffering with a chronic illness to choose not to disclose for fear of stigma. Another possible influence in this regard is the actual person themselves, in that the person disclosing reproduces an internal discourse of ableism (Butler, 1990) because that is the discourse they expect from others. In section 5.2, I will explore the nature of disclosure based on different relationships held by the participants, including those of a professional nature in a school workplace.

## **5.2 - Autoethnographic analysis (*Disclosure/Credibility*)**

In my journal extract found in Appendix 9, I share the interviewees' unease about disclosure on a professional level to colleagues, based on my own concern about being professionally credible in my job. In the extract, I refer to a close musical colleague of mine who was dealing with a terminal cancer diagnosis of her own, and for whom relationships were brought into stark relief towards the end of her life.

This journal extract is clearly very personal on a number of levels. However, in many ways it speaks to the heart of this research project. Yes, there are aspects of illness which are quantifiable and measurable (taking a temperature, limb function, memory tests and more). However, with MS there are so many embodied, subjective symptoms – partially due to being hidden – that are not measurable in the same way. It is up to the individual to disclose. Or not. The symptoms may well be physical or cognitive, but it is also impossible to quantify how a person is feeling emotionally due to the impact of their MS. The lived experience of a person with MS is intrinsically much more multi-layered than just listing physical symptoms, and it is this holistic view of the illness for teachers with MS that I am exploring. As Carel (2016) outlines in her *Phenomenology of Illness*, chronic illness is extremely subjective and, therefore, seemingly difficult for others to comprehend. The type of relationship has an impact on the decision to disclose because we make assumptions based on the nature of relationships about the possibility or otherwise of comprehension, and I will examine this theme in more detail in section 5.3.

As I have described in this extract, I have previously made the choice not to widely disclose to professional colleagues, because of what Gabe et al. (2004) and Charmaz (1983) have noted as a reluctance to be viewed as different, or less than. However, I accept that completing this thesis is, by extension, a form of disclosure. It is by re-reading and casting a critical eye over my extract that I begin to move beyond the mere description of desire for ‘credibility’ as a teacher working amongst colleagues and start to explore my emotional response to that desire to not be ‘othered’ (Richards, 2008). As Bourgoin & Harvey (2018) outline, gaining professional credibility amongst colleagues is at the forefront of most people’s minds, whatever the profession: *“So, for me in my professional life (as both a musician and an educator), the over-riding concern is one of ‘credibility’. Can I ‘walk the walk’ as well as ‘talk the talk’?”*.

However, in the above quote my desire to obtain this credibility and lead by example to my music department colleagues is juxtaposed with my deteriorating physical ability to do so, both in relation to dexterity at the piano and with fatigue: *“But I want, so desperately, to cling onto as much of my musical skills and abilities as I can before they get taken away from me for good.”*

The things that I personally refer to as symbolic of normality in the extract, such as the *“ability to do my job”* generate an emotional response regarding my experience of living through that discourse in relation to being a teacher living with a hidden illness. My own writing, in this case, adds to the societal discourse outlined above in section 5.1 regarding what qualities individuals with illness themselves regard as ‘normative’ (Vickers, 2001; Ball, 2021) and to which they are trying to adhere. Elly, my colleague who passed away, was not able to hide her terminal illness and I refer to her being *“at peace”* with her situation as a result. Even in this extract alone, it is clear to me that I am purposefully pushing myself – quite possibly to the detriment of my long-term health - despite my illness in order to both hide it and retain what I perceive to be credibility amongst my professional teaching colleagues: *“However, I feel that I cannot, therefore, show or reveal any weakness (musical; through diminished technical cognitive ability, or physical; through fatigue) for fear of being seen as ‘less than equal’ and thus reducing my ‘credibility’.”*

As a result, and unlike Elly, I am not – yet – at peace with my situation or illness because of the internal tension I have between my own perception of what a teacher ‘is’ in this normative, ableist society (Butler, 1990; Williams, 2000; Lyn, 2021) and my desire to not be ‘othered’ (Goffman, 1963; Charmaz, 1983; Richards, 2008) as a result of my MS. I am, therefore, still seeking the most suitable path to follow regarding disclosure.

### **5.3 – Relationships**

As outlined in Chapter 2, MS is an often-misunderstood illness, and each of the participants have expressed uncertainty about aspects of their illness – whether understanding symptoms, future disease progression, the effect on their professional lives or medication. If, as individuals suffering from the disease, we do not fully comprehend the scope and severity of the effect MS has on our lives then it is virtually impossible to expect others to do the same in our professional workplace environment. That seems to be at the root of so many issues surrounding having MS on both a personal and professional level for the

participants. For example, Sally described the initial reaction to her diagnosis from her mother:

*As soon as my mum heard that it could be MS she just went into tears as one of her cousins had MS, but primary progressive, whatever it is, but was in a wheelchair so that's all she could think about.* (Sally, p.5)

Sally went on to explain her mother's negative reaction was due to the assumption of the severity of MS due to personal knowledge of someone else (her cousin) with the disease:

*But that's because she knew someone and how it could end up like that [being in a wheelchair].* (Sally, p.7)

Lucy had a similar experience with her family members at the point of diagnosis, but this reaction then subsequently improved through greater explanation of the disease and what it actually entailed for her:

*I told my family straightaway, and my mum and dad were quite upset as were my brothers. But I think that a lot of that was they didn't really know what it was. And also, you think 'MS equals wheelchair', that's what you think, right? So my family were upset until they researched it a bit more and I explained it a bit more.* (Lucy, p.13)

Emily had a more positive experience, and described her family being supportive whilst acknowledging the seriousness of the diagnosis:

*We're a pretty strong family. I think it was quite a shock to them, but they were great. Everybody was there for me.* (Emily, p.8)

Relationships are always bound up with symmetries of power and solidarity (Diefendorff et al. 2010), of relational agency (Edwards, 2005) and care of others and the self (Foucault, 1988a). There is both a dynamic of power mixed with intimacy, depending on who it is a person has a relationship with – whether in the

workplace or in private. For those of us with MS, part of the potential anxiety is the balance shifting away from our perception of an equal relationship as it moves towards our reliance (gradual or more immediate) on the other person or people in our lives. On a personal level this is difficult, as you are often wanting to protect your friends and family from feeling burdened with the knowledge and reality of your MS diagnosis. The reaction from friends and family is very mixed, as outlined above through participant experiences. However, as the person with MS, it is very easy to assume your loved ones are feeling or thinking about it in a particular way when, in reality, they are not. In the examples above participants regularly signalled the interplay between personal relationships and the professional realm. In another example, Lucy outlined her surprise when her husband articulated needing to be cautious with a financial insurance pay-out in case Lucy was unable to work in the future, when that was not something she had considered herself:

*But quite soon after that [MS diagnosis], I had an insurance pay-out because I had critical illness insurance cover, and so I was like “what are we going to do with this money?”, and [my husband] said “you can’t do anything with this money, because you’re going to need it if we need to adapt the house, or if we need to...”. And that hit me... absolutely hit me like a ton of bricks... that he’d even thought about it... and he was already thinking “she might not be able to work”, “we might need to adapt the house”. He was one step ahead of me thinking further down the line. I think, really, I thought that “that won’t happen to me, this is how I’ll always be”. (Lucy, p.11)*

Whilst the participants have all described close family members showing and offering support for their MS diagnosis, albeit eventually for some, following initial shock or misunderstanding, it has the potential to lead onto a feeling of dishonesty between loved-ones. Is the danger that one party or the other seeks to hide away feelings or thoughts they may have surrounding the impact of MS? The situation can easily arise when the sufferer themselves attempts to minimise the detrimental effect of the disease to their loved ones, not wanting to appear more of a burden than necessary. Equally, as above with Lucy and her husband, the close family member may be having thoughts about the impact of the disease (actual or potential) without wanting to or, possibly, knowing how to raise the issue with the

person that has MS. It becomes an ‘elephant in the room’ and, as soon as one member of a relationship has seemingly not openly discussed an anxiety, fear or just a desire to understand more about the situation, it causes the other person to assume discussions cannot be had or are not wanted. The intersubjectivity of the nature of chronic illness (Carel, 2016) means that the phenomenological perspectives of the participants, as explored in this project, have been allowed to come to the fore and this allowed them a voice which has not always been used in other situations (Richards, 2016).

All social relations are political in some way and contain balance of power issues. As a result, someone disclosing MS to their children (or other loved ones) does not want them to be over-anxious about it because they – as the adult – are supposed to be the carer and responsible one in the relationship. This is outlined by Richards (2016) in her research describing her reluctance to disclose chronic illness to her family *“perhaps I did not want to alarm and depress my family any further”* (p.238). It is also about the politics of identity (Charmaz, 1983; Bury, 1991) linked to one’s social relations with others, and one’s relationship with wider normative discourses (Vickers, 2001; Ball, 2021; Lyn, 2021). Whatever the reason, how close someone with MS is to the person they disclose to undoubtedly has a bearing on the detail and depth of the disclosure. As summed up by Sally in her participant interview, she delineates the ease of disclosing to family and friends as opposed to work colleagues:

*Sally: It's one thing telling family and friends, but people that you're not as close to in a work environment is a bit different... because you don't know them on a personal level. (Sally, p.10)*

That uncertainty about the reaction from work colleagues was echoed by Lucy in her interview. She had already told a close work colleague and had a positive experience with support from that person, but it led her on to wonder whether other colleagues at the school knew, including her Headmaster:

*I was comfortable with her and comfortable with her knowing, and in that context I didn't mind at all. But it did make me think “does the Headmaster know?”*

*and “if he doesn’t know, will it affect him if he does know?” kind of thing, and “why doesn’t he know?”. (Lucy, p.22)*

The distinction between professional and personal relationships can become blurred when a person develops a strong personal relationship with someone from a workplace setting (Dutton, 2007). For Lucy, it was the strength of the relationship that she had with a close colleague that led to her initial disclosure at school. The colleague, a teaching assistant who worked closely with her every day when Lucy was the class teacher, could see the way Lucy was starting to struggle and the effect (physical and mental) that MS was having on her:

*I couldn’t go on anymore. Yeah. And my TA [Teaching Assistant] who knew and obviously was seeing me every day, sat me down and said “you can’t go on anymore, I can see it”. (Lucy, p.32)*

Lucy’s Teaching Assistant colleague understood her well enough to be able to talk openly about disclosure and seeking help. It was not just a case of her simply knowing about Lucy’s MS, but understanding the detrimental effect it was having on her lived experience and that something needed to be done. It is worth noting here that relationships, and the ability to cultivate them, is an often-overlooked part of the teaching role. Whilst, as outlined when reviewing the literature, the perception is that exertion and stamina are fundamental to being a teacher (Patrick et al. 2000; Serin, 2017; Holley-Boen, 2018), being a teacher is also deeply affective and about human relationships too (Edwards, 2005; Tormey, 2021).

During my interview with Emily, she used a phrase that struck a chord with me when discussing the issue of relationships for someone with MS. It is something that I kept returning to in my analysis of this excerpt, and – as above - was essentially a well-made point distinguishing the difference between someone knowing about MS (or that you have been diagnosed with it) and understanding what it actually means in reality. That difference between knowing and understanding something is at the very heart of this thesis, and Emily touched on it when she described the reason behind why she chose to disclose to her whole staff room at the same time:

*I wanted to do it, and I wanted all the staff to be in as well... they probably would have known because teachers talk! They all would have known, but I just wanted them to understand. (Emily, p.29)*

This conversation followed on from an earlier one in which Emily was outlining the interaction that she has with colleagues who ask her about MS and its effect on her, but she stressed the importance of wanting them to fully understand the limits and difficulties MS places upon her:

*They do ask about how it [MS] affects me and things, yeah, and I'm quite open with that. I almost... I want them to... to just appreciate how difficult it can be sometimes because they just see me as this – you know – happy, smiling person who gets on with life, and actually sometimes its bloody hard! And I kind of want to let people know that. That it's not easy. (Emily, p.26)*

Emily actively wants her colleagues to understand the complexities and difficulties that MS has on her lived experience, rather than simply knowing that she has the disease. Relationships can, often, be compassionate when it comes to disclosure whether personal or professional (Munir et al. 2005). However, the traditional hierarchical structure of power in a school (a board of governors, a Headteacher, a senior team and a raft of middle management positions), in parallel with other organisations, does not always allow for the same level of compassion and understanding due to the numbers of people involved at various different levels and the danger of the accommodations needed being misunderstood or misinterpreted (Frndak et al. 2015). As Ball (2018) suggests, one way that colleagues know each other in a school environment is through specific taxonomies of audit and identification (e.g. test scores, assessments, records), and this way of 'knowing' someone professionally might not require or seek any 'understanding' of their wider, personal context. Emily had elected to disclose in the staffroom, but still found that the complex structures of hierarchy, power and accountability in the school led to situations which could take agency away. For example, she referenced this very issue when describing an incident where her Head's personal assistant had

told her of the Head organising a mobility scooter without having a conversation with Emily about her mobility:

*What's funny, actually, is my Head suggested to our school office administrator at the time about getting a scooter for me, but didn't say it to me! So she [the school administrator] said to me "oh have you spoken to [the Head] about the scooter?", and I was like "no, what scooter?". He didn't know how to broach the subject with me. (Emily, p.30)*

So, for Emily, whilst the supportive intention was admirably there from her employer (in this case, her Headteacher), her own personal voice was not anywhere to be found in the process. It was a taboo subject that her Head did not feel able to discuss with her, despite wanting to offer help and support. As Flockhart (2001) has suggested in her study of teachers working with MS, an ideal situation would be for a school Principal (or Headteacher) to have "*knowledge of the disability and a sensitivity to it*" (p.179). However, that is not going to be possible unless a disclosure is made and the employer already has a knowledge and understanding of the disease. In Emily's case, it could be argued that her Headteacher did have a knowledge of her MS and attempted to do something to help on a practical level, but they showed a degree of insensitivity due to not communicating with her about her specific needs in the process. In their study of women with MS and employment issues, Dyck and Jongloaed (2000) found that employers were more likely to make modifications to the workplace for an employee with MS if they had proven themselves to be a valuable employee over time. In addition, they acknowledge that employees in a public sector job rather than the private sector, such as a teacher like Emily in a state school, are more likely to receive accommodations to enable them to remain in the workplace. That has been the case for Emily, despite her not requesting the modification herself. This further outlines the complexity of relationships within the workplace (Dutton, 2007), and how difficult the choice to disclose has been for our various participants.

The uncertainty surrounding how someone that you interact with views you as a person with MS, particularly regarding the ability to fulfil various aspects of one's job, extends to a number of different relationships. For example, Emily cited a

period of her early teaching career when working alongside other staff who seemed to accept her limitations because she was outwardly making every effort to involve herself in the activity at the time:

*No problem [with me or my effort at work from my two colleagues] at all, because they could see I was keen and enthusiastic, you know? I love rugby, so I was trying to play rugby with them. I just couldn't run or do the warm-ups and things like that. But I was trying to get as involved as I could. (Emily, p.19)*

In addition to colleagues, Emily outlined the relationship that she has with parents at her school who she cites as being grateful for her efforts when taking their children for tennis at school:

*I was a tennis coach, so I always take the tennis team and I take them in my wheelchair. They [the parents of the pupils] are always very grateful that I've made the effort because obviously they can see it is an effort. I've spoken to the tennis parents and they're always really.....yeah, and I used to play wheelchair tennis as well, so I talk to them about my wheelchair tennis. So, they're always quite good, you know, because I've given their children an opportunity to play tennis. (Emily, p.30)*

Am I surprised by the fact that parents are showing gratitude to Emily for taking the tennis team from her wheelchair? No. No, I am not. As someone with MS myself, I can fully imagine the effort that Emily is putting herself through to give time to that activity for those children, and this resonates clearly with an ableist discourse (Butler, 1990) for someone like Emily who does not want to be 'othered' (Richards, 2008). More than that, though, would I be surprised if the same parents would prefer their children to be coached by someone who was not in a wheelchair? No. No, I would not be.

There is an argument to be made – given the power of parental perception in a school environment (Gupta, 2022) – that the relationship that Emily has with those parents at her school is one based on gratitude due to pity, rather than one where the parents view her in the same way as they would someone without any visible

disability. The issue of perception is significant here, and one that I explore in section 5.5 of the thesis. In asking the various questions above, I have offered an insight into my own perception of my ability and the ability of others. The perception of colleagues, school parents, our own family and friends all come into play when making choices about disclosure allied to the type and strength of the relationship held between that person and the person with MS.

The final issue to address here in this section regarding relationships, is the fact that the participants expressed an appreciation to me – as the interviewer – because they were grateful to be able to discuss MS and their lived experience of having it with someone that understood. As a fellow teacher who is living with MS, I have made aspects of their own life discourse visible and provided a context for them to tell their story. For example, Emily remarked about this when we were discussing the compulsion (or not) to take medication for our MS:

*I'm glad you said that, because I do things like that and then my husband's like "you need to take it". Well, you don't have to take it! (Emily, p.12)*

This goes back to the discussion earlier in this section regarding the difference between someone knowing something versus them truly understanding it, and what that thing or experience means (Terry, 2020). However close the participants may be to their spouses, partners, friends or family, and however much they attempt to be open, frank and honest about how MS is affecting them it is almost impossible for someone who does not share that lived experience to fully empathise, imagine or understand (Carel, 2016). They might *know* that the person with MS feels tired because of fatigue and because they have openly said so, but unless they have ever been subject to an illness where fatigue is so debilitating you cannot really function (cognitively or physically) at all, then they cannot truly *understand*. A person may well *know* that the MS sufferer has an issue called 'drop foot' which makes them prone to tripping up when walking because they are not as in control of their limb(s) as they might otherwise be, but they cannot possibly *understand* the anxiety that goes along with having that particular problem every hour of every day when you fear you might fall and seriously hurt yourself in the process. A spouse or partner might well *know* that their other half suffering from

MS has to take some kind of disease modifying therapy medication. But they might not realise the psychological angst this can cause that person, who knows taking the medication is the right thing to do and that they feel compelled to take it to placate their partner who assumes the medication is a way to help solve the problem of MS, despite the fact the injection causes them pain itself plus a whole host of other side-effects that make daily pain-free living a challenge. They do not really *understand* the intricacies of the situation, which is why being able to focus on the lived experience through a phenomenological lens is so important.

So, even though one person's lived experience of MS is potentially different to another given the spectrum of symptoms caused by the disease, being able to talk to someone else that has to live with the illness and negotiate at least some of the similarities seems to have been a release for the participants:

*It's quite nice to talk about it with somebody who 'gets it'. Because [my husband] tries his best, but....* (Lucy, p.41)

And I do 'get it'. I get it because I have MS and I must live with the illness each and every day. This 'insider' element of my research project strengthens the value of the original contribution I offer. This is reflected in an evocative manner as part of my journal extracts, which includes the one that follows here.

## **5.4 – Autoethnographic analysis (*Relationships & Fear*)**

In my journal extract in Appendix 10, I discuss the fear and anxiety I feel about the impact it has on my relationship(s) with my family moving on, particularly when MS causes a problem for me that has not occurred before. In this case, it is something as simple as losing balance and falling in the bath which I could easily tell somebody had happened so that they would *know* of the incident. However, without describing it more fully, particularly the anxiety it led me to have surrounding my ability to fulfil my role as father and husband, then someone else would not be able to fully *understand* why the incident was even a problem in that moment or for me at all: *"It gave me visions of all the things that I fear the most about MS (losing my*

*ability to be everything that makes me, 'me'). Being (or feeling) so helpless and unfairly burdening (as I see it) my wife/family into being 'carers' for me."*

The extract predominantly focuses on my relationships with my close family who are aware of my MS, albeit my children being less aware. However, in relation to my career and work as a teacher, I have chosen not to widely disclose. As a result, I am imposing on myself an 'inner and outer self' split (Van Manen and Levering, 1996). Whilst all three of the participants in this research project have openly shared and disclosed their MS with family, I still choose to internalise much of my daily lived experience of MS. As a result, as per the extract above, when something goes wrong (for example, losing my balance in the bath), I feel a greater degree of emotional vulnerability: *"I dissolved into tears."*

According to Pakenham (1999), a lower level of physical disability leads to a patient's greater ability to psychologically adjust to living with their MS. Re-reading the extract above, it is possible to see the theme of visibility emerging. My low level of visible, physical MS disability is partially responsible not only for my continued professional non-disclosure, but also my lack of desire to openly discuss it in my home environment. Perhaps it is, then, that same reason which manifests itself as a greater emotional shock when I am then faced with physical trauma in some way (such as slipping and falling in the bath). It is possible that the findings of the gendered research study by McCabe et al. (2004) would have value for me, given that they suggest that male patients with MS should employ greater emotional and social support coping strategies to help manage their psychological adaption to living with the illness: *"My wife loves me, that much I know. But she didn't sign up to look after a husband who can't look after himself. That should be my job for her and the kids."*

My current 'twin-identities' (Smith, 1990), of having disclosed to some (family and friends) but not to others (work colleagues) contrasts with the other participants as they have now disclosed in the workplace as well as to friends and family. As a result, it seems that my insistence on maintaining these twin-identities might be contributing to a greater feeling of both shame and guilt, which are potentially detrimental to my ongoing mental well-being.

## 5.5 – Perception

Learning one's place in the world when suffering from MS seems to be influenced a great deal by the issue of perception. As outlined in section 5.3 discussing relationships, it may be that the relationships that we have, maintain, develop or stop are all coloured in some way by perception. Perception of the other person (or people) in a relationship about how you – as the person with MS – are viewed. Or, as may very well be the case, how you – as the person with MS – view and perceive yourself. As outlined in Chapter 2, misunderstanding of the illness by others is common (Joachim and Acorn, 2000, Fesko, 2001), so disclosure for some MS sufferers depends on who needs to know (what type of relationship they have with that person or people). Also if they do choose to disclose, there are potential issues that perception will - or may - create with the person you are disclosing to. The inherent problem for the person with MS making that decision (of whether to disclose or not) to either avoid creating a particular perception from others or to manage one that already exists, is that they cannot possibly know what actual perception another person may have or hold about them - regardless of whether they know about the MS illness or not. Disclosing could be a positive action to take to strengthen the understanding of another person, or could have a negative effect should they perceive the illness to be of a more significant detriment to the MS sufferer than it actually is. I have not included a separate autoethnographic journal entry linked to perception, as the excerpt linked to identity in Appendix 8 also considers the issue of credibility in a professional context.

Sally felt that, because her symptoms were largely hidden she did not need to disclose to many of her work colleagues, and those that she had disclosed to did not seem to be affected negatively in their relationship with her because of their perception of normality (and not detrimental disability):

*No. I've noticed no difference in anyone. Which is correct. That's how it should be. No one makes a big deal out of it. I don't make a big deal out of it.* (Sally, p.14)

However, she initially disclosed to her school employer (and, also, some of her colleagues) because of the possible obvious physical effect that MS had on her walking on occasion:

*I just said, you know, "I just feel I ought to tell you because I've been diagnosed with MS and it does affect my legs and I start walking funny. I don't want people coming telling you I'm drunk". (Sally, p.13)*

Sally was concerned that that particular physical symptom for her would create a false perception amongst work colleagues who did not understand what it was or why it was happening, and who would then assume something incorrect (that she was under the influence of alcohol). When we discussed this further, Sally was quick to point out that the strength of feeling she had about not wanting to be perceived incorrectly was partly to do with her working environment. Her own perception was that any visible signs of her MS would be viewed differently in an alternative workplace. However, in a school it is the sheer number and spectrum of people (being all different ages and having varying ability to understand a complex illness like MS as a result) that dictated her actions surrounding not widely disclosing. Sally felt that in a school there were too many people - who might potentially misunderstand MS - to make disclosing widely a feasible option:

*I think if I was going to work in an office or just working with a boss and no kids around and not in school, then would they necessarily need to know if I turn up one day and I'm wobbling? I'd just say I had MS! No biggy! But I just thought that in a school, and it's filled with... it's not just colleagues... it's the kid's parents. It's such a bigger circle of people that wouldn't know [about the MS]. (Sally, p.17)*

Beyond this anxiety of a wide variety of people understanding, or not, about her MS, Sally alluded to the type of school also being a factor in her views on the perception of others when disclosing. She referenced the fact the people (pupils and parents) and the environment (type of school) were different in her current employment. Her current school is an independent preparatory school which, in her interview, she was comparing to a state primary school:

KPW: *At what point is an independent school the same or different regarding perception? Does that play a part for you in disclosure?*

Sally: *It could do. It could do. I'm trying to think how long I'd been at school when I was diagnosed. I'd probably only been there... maybe three or four years... and, as I say I was part-time so I didn't really see much of the parents, but you were certainly aware of them. Whereas because it was such a different environment from my village school that I took my kids to and stuff... and the people I mixed with... a whole different world, so I thought I'd never fit in here.*

KPW: *Has that ever played a part in your decision-making to deal with the illness or disclose?*

Sally: *I think it probably did back at the start because I... yeah... I mean, now I don't think prep schools are as... what I first thought they were, shall we say [laughs]?! So, maybe I wouldn't worry quite so much now. But at the time it was all new to me, and I was all "Shall I, shan't I? What shall I do?"*

(Sally, p.18)

Sally's perception of the increased demands of the independent school parents and their possible perception of her weakness due to MS led her not to widely disclose when she joined her private school as a member of staff. However, her perception of the different type of school and the people associated with it, whether pupils, parents, or other staff, was shared by Lucy. Having originally trained and taught in the state education sector, both Lucy and her husband (also a teacher) have ended up teaching at the same independent preparatory school, and they currently work as boarding house-parents whose job it is to run the full-time residential accommodation for the 50+ boarders (from all around the world as well as the UK), as well as teach in a classroom. Lucy gave a very similar description of her perception of the private school to Sally's, as a response to my asking where she currently taught (I was not asking about different education sectors, or about perception at this stage):

*He [husband] was just doing a bit of supply and then a term's contract came up here. Because I grew up in [the same town as the private school] my view of [the private school] was a 'walled fortress' or something completely out of my league! And [my husband's] league, who was state school educated and only ever taught in*

*state schools and this walled fortress would not even let me in the car park... kind of thing! And he said "oh, there's a job going at [the private school] just for a term". I said "Don't be so silly! They won't even... [that private school]! Are you joking?! They're never even going to look at you, let alone give you an interview!". So he was like, "Well, I might just apply", and I was like "No! That is way out of your league. No way!". So he cycled there, he got changed in the car park and then got the job, came home and said "Everyone's normal. They're just normal people, it's not some kind of ... it's not what's in your head". And so he got the job, loved it, just got on really well with everybody. And then that summer, he broke up three weeks before me [private schools have a longer holiday period than state schools] and I had to wait three more weeks! And I said, "That's never happening again, I need to apply for a job there!". (Lucy, p.19)*

For both Sally and Lucy (and Lucy's husband), the perception of private school was different to the reality. However, that perception dictated the actions leading to their disclosure of MS. In Lucy's case, her line manager at school invited her to play netball knowing that Lucy used to play to a high standard in the past (before MS prevented her from doing so). However, Lucy had assumed her MS was known about by the line manager as she had disclosed it on a medical form when she started at the school – but they did not know:

*Lucy: [the Head of Lower School] was my line manager then, and she invited me to play netball. And I said "I can't". And I assumed she knew because she was my manager. I assumed that she would know but she didn't. She didn't know.*

*KPW: So you told her about your MS? How did she react to that?*

*Lucy: She was really surprised, because on the surface – you can't see anything! (Lucy, p.21)*

Lucy then felt compelled to disclose about the severity of her MS at length to this line manager in an attempt to manage the understanding and perception that was or was not generated following the accidental disclosure. In her own words later in our interview, Lucy outlined the fear that she had regarding an employer's perception or regret about appointing a person with MS:

*It's increasingly kind of natural for, I think, people to think "Oh no, I've employed this person and actually, it could all go wrong". (Lucy, p.35)*

Lucy went on to express her anxiety about disclosing too openly to employers, because of creating the wrong perception regarding MS as a degenerative illness, and the subsequent fear that employers may have surrounding the investment they have made in you as an employee:

*Because it does matter [whether you disclose MS to an employer or not] and... or maybe it doesn't matter right now, but at some point it might matter. (Lucy, p.36)*

I sought to explore her reticence about disclosing due to employer perception a little more with her as the interview went on:

KPW: *Is that the fear?*

Lucy: *Yeah, it is.*

KPW: *That they treat you differently or think about you differently?*

Lucy: *Yeah. I think more on a professional level I worry about that more and more. Rather than a personal level. Because I think most people that I tell are just really surprised because you can't... you can't see it [my MS] and you can't tell. (Lucy, p.39)*

For Emily, her sporting background meant that she felt compelled to explain her physical restrictions at times to other staff, as she did not want to appear 'lazy' or that she was not pulling her weight in the same way as her other teacher colleagues:

*To look at me, you wouldn't have known [that I have MS]. But walking long distances was a bit of an issue, and I obviously couldn't run. I just didn't want them to think that I was being lazy. (Emily, p.17)*

That fear of other people's perception of her due to the variety of physical restrictions caused by MS for Emily led her to start to overcompensate in her role, almost to make up for any perceived weakness. This is another example of one of

the participants reproducing an ableist discourse (Goffman, 1963; Butler, 1990) in order to make less visible their illness:

Emily: *I don't take the mick, you know? I do not shirk any responsibilities. I will do everything to the extent that people say "you shouldn't be doing that".*

KPW: *Do you ever think that you go too far?*

Emily: *Yeah, probably. So, duties, for example. We have a rota for playtime duties and I get very, very cold. So, people are like "you shouldn't be doing a duty", and I'm like "well, I'm a teacher. That's my job. I should.". I am a teacher and a teacher does a duty once a week. So, therefore, I'm going to do it and if I'm cold, I'll just keep my coat on! (Emily, p.27)*

Because her MS makes Emily more susceptible to temperature changes and the effect of temperature (MS makes it more difficult to self-regulate body temperature), she forces herself to undertake tasks to the detriment of her health and wellbeing. She does this due to the perception that she has about herself as a teacher who *"should"* be doing all these things, as well as affecting the perception of her colleagues regarding the effect that MS has on her. That same worry was there for Emily all throughout her teaching career, even from the beginning when she was starting out in teaching, as she described in this part of our conversation when I asked her why she did not disclose straightaway to colleagues:

*Good point! I guess I was a little bit... not embarrassed... a bit like... I don't want them to know straightaway. They've just got a new teacher and I don't want them to judge me straightaway. I think I remember when I was at [Emily's first teaching post] and they were doing rugby, and I thought "I'm going to have to tell them" because I couldn't run. I wanted to join in. I didn't want to be seen as this person who, you know, is literally on the side-lines just standing there doing nothing and for the teacher to, like, 'mark me down' a bit.... (Emily, p.18)*

Emily did not want other staff – in her own words – to ‘judge her straightaway’ and, by ‘judge’, she is implying that her fear was one of their misconception about MS and its effect on her. Her fear was one of her colleagues creating a label for her and her abilities and seeing her as ‘less than’ or ‘different’ from what teachers *"should"*

do. A phrase Emily used earlier in our interview was about her seeming 'well' because her MS was hidden:

*I was well. You wouldn't know I had MS at all. (Emily, p.15)*

This implies that now – in the present – for Emily, given that she is in a wheelchair and MS has a significant effect on her in a variety of ways (not just the obvious physical symptoms), she views herself as unwell. If our illness is hidden, then we can pass for being 'well' and normal. If our illness is apparent and clear to others, we are unwell and abnormal. This type of language was used precisely by Emily as she outlined her initial bouts of MS around the point of diagnosis:

*I just thought, "well, that's OK" because everything else had sort of just righted itself, so "if I have some steroids, then I'll just go back to normal. It's just one of those things.". Yeah, I think that's how I sort of felt about it at the start, really. It was just "oh, it'll take a bit of time and then I'll get back to normal." (Emily, p.16)*

Normal. Being perceived to be normal (Wood et al. 2007). Rather than abnormal.

The description of being seen as different was also used by Sally and Lucy:

*Fortunately, I didn't have another bad one [MS episode] that everything was visible outside. A lot of the time it was just how... the sensation... I felt it. I didn't look any different, or walk any different. (Sally, p.6)*

*Then I thought, well... does this affect my job? Does this, um, just how does this affect my job to... do they [my colleagues] see me differently now? I did kind of worry about them knowing... (Lucy, p.16)*

Different. Being perceived to be different to normal (Charmaz, 1983). Less than.

As the following conversation outlines, Lucy explains that her reason for hiding her illness is essentially to do with fear of other people's perception of both MS as a disease, but also of her as a person and as a teacher living with MS:

*Lucy: I just felt like I had to get on with it [my work] and fake it.*

*KPW: Would it not have garnered some understanding from people had you said something?*

*Lucy: Yeah, it would. But you don't really want that. I don't want people to feel sorry for me. I don't want to feel like they need to do something for me or to be treated differently. I'd rather just get on with it. (Lucy, p.27-28)*

Lucy did not want to be seen differently, or that she needed help or special dispensation. Neither did Emily. Neither did Sally. They have all expressed concern about how they would be viewed by work colleagues in addition to people they have alternative relationships with, such as pupils and parents at the schools where they work. This fear of being viewed differently due to living with MS as an illness leads our participants to work to a level no less than one they themselves perceive other colleagues to work to. Whether it is to the detriment of their health in the case of Emily insisting on doing outside playground duties (that make her very cold due to her MS), or like Lucy, 'faking' that she was feeling OK whilst working due to not wanting to disclose her MS to colleagues to be able to ask for help or alternative work instead.

Perception is a powerful determinant of our actions. Merleau-Ponty (1969) refers to the significance of the body as the 'body-subject' and emphasises that the physical embodiment of our consciousness is the only way through which a person can truly experience the outside world. If Merleau-Ponty's statement 'I am my body' is true, then the inextricable link between mind and body will undoubtedly feed into how we perceive ourselves as a person with MS (affecting our minds and bodies) and how we think others will perceive us too. Whilst it would be easy to say that the perception of our participants is incorrect - and in actual fact the majority, if not all, of their colleagues would be understanding and accommodating of their various needs due to MS - the reality has been evidenced differently through the participant interviews. They have all cited unfounded fears of what *might* have

been in particular situations outlined above, but these fears are based on the actions and responses they have received in reality from other people (colleagues, friends and family) throughout their lives as someone with MS. All three participants, as well as me, have all been party to the reaction from someone who assumes something about us, or our MS, without any first-hand knowledge.

As stated previously, there is a difference between knowing something and understanding what it means (Terry, 2020). So, another person might be aware of and, therefore, *know* about our MS. But they do not truly *understand* what it uniquely means for us as an individual. They do not know what it means for us at that point in time, nor how it may or may not develop in the future. They are assuming something about us, or our MS, based on perception, and we have our own perceptions of lack of understanding on the part of others too. That has led all of the participants, including me, to make certain decisions about disclosure moving forward. As outlined by Grytten et al. (2005) in their study of MS disclosure, complexities on the part of the person with MS and on the part of others has resulted in a mixture of both protective non-disclosure in certain circumstances (in order to guard a sense of 'self') and also preventative disclosure (used to obtain assistance or understanding from others).

## 5.6 – Summary

In this chapter, I have examined issues relating to disclosure for the participants and myself, relationships and perception linked to themes of power and discourse. As stated previously, there is a natural blurring of some of the themes regarding whether they discretely occurred in the past or the present. For example, elements of disclosure may have taken place already for the participants, but the factors involved are related to their current employers or employment which, in turn, leads on to affect aspects of their professional relationships. The theme of relationships is, likewise, blurred in various ways. It is blurred in a temporal way due to the participants and I already having disclosed to some people in our lives (family or colleagues), although this also has an impact on how we seek to interact with all these people currently in the present time. It is also blurred since the type of relationship between friends and family and that of work colleagues is also

potentially one and the same. The issue of 'knowing' versus 'understanding' is interwoven throughout this chapter due to the fact that the experience of chronic illness involves ambiguity, and this ambiguity does not fit well with otherwise binary discourses about illness and being well. Disclosure is normally considered a matter of telling and knowing, rather than revealing and understanding, and the participants have all made reference to wanting an empathy that goes beyond knowledge and attempts to understand their individual, lived-experience.

How, when, and why the participants and I have chosen to disclose (or not) and to whom - in terms of relationships - has been influenced by the final theme in this chapter of 'perception'. Perception of MS as an illness by me and the participants, and our perception of the perception of others. The experiences of the past and the present have a bearing on our actions in the future, and in the next chapter I will look at how retaining the element of choice plays a part in how and why we may disclose in future, how compatible MS seems to be with being in the teaching profession, how MS affects our sense of identity, and how all of these things have an impact on our careers moving forward.

## Chapter 6 | *The Future (Learning who I am to become)*

Having explored the past for the participants and myself, with all of us learning to live with MS as an illness and what it means for us, and having then looked at how MS affects us now, in the present, as we navigate our current place in the world, I now discuss some of the issues facing the participants and I moving forward in our lives as we consider who we are to become and the impact that MS has on our professional lives. The connections inherent in many of the themes across the temporal realms are blurred most starkly here in this chapter. That is due to our inability to know what the future holds and, as Deleuze (1990) states in his *Logic of Sense*, only the present fills time. The past and future are both aspects of the reality of the present, so the situated experience of the participants (and me) informs what may be still to come for us all. Our imagined futures reveal how we – as individuals – imagine our life course ahead of us, but how illness can disrupt and alter these imaginings. First, I examine the concept of choice, then investigate the impact MS has on an individual's identity, then finish by returning to explore the central theme of the compatibility of teaching for someone with MS.

### 6.1 – Choice

During the discussion of disclosure in the previous chapter focusing on issues from the present time, I raised the issue of whether the participants were able to keep their MS symptoms hidden or not. For Emily, that is now not the case – she is in a wheelchair with significant physical impairment as a result of her illness. However, for both Lucy and Sally (and also me), their symptoms are almost all hidden, the exception being balance issues for Sally when walking at times when she has a relapse. The reason why I have sought to distinguish between the broader disclosure issues which are ever-present for someone with MS (particularly with hidden symptoms), and the issue of choice, is because of the degenerative aspect of the disease. Lucy, Sally and I may well be able to choose to conceal our diagnosis of MS at the moment because it is hidden. However, how long will that be the case?

At what point will we lose the ability to control that aspect of our lived experience with MS? The fact we can make decisions for ourselves (Bruine de Bruin et al. 2020) is such a fundamental tenet of what it means to be a human being. The fact that we have control over our actions, our feelings, our bodies - which Foucault (1988a) argues is a manifestation of agency in a world of structuring and discursive forces that place a heavy weight on the actions of the individual. The fact that we have choice. As Charmaz (1983) clearly states, if choice is removed from us, then it either contributes to our own perception of being less-than, or the reality of actually being so. Choice is important, and avoiding disclosure is a way of preserving control (Grytten et al. 2005).

Choice to disclose can sometimes be taken away by accident. For all three of our participants, they have had instances in their professional lives where disclosure has occurred not of their choosing:

*Yeah... because [my husband's] got a big mouth! Would I have told him [my employer]? Would I have been so open about it? I don't know, because it's having that first conversation, and I'm quite shy. I'd have found it quite hard to bring up, I think. (Sally, p.18)*

*I do remember we [teaching staff] went out for Christmas dinner, and I parked in a disabled spot. I remember the TA [Teaching Assistant, who did not know about Emily's MS]... she said "you do realise you've parked in a disabled spot don't you?", and I said "yeah!". (Emily, p.24)*

*Lucy: [the Head of Lower School] was my line manager then, and she invited me to play netball. And I said "I can't". And I assumed she knew because she was my manager. I assumed that she would know but she didn't. She didn't know.*

*KPW: So you told her about your MS? How did she react to that?*

*Lucy: She was really surprised, because on the surface – you can't see anything! (Lucy, p.21)*

For Sally, the accidental disclosure by her husband to her employer has shaped how she now chooses to disclose in a professional context. Because her symptoms are

essentially hidden for the most part, her MS diagnosis is on her employment record from the initial disclosure, and she selects close working colleagues to inform as well:

*It's in my records... I don't need to tell anyone. It's in my records that I've got it [MS], and those people I work with know. (Sally, p.15)*

However, there was a sense of compulsion for Sally to more broadly explain her diagnosis to her employer following the accidental disclosure by her husband:

*I just said, you know, "I just feel that I ought to tell you because I've been diagnosed with MS and it does affect my legs and I start walking funny". (Sally, p.13)*

This compulsion seemed to be to do with the element of choice and the fact that control surrounding disclosure had been taken away from her (accidentally by her husband), so she chose to subsequently control perception and understanding (Grytten et al. 2005) moving forward by outlining the effect MS had on her:

*I just felt as though it was sensible for me to follow it through and just let them know. (Sally, p.12)*

The emotion that drove Sally to follow through with the full disclosure to her employer following her husband's accidental disclosure, was one of embarrassment:

KPW: *How did you feel then* [following the accidental disclosure]?

Sally: *A bit embarrassed, I suppose, because I probably wouldn't have mentioned anything yet.*

(Sally, p.10)

Sally would not have disclosed at that point. The choice and control were taken away from her, and she felt embarrassed due to the potential negative perception of her employer which then led her to fully disclose in an attempt to wrestle back

some control of the disclosure and understanding of how MS affected her. Whilst those occasions occurred in the past and the present, I have included them in this section because it has all resulted in informing Sally's future actions regarding professional disclosure, as she is clear moving forward in her career that she would only disclose her MS to a future employer if she lost the ability to hide it:

*Sally: Talking to new... new situation, new bosses, I probably wouldn't. Yeah, as I say, probably because I know that it hasn't really progressed. I wouldn't necessarily think they would need to know.*

*KPW: Does anything about that sit uncomfortably with you or not?*

*Sally: No, I don't think it does. Purely because I've had years when no one would know and not much happening. If I thought I was going to have relapses regularly, then I would be more forthcoming. Yes. Because I couldn't hide it. (Sally, p.18-19)*

The same sense of anxiety about losing control of disclosure is felt by Lucy. She has also had to disclose to colleagues at points in her teaching career which was not planned. In a similar way to Sally, Lucy's husband had offered Lucy's services to the Head of Girl's Games for driving a minibus of pupils to a sports fixture forgetting that Lucy was unable to do so anymore from a medical driver's licence point of view:

*She wanted me to drive the minibus as well, and I couldn't because I had my driving licence changed to one of the medical ones [with medical restrictions by the DVLA], whereas before I'd done my minibus test and I was able to drive a minibus. And [my husband] had forgotten that my licence had changed, and he said to her "Oh, Lucy will drive the minibus", so then I had to tell her why I couldn't. (Lucy, p.25)*

But as Lucy had already outlined in her interview with me, she was afraid about other colleagues' perceptions of her as being inferior or different in some way due to the MS:

*Because I knew [my colleague who knew about the MS] would tell the Head, and then I thought, well, is this... does this affect my job? How does this affect my*

*job to... do they see me differently now, or..? I did kind of worry about them knowing... (Lucy, p.16)*

Lucy wanted to retain control about who knew about her MS, when they knew and why. Similar to Sally, Lucy maintains that she would not choose to disclose her MS to work colleagues unless it affected her ability to do her job:

*I think the degree that it was affecting me when I was at [my previous school], even then I didn't tell anybody, because you couldn't see.....I wasn't visibly not able to do my job. (Lucy, p.30)*

However, that desire to retain control of disclosure is juxtaposed with our own assessment of our ability to do our job. If that is not accurate, or perceived by others to be accurate, then we risk other colleagues questioning our efficacy as a teacher without understanding the mitigating medical factor involved. The traditional understanding of choice or agency is that you either have it or you do not. However, Emily was keenly aware that this sense of control was being gradually taken away from her as her MS degenerated over time, causing ever-increasing physical, visible symptoms. As a result, she decided to retain control and release the information about her diagnosis and what it meant on a physical level to her entire school (staff and pupils):

*I think because things happened quite slowly, it's a gradual decline and, um, I don't know... I think I spoke to people as and when it comes. So, I was completely fine, then I had a stick and actually I did an assembly to the whole school because I thought kids are going to be, like, "why has she got a stick?". (Emily, p.28)*

Emily was managing the release of information, and the control of perception. She was attempting to help people – staff and pupils – understand about her MS and what it meant for her, and not just know that she had it. For each of the participants, retaining this element of choice is important to them. They have not always had the option due to accidental disclosure or being forced into disclosing due to their MS preventing them from doing a particular task, but moving forward in their lives they all still want to retain that ability to choose what they disclose, to

whom, and when. For Emily, the issue of disabled parking may continue to compel her to disclose:

*Sometimes if I park in a disabled spot and people notice... I'm like, "oh, actually, yeah, I've got MS". (Emily, p.23)*

However, she states clearly that – should she have had to deal with an MS diagnosis while working in a school (rather than having been taken on with MS already, as in her current role) – people's perception may well be different, and that also gives her cause to be reticent about disclosure despite not being in a position to keep many of her symptoms hidden. That might be due to the fact she had not managed to control the information to colleagues in the same way as in her current position, and the element of choice would be removed:

*If, however, I was diagnosed while I was working, I would have had to have quite a lot of time off. Maybe people's opinions may have changed then. (Emily, p.33)*

Lucy is also clear about not disclosing her MS to a future employer beyond what is asked for on a medical declaration form at the point of job offer:

KPW: *If you decide you're going to move elsewhere, what will you do about disclosure?*

Lucy: *I think I would just see what it said on the medical form. I wouldn't actively tell the senior leadership or whatever. I wouldn't have a formal conversation to say. (Lucy, p.33)*

If their symptoms remain hidden, despite the considerable effects that MS may still have on them, their daily lives and the ease with which they retain the ability to do their jobs as a teacher, all of the participants would choose not to disclose their MS to an employer in the future. Some of that is influenced by their current relationships and experiences of disclosure to those people in the present time, and some of it is their own perception of what others may possibly think of them in the future should they know about their MS. Referring back to the previous chapter

and the concept of ableist discourse (Williams, 2000; Vickers, 2001; Ball, 2021), there seem to me to be two possible interpretations regarding the actions taken by the participants. Firstly, it possibly reflects the complicity of them all through reproducing the same discourse via their own anticipation of it. Equally, it could be due to their desire to control that discourse. However, it is telling that this issue of choice, and retaining the ability to make choices and decisions for ourselves, is a key factor for the participants in learning who they are to become in the world. This desire for control and agency is despite the inherent uncertainty surrounding MS and its potential detrimental effect on their lives. I, too, share this desire to retain control given the irony that as a disease, MS already takes so much control away from you. That view is outlined by Kaushansky et al. (2017) in their study of disclosure by young people with chronic illness, who outline the importance of wanting to keep the ability to retain choice over as many aspects of future lived experience of illness as possible. Choice, control and agency, according to their study and echoed by this one, are an important justification for (non) disclosure.

## **6.2 – Autoethnographic analysis (*Control/choice*)**

The issue of control, or being able to choose actions and decisions in relation to an illness like MS is something that I was aware of when analysing the journal extract in Appendix 11. In it, I refer to the same colleague of mine that I was responsible for as a line-manager who passed away through cancer. However, the way she chose to live her life (despite the illness that was killing her) right up until the end was inspiring. So much so, that I can see through analysing this extract that it has had a deep and very real impact on my own, personal thought process regarding the way I would like to attempt to live my life and take control of my MS moving forward in the future: *“I increasingly think finding the balance between trying to affect positive change when one is living with an illness (for well-being, general/wider health benefits, emotional as well as physical health, etc) and trying to ‘let go’ of the things that are beyond your control, is so important.”*

The choice for a person to conceal their MS is made within a situational context (Grytten et al. 2005). Whilst I acknowledge that my musical ability is diminishing through time due to my MS, my desire to move up the career ladder as a senior

teacher (and, ultimately, consider headship) increasingly negates my need to disclose because my symptoms relating to musical ability (or disability) are not needed in the same way for those teaching leadership roles. As my daily tasks within a school context become less about leading the musical life of the school and more about the strategic, operational and organisational life of the school, my hidden symptoms that affect my musical prowess are of less relevance. As Dyke et al. (2000) outline, hiding MS in the context of employment is a question of maintaining work by performing adequately. Even as a musician, I can perform more than adequately because of my relatively high starting point and my ability to hide the MS symptoms that affect my music making. However, I do not need to use those skills as much (or, increasingly, at all) for my day-to-day work as a senior leader in school, and therefore the skills required to adequately perform my function as a senior teacher are, currently, untouched. The need to disclose is not currently there on a practical level, yet I acknowledge in the extract that the future is not certain regarding what else may change: *"It is the sense of loss that overwhelms. Not just losing a friend, but losing all the things (musical at the moment, but who knows what over time) that form part of my identity."*

That is very much at odds with how my colleague, Elly, treated her illness. She lost the ability to control what the illness was doing to her physically, the control regarding need for treatment requiring stopping work and the visibility of her situation to everyone else (through changing physical features such as weakness, hair loss and loss of weight). Some elements of suffering from cancer are hidden, others are visible. That is similar in some ways for some people with MS, but in my case, it is all hidden. Maybe I am fearful of the perceived stigma outlined by Charmaz (1983) of having a physical, visible illness. As a musician and a teacher, I have the need to be 'adequate' on a practical level with a varying set of skills, whether playing an instrument, using a computer, standing at the front of a classroom teaching and leading activities, or at the front of a staffroom leading meetings. What this journal extract tells me when I analyse it is that I am scared. I am scared of losing the ability to present myself in a certain way. Scared of being able to choose my destiny and my future path because of what MS might take away to prevent it: *"Illness is cruel. It takes. Only takes. And doesn't give back."*

That fear stems from my perception of the stigma associated with being disabled as discussed in section 5.5, and, as Waskul et al. (2002) outline with their concept of illness embodiment, the role of humiliated bodily experience is fundamental in the construction of stigma. If I hide my illness, I am attempting to reduce the potential for any stigma, and that is my choice to do so. I currently have that ability. Elly did not.

However, what I find so inspiring about Elly is the way that she took back what (little) control that was available to her right up until the end of her life – including planning her own funeral and financial plans for when she was gone. She was relentlessly positive despite knowing she was going to die, and that desire to maintain the ability to choose and retain control is what motivates me to do the same as I potentially (re)negotiate my future career path living with MS.

### **6.3 – Identity**

A person's present and future identity is informed by their perception of themselves and the perception of themselves by others (Giddens, 1991). As I described above in the previous journal entry, I am aware of my own personal identity changing, and control over it - due to MS diminishing my ability as a musician - being lost. So, my desire to maintain control over as many aspects of my illness as possible, which includes the when, where, how and to whom of disclosure, looms large as a result.

During the interview with Sally, what struck me was how the way she articulated the potential effects of MS on her in the future changed during our discussion. For example, she is a naturally positive person by her own admission, and early on in our interview she appeared very matter of fact about the potential restrictions that MS might place on her in the future:

*I think, "Well, if you're in a wheelchair it just gets you from A to B". (Sally, p.5)*

However, later in our interview discussing how she would feel if MS started to prevent her from being able to do her job, she articulated things differently, citing potentially being 'very frustrated' if that situation were to arise:

*I just get on with it... because it hasn't affected my work. If it got to a stage where it affected my work... I'd probably be more frustrated by not being able to do something. Yeah, I would be if it was stopping me from doing stuff. (Sally, p.20)*

Her identity, or the identity of an inherently positive person that she was attempting to convey, changed. The language in the second quote was intrinsically more speculative ("if it got to" and "I'd probably"), and this would suggest that uncertainty surrounding the future impact of chronic illness for an individual does indeed play a role in increased anxiety as suggested by Moore (2012).

As she described, Sally is not affected very visibly by MS and chooses not to disclose to many people as a result, which is the same as for me personally. However, both Lucy and Emily are affected by MS to a greater degree. Emily is the most visibly affected being in a wheelchair and unable to utilise many of her limbs as a result. Lucy is affected physically both in terms of fatigue but also the use of her limbs which prevent her from playing sport like she used to previously in her adult life (to quite a high, competitive standard). For both of them, this issue of identity and losing a part of what makes them who they are came out at various points in my interviews with them. In this extract, Lucy outlines the feelings she had when MS prevented her from being able to play netball in her local league with friends and teammates:

*I used to come back from netball and just felt really down and really depressed and would want to cry, because I could see my symptoms more clearly and I would feel really down that I couldn't play netball like I used to be able to do. (Lucy, p.14)*

In relation to how Lucy feels, this forms part of her identity in the same way that music does for me. She outlined further on in our interview how detrimental that

lack of ability for something she used to be able to do, and felt was a part of her, really is:

*It's funny because, you know, last term we had to make videos [at school]. We had to make a video for a new class and think about ourselves and say who we are, and I had my phone there ready to make a video but I was like, "What am I going to say?"! Like, in the past, I would have said "and I love playing loads of netball", but no. I don't do that anymore. I used to. That's who I used to be, and I'm not... that's not me anymore. So, it's like, um, "I live in a Boarding House with lots of children...!". That is me. (Lucy, p.38)*

Lucy is referring to herself in the past tense. That's who she 'used to be'. Netball is not a part of her, or her identity anymore, and she does not know who she is as a result or how to describe herself to a new class of children coming into her school. MS has taken that from her, and the ramifications of attempting to cling onto your perceived identity for as long as possible can lead to a number of negative outcomes. According to Grytten et al. (2005), not only can it remove the control you have over disclosure as your ability in a particular field diminishes and other people notice and start to ask questions, but it can lead to the perception of others changing negatively towards you if you are seen as not being up to a particular task as well. Exactly this is outlined by Lucy in her description of two other teachers that she knows who have MS. One has recognised the impact that MS is having on her ability to fulfil her role as a teacher, has disclosed as a result, asked for accommodations to be made to her workload and the nature of the work within the school and has been able to carry on in some capacity:

*That was a really hard thing for her to face [disclosing and stepping away from her previous teaching role]. She's a brilliant teacher. But to have that kind of self-awareness that actually "I'm not doing this well anymore" is, um, hard to accept. (Lucy, p.37)*

Whereas the other teacher has not disclosed her MS and attempted to continue in her role regardless of the impact it has on other colleagues around her:

*There's a teacher at [another local school] who I think hasn't... who is struggling, but doesn't want to start to give up her teaching. And, you know, that's perfectly within her rights, but that's very difficult for everyone else around to pick up the slack, essentially by trying to support her. (Lucy, p.37)*

By needing support, but not disclosing the reasons why, this particular member of staff is potentially being viewed as 'less-than' by her colleagues (Gabe et al. 2004) which is exactly what our participants have outlined wanting to avoid for themselves during the interviews, and as discussed in section 5.5 on perception. This emphasises the importance of one of the intended outcomes of this research, namely that of shining a light on MS within the teaching profession. The participants, all of whom have made reference to the ability to discuss their experience of being a teacher with MS with me during the project as a positive, as well as anyone reading this that might also be in the same position, are able to use the research as a lens through which to consider their own position and actions. Emily, who is the most affected by MS of the three participants, is very open about the fact that she wants to remain as a teacher for as long as possible:

*I want to work. I do not want to stop working. (Emily, p.32)*

However, she recognises the extent to which MS has changed her own identity and how she views herself. In a similar way to Lucy, Emily was a very able sportswoman prior to MS affecting her mobility, and this detrimental effect of MS on that aspect of her life plays a significant part in her ongoing frustration and the feeling that she is not the person she used to be:

Emily: *How have I ended up in a wheelchair? And that's what gets to me.*

KPW: *Does it?*

Emily: *Yes, it does. Yeah. That is probably the main thing. Particularly, like, it's friends who have never done any sport are suddenly running 5k or 10k races and doing mud runs and lots of cycling. You've never been interested in sport! I've played sport every day for like my whole teenage years and you did nothing. And, why are you suddenly doing things?! That's all I want to do, and I can't do it. And it's just*

*really... yeah... really frustrating. I want to go and play tennis. I want to go have a good time playing hockey or netball or whatever. (Emily, p38-39)*

This interaction between Emily and myself - which I perceived to be a mixture of frustration and jealousy on her part - is very much to do with what MS is preventing her from doing and removing that sense of choice (Grytten et al. 2005), as well as who we perceive ourselves to be. When I asked her about this sense of identity, Emily was quick to confirm that this forms the basis of her frustrations, and by feeling like a part of her was missing due to MS that she felt less valued or recognised by others:

*Yeah. That's exactly what it is. I was, you know, I was "Emily? Oh yeah, she played tennis, hockey", you know? I played five sports for the county. You know, I was a sports person and that was me, and yes – OK – people thought of me with my personality, but essentially it was part of me. And then, that's been taken away. (Emily, p.39)*

This admission from Emily reveals how an experience of chronic illness situates identity within specific temporal realms, in this case the 'sporty' version being relegated to the past in a way that resonates deeply with the concept of biographical disruption. The version of professional identity that can exist in the present is shaped in profound ways by this. MS changes you. It changes the essence of who you are, whether visibly or not due to the associated thoughts, feelings and anxiety that go with your sense of identity changing (Charmaz, 1991). In section 6.5, I discuss the central theme of compatibility of MS with the teaching profession and the effect it may have on a teaching career in the future. However, for some people within the teaching profession, it is a calling or a way of life, not just a job (Schwehn, 2001; Metcalfe, 2013; Onyefulu et al. 2022). It becomes a part of who we are and so, in the same way as sport being taken away from Emily and Lucy by MS, or music from me, our ability to fully function as educators also forms a significant part of who we are. The experience of chronic illness in the professional domain is not simply about technical ability or even power relations, but also fundamentally about the self. This exact issue is described by Emily towards the end of our interview when she outlines how grateful she is to her current school for enabling

her to continue teaching in some, reduced, capacity. In the extract below, she firmly establishes her work as a teacher with giving her a sense of purpose in her life. Work gives her purpose and identity (Dyck et al. 2000) and, like the other participants, Emily wants to hang onto that for as long as she is able to:

*I just know that I'm very grateful for my school for letting me carry on, because if I didn't have the scooter I wouldn't be able to. So that is the one thing that means I can carry on teaching, which is what I trained to do, which is the career that I wanted. And if I didn't, then yeah, I'd be stuck at home doing... being miserable, not really doing much. Because I know my friend [another teacher with MS], as I said, she's retired [through ill health retirement]. She put something on Facebook the other day "Does anyone want any voluntary work done?". She's feeling a bit... what's the phrase? That basically she's not really got any purpose anymore. Which I really feel for her, um, because I'd hate that I wouldn't have anything to do. I go to work because it gives me a purpose and, yeah, I definitely need that. Definitely. Definitely. So, hopefully I'm not going to let it stop me! (Emily, p.42)*

## **6.4 – Autoethnographic analysis (Identity)**

In the journal extract regarding identity in Appendix 12, you can read that I express the same sentiment as all three participants above – namely that of sadness - that MS is having a detrimental effect on what I describe as the 'essence' of what makes me, me.

As outlined in this section of the chapter, all three participants as well as I have made reference to MS changing the essence of who we are, and that relates to skills or experiences that we are no longer able to practise or partake in (either at all, or certainly to a lesser degree than previously, prior to MS affecting us). The idea of these skills or attributes forming part of our identity then being taken away from us by MS contributes to the feeling of being 'less than' (Gabe et al. 2004). As I state in the extract: *"For so long, music formed part of my identity (and, I suppose, still does to a certain extent...), and yet that gradually ebbs away. Gradually diminishes*

*like the dying light outside, and I feel that sense of loss. Of sadness. That ever-present feeling that my very 'essence' is being taken away from me over time."*

However, who is constructing this identity? Is it us as individuals, or is it other people who view these skills, attributes, and characteristics as part of what makes us who we are? On further analysis, this extract reveals that it is more a question of how, where and when a sense of identity is constructed rather than merely what identity is (Moerman, 1988). By analysing the skills and attributes that form part of my identity that are being diminished by MS, I am allowing MS itself to form a part of my (new) identity. To follow what Moerman is articulating, my objective should actually be to examine what I view to be the relevant context(s) in which I believe any MS-related stigma becomes a problem. If I am not now attempting to make my living primarily from making music and, as a result, it is only really me that is aware of my gradually diminishing talent, then my identity as perceived by others remains unaffected. I am creating a new identity as I move through my career and attempt to fulfil other professional roles as a teacher.

Both Emily and Lucy share in the sadness that they both no longer have the ability to play sports to a high level in a way that they both used to. However, they are both still working as teachers, whether their MS is visible or not. Their identity as a teacher currently remains. So, although an individual may permanently identify as a person with MS (either on an internal level if the symptoms are hidden and they choose not to disclose, or as part of their external identity if their symptoms are visible), it is their choice as to the extent to which they have a continuing social identity as a person with MS (Grytten et al. 2005). Whilst for someone like Emily (in a wheelchair) this is naturally more difficult, for me, Lucy and Sally this social MS identity can be – if we allow it to be – discontinuous, and can vary in both time and space. We have that choice and that ability to form our own identity with, or without, MS as a factor.

This leads me back to the previous extract from my journal featuring my colleague Elly who passed away from cancer. My perception is that she did not let cancer define her at the end of her life. I feel that she allowed it to be a part of her identity as necessary on a practical level, but lived what was left of her life regardless of

being (terminally) ill so that to everyone else she was still 100% and completely 'Elly'. The same strong, brilliant, kind, good-humoured and loving person she always was. She made that choice about her identity, and the result was that it guided others to think the same about her too. According to Mol (2002), a person with a disease can manipulate their identity. His description of the 'body multiple' outlines a complex reality whereby individuals can live and behave in a variety of ways to suit their changing situations. MS is not the same for any two people that have it. Emily, Lucy, Sally and I can all act out our diverse version of the illness as MS itself will have a variety of meanings to us as individuals. This includes our identities as teachers, regardless of whether we can partake in sport or play a musical instrument to the standard we once could. The use of phenomenology and IPA in this project has enabled our subjective voices to come to the fore in describing these issues, hopes and fears. The problem then comes, as I perceive it through this intersubjective analysis, if and when our ability to function as a teacher is called into question due to our MS. Exactly this was described by Lucy in the section above with regards to another teacher with MS that she knew and who had been unable to continue in her role as a teacher. Her ability (or inability) was noted by those colleagues that worked alongside her, and it was agreed amongst them that her desire to continue in her role was to the detriment of the pupils and the staff who needed to compensate for her shortcomings. These issues are discussed in the next and final section of analysis, focusing on the compatibility of MS with teaching.

## **6.5 – Compatibility of MS with teaching**

As part of the participant interviews, there were opportunities through one of my areas of questioning to explore what each of them saw as being fundamental aspects of the nature of teaching. The interviews also drew out some interesting moments of contradiction from the participants who, on the one hand, had previously outlined some of the specific tasks or requirements that they see as being important as a teacher. But, on the other hand, and at other points in their interview, there were times when they seemed to imply – perhaps without realising they were doing so - that MS was detrimentally affecting their ability to completely fulfil the role of a teacher as they had previously outlined.

Cognitive ability for teachers, in terms of critical thinking and speed of processing information, was cited as important by Sally:

*They've got to be able to think on their feet because not everything is black and white. Things come up. You have to be able to react to them straightaway. I just think you've got to be flexible. (Sally, p.1)*

Both Lucy and Emily described the qualities of drive, energy and passion as needed to be an effective teacher:

*I think it's not even necessarily about your knowledge, but your... your drive, and your passion. And that kind of comes out in the classroom and infects the children, and then they become passionate about it as well. (Lucy, p.1)*

*Well, I think you've got to have a lot of energy, definitely, and passion about what you do. And you can't go into teaching half-heartedly. There's absolutely no way, because you just won't survive. Really. I think you've got to... I think that's the main thing.....enthusiasm. Energy. (Emily, p.1)*

Emily went on to outline her reason for energy being needed as a teacher, particularly for pupils of a younger, primary school age, due to the requirement to be 'hands on' with tasks and activities for the children to help them to learn:

*I absolutely love the relationship that you form with the children, and just seeing them in the 'light bulb' moments is just brilliant. I'm very much a hands-on kind of teacher. I don't just sit at the front, and while I kind of do now being in a wheelchair, I do like to really find out about the children and build relationships with them. (Emily, p.2)*

It was interesting to note that Emily's MS is currently preventing her from being 'hands-on' in a literal sense because of the mobility issues that she has (in a wheelchair) and the restricted use of her limbs. She did not seem to connect or perceive being in a wheelchair as restricting the energy, drive and passion in any

way that was mentioned by her earlier. However, more than that description of energy, drive and passion, all three of the participants further outlined the fundamental need for stamina in what is a physically tiring and demanding job and how MS has affected that for them:

*Teaching's an effort, and I'm so relieved when I get in and have to sit down! Yesterday my legs were tired. It's like running a marathon! (Sally, p.14)*

*Fatigue is a huge, huge part of MS, and I was just finding it too much. I was struggling to walk around the school. I just said "I can't do this anymore. It's too much". (Emily, p.22)*

*I went into a relapse because I was completely burnt out. I was exhausted. Not just... not just tired. Literally every time I sat down, I would fall asleep. (Lucy, p.12)*

Emily outlined her opinion regarding teachers needing stamina in the profession due to the demands naturally being in excess of the assumed workload. Teaching is not a 9-5pm job. Many teachers are in from 7.30am in the morning, as breakfast clubs or wrap-around care for the pupils of working parents often starts from 8am. The teaching day itself may well finish at 3.15pm or 3.30pm (it is later in an independent school where the days are longer, with the finish being around 4.30pm), but that is then followed by the expectation that you run duties or after school clubs for the pupils, usually until around 5.30pm or 6pm. It is then, at that point, where a teacher may have to take books home to mark and grade, or plan lessons for the following day, or follow up any issues or e-mails that they did not have time for during the day itself. Their work goes into the evening, and some also have their own families at home that require their time and attention. This was Emily explaining how, due to these expected demands of her job conflicting with how she was physically able to function due to MS fatigue, she sought to go part-time in her teaching role:

*As you know, you can't leave school and that's it until the next day! In the evenings, I'd had it, you know? I wasn't doing anything, and I needed to be doing*

*lots of things for the children – the marking, the assessment, everything. But I just didn't have the energy to do that. (Emily, p.23)*

A little later in the interview, Emily was discussing how she was still finding the long, demanding days of teaching hard despite being part-time which led to her moving onto a mobility scooter at work and home:

*When you get tired at the end of the day, you get tired.....but anybody gets tired as a teacher. So, then we went for the scooter. (Emily, p.32)*

In a similar way, the physically demanding aspect of the teaching profession was also causing issues for Lucy with her MS. She was relapsing and struggling with sensations in some of her limbs (hands and feet) whilst at school. Stress is a recognised trigger for many MS patients which exacerbates symptoms or triggers a relapse as this exchange between us highlighted:

KPW: *How long did these bouts last?*

Lucy: *Probably about a month, and then the holidays would come, stress would go and the feeling would come back.*

KPW: *So you think that stress was playing a part of that?*

Lucy: *Yes, looking back now. Yes. Because it always seemed to happen at the same time – at the busy times of school. (Lucy, p.7)*

The main factors that the participants have associated with being an effective teacher are cognitive ability (the need to be able to think and react quickly in a fast-paced environment with young people), the physical demands of the job (being active and hands-on with the children) and the physical and mental stamina required (to cope with the long days and variety of tasks involved). I would not disagree with any of those factors, and whilst there are others you could specify such as subject knowledge, they certainly form the basic requirement for any teacher. It is interesting, then, that despite Sally – as one participant - recognising the importance of cognitive ability as an educator, Emily as another referenced her ability to teach *because* her mind is not affected by MS, and yet stating that she does suffer from occasional bouts of cognitive impairment in the same extract:

*Other jobs, I often think, well, I wouldn't be able to do that or I won't be able to do that. But teaching you can do, because luckily, my mind is not really affected. I get occasional sort of brain fog where I have to shut my eyes and have a sleep. But you can... you can still do it. (Emily, p.34)*

There is potentially an inherent contradiction in what Emily has just outlined. If she is in the middle of teaching a lesson to thirty pupils and has a moment where she has to shut her eyes and have a sleep, or, if she would claim to put off needing to do that until she was not with the class of children then she would still be teaching through the cognitive impairment and 'brain fog'. Neither of these are conducive to effective teaching, which raises the question of compatibility for that particular type of symptom. It is important to acknowledge that there are also other reasons for a teacher to suffer cognitive impairment, for example such as viruses or menopause. However, those conditions are treatable and for a defined period of time in the course of a person's life, as opposed to MS which cannot be cured and is degenerative by its nature. Lucy also shares that particular cognitive impairment when her MS flares up:

*Lucy: It was affecting my ability to do my job.*

*KPW: Was that general stress or stress causing MS?*

*Lucy: It was a bit of both. I was really tearful, really tired. I couldn't really concentrate or focus or anything. (Lucy, p.30)*

Yet despite this, Lucy had contradicted herself in an earlier part of the conversation when I asked what would make her disclose to her current or future employer:

*KPW: What would make you disclose?*

*Lucy: I think if I got... got worse and it was affecting my ability to teach...*

*KPW: In what way?*

*Lucy: Just like, moving around the classroom or losing my balance. (Lucy, p.29)*

Whilst she did not outline cognitive symptoms as a reason to disclose due to her teaching being affected, she then later – as outlined above – accepted that there were occasions when MS had affected her ability to teach.

In the next chapter of the thesis, I will discuss some of the issues that have been outlined here in this chapter of findings from the data. There is an inherent tension between what a teacher with MS outlines as basic requirements of the job of a teacher and how symptoms of MS invariably affect them to a greater or lesser extent throughout their lives. The idea of how we, as individuals, perceive ourselves and others also plays a significant role in this. Studies by Green et al. (2017) and Van der Hiele et al. (2016) which focus on the impact of MS for people in the workplace, show that it is common for one person with MS to relate their severity of disease to that of another. By extension, if a teacher with MS perceives their level of disability to be less severe than another person teaching with MS, they might view their impairment as inconsequential to the ability to teach because of seeing someone fulfilling that role. Allied to the notion of perception, our sense of personal identity and desire to retain elements of control over our illness both fuel our actions regarding disclosure. Having highlighted these issues drawn from the data by our participants, I will explore these and suggest potential ways forward as part of my conclusion.

## **6.6 - Autoethnographic analysis (*Career & Future*)**

To draw this chapter to a close, I finish by analysing one more journal entry of mine found in Appendix 13. In this, I touch on a variety of the issues outlined above and wonder what will become of me in the future as I learn who I am to become.

In this section of the chapter examining the compatibility of teaching for a person with MS, I have noted several contradictions contained in the interview data from the participants. For example, they all agree that physical energy and stamina are important (particularly with younger, primary school aged pupils), and yet all three participants have described the ongoing effect of fatigue on their daily living. In addition, cognitive function (including ability to think quickly, memory, concentration) has also been highlighted as an important facet of fulfilling the role

of a teacher. However, both Lucy and Emily have described intermittent problems with this due to their MS as well. As stated in this section, I am in complete agreement with them all regarding these being important elements of fulfilling the role of a teacher. In the journal extract here, I am referring to concern for my *“future ability to do the job”*, and yet going back and analysing other journal extracts contained in this thesis, I very clearly outline having to deal with fatigue myself as well as other symptoms. So just as there is a tension in the interview data between the participants and their ability to fulfil their professional duties due to the impact of MS symptoms, so too in my journal entries it is possible to identify contradiction given one could argue that MS also affects me now.

I would argue that I am affected the least by my symptoms of MS out of all the participants involved in this project, but fatigue is not measurable as discussed previously. Critically examining my own utterances in the journal, there is a danger that if I am just as fatigued (if not more) as Emily, Lucy or Sally, my stubbornness to not allow my MS to affect my ability to do my job might be the thing that – ultimately – proves to be my downfall. My fear of being ‘othered’ (Richards, 2008) is driving me to adhere to the ableist discourse (Williams, 2000; Vickers, 2001; Lyn, 2021) that I perceive to be inherent in our society. What if, as I muse in the journal extract, I am intent on pushing myself to such an extent that it brings on a relapse/episode that requires me to take time off work: *“Or will I ultimately regret pushing myself unnecessarily when it might be to the detriment of my health and, quite possibly, my relationships with loved ones...?”*.

It is interesting to read the research study by Honan et al. (2012) which found that physical disability for people with MS led to a greater withdrawal from the workplace than cognitive disability, but what was not clear is whether that was due to non-disclosure. My symptoms are hidden, so I hide my MS. However, as was also outlined by Honan et al. (2012), people who expect future issues with their MS to affect potential career and employment were discovered to have these fears unfounded. The experience of others who have MS that are older and have left employment at the end of their careers proves otherwise. That is reassuring to discover. However, that particular study involves a mix of professions (not just teachers) and it does not outline whether the people with MS who reach the end

of their career continue to do so in the same role or type of role (or are, in fact, merely just still in some kind of general employment rather than unemployed). Some of my fears may be unfounded and, as outlined earlier in this thesis, based on my perception (Green et al. 2017). What is clear from wider research is that job loss *is* common in MS patients (Van der Hiele et al. 2016). That is what drives my fear for the future and my present non-disclosure, and I presently believe that my MS does not affect my ability to do my job: *“MS just makes me feel so uncertain. So shackled by something I don’t really know what it is. A burden, yet one I struggle to articulate. It is like a black cloud hovering over my head constantly. Yet I know it will never go away.”*

However, it is only me that is making that decision as to whether MS affects my ability to work as a teacher. The moral imperative rests solely with me to disclose should I believe that my MS develops to such an extent that it is subsequently affecting my ability to function effectively in my role as a teacher. That is the same for the participants, and only Emily has disclosed to her employers rather than other colleagues because of the more significant, visible symptoms that she has. Lucy, Sally and I continue to hide our symptoms and our MS. But whether we would know if MS has affected our ability to do our respective jobs, or whether we would want to even admit to it given the often-gradual degenerative nature of the disease, is a difficult question to answer, and one I will refer to in the following chapter whilst looking at the themes that have arisen from the findings.

## **6.7 – Summary**

In this final chapter detailing the findings from the participant interviews and incorporating autoethnographic material, I have examined three main themes of choice, identity and the compatibility of MS for people in the teaching profession. Retaining the choice to disclose (or not disclose) relies on hidden MS symptoms. Emily does not have that choice anymore due to her visible physical symptoms (being in a wheelchair and not able to use all of her limbs). However, she still made the choice to decide when and to whom she wanted to disclose her MS as her condition worsened. For Lucy, Sally and I, we all still have the ability to choose whether to disclose or not due to our (generally) hidden symptoms. The issue to

consider, and one which creates anxiety for those of us that have not disclosed is associated with the degenerative nature of the illness. How long will we be able to maintain non-disclosure? The potential loss of control, should MS manifest itself with obvious, visible symptoms, affects how we perceive ourselves and – in turn – how others may perceive us (Charmaz, 1983; Wood et al. 2007). The theme of identity is related to our own perception of what makes us who we are and how that is affected by MS which is, in turn, linked to retaining our ability to choose whether to disclose or not whilst we still have hidden symptoms. Teaching is seen as a profession, if not a vocation (Schwehn, 2001; Metcalfe, 2013; Onyefulu, 2022), and forms part of the identity of all of the participants (including myself), and the data has shown anxiety regarding how and when MS might alter that identity. However, I have referenced our ability to take control and choose to develop our personal identity over time (Castells, 1997; Gabe et al. 2004; Quinn et al. 2009). Identity is not fixed, and does not have to be defined by MS, particularly for those of us with hidden symptoms.

Finally, I have examined the compatibility of MS with teaching. The participants themselves have highlighted physical and cognitive demands associated with the practice of teaching (Patrick et al. 2000; Kunter & Holzberger, 2014; Serin, 2017; Holley-Boaen, 2018), and these are not easily compatible for some symptoms of MS. However, it is important to recognise that these are subjectively unique for each participant (and each person that has MS), and accommodations can be made following disclosure. The decision to disclose rests with the individual, and that interlinks the various themes discussed in these chapters relating to the past, present, and future. These themes include having learned what it means to live with MS symptoms in the past, learning one's place in the world regarding how we perceive ourselves as a person with MS, and also how we perceive that others perceive us. Finally, I explored the theme of learning who we are to become in the future regarding how we may choose to let MS form part of our identity, and I will consider how that identity is compatible with teaching as a profession in the final chapter.

## Chapter 7 | *Conclusions*

In this chapter, I highlight reasons to disclose (or not) for a teacher with MS that were raised within the analysis of the data from myself and the participants in Chapters 4 to 6. Having identified various wider issues surrounding disclosure of MS through analysis including accommodations being needed, relationships, perception, understanding, choice, and identity, I now focus on what impact these have on our participants for their teaching careers. These areas to consider have been drawn together through continued analysis of the findings from both the autoethnographic elements and from the participants, and extrapolating the factors which have the greatest impact on answering the research questions outlined in Chapter 1, as well as considering wider implications.

The first consideration for myself and the participants throughout our teaching careers so far has been to consider the reasons why we might, or should, disclose our MS. Secondly, if we already have disclosed or do choose to disclose in the future, then to whom does that disclosure occur and why. Thirdly, if, on the other hand, we choose not to disclose our MS, what consideration do we give surrounding that decision. The final consideration is how compatible the teaching profession is for those with MS.

### **7.1 - Reasons to disclose**

As outlined in the previous chapters discussing findings from the data, the participants felt that disclosure was something private and personal and they only sought to divulge for specific reasons and to specific people. Previous studies within the field of psychology echo this finding because disclosure inherently reveals an aspect of “self” (Rosenfield, 2000, Charmaz 1991 and Beatty 2004). There is nothing easy about disclosure due to the personal nature of any health condition, and that is true whether the disclosure occurs purposefully or accidentally (Williams and Healy, 2001), but the participants perceived that the disclosure needed to have a function. This study has found that visibility of MS symptoms is one reason that leads to full disclosure. For example, in Emily’s case, when she started to use a

walking aid and then subsequently needed a wheelchair due to her mobility issues, she decided to widely disclose to the staff and the pupils in her school as a protective measure (Joachim and Acorn, 2003; Grytten et al. 2005; Quinn et al. 2009; Benson et al. 2015) to control their understanding of the disease.

Another reason for a teacher with MS to disclose their illness to an employer found in this study is the need for accommodations in the workplace. This would be in line with Dyck and Jongbloed's (2000) study into women with MS in the workplace who highlighted physical factors leading to a person with MS needing assistance at work. For example, when mobility became more of an issue for Emily and this meant that she struggled to be able to access the main staffroom printer which was situated away from her teaching space, she requested her own printer that the school subsequently supplied for her. Emily's current employer has been supportive in practical ways in relation to making accommodations for her MS, and this includes organising a mobility scooter for her. However, it was interesting to note Emily's acknowledgement that her physical school environment was luckily conducive to her being able to use the scooter:

*I go round on a mobility scooter around school. Luckily, it's all flat. The only steps are down into the school hall, but we've had a child in a wheelchair before, so we've got a lift down into the hall and that's it! (Emily, p.28)*

The same type of accommodation may simply not be possible in other school environments, particularly if they are older, period buildings protected by planning regulations. The school would not be permitted to make structural changes (such as install a lift) even if they were prepared to do so. In her participant interview, Sally outlined one of her hidden symptoms as the need to use the toilet more frequently. There is only one toilet for a number of staff in her part of the school, but because it is a Victorian school with listed, period buildings the creation of additional facilities for her would not be possible. She fears just being told to use the disabled toilet which is in a different part of the school to where she works but is frequently used as a general staff toilet by others, so continues not to widely disclose as she does not feel that it would achieve anything in this practical regard.

Disclosure to specific work colleagues took place for participants in this study purposefully, but for all three of them it also happened on occasion due to accidental disclosure (for example, due to parking in a disabled space and needing to explain why). Munir et al (2005) outlined two specific types of disclosure, “partial self-disclosure” and “full self-disclosure”. Following accidental disclosure, the participants felt the need to go on to outline the meaning of their diagnosis to their work colleagues so as to manage expectations and perception. Even when the disclosure had occurred by accident, “full self-disclosure” was then felt necessary by the participants to manage others’ perception of the impact MS may have on the ability to work. However, during the time that the participants in this study were able to maintain hidden symptoms of MS, they were (or are still) reluctant to willingly “fully self-disclose” to employers, as they associated disclosure with their own – and others’ - acknowledgement of their difference and the stigma that they perceived to be attached to that.

Grytten et al. (2005) conclude in their study that *“disclosing, then, is not a passive strategy that people with MS are forced to adopt, but a choice”* (p.236). However, the findings from this study have shown that all three participants have, at one time or another, had the choice taken away from them because of accidental disclosure at work. The motive for them, as it is for me, may be to strategically conceal their MS to maintain an appearance of normality in the workplace, but that attempt at concealment relies on visibility of symptoms, whether accommodations are required, and the individual’s ability to fulfil their professional role as a teacher to a satisfactory standard as judged by their employer. Following a loss of control over disclosure, our participants have subsequently sought to claim back a sense of control by targeting disclosure to certain members of their school communities as they have felt it of benefit to avoid discrimination through potential misunderstanding about symptoms, or because they need assistance in the workplace. For all three participants, this subsequent retention of control and choice over disclosure has become an active strategy, perhaps due to learning the danger of not controlling disclosure previously. These disclosure choices by the participants may possibly reproduce the ableist discourses outlined throughout this thesis.

## 7.2 – Who to disclose to

Existing studies refer to people living with a chronic illness learning to disclose (Schneider and Conrad, 1980, Charmaz, 1991) and, by learning how to disclose, they develop a strategy to minimise any stigma associated with their condition from others. However, the participants in this study (which includes me) who have hidden MS symptoms have not yet navigated wide ranging disclosure in the workplace beyond telling a few close colleagues. We have not, as yet, learned how to disclose effectively to prevent stigma or negative perception, or as Schneider and Conrad (1980) describe it, “preventative telling” (p.39). A lack of knowledge of who to tell, how and when, contributes to our desire to keep the condition hidden. The participants and I have made a strategic decision to inform certain colleagues about our MS condition and not others. The participants – such as Lucy and Sally - who are able to keep their condition hidden through lack of visible symptoms may choose to purposefully disclose to close colleagues who they consider friends, but they also choose not to openly disclose to their employer. However, the partial concealment still has an impact on the mental wellbeing of the person with MS due to retaining the significant information about themselves, and that would concur with the findings of Kever et al. (2022) who highlighted that non-disclosure of MS can result in a sense of loneliness. I have also referred to feeling lonely in extracts from my journal due to disclosure to some, but not others including my own family members. Given that the lines become blurred between personal and professional colleagues as friendships are forged over time (Dutton, 2007), it seems likely that the participants and I would seek to strategically inform a limited number of close colleagues that they regard as friends about their MS in the future.

The participants highlighted an uncertainty surrounding how to disclose in the workplace, what to say and to whom. Sally described accidental disclosure by her husband following her line-manager calling her house phone actually making disclosure easier for her as it removed the option or decision from her own control. However, she was quick to question whether she would have disclosed to work had the accidental disclosure not taken place. Lucy also made a similar point during her participant interview, stating that should she go for another school job somewhere, she would not disclose her MS.

As discussed in Chapter 6, the participants and I all suggest that the potential for negative perception in the workplace contributes to our reluctance to disclose MS. This reluctance is two-fold. Firstly, we all cited not wanting colleagues and fellow teachers to consider us a weak team member not contributing the same amount of time or effort due to their illness. For example, Lucy cited: *It [my MS] was so unpredictable how I was going to be. And it's not fair on the team*".

However, more than that, the main concern for me and the participants surrounds potential disclosure to a school employer and the negative perception that might occur as a result, as is evidenced in the example quotes:

*You're thinking, "would someone take you on?" [if a person with MS went for a job and disclosed]. I don't know. (Emily, p.34)*

*They might think "Oh, I've given her this job, oh no, she's damaged", just that kind of thing. And maybe they would regret employing me? (Lucy, p.20)*

*It's increasingly kind of natural for, I think, people to think "Oh no, I've employed this person and, actually, it could all go wrong". (Lucy, p.35)*

Both Lucy and Emily were referring to disclosure of MS with hidden symptoms to a future employer in the extracts above. However, Emily – who is in a wheelchair herself – also suggested that having MS to the extent that the illness is visible might also make an employer reluctant to give a job when she stated: *"I don't know what people would think, you know, if I turned up in a wheelchair. Are people going to take you on? Really?"*.

Another concern of the participants when describing disclosure of their MS to an employer was the uncertainty from the employer regarding what impact the illness had on the participant and the school as a result. Emily cited the fact that, despite her employer being supportive in practical terms, providing a mobility scooter, her headteacher never actually discussed it with her or asked her whether she would like one. She also referred to a potential future employer possibly having concerns

regarding uncertainty surrounding what support they might be required to offer a teacher with MS and any ongoing support.

The concern that an individual with MS has over their relationship with other people is linked to issues of perception, disclosure and 'self'. The relationship may be on a personal or a professional level, but the fear for the individual with MS is that the impact of their illness not only affects them but the others in their life as well. In Charmaz's (1983) study into a chronic health condition causing a negative "loss of self" to the individual, the focus was on the potential restrictions caused by the illness creating a negative sense of identity. However, in this study, the data from the participants and me has shown a sense of fear surrounding disclosing to other people – both personal and professional – due to the possible negative perception that it would bring on the part of others. Therefore, the concept of "loss of self" is further felt by the person with MS if or when they struggle with considering how to manage disclosure in terms of when, why and to whom.

Disclosure in a professional setting, or place of work, brings with it uncertainty and anxiety surrounding potential reactions and consequences according to the participant data. Whilst there is a degree of protection against discrimination for those with a disability through government legislation (Equality Act, 2010), this relies on disclosure in the first place. For those with a hidden illness, such as MS for those people with that diagnosis, there remains a sense of trepidation surrounding disclosure to an employer for fear of being viewed as less able as a result, and that might be why there is no mention of this legislation by the participants as part of our interview process. Those participants who have hidden MS symptoms choose not to disclose and consider this to potentially be a reason for their successful ongoing employment. I would also count myself as one of those. I am not certain that I would be in the senior leadership position I am had I widely disclosed my MS and asked for any accommodations at work. However, Goffman (1963) outlines an inherent risk behind attempting to "pass as normal" (p.138) for an individual with a chronic condition. The unpredictable, degenerative nature of MS means that any gradual or sudden visibility of the disease to other people could eventually lead to the person with the chronic illness being "discredited" (p.3), and that is a risk that I – and others - continue to live with.

The issue of managing perception of others relating to disclosure was raised by all the participants as well as me within this study. As described by Terry (2020), the difference between knowing something (for example, that someone has MS) and understanding it (what it actually means for the person with MS on a day-to-day basis) drives many people with MS to disclose professionally as well as personally. Trostle's (2007) study into the social issues surrounding chronic health conditions outlines the reasons why, namely that uncertainty and fear are both linked with any unpredictable illness which necessitates an explanation to others being made aware as a result. However, whilst it may well be true that people who become aware of someone with a chronic illness (such as MS) may perceive them to be 'different' or 'less-than', an illness that is hidden enables the person with MS to choose whether to disclose or not. Retaining this element of control over their illness allowed the participants to maintain a greater invisibility to others, to not appear 'different', and potentially to integrate themselves personally and professionally to a greater degree as a result.

None of the other participants involved in this research described receiving any negative reactions from school colleagues or an employer following disclosure. However, as outlined in this study, any disclosure of MS that has taken place by the participants has only been once they were already in an existing job. Their comments suggest – and I would agree with this – that it has provided them with a sense of security in terms of feeling like they were already known to the employer and had proven their worth. It also gave them a sense of security knowing that others (however many or few) were aware of their illness should it affect them negatively at work in the future. The participants and I harbour an ongoing fear of negative perception from employers and work colleagues and, subsequently, a reluctance to widely disclose in the workplace if we have invisible symptoms, but we lack personal experience of negative consequences to warrant that reluctance. This is similar to the findings from the Kaushansky et al. (2016) study of young adults living with a chronic illness who choose to conceal their illness: *"very few described actual experiences in which their fears of rejection, pity and isolation... had been realised"* (p.57). Perception of the individual person with MS about the perception of others towards them then, rather than actualised, experienced

negativity, is a powerful motivation behind concealment. This was partially evidenced in the participant data when Lucy described her knowledge of another local teacher with MS and the negative way that they are viewed by their colleagues due to their inability to function effectively in the teaching role. This has led Lucy to fear that same perception of others towards her, and adds to her reluctance to disclose.

### **7.3 – Reasons not to disclose**

As outlined by Fesko (2001) there are practical reasons for a person with chronic illness to consider concealing their illness in the workplace if they fear negative perception from an employer, such as possible unemployment and a future lack of income. The participants highlighted their concerns about a potential future employer being prepared to give them a job should they disclose their MS which is a fear I also hold. Whilst studies relating to people with MS and employment (Honan et al. 2012, Frndak et al. 2015, Van der Hiele et al. 2016), refer to job loss being common for people with MS, they are not specific to the teaching profession. Van der Hiele et al. (2016) found that a person with MS requesting accommodations at work not only adds to a perception of disease severity from others, but those requests are also more commonly found from MS patients prior to job loss. This is at odds with the study of women with MS in employment by Dyck and Jongbloed (2000) who note the type of workplace and also the relationship with a person's employer as factors influencing ongoing employment for a person with MS. Emily has remained in employment as a teacher following disclosure and receives accommodations for her to continue in her teaching role. However, Emily has visible symptoms. Lucy, Sally and I choose not to widely disclose our MS at work due to having hidden symptoms and the ability to conceal our illness, and we have stated clearly our reluctance to disclose to a potential future employer also. This is both due to fear of negative perception from others as outlined in the previous section and the desire to maintain a 'healthy', 'normal' identity and sense of self as well as a care for others (Foucault, 1988a).

In Bury's (1982) study of identity, or 'biographical disruption', for an individual following the diagnosis of a chronic health condition, the focus was on aspects such

as inability to work or restrictions on being able to drive. However, following this study, and in line with other studies that place emphasis on the ongoing disruption to a person's life (Charmaz, 1991, 2002; Williams, 2000; Beaty, 2004; Diloranzo et al. 2008; Quinn et al. 2009; Simmons et al. 2010) my research suggests that this sense of 'disruption' to the life of an individual with MS continues beyond the initial diagnosis stage. Due to the long-term, degenerative nature of MS, the decisions surrounding disclosure aligned to the daily management of the disease for the person concerned have significant potential for ongoing 'disruption' in their life. This disruption has led to a negative impact on the sense of identity for Lucy and Emily in relation to their prior sporting prowess, and also for me with my practical musical skill, all of which continue to be affected by our MS symptoms. However, the degree of control over the extent to which we allow MS to define our identity to others remains connected to the visibility of our symptoms (Vickers, 1997).

In Parson's (1954) seminal work, he described how sickness is a socially accepted category. A person with sickness is not held responsible for their condition if it is beyond their control, as with MS. However, as has been outlined above in several different studies, stigma is often associated with chronic illness and illness is not perceived by society as legitimate. For that reason, the participants (including myself) with hidden symptoms regard assuming the role of a chronically ill person as a threat to ourselves and our identity. Therefore, to negotiate what we perceive as the 'illegitimacy of negative perception' (Grytten & Maseide, 2005, p.240), Lucy, Sally and I with invisible symptoms are inclined to objectify our MS. We do that so we can create distance between the illness, ourselves and others.

One element of identity that may require further investigation is that of gender, and particularly motherhood in relation to teachers with MS. There are twice as many women diagnosed with MS than men (Cosh & Carslaw, 2014), and all three participants in the study are women. I did not purposefully seek to recruit female participants, but was more concerned with being able to find available participants that were actively teaching whilst suffering from MS. As outlined by Dyck & Jongbloed (2000) in their study focusing on women with MS in employment, gender is significant due to the fact that the majority of women in employment also retain the role of primary caregiver to any children. These are additional parts of a

person's identity, that of being a woman and also a parent. Flexibility in working arrangements could be particularly important for someone with a chronic illness in this situation. Flexible arrangements - which facilitate ongoing employment - are more likely when an employer has invested in the employee (Hashiguchi 2010). This investment is made up of a variety of factors, such as training, age, length of service and return on investment, and follows the long-standing theory of human capital by Schultz (1959). This same theory would seem to be in line with the accommodations made for a participant in this study, such as Emily, who is currently in a job and has had to disclose due to the deterioration of her MS symptoms and whose employer has supported her to help her retain her job in some capacity. This could be, in part, to protect a continued return on the prior investment of time and money into their employee.

Flexible working practices in the UK are becoming more widely accepted by employers (Hashiguchi, 2010), particularly with returning to work following maternity leave. This should also benefit those people in employment that are diagnosed with a chronic illness. Whilst that has been evidenced in this study, it is important to note two things. Firstly, both Lucy and Sally are also mothers teaching with MS. This is not something the participants chose to explicitly make reference to during the interviews, but something that I think is relevant given they choose not to widely disclose their illness because they do not currently have visible symptoms. They have, however, both had children whilst in the teaching profession and taken maternity leave as part of navigating that accepted, normalised life event. Secondly, human capital theory in this instance is related to a person being in current employment. Emily was known and had been invested in by her school and it was prepared to make accommodations to keep her as a result. Whilst Lucy, Sally and I are also in current employment, we wish to retain our identity of being 'healthy' and 'normal'. As per human capital theory (Schulz, 1959), we seek to maintain a position as healthy and normal to the people we work for and with, so that we are not identified as weak in any way due to our MS.

For a teacher with MS wishing to gain employment or promotion in a different school, references would be sought by the current employer (usually the headteacher). Even if they had disclosed to their current employer as a protective

measure (Grytten & Maseide, 2005) to control understanding and in case something should occur in the future, there is no guarantee that the disclosure would feature in the reference to the potential new employer. If it did feature because the current employer felt compelled to mention it on principle, there is then no guarantee how the potential future employer would react regarding offering the job should they read about MS in the reference. Whilst an employer may not be permitted to explicitly refer to an illness or condition such as MS, this can still easily be implicitly referred to through references to attendance, reliability, ability to fulfil certain functions in the workplace, and so on.

Human capital is, it seems, earned by an employee whether in relation to flexible working for maternity or disability accommodations. There is a degree of protection by the Equality Act 2010 for all protected characteristics, including maternity and disability, but the extent to which an employer is prepared to make accommodations for an employee is related to the effectiveness of their work and the value they are perceived to bring to the workplace (Frndak et al. 2015). This cannot easily be quantified or valued by a potential future employer, and so the teacher with MS has no existing human capital to carry forward when applying for a new job or promotion with a new school. In this study, Lucy, Sally and I all agreed that we would not disclose our MS to a potential new employer, and Emily also stated that she would not if she had the choice and was still able to hide her symptoms. However, as noted previously in the thesis, during the course of this study Sally has applied for a new job with a different employer. Because of discussing MS and employment as part of this research project, she subsequently felt empowered to raise it as part of the interview process and was successful in gaining the post.

## **7.4 – Compatibility of teaching for a person with MS**

The ability to do their job is a consideration for the participants regarding whether to disclose or not. As outlined in the previous chapter of this thesis, Lucy disclosed to one colleague because she had been asked to drive a minibus and was not medically allowed to due to her MS. There are any number of staff members within a school environment that are not able to drive a minibus for a variety of reasons,

which may include their young age or the fact that they have not taken the additional driving test which enables you to drive passengers in a larger vehicle such as a minibus. MS does not need to be disclosed as a standalone reason, per se. However, if driving a minibus forms part of your role - for example you are a sports teacher needing to transport children to matches and fixtures - then in that instance, MS has made you incompatible for your teaching role. Accommodations could easily be made in that scenario, such as an alternative driver for the minibus or the teacher with MS is only scheduled for sport sessions and matches that take place at their school (not away at other venues which require driving). However, such accommodations would necessitate disclosure.

The participants have also described various traits they felt were important parts of teaching, especially energy and stamina which is then starkly juxtaposed with the underlying symptom that the majority of MS sufferers live with, namely fatigue. All three participants along with myself have outlined the impact that fatigue has had on aspects of our lives, both personal and professional. Emily has subsequently negotiated an alternative role for herself, only covering teaching for her colleagues so that they can complete their administration throughout the week, thus allowing her to have a lighter overall workload in relation to planning lessons and marking work (both of which are the responsibility of the teachers for whom she is covering classes). Alternative roles are certainly possible for teachers, including part-time roles, and as discussed above, there is a degree of protection enshrined in law through The Equality Act 2010 which requires any employer to make reasonable adjustments. Frndak et al. (2015) note that adjustments and flexible working arrangements could benefit people with MS by providing a higher sense of self-control and self-worth. However, and once again, these protections are only in place once a disclosure has been made.

The study by Frndak et al. (2015) also highlights that disclosure amongst MS patients was associated with physical disability, but not cognitive impairment. That is in line with the findings from this study, whereby Emily has had to disclose widely at work due to her severe disability and wheelchair use, and Sally has also disclosed to targeted colleagues so that they understand why she may walk in an uneven way due to balance issues. However, the participants have also made reference to

cognitive impairment through concentration, focus and memory problems, and these have not been disclosed or any accommodations requested. Frndak et al. (2015) refer to the difficulty in accommodations for cognitive problems not being readily available because employers find it difficult to know what accommodations to make. This would concur with other studies by Rao et al. (1991) and Benedict et al. (2005) which highlight that disclosure of cognitive symptoms in MS patients leads to increased unemployment more than disclosure of physical symptoms. If the perception of a teacher with MS is that potential disclosure of cognitive symptoms may lead to unemployment, or being viewed negatively by an employer because of an inability to accommodate the problems, then the data from this study would confirm that perception.

The final point that this study has raised is a potential ethical or moral obligation to consider. Whilst the participants and I are under no legal obligation to disclose our MS to an employer (current or future), and in the case of Lucy, Sally and I, we choose not to, from an ethical perspective a teacher is responsible for the welfare and safety of children in their care. Should a person with MS feel that their symptoms (hidden or visible) are starting to have any impact on that aspect of the ability to do their job, then they have a professional duty to disclose their MS so that accommodations can be made. All teachers are, according to the Teachers' Standards (DfE, 2011) "*accountable for achieving the highest possible standards in work and conduct*" (p.10). The problem in that scenario, is that there is no external compulsion to disclose, and so the decision rests on the person with MS. Hence the internal, moral obligation to consider, and this is where issues of temporality come into focus as well. There is no clarity to be found from a legal or medical perspective regarding the moral obligation for a person to disclose MS as an illness if it does not affect their ability to teach. Non-disclosure in the present and the future is based on an individual's lived experience of the disease. However, the temporal nature of a degenerative disease is a factor, as the lived experience of the past and present cannot fully inform the future because the extent of any degeneration of health cannot be forecast. This study suggests that an individual with hidden MS symptoms would not choose to disclose to a future employer despite any internalised moral obligation, and this contrasts with a study into Cystic Fibrosis from Lowton (2004) which outlines how a person with a chronic illness, with

symptoms that are less hidden, may decide to disclose their condition if they are concerned that it will deteriorate further in the future.

## 7.5 – Conclusions

This study has examined the role of disclosure for a teacher with MS in relation to both present employment and future career. The rationale for the study originated from a lack of specific research in the area of MS disclosure for people in the teaching profession. This study adds to the field of research due to the insight that it brings to the reasons behind disclosure and non-disclosure for teachers living with MS. It complements existing research on the wider topic of disclosure due to identifying temporal issues regarding the degenerative nature of the disease and the passage of time. In addition, it builds on the work of Carel (2016) and others who use a phenomenological approach to explore experiences of living with illness whilst utilising my position as an 'insider' through my autoethnographic data. Through the lens of interpretative phenomenological analysis, data was examined with themes identified, and the study has found disclosure to be a dynamic process influenced by several different factors. These are:

- 1) The purpose of disclosure.
- 2) The context of disclosure.
- 3) The role of non-disclosure.

If it occurs, then disclosure plays a functional role. The purpose of disclosure for a teacher with MS is predominantly due to the visibility of MS symptoms and, as such, disclosure is used as a method to retain a sense of control over the understanding and perception of other people. Linked to this, the role of disclosure is to gain access to practical support through accommodations in the workplace. These may include adjustments to working patterns or roles within a school, or requesting logistical support such as mobility aids or positioning on the ground floor of a building to make access easier. If a teacher with MS is unable to fulfil a certain aspect of their role due to their symptoms, then disclosure may occur accidentally rather than purposefully. However, in this instance, further disclosure is then necessary to dispel any misunderstanding or negative perception. If a teacher is no

longer able to fulfil aspects of their role due to MS symptoms, then this also may necessitate disclosure. Other studies suggest that once a person is established in a work environment that disclosure does not lead to unemployment (Frndak et al. 2015; Kaushansky et al. 2016). That has also been suggested in this study in the case of Emily and, to a certain extent, following the limited disclosure at work by Sally.

With regard to the context of disclosure for a teacher with MS, this study has identified that there is a sense of reassurance that somebody knows about their condition at work, even if this is a close colleague rather than a line manager. This protective disclosure enables a degree of social support and understanding given the potential unpredictability of the illness, and it also contributes to a reduction in the psychosocial impact of potentially dealing with the consequences of worsening symptoms (or symptoms becoming visible) completely alone in the work place. This study has also suggested that a teacher with MS is more likely to control their disclosure through targeted, strategic disclosure to close colleagues and possibly a direct line manager rather than a headteacher or more widely to other colleagues. This distinction is to control negative perception and being seen as a weak member of the team. However, it is interesting to recognise that the findings did not identify disclosure to wider colleagues as contributing to any negative outcome for the participants in this study. Both Emily and Lucy spoke anecdotally of another teacher with MS who is perceived by her colleagues in a negative way due to being a weak member of the team, unable to fulfil the duties and tasks expected of a class teacher, but that is not the experience of the participants themselves. My analysis of data for this study suggests that additional advice and guidance is needed at the point of diagnosis regarding disclosure at work. There seems to be a lack of clarity surrounding best practice to both protect the patient with MS from negative work events as well as any obligations to their employer regarding ability to carry out all aspects of their teaching role. Additional support and advice in this area of employment rights and best practice for all parties would be welcome. That is certainly true from my own experience, and something which has shown in the data from the other participants where they have highlighted a lack of guidance.

The purpose of non-disclosure has been found in this study to be related to a desire to protect personal identity, and to whether a teacher has further promotion or

career aspirations, or whether they just wish to remain in their current teaching role. This study has reinforced the idea that teaching can be seen by the teacher with MS as more than just a job. The participants in my study see teaching as much more akin to that of a vocation which contributes to their sense of identity, and this adds to the reluctance to disclose if the teacher with MS fears any negative perception towards their ability to fulfil that aspect of their identity. Whilst Charmaz' (1983) work in relation to identity suggests that an individual with a chronic illness *"learns new definitions of self and often relinquishes old ones"* (p.170), if a teacher is looking to move to a new school for a new job, or seek promotion in their current or a new school, then to control perception of their identity as a teacher rather than their identity as a teacher with MS, it is non-disclosure that purposefully forms part of that *"new definition of self"*. Credibility and the intrinsically positive effect of human capital that is accrued over time with an employer would not be automatically afforded to a teacher with MS applying for a job at a new school, or if seeking promotion. This leads to continuing non-disclosure for those individuals who aspire to move up the career ladder within the teaching profession as a method to protect their identity from stigma. Any moral obligation felt by a teacher with MS to disclose can manifest itself in disclosure once that individual is established in their role and has built up human capital with their employer. It is possible to see, therefore, how those with chronic illness are – themselves – engaged in the complex nature of the ableist discourse (Foucault, 1988a), given that through the process of disclosure or non-disclosure those people with an illness such as MS are resisting and reproducing the same discourse.

## **7.6 – Reflections on this study**

Earlier in this study, I outlined my position as a researcher and an aspirant headteacher who also has MS. I accepted that this had the potential to influence my thinking and actions during the process of interviewing the participants and analysing the data. Through a thorough use of IPA, I have attempted to set aside any predetermined judgements about my own lived experience as a teacher with MS when examining the lived experience of the participants. I note, however, that my own positionality is accepted as an integral part of the analysis and being an 'insider' (as noted earlier), influenced the interview process and what interviewees

were prepared to say. The iterative nature of the analysis and the requirement to continually revisit the data for each participant as well as my own autoethnographic content played a significant role in my interpretation and extrapolation of possible themes. My ontological position and my epistemological understanding of social constructionism has also influenced my interpretation of the data, as it emphasises the construction of meaning behind the data given by the participants and myself through my journal analysis, and outlines it as being reflective of their social context.

There have been challenges for me completing this study. My incorporation of autoethnography in addition to the phenomenological approach used with the participants has meant implementing a highly reflexive gaze in two directions, both inwardly and outwardly. I would argue that the synthesis of autoethnography interweaved with the phenomenological data from the participants has strengthened the outcome of this project. I entered it not knowing whether or how my own experience(s) would be juxtaposed with those of the participants and was fully prepared for that to be the case. In the final analysis, there is a close alignment with many of our experiences regarding disclosure of MS within the teaching profession. The emotive impact of autoethnography is stark. Accessing and using memories as data requires thoughts and feelings from a previous temporal realm to be brought to the fore and felt in the present. Disclosure is both a moment in time as well as having an impact on all future moments. The nature of inquiry has become embodied for me whilst also requiring me to step outside myself to look inward at the same time, making connections to the world and culture that I am situated within. The iterative nature of both autoethnography and Interpretative Phenomenological Analysis, and the sense of looking to the future have meant that it is actually quite challenging to bring the process to a conclusion. However, this then provides further opportunity for study and development of the issues and findings contained here.

## **7.7 – Limitations**

As a small-scale qualitative study with very few participants there is limited ability to generalise, and the findings from my study should be understood as emergent.

There may have been greater differences or similarities amongst participants had the sample size been larger. However, the data provided by the three participants, added to that of my own experience, has a richness and depth that has provided considerable insight into the lived experience of a teacher with MS. The insights gained in this study are possible due to the quantity of data gained from each participant and the in-depth analysis undertaken with a small sample size. In addition, it is important to note the participants' relationship with me as the researcher due to my own participation in the research and being a fellow teacher with MS. That should be seen as a positive regarding ability to both collect, and connect with, the data. However, as outlined, there have been challenges for me with regards to attempting to set aside any bias or preconceived ideas about the issues discussed with the participants due to my own experiences with the subject matter. The limitations of the Interpretative Phenomenological Analysis approach utilised in this study which were outlined earlier in Chapter 3, remain relevant as a result. For example, the 'position' of the researcher and the resulting interpretation of the data has informed the way that the themes have been developed and outlined, and it is impossible for me to 'bracket' myself away entirely from the material collected. However, due to the comprehensive nature of the reflexivity and iterative nature of the analysis surrounding the data interpretation, this helps to ensure appropriate process and outcome.

## **7.8– Further work**

Whilst this study offers an insight into the lived experience and thought process behind whether to disclose or not for a teacher with MS, further study would be valuable in order to unpack some of the wider issues that have been uncovered. These include examining the importance of the differing type of role available within the teaching profession. For example, what difference does it make teaching one subject, particularly a more practical subject requiring less physical inhibition or disability, over another subject where a teacher could sit and deliver a lesson from the front of a classroom. In addition, another focus could be the role that gender plays, if at all, for a teacher with MS deciding whether to disclose or not.

In order to be able to supplement more of the speculative data from our participants in the present time about possible future effects of their MS, it would also be helpful to complete a study with teachers that have had MS for much of their working life who are older and further into their career (or possibly even retired). They would then be able to provide data on their personal experience of living through some of the issues that our current participants have perceived may be the case in the future, and be able to confirm whether the perception has been an accurate reflection of reality for them or not.

It would be interesting to examine what function expectation has with regard to employer and parental perception comparatively between the independent (private) and state school sectors. Two of the participants in this study, along with myself, teach in a private school. We all choose not to widely disclose our MS in our professional settings, but is that because we have hidden symptoms that enable us to keep our condition undisclosed, or is it also partly because of the environment that we work in? I have explored this in sections 2.4 and 2.5 where I have considered how the commercial imperative of private schooling means that schools market themselves on the basis of normative discourses of success, including heteronormativity and ableness. This is not to say that state schools do not also do this, but perhaps it is more explicit in the private sector. The final participant (Emily) works in a state school and has disclosed, but that is due to the severity of her symptoms. Therefore, with this small sample size and unique nature of the symptoms for the participants it was too difficult to compare the context of the setting. Further study into this would be valuable with regards to informing a teacher with MS about whether one sector is more accommodating than another should disclosure occur.

Finally, it would warrant further study to examine the perception of employers within a school setting. Being able to compare the potential perception of a school employer (head or governing body) about the impact of employing a teacher with MS, with the reality of a school employer who has already employed a teacher with MS, would provide insight into the actual issues on a practical level that the school faces (if any).

## 7.9 – Implications and practical meaning

As outlined in this chapter, my hope is that this work will give help and support to fellow educators who have been diagnosed with MS. This is potentially in different ways. Firstly, as with the participants, a teacher with MS reading this thesis will know that they are not alone. Whilst they will have a unique set of individual symptoms and challenges, there are similarities to be found amongst the personal and professional challenges that they – and we, as participants in the project – have in common. Knowing that you are not the only person experiencing these types of issue in your daily life can be both comforting and empowering.

Secondly, a teacher with MS may like to consider the following practical steps:

- Targeted disclosure (to professional colleagues or team members who they are close to on a personal level, or a line manager) if they have not disclosed already. This would enable them to outline their unique symptoms which may or may not require support or accommodations, but the psychological comfort of knowing that one or more people at work are aware may be of benefit in the longer term.
- Consider alternative teaching positions. As discussed in this project, there are different options within any school environment, with some naturally more physically demanding than others. Seeking, or requesting an alternative role so that they can still utilise your knowledge and skills as an educator may be beneficial to long term health whilst also maintaining an important sense of identity as a teacher.
- Request accommodations if required. This may range from having a dedicated disabled parking space, through to a printer in their classroom to avoid having to travel to a centralised facility, through to having their classroom located nearby to toilet facilities. Whatever may benefit them regarding their specific symptoms which, in turn, may allow them to focus more fully on their role as a teacher rather than worrying about how to manage their symptoms would be a positive step.

Thirdly, for school leadership (either headteachers, and/or governing bodies), knowledge and understanding of various disabilities, but specifically MS, would be

helpful. Production of material and resources for school leadership is worth considering, and this is something in which the various education unions (such as the National Education Union) could play an important part. Offering workshops for headteachers, senior leadership teams and governing bodies to enhance their understanding of what it means to teach with MS and how to support staff members who have it, would be strongly recommended.

My final, main recommendation is related to clinical practice. Health care professionals should more widely consider the psycho-social impact of being diagnosed with MS, and should spend time to individualise the support offered to people newly diagnosed with MS. There is, at present, an overreliance on the biomedical model of care which focuses on the experience of physical symptoms over the wider psychosocial impact of MS. Consideration should be given to how any diagnosis is communicated, and psychological support should be made readily available for people who are newly diagnosed and express a wish for support. Individualised support for newly diagnosed MS patients should also focus on practical matters appropriate to the circumstances, such as disclosure requirement, ability to continue working, to continue driving, and what ongoing support there is available in the longer term.

# Epilogue

As an educator, I believe that I have a duty to provide the best possible education to all the children in my care regardless of gender, ability, race, skin colour, religion, background or disability. Equality, Diversity and Inclusion are – thankfully – becoming ever more present in schools and are taught as important issues to understand to pupils of all ages. If schools and educators embrace inclusivity as fundamentally important to enhance the understanding of diversity for the pupils in their school community, then surely this should also be extended to teaching staff as well. I believe that inclusion will be the catalyst for building a world where we all learn to accept and support each other. It enables us to value people for who they are and helps people to examine themselves. This study has created one form of insight into the lived experience of a teacher with MS in relation to the decision to disclose (or not). Whilst there is a great deal of important knowledge for those involved in educational leadership (whether governing bodies, headteachers or senior leaders), the greatest benefit will be that the research will help other teachers with MS who are also learning their place in the world and are considering what the future may bring from a professional perspective. I am aware, for example, that at least one of the participants who successfully applied for and gained a new job following this project did so because of the confidence gained when discussing MS in the workplace with a fellow MS sufferer as part of this research. She felt empowered to bring it up at interview in a factual, informative way which allowed the potential employer to ask any questions they may have prior to offering the job. My hope is that others, both teachers with MS as well as employers, will be able to use this material as the starting point for conversations surrounding MS and the broader issues of disability and illness (visible and invisible) in the teaching profession. I would also hope that it may inform others who wish to undertake similar research into this important topic to further shed light on it.

# References

- Adams, R. (2019) Teachers in England have unimaginable job *The Guardian UK* (19/6/19). Available at:  
<https://www.theguardian.com/education/2019/jun/19/teachers-in-england-have-unmanageable-job-global-survey>
- Adams, T. E., Jones, S. H., and Ellis, C. (2015) *Autoethnography: Understanding Qualitative Research* New York: Oxford University Press
- Alexander, R. (2010) *Children, Their World, Their Education* London: Routledge
- Allbon, C. (2013) *The Being in some body: An Autoethnographic Account of Being and Becoming-in-the-world with Multiple Sclerosis* PhD Thesis, University of Waikato
- Allen, A., Benhenda, A., Jerrim, J & Sims, S. (2019) *New evidence on teachers' working hours. An empirical analysis of four datasets* (downloaded from [www.johnjerrim.com](http://www.johnjerrim.com) on 2.6.21)
- Alonso, A., & Hernan, M. (2008) Temporal trends in the incidence of multiple sclerosis: a systematic review *Neurology* 71, pp.129-135
- Anderson, L. (2006) Analytical autoethnography *Journal of Contemporary Ethnography* 35 (4), pp.373-395
- Annells, M. (1996) Hermeneutic phenomenology: philosophical perspectives and current use in research. *Journal of Advanced Nursing* 23, pp.705-713
- Aoki, T. (1992) Layers voices in teaching: The uncannily correct and the elusively true. In Pinar, W. & Reynolds, W. *Understanding curriculum as phenomenological and deconstructed text* (pp.23-31). New York: Teachers College Press

Atkinson, P. (1997) Narrative turn or blind alley? *Qualitative Health Research* 7 pp.325-344

Au, W. (2010) The idiocy of policy: The anti-democratic curriculum and high-stakes testing *Critical Education* 1, pp.1-15

Ayers, W. (2010) *To Teach* (3<sup>rd</sup> ed.) New York: Teachers College Press

Ayers, W. (2013) *Public Enemy* Boston: Beacon Press

Ball, S. J. & Goodson, I. F. (1985) Understanding teachers: Concepts and contexts. In Ball, S. J. & Goodson, I. F. (Eds). *Teachers' lives and careers*. London. Falmer Press

Ball, S. J. (2003) *Class strategies and the education market: The middle classes and social advantage* London: Routledge

Ball, S. J. (2018) The tragedy of state education in England: Reluctance, compromise and muddle – a system in disarray *The Journal of the British Academy* 6 pp.207-238

Ball, S. & Collet-Sabe, J. (2021) Against school: an epistemological critique *Discourse: Studies in the Cultural Politics of Education* 43 (6) pp.985-999

Beatty, J. E. (2004) *Chronic Illness as Invisible Diversity: Disclosing and Coping with Illness in the Workplace* PhD Thesis, Boston College.

Benedict R. H., Wahlig E., & Bakshi R. et al. (2005) Predicting quality of life in multiple sclerosis: Accounting for physical disability, fatigue, cognition, mood disorder, personality, and behaviour change *Journal of Neurological Science* 231 pp.29–34.

Benson, A., O'Toole, S., Lambert, V. et al (2015) To tell or not to tell: a systematic review of the disclosure practices of children living with epilepsy and their parents *Epilepsy Behaviour* 51 pp.73-95

Berry, K. and Clair, R. P. (2011) Special Issue: The Call of Ethnographic Reflexivity: Narrating the Self's Presence in Ethnography *Cultural Studies <=> Cultural Methodologies* 11 (2) pp.95-209

Bishop, J. (2011) *The anticipatory corpse* Notre Dame: Notre Dame University Press

Biesta, G. (2007) Why "what works" won't work: Evidence-based practice and the democratic deficit in educational research *Educational Theory* 57 (1) pp.1-22

Biesta, G. & Safstrom, C. A. (2011) A Manifesto for Education *Policy Futures in Education* 9 (5) pp.540-547

Biesta, G. (2015) One the two cultures of educational research, and how we might move ahead: Reconsidering the ontology, axiology and praxeology of education *European Educational Research Journal* 14 (1) pp.11-22

Biesta, G. (2020) *Educational Research: An Unorthodox Introduction* Bloomsbury: London

Bochner, A. P., and Ellis, C. (1999) Which way to turn? *Journal of Contemporary Ethnography* 28 (5) pp.485-499

Bohlmeijer, E. T., Westerhof, G. J., Randall, W., Tromp, T., & Kenyon, G. (2011) Narrative Foreclosure in later life: Preliminary considerations for a new sensitising concept *Journal of Aging Studies* 25 (4) pp.364-370

Bourgoin, A. & Harvey, J-F. (2018) Professional image under threat: Dealing with learning-credibility tension *Human Relations* 71 (12) pp.1611-1639

Boyd, K.M (2000) Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts *Medical Humanities* 26 pp.9-17.

Bruine de Bruin, W., Parker, A.M., Fischhoff, B. (2020) Decision-Making Competence: More than Intelligence? *Current Directions in Psychological Science* 29 (2) pp.186-192

Bruner, J. (1990) *Acts of meaning*. Cambridge, MA: Harvard University Press

Bryman, A. (2004) *Social Science Research Methods* (2<sup>nd</sup> edition). Oxford: Oxford University Press

Burgess, R. G. (1989) Grey areas: Ethical dilemmas in educational ethnography. In R. G. Burgess (Ed.) *The ethics of educational research*. Barcombe, Lewes, E. Sussex: Falmer Press

Burn, K., Mutton, T. & Thompson, I. (2022) The role of practical theorising in teacher education. In K. Burn, T. Mutton, & I. Thompson (Eds) *Practical Theorising in Teacher Education* London: Routledge

Burnfield, A. (2003) *Multiple Sclerosis (Just the facts)* Portsmouth, NH: Heinemann

Burr, V. (1995) *An introduction to Social Constructionism* London: Routledge

Butler, J. (1990) *Gender Trouble: Feminism and the Subversion of Identity* Routledge: New York

Bury, M. (1982) Chronic Illness as Biographical Disruption *Sociology of Health and Illness* 4 (2) pp.167-182

Bury, M. (1991) The Sociology of Chronic Illness: a Review of Research and Prospects *Sociology of Health and Illness* 13 (4) pp.451-468

Cardano, M. (2010) Mental Distress: Strategies of sense-making *Health* 14 (3) pp.253-271

Carel, H (2008) *Illness* London: Routledge

Carel, H (2016) *Phenomenology of Illness* Oxford: Oxford University Press

- Campbell, R. J. & Neill, S. (1994) *Primary Teachers at Work* London: Routledge
- Castells, M. (1997) *The Power of Identity* Malden, MA: Blackwell
- Chan, P. E., Hakala, A., Katsiyannis, A., Counts, J., & Carlson, A. (2022) Litigation on Accommodating Teachers with Disabilities *Journal of Disability Policy Studies* 33 (2) pp.112-121
- Chang, H. (2008) *Autoethnography as Method*. Walnut Creek, CA: Left Coast Press
- Charmaz, K. (1983) Loss of Self: a Fundamental Form of Suffering in the Chronically Ill *Sociology of Health and Illness* 5 (2) pp.162-195
- Charmaz, K. (1991) *Good Days, Bad Days: The Self in Chronic Illness and Time* New Brunswick, NJ: Rutgers University Press
- Charmaz, K. (2000) *Grounded theory objectivist and constructivist method* In Denzin, N. and Lincoln, Y. (Eds.), *Handbook of Qualitative Research* (pp. 509-535). Thousand Oaks, CA: Sage
- Charmaz, K. (2002) Stories and Silences: Disclosures and Self in Chronic Illness *Qualitative Inquiry* 8 pp.302-328
- Charmaz, K. (2006) *Constructing Grounded Theory: A practical guide through qualitative analysis* Thousand Oaks, CA: Sage.
- Clandinin, J. D., & Connelly, F. M. (2000) *Narrative inquiry: Experience and story in qualitative research* San Francisco, CA: Jossey-Bass.
- Coe, R. and Aloisi, C. and Higgins, S. and Major, L.E. (2014) *What makes great teaching? review of the underpinning research* Project Report. Sutton Trust, London
- Cohen H. (1955) The Evolution of the Concept of Disease: President's Address *Journal of the Royal Society of Medicine* 48 (3) pp.155-160

Cohen, L., Lawrence, M. and Morisson, K. (2000) *Research methods in education* London: Routledge

Cole, A. L. (1991) Interviewing for life history: A process of ongoing negotiation. In I. F. Goodson & J. M. Mangan (Eds.) *Qualitative educational research studies: Methodologies in transition* (pp.185-208) London, ON: Ruccus.

Cooper, R. (2002) 'Disease' *Studies in History and Philosophy of Biological and Biomedical Sciences* 33 pp.263-282.

Corlett, S. & Marvin, S. (2018) *Reflexivity and Researcher Positionality* SAGE publications. <https://doi.org/10.4135/9781526430212>

Cosh, A. and Carslaw, H. (2014) Multiple Sclerosis: symptoms and diagnosis *InnovAiT* 7 (11) pp.651-657

Courtenay, W. H. (2000) Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science & Medicine* 50 (10) pp.1385-1401

Couser, G. T. (2004) *Vulnerable subjects: Ethics and life writing* Ithaca, NY: Cornell University Press

Craig, C. J. (2012) "Butterfly under a pin": An emergent teacher image amid mandated curriculum reform *Journal of Educational Research* 105 (2) pp.90-101

Dallek, R. (2003) *An unfinished life* New York: Little, Brown and Co

Darlston-Jones, D. (2007) Making the connections: the relationship between epistemology and research methods *The Australian Community Psychologist* 19 (1) pp.19-27

Davison, K. P., Pennebaker, J. W., Dickerson, S. S. (2000) Who talks? The Social Psychology of Illness Support Groups *American Psychologist* 55 (2) pp.205-217

Day, C., Kington, A., Stobart, G., & Sammons, P. (2006) The personal and professional selves of teachers: stable and unstable identities *British Journal of Educational Research* 32 (4) pp.601-616

Day, C., & Gu, Q. (2007) Variations in the conditions for teachers' professional learning and development: Sustaining commitment and effectiveness over a career *Oxford Review of Education* 33 (4) pp.423-443

Delamont, S. (2009) The only honest thing: autoethnography, reflexivity and small crises in fieldwork *Ethnography and Education* 4 (1) pp.51-63

Deleuze, G. (1990) *The logic of sense* (trans. M. Lester) New York: Columbia University Press

Deleuze, G. (1994) *Difference and Repetition* (trans. Paul Patton) London: Athlone

Denzin, N. K. (2005) Emancipatory discourses and the ethics and politics of interpretation. In N. Denzin & Y. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (Fourth., pp.933-958) California: Sage Publications, Inc.

Denzin, N. & Lincoln, Y. (2011) The Discipline and Practice of Qualitative Research. In N. Denzin & Y. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (Fourth., pp.1-20) California: Sage Publications, Inc.

Department for Education (DfE) and Teacher Training Agency (TTA) (2002) *Qualifying to Teach: Professional Standards for Qualified Teacher Status and Requirements for Initial Teacher Training* London: DfE/TTA

Department for Education (DfE) (2011) *Teachers' Standards* London: DfE

Dewey, J. (1909). *Moral principles in education* Boston: Houghton Mifflin

Dewey, J. (1916). *Democracy and education* Mineola, NY: Dover Publications

- Dick, S. (2018) Is Human Knowledge Universal? In *Astrobiology, Discovery, and Societal Impact* (Cambridge Astrobiology, pp.141-175). Cambridge University Press
- Diefendorff, J., Morehart, J., & Gabriel, A. (2010) The influence of power and solidarity on emotional display rules at work *Motivation and Emotion* 34 pp.120-132
- Dilorenzo, T., Becker-Feigeles, J., Halper, A., & Picone, M. (2008) A qualitative investigation of adaptation in older individuals with multiple sclerosis *Disability & Rehabilitation* 30 (15) pp.1088-1097
- Dowrick, C., Dixon-Woods, M., Holman, H., & Weinman, J. (2005) What is chronic illness? *Chronic Illness* 1 pp.1-6
- Drever, E. (1995) *Using Semi-Structured Interviews in Small-Scale Research*. SCRE: Scotland
- Dutton, J. (2007) *Exploring positive relationships at work (building a theoretical and research foundation)* New York: Lawrence Erlbaum Associates Inc.
- Dyck, I., & Jongbloed, L. (2000) Women with multiple sclerosis and employment issues: a focus on social and institutional environments *The Canadian Journal of Occupational Health* 67 (5) pp.337-346
- Esterberg, K. G. (2002). *Qualitative methods in social research* Boston, MA: McGraw-Hill
- Eatough V, Smith J (2006) 'I was like a wild wild person': understanding feelings of anger using interpretative phenomenological analysis *British Journal of Psychology* 97 pp.483-498
- Edwards, A. (2005) Relational agency: Learning to be a resourceful practitioner *International Journal of Educational Research* 43 (3) pp.168-182

Eisner, E. (1991). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice* NY: Macmillan

Ellis, C. and Bochner, A. P. (2000) Autoethnography, personal narrative and reflexivity. In Denzin, N. K. and Lincoln, Y. S. (eds) *Handbook of qualitative research* (2<sup>nd</sup> ed. pp.733-768) Thousand Oaks, CA: Sage

Ellis, C. (2004) *The ethnographic I: A methodological novel about Autoethnography* Walnut Creek, CA: AltaMira Press

Ellis, C. (2007) Telling secrets, revealing lies: Relational ethics in research with intimate others *Qualitative Inquiry* 13 (1) pp.3-29

Ellis, C. (2009) *Revision: Autoethnographic reflections on life and work*. Walnut Creek, CA: Left Coast Press

Ellis, C., Adams, T., & Bochner, A. P. (2011) Autoethnography: An overview *Qualitative Social Research* 12 (1) pp.1-14

Equality Act (2010). Published by the UK Government Equalities Office.

<https://www.legislation.gov.uk/ukpga/2010/15/contents>

Fesko, S.L. (2001) Disclosure of HIV status in the workplace: Considerations and strategies *Health and Social work* 26 (4) pp.235-244

Field, J., & Latta, M. M. (2001) What constitutes becoming experienced in teaching and learning? *Teaching and Teacher Education* 17 pp.885-985

Fielding, N., Lee, R., & Blank, G. (2017) *The SAGE Handbook of online research methods* London: SAGE Publications Ltd.

Finlay, L. (2011) *Phenomenology for Therapists. Researching the Lived World* London:Wiley-Blackwell.

Fleming, J. & Carrithers, M. (2010) Diagnosis and management of multiple sclerosis  
*Neurology* 74 pp.876-877

Flick, U. (2010) Gutekriterien qualitativer Forschung. In G. Mey & K. Mruck (Eds.)  
*Handbook Qualitative Forschung in der Psychologie* (pp.395-470) Wiesbaden: VS  
Verlag/Springer

Flockhart, K. M. (2001) *The experience of teaching with multiple sclerosis: an  
emerging blend of theory with practice* PhD Thesis, University of Toronto.

Follmer, K. B., Sabat, I.E., Siuta, R.L. (2019) Disclosure of stigmatized identities at  
work: An interdisciplinary review and agenda for future research *Journal of  
Organisational Behaviour* 41 (2) pp.169-184

Foucault, M. (1976) *The birth of the clinic: Archaeology of medical perception*  
London: Tavistock.

Foucault, M. (1988a) *The Care of the Self* (R. Hurley, trans) New York: Vintage Press

Foucault, M. (1988) *Madness and Civilisation: A History of Insanity in the Age of  
Reason* New York: Vintage Press

Frank, A. (1991) *At the will of the body* New York: Houghton Mifflin

Frndak, S. E., Kordovski, V. M., & Cookfair, D. (2015) Disclosure of disease status  
among employed multiple sclerosis patients: association with negative work events  
and accommodations *Multiple Sclerosis* 21 pp.225-234

Friere, P. (1992) *Pedagogy of Hope* London: Continuum

Fullan, M. G. (1991) *The new meaning of educational change* New York: Teachers  
College Press

Gabe, J., Bury, M. and Elston, M. (2004) *Key Concepts in Medical Sociology*  
London: SAGE publications

Gadamer, H. (1976). *Philosophical Hermeneutics* Berkley, CA: University of California Press.

Gerber, P. J. (1992) Being disabled and a beginning teacher and teaching a class of students with learning disabilities *Exceptionality* 3 (4) pp.213-231

Gicheva, D. (2022) Altruism and Burnout: Long Hours in the Teaching Profession *ILR Review* 75 (2) pp.427-457

Giddens, A. (1991) *Modernity and Self-Identity* Stanford: Stanford University Press

Gillham, B. (2005) *Research interviewing: the range of techniques* Berkshire: Open University Press

Giorgi, A. (2000) *Phenomenology and psychological research*. (A. Giorgi, Ed) *Phenomenology and Psychological Research*. (pp.23-85). Pittsburgh: Duquesne University Press

Giorgi, A. (2010) Phenomenology and the practice of science *Journal Social Existence Analysis* 21

Glaser, B. G. & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research* Aldine de Gruyter. ISBN 0202302601

Glesne, C. & Peshkin, A. (1992). *Becoming qualitative researchers* White Plains, NY: Longman

Goffman, E. (1963) *Stigma: Notes of the Management of Spoiled Identity* Englewood Cliffs: Prentice-Hall

Goffman, E. (1987) *Asylums: Essays on the Social Situation of Asylum Patients and other Inmates* London: Penguin

Gonzales, L., Davidoff, K. C., Nadal, K. L. and Yanos, P. T. (2015) Microaggressions Experienced by Persons with Mental Illnesses: An Exploratory Study *John Jay College of Criminal Justice, City University of New York Psychiatric Rehabilitation Journal*. American Psychological Association 38 (3) pp.234-241

Goodwin, S. A., Morgan, S. (2012) Chronic Illness and the Academic Career *Academe* 98 (3)

Gorard, S. (2005) Current Contexts for Research in Educational Leadership and Management *Educational Management Administration & Leadership* 33 (2) pp.135-253

Gottberg, K., Gardulf., Fredrikson, S. (2000) Treatment for patients with multiple sclerosis: the patients' perceptions of the side-effects *Multiple Sclerosis* 6 (5) pp.349-354

Green, R., Cutter, G., Friendly, M., Kister, I. (2017) Which symptoms contribute the most to patients' perception of health in multiple sclerosis? *Multiple Sclerosis Journal* 3 (3) pp.1-6

Grytten, N., Maseide, P. (2005) What is expressed is not always what is felt: coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis *Chronic Illness* 1 pp.231-243

Guba, E. G., & Lincoln, Y. S. (1994) Competing paradigms in qualitative research *Handbook of qualitative research* 2 pp.163-194.

Gupta, A. (2022) Revisiting educational advantage and social class: a Bourdieusian analysis of middle-class parents' investment in private schooling and shadow education *British Journal of Sociology of Education* 44 (1) pp.26-42

Hadot, P. (1995). *Philosophy as a Way of Life: Spiritual Experience from Socrates to Foucault* New York: Blackwell

Hargreaves, A. (2000) Educational change takes place: Life, career and generational factors in teachers' emotional responses to educational change *Teachers and teaching* 21 pp.967-983

Hashiguchi, M (2010) Flexible working arrangements and specific training in the UK voluntary sector: a case study *Economic and Industrial Democracy* 31 (4) pp.431-447

Hatch, J. A. (2002) *Doing qualitative research in education settings* SUNY Press.

Hayes, C. and Fulton, J. A. (2015) Autoethnography as a method of facilitating critical reflexivity for professional doctorate students *Journal of Learning Development in Higher Education*. Issue 8

Hehir, T. (2002) Eliminating Ableism in Education *Harvard Educational Review* 72 (1) pp.1-32

Heidegger, M. (1962) *Being and time* London: Blackwell

Henderson, L. R., (2009) *A Grounded Theory Study of the Role of Disclosure in the Management of Long-Term Conditions: Who needs to know?* PhD Thesis, University of Warwick

Henriksson, C. Friesen, N., Saevi, T. (2012) *Hermeneutic phenomenology in education: method and practice* Sense Publishers, Netherlands.

Holley-Boen, W. (2018) Practising fiercely: Fulfilment through stance, supports and stamina *Kairaranga* 19 (2) pp.15-23

Holman, H. and Lorig, K. (2000) Patients as Partners in Managing Chronic Disease *British Medical Journal* 320 (7234) pp.526-527

Holt, N. L. (2003) Representation, legitimation and autoethnography; An autoethnographic writing story *International Journal of Qualitative Methods* 2(1)

Honan, C.A. Brown, R.F. Hine, D. W., et al (2012) The Multiple Sclerosis Work Difficulties Questionnaire *Multiple Sclerosis Journal* 18 (6) pp.871-880

Hook, D. (2001) Discourse, Knowledge, Materiality, History, Foucault and Discourse Analysis *Theory and Psychology*. 11 (4) pp.521-547

Horlick-Jones, T. (2011) Understanding fear of cancer recurrence in terms of damage to 'everyday health competence' *Sociology of Health & Illness* 33 (6) pp.884-898

Huberman, M. (1993) *The lives of teachers* London: Cassell

Hunt, D. E. (1992) *The renewal of personal energy* Toronto: OISE Press

Hutchinson, M. (2012) Do not treat CIS from onset: Evaluate disease course and prognosis first *Multiple Sclerosis Journal* 18 (4) pp.396-397

Jamison, K. R. (1995) *An Unquiet Mind* New York: Random House

Jasper, M. A. (1994) Issues in phenomenology for researchers of illness *Journal of Advanced Nursing* 19 (2) pp.309-314

Jick, S.S., Li, L., Falcone, G.J., Vassilev, Z.P, & Wallander, M.A (2014) Mortality of patients with multiple sclerosis: a cohort study in UK primary care *Journal of Neurology* 261 (8) pp.1508-1517

Joachim, G., and Acorn, S. (2003) Life with a Rare Chronic Disease: the Scleroderma experience *Journal of Advanced Nursing* 42 (6) pp.598-606

Joachim, G., and Acorn, S. (2000) Stigma of Visible and Invisible Chronic Conditions *Journal of Advanced Nursing* 32 (1) pp.243-248

Josselson, R. (2007) The Ethical Attitude in Narrative Research. In Clandinin, D. L. *Handbook of Narrative Enquiry* Thousand Oaks, CA: Sage

Katmon, N., Mohamad, Z. Z., Norwani, N. M., Farooque, O. A. (2019) Comprehensive board diversity and quality of corporate social responsibility disclosure: Evidence from an emerging market *Journal of Business Ethics* 157 pp.447-481

Kaushansky, K., et al. (2017) Living a secret: Disclosure among adolescents and young adults with chronic illnesses *Chronic Illness* 13 (1) pp.49-61

Kaushik, V. Walsh, C.A (2019) Pragmatism as a Research Paradigm and its implications for Social Work Research *Social Sciences* 8 (9) pp.255-263

Keller, C. , Karp, J. , & Simula, V. (1998) *Stories from educators with disabilities: Attitudes toward them* In R. Anderson , C. Keller , & J. Karp (Eds.), *Enhancing diversity: Educators with disabilities* (pp.172-190). Washington, DC: Gallaudet University Press

Kever, A., Riley, C. S., & Leavitt, V. M. (2022) Diagnosis concealment is associated with psychological outcomes in persons with multiple sclerosis *Multiple Sclerosis Journal* 28 (8) pp.1311-1314

Kincheloe, J. (2001). Describing the bricolage: conceptualising a new rigor in qualitative inquiry *Qualitative Inquiry* 7 pp.679-692

Kinman, G., Wray, S & Strange, C. (2011) Emotional labour, burnout and job satisfaction in UK teachers: the role of workplace social support *Educational Psychology* 31 (7) pp.843-856

Kirsch, M. (2000) *Queer Theory and Social Change* London:Routledge.

Kissling, M.T. (2014) Now and then, in and out of the classroom: Teachers learning to teaching through the experiences of their living curricula *Teaching and Teacher Education* 44 pp.81-91

Knight, D & Wadsworth, D. (1996) Preparing pre-service teachers with disabilities for the student teaching experience *The Teacher Educator* 32 pp.313-324

Kock, T. (1995) Interpretative approaches in nursing research: the influence of Husserl and Heidegger *Journal of Advanced Nursing* 21 (5) pp.827-836

Kolleck, N., Schuester, J., Hartmann, U., & Grasel, C. (2021) Teachers' professional collaboration and trust relationships: An inferential social network analysis of teacher teams *Research in Education* 111 (1) pp.89-107

Korthagen, F. A. J. (2004) In search of the essence of a good teacher: towards a more holistic approach in teacher education *Teaching and Teacher Education* 20 (1) pp.77-97

Koopman, W. J., Watling, C. J. and LaDonna, K. A. (2020) Autoethnography as a Strategy for Engaging in Reflexivity *Global Qualitative Nursing Research* Published on-line doi: 10.1177/2333393620970508

Kunter, M., & Holzberger, D. (2014) *Loving teaching: research on teachers' intrinsic orientations* (p.83-99) in P.W Richardson, S. Karabenick, and H.M.G Watt (Eds) *Teacher Motivation: Theory and Practice* New York: Routledge

Labaree, D. F. (2010) *Someone has to fail: The zero-sum game of public schooling* Cambridge MA: Harvard University Press

Lachner, A., Jarodzka, H., & Nuckles, M. (2016) What makes an expert teacher? Investigating teachers' professional vision and discourse abilities *Instructional Science* 44 (3) pp.197-203

Larkin M, Watts S, Clifton E (2006) Giving voice and making sense in interpretative phenomenological analysis *Qualitative Research Psychology* 3 pp.102-120

Leshem, S., and Trafford, V. (2007) Overlooking the conceptual framework *Innovations in Education and Teaching International* 44 (1) pp.93-105

Lexwell, E. M., Iwarsson, S., & Lund, M. L. (2011) Occupational adaptation in people with multiple sclerosis *OTJR: Occupation, Participation & Health* 31 (3) pp.127-134

Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic Inquiry* Beverly Hills, CA: Sage

Lieblich, A., Tuval, L., Mashiach, R., Zilbert, T. (1998) *Narrative Research* Sage Publications: New York

Liston, D. (2004) The Lure of learning in teaching *Teachers College Record* 106 (3) pp.459-486

Loh, C. E. & Liew, W. M. (2016) Voices from the ground: The emotional labour of English teachers work *Teaching and Teacher Education* 55 pp.267-278

Lofland, J. (1995) Analytic ethnography: Features, failures, futures *Journal of Contemporary Ethnography* 24 pp.25-40

Lowes, L. & Prowse, M. A. (2001) Standing outside the interview process? The illusion of objectivity in phenomenological data generation *International Journal of Nursing Studies* 38 (4) pp.471-480

Lowton, K. (2004) Only when I cough? Adults' disclosure of Cystic Fibrosis *Qualitative Health Research* 14 (2) pp.167-186

Lyn, M. A. (2021) *Disabled Teachers* PhD Thesis, University of Roehampton

Mackenzie, I.S., Morant, S.V., Bloomfield, G.A., MacDonald, T.M., & O'Riordan, J. (2013) Incidence and prevalence of multiple sclerosis in the UK 1990-2010: A descriptive study in the General Practice Research Database *Journal of Neurology, Neurosurgery & Psychiatry* 85 (1) pp.76-84

Magliano, L., Fiorillo, A., Malangone, C., De Rosa, C., Maj, M., and National Mental Health Project Working Group (2006) Social Network in Long-Term Diseases: A Comparative Study in Relatives of Persons with Illness Versus a Sample from the General Population *Social Science and Medicine* 62 (6) pp.1392-1402

Marland, M. (1975) *The Craft of the Classroom* London: Heinemann Educational

McCabe, M. P., McKern, S., & McDonald, E. (2004) Coping and psychological adjustment among people with multiple sclerosis *Journal of Psychosomatic Research* 56 (3) pp.355-361

McMullin, C. (2021) Transcription and Qualitative Methods: Implications for Third Sector Research *VOLUNTAS: International Journal of Voluntary and Non-profit Organizations* 34 pp.140-153

McIlveen, P. (2008) Autoethnography as a method for reflexive research practice in vocational psychology *Australian Journal of Career Development* 17 (2) pp.13-20

McRuer, R. (2002) Critical Investments: AIDS, Christopher Reeve, and Queer/Disability Studies *Journal of Medical Humanities* 23 (3/4) pp.221-224

Meijer, P.C., Korthagen, F.A.J., & Vasalos, A. (2009) Supporting presence in teacher education: The connection between the personal and professional aspects of teaching *Teaching and Teacher Education* 25 (2) pp.297-308

Merleau-Ponty, M (1964) *The Primacy of perception* C. Smith (trans) London: Routledge

Merleau-Ponty, M (1969) *The visible and the invisible* Evanston, IL: Northwestern University Press

Merleau-Ponty, M. (2012) *Phenomenology of perception*. New York: Routledge

Merriman, S. B. (1988) *Case study research in education: A qualitative approach* San Francisco, CA: Jossey-Bass Inc

Metcalf, A.W. (2013) Sociology teaching as a vocation *Journal of Sociology* 49 (4) pp.531-544

Minden, S.L., Marder, W. D., Harrold, L. N., et al. (1993) *Multiple Sclerosis. A Statistical Portrait* Cambridge. Abt Associates Inc.

Mockler, N. (2022) *Constructing Teacher Identities: How the Print Media Define and Represent Teachers and their Work* Bloomsbury: London

Moerman, M. (1988) *Talking culture: ethnography and conversation analysis* Philadelphia: University of Philadelphia Press

Mol, A. (2002) *The body multiple: ontology in medical practice* Durham: Duke University Press

Moore, I. S. (2012) "The beast within": Life with an invisible chronic illness *Qualitative Inquiry* 19 (3) pp.201-208

Morse, J. (2002) Writing my own experience *Qualitative Health Research* 12 (9) pp.1159-1160

Moustakas, C. E. (1994) *Phenomenological research methods* Thousand Oaks: Sage.

Muijs, D. & Reynolds, D. (2001) *Effective Teaching: Evidence and Practice*. London: Paul Chapman

Muncey, T. (2005) Doing Autoethnography *International Journal of Qualitative Methods* 4 (1)

Munir, F., Leka, S., Griffiths, A. (2005) Dealing with Self-Management of Chronic Illness at Work: Predictors for Self-Disclosure *Social Science and Medicine* 60 pp.1397-1407

Myers, K. R. (2004) Coming Out: Considering the Closet of Illness *Journal of Medical Humanities* 25 (4) pp.255-270

Nel, J. P. (2007) *Epistemology vs Ontology*. Mentornet  
(<http://mentornet.co.za/files/documents/EPISTEMOLOGYVSONTOLOGY.pdf>)

Nias, J. (1989). *Primary teachers talking: A study of teaching as work* New York. Routledge

Nowakowski, A. C. H. (2016) You poor thing: A Retrospective Autoethnography of Visible Chronic Illness as a Symbolic Vanishing Act *The Qualitative Report* 21 (9) pp.1615-1635

Nowakowski, A. C. H. (2016b) Hope is a four-letter word: riding the emotional rollercoaster of illness management *Sociology of Health & Illness* 38 (6) pp.899-915

O'Byrne, P. (2007) The Advantages and Disadvantages of Mixing Methods: An Analysis of Combining Traditional and Autoethnographic Approaches *Qualitative Health Research* 17 (10) pp.1381-1391

Oancea, A. & Furlong, J. (2007) Expressions of excellence and the assessment of applied and practice-based research *Research Papers in Education* 22 (2) pp.119-137

OFSTED (2019) *Teacher well-being at work in schools and further education providers* (report no. 190034, downloaded from <https://assets.publishing.service.gov.uk> on 2.6.21)

Oliver, M. (1996) *Understanding Disability: From Theory to Practice* Basingstoke: MacMillan

Onwuegbuzie, A. J., & Leech, N. L. (2005) On becoming a pragmatic researcher: The importance of combining quantitative and qualitative research methodologies *International Journal of Social Research Methodology* 8 (5) pp.375-387

Onyefulu, C., et al. (2022) Teachers' motivation to choose teaching and remain in the profession: a comparative mixed methods study in Jamaica, Poland and Turkey *Power and Education* 0 (0) pp.1-29

Pakenham, K. I. (1999) Adjustment to multiple sclerosis: application of a stress and coping model *Health Psychology* 18 (4) pp.383-392

Pakenham, K. I. (2007) The nature of caregiving in multiple sclerosis: development of the caregiving tasks in multiple sclerosis scale *Multiple Sclerosis (Houndmills, Basingstoke, England)* 13 (7) pp.929-938

Parke, E. (2018) Writing to Heal: Viewing Teacher Identity through the Lens of Autoethnography *The Qualitative Report* 23 (12) pp.2953-2972

Parsons, T. (1954) *The Social System*. London: Routledge

Pascoe, E. (1996) The value to research of Gadamer's hermeneutic philosophy *Journal of Advanced Nursing* 24 (6) pp.1309-1314

Patrick, B.C., Hisley, J., and Kempler, T. (2000) What's everybody so excited about?: The effects of teacher enthusiasm on student intrinsic motivation and vitality *Journal of Experimental Education* 68 (3) pp.217-236

Peng, X., Qi, T., & Wang, G. (2022) Board Gender Diversity, Corporate Social Disclosures, and National Culture *SAGE Open* 12 (4)

Polkinghorne, D. (1998) *Narrative Knowing and the Human Sciences* State University of New York Press, New York

Polkinghorne, D. E. (2005) Language and meaning: Data collection in qualitative research *Journal of Counselling Psychology* 52(2) pp.137-145.

Porter, R. (1985) The Patient's View: Doing Medical History from below *Theory and Society* 14 (2) pp.175-198

Public Health England (2020) Multiple Sclerosis: prevalence, incidence and smoking status – data briefing <https://www.gov.uk/government/publications/multiple-sclerosis-prevalence-incidence-and-smoking-status>

Quinn, D.M., and Chaundoir, S.R. (2009) Living with a concealable stigmatized identity: the impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health *Journal of Personality and Social Psychology* 97 (4) pp.634–651

Radley, A. (1989) Style, Discourse and Constraint in Adjustment to Chronic Illness *Sociology of Health and Illness* 11 (3) pp.230-252

Radovan, M. (2011) The relation between distance student's motivation, their use of learning strategies and learning success *Turkish Online Journal of Educational Technology* 10 (1) pp.216-222

Rao SM, Leo GJ, Ellington L, et al. (1991) Cognitive dysfunction in multiple sclerosis II: Impact on employment and social functioning *Neurology* 41 pp.692–696.

Rao, S., Huber, S., Bornstein, R. (1992) Emotional Changes with Multiple Sclerosis and Parkinson's Disease *Journal of Consulting and Clinical Psychology* 60 (3) pp.369-378

Rao, K., & Tilt, C. (2016) Board composition and corporate social responsibility: The role of diversity, gender, strategy and decision-making *Journal of Business Ethics* 138 (2) pp.327-347

Ratchford, J., & Calabresi, P. (2008) The diagnosis of MS: White spots and red flags *Neurology* 70 pp.1071-1072

Rath, J. (2012) Autoethnographic layering: Recollections, Family tales and Dreams *Qualitative Inquiry* 20 (10) pp.1-7

Ravitch, S. M., and Riggan, M. (2017) *Reason and Rigor* California: Sage

Reed-Danahay, D. (1997) *Auto/Ethnography: Rewriting the self and the social* Oxford: Berg

Reisner, R. (1990) Backlash: Don't disable teachers with disabilities *British Journal of Special Education* 17 (3) pp.94

Rhoads, R. A., (1994) *Coming Out in College: The Struggle for a Queer Identity* Westport, Connecticut: Bergin & Garvey

Richards, R. (2008) Writing the othered self: Autoethnography and the problem of objectification in writing about illness and disability *Qualitative Health Research* 18 (12) pp.1717-1728

Richards, R. (2016) Saying the word: Voice and silence in an autoethnography about chronic illness *Stellenbosch Papers in Linguistics Plus* 49 pp.233-247

Robinson, S., Kendrick, K. and Brown, A. (2003) *Spirituality and the Practice of Healthcare* Hampshire: Palgrave Macmillan

Robson, C. (1993) *Real world research* Oxford: Blackwell

Rodrigues, L. D., de Pietri, E., Sanchez, H. S. & Kuchah, K. (2018) The role of experienced teachers in the development of pre-service language teachers' professional identity: revisiting school memories and constructing future teacher selves *International Journal of Educational Research* 88 pp.146-155

Ronai, C. R. (1995) Multiple Reflections of Child Sex Abuse: An Argument for a Layered Account *Journal of Contemporary Ethnography* 23 (4) pp.395-426

Rosenfield, L. B. Overview of the Ways Privacy, Secrecy and Disclosure are Balanced in Today's Society. In Petronio, S. (2000) (Editor) *Balancing the secrets of private disclosures* Lawrence Erlbaum Associates: Mahwah: New Jersey pp.3-17

Rusch, N., Angermeyer, M. and Corrigan, P. (2005) Mental illness stigma: Concepts, consequences and initiatives to reduce stigma *European Psychiatry* 20 (8) pp.529-539

Ryan, A. & Wilson, S. (2008) Internet healthcare: do self-diagnosis sites do more harm than good? *Expert Opinion on Drug Safety* 7 (3) pp.227-229

Samuel, M. & Stephen's, D. (2000) Critical dialogues with self: Developing teacher identities and roles – as case study of South Africa *Journal of Educational Research* 33 (5) pp.475-491

Schapiro R. (2006) *Managing the symptoms of multiple sclerosis* New York: Demos Medical Publishing

Schneider, J. and Conrad, P. (1980) In the closet with illness; Epilepsy, stigma potential and information control *Social Problems* 28 pp.32-44

Schock, N., Cossyleon J. E. and Nerenberg, K. M. (2022) "We want to make our customers happy": How principles of zoned elementary schools navigate inequity and marketing across neighborhood contexts *Urban Education* (online article) <https://doi.org/10.1177/00420859221140064>

Schulz, D., Kopp, B., Kunkel, A., Faiss, J.H. (2006) Cognition in the early stage of multiple sclerosis *Journal of Neurology* 253 pp.1002-10

Schultz, T. W. (1959) Investment in man: an economist's view *Social Service Review* 33 (2) pp.109-117

Schwehn, M.R. (2001) Teaching as a profession and vocation *Theology Today* 59 (3) pp.396-407

Seidman, I. E. (1991) *Interviewing as qualitative research* New York: Teachers College Press

Serin, H. (2017) The Role of Passion in Learning and Teaching *International Journal of Social Sciences and Educational Studies* 4 (1) pp.60-64

Shammas, A. (1988). *Arabesque* Viking: London.

Shaw, K. (2001) Disclosure or not? A place in the workforce *Inside MS* 19 (5) pp.62-65

Simmons, R. D., Tribe, K. L., McDonald, E. A. (2010) Living with multiple sclerosis: Longitudinal changes in employment and the importance of symptom management *Journal of Neurology* 257 pp.926-936

Smith, D. E. (1990) *The Conceptual Practices of Power: A Feminist Sociology of Knowledge* Boston: Northeastern University Press.

Smith, J., Flower, P., Larkin, M. (2009) *Interpretive Phenomenological Analysis: theory, method and research* Sage Publishing, USA.

Smith, J. A. (2003). Shifting identities: the negotiation of meanings between texts and between persons. In Finlay, L. & Gough, B. (Eds) *Reflexivity. A Practical Guide for Researchers in Health and Social Sciences*. Oxford: Blackwell

Smith, J. K. (1983) Quantitative versus qualitative research: An attempt to clarify the issue *Educational researcher* 12 (3) pp.6-13

Smith, A-M., & Lambeth, D.T. (2016) Pre-Service Teachers' Perceptions of Culturally Responsive Teacher Preparation *Journal of Negro Education* 85 (1) pp.46-58

Snow, D., Morrill, C. and Anderson, L. (2003) Elaborating analytic ethnography: Linking fieldwork and theory *Ethnography* 2 pp.181-200

Solomon, A.J., Klein, E.P., & Bourdette, D. (2012) 'Undiagnosing' multiple sclerosis: The challenge of misdiagnosis in MS *Neurology* 78 pp.1986-1991

Some, M. P. (1994) *Of Water and Spirit: Ritual, Magic, and Initiation in the Life of an African Shaman* New York: Tarcher/Putnam

Sparkes, A. C. (2000) Autoethnography and narratives of self: Reflections on criteria in action *Sociology of Sport Journal* 17 pp.21-43

Stage, C. (2022) Shame, Chronic Illness and Participatory Story Telling *Body & Society (Online article)* pp.1-12

Stenhouse, L. (1983) Curriculum, research and the art of the teacher. In L. Stenhouse (Ed) *Authority, Education and Emancipation: a collection of papers* London: Heinemann

Strauss, A. (1975) *Chronic Illness and the Quality of Life* Saint Louis: The C. V. Mosby Company

Struthers, J. (2014) "Analytic autoethnography: one story of the method" *Theory and Method in Higher Education Research* 10 pp.183-202

Tah, J. K., Knutes-Nyqzist, H. (2022) School marketing on their websites and students in need of special support: Independent Schools in the Stockholm local education market *Policy Futures in Education* 20 (6) pp.681-695

Terry, P.E. (2020) Knowing Well, Being Well: Well-Being Born of Understanding *American Journal of Health Promotion* 34 (6) pp.584-586

Thorne, S. (2000) Data analysis in qualitative research. *Evidence Based Nursing* 3 pp.68-70

Thomas, S. L., Williams, R., Williams, T., & Hall, A. J. (2009) Prevalence of MS in general populations. *Multiple Sclerosis Resource Centre*. London: London School of Hygiene & Tropical Medicine. Retrieved from [www.msrc.co.uk/index.cfm/fuseaction/show/pageid/2871](http://www.msrc.co.uk/index.cfm/fuseaction/show/pageid/2871)

Tolich, M. (2010) A Critique of Current Practice: Ten Foundational Guidelines for Autoethnographers *Qualitative Health Research* 20(12) pp.1599–1610.

Toombs, S. K. (1987) The meaning of illness: a phenomenological approach to the patient-physician relationship *Journal of Medicine and Philosophy* 12 pp.219-240

Tormey, R. (2021) Rethinking student-teacher relationships in higher education: a multidimensional approach *Higher Education* 82 pp.993-1011

Towers, E. Gerwitz, S. Maguire, M., & Neumann, E. (2022) A profession in crisis? Teachers' responses to England's high-stakes accountability reforms in secondary education *Teaching and Teacher Education* 117 (online article) <https://doi.org/10.1016/j.tate.2022.103778>

Troster, H. (1997) Disclose or conceal? Strategies of Information Management in Persons with Epilepsy *Epilepsia* 38 (11) pp.1227-1237

Trostle, J. A. Social Aspects: Stigma, Beliefs and Measurement. In Engel, J., Pedley, T. A., (Editors) (2007) *Epilepsy: A Comprehensive Textbook* Philadelphia: Lippincott-Raven Publishers pp.2183-2189

Toombs, S. K. (1998) Illness and the paradigm of the lived body *Theoretical Medicine* 9 pp.201-226

Tullis, J. (2013) *Self and Others: Ethics in Autoethnographical Research* in Holman-Jones, S., Adams, T. and Ellis, C. *Handbook of Autoethnography*. USA: Left Coast Press pp.244-261.

- Turner, L. (2013) *The Evocative Autoethnographic I: The Relational Ethics of Writing About Oneself* in Short, N.P., Turner, L and Grant, A. (eds) *Contemporary British Autoethnography* Sense Publishing, pp.213- 229.
- Uccelli, M., Specchia, C., Battaglia, M.A., et al. (2009) Factors that influence the employment status of people with Multiple Sclerosis *Journal of Neurology* 256 pp.989-996
- Van der Hiele, K., Van Gorp, D.A.M., Benedict, R.H.B, Jongen, P.J., et al (2016) Coping strategies in relation to negative work events and accommodations in employed multiple sclerosis patients *Multiple Sclerosis Journal – Experimental, Translational and Clinical* 2 pp.1-9
- Van Manen, M. (1990) *Researching lived experience: Human science for an action sensitive pedagogy* Althouse Press: London: Ontario, Canada.
- Van Manen, M. (1997) From meaning to method *Qualitative Health Research* 7 pp.345–369.
- Van Manen, M. and Levering, B. (1996) *Childhood Secrets: Intimacy, Privacy and the Self Reconsidered* London: Teachers College Press
- Vickers, M. (1997) “Life at work with ‘invisible’ chronic illness (ICI): the ‘unseen’, unspoken, unrecognised dilemma of disclosure” *Journal of workplace learning: Employee Counselling Today* 9 (7) pp.240-52
- Vickers, M. (2001) *Work and unseen chronic illness: Silent Voices* London: Routledge
- Walters, A. J. (1995) The phenomenological movement: implications for research *Journal of Advanced Nursing* 22 (4) pp.791-799
- Warne, A., & McAndrew, S. (2009) Constructing a bricolage of nursing research, education and practice *Nurse Education Today* 29 pp.855-858.

- Waskul, D.D., & Van der Riet, P. (2002) The abject embodiment of cancer patients: dignity, selfhood and the grotesque body *Symbolic Interaction* 25 pp.487-513
- Watson, S. (2013) Getting the job when you have MS *Momentum* 6 (2) pp.43-45
- Weale, S. (2019) Funding for 80% of schools in England 'worse next year than 2015' *The Guardian* (30/9/19) available at:  
<https://www.theguardian.com/education/2019/sep/30/funding-80-percent-schools-england-worse-next-year>
- Weimer, K. R., & Vaughan-Marra, J. (2022) You Don't Look Sick: Voices of Music Educators Living with Chronic Illnesses *Journal of Research in Music Education* (On-line article) <https://doi.org/10.1177/00224294221118899>
- White, B. (2011) The vulnerable population of teacher researchers *English Education* 43 (4) pp.321-340
- Williams, B., Healy, D. (2001) Disclosure of Health Problems: An Exploratory Theoretical Study *Journal of Advanced Nursing* 35 (1) pp.108-116
- Williams, S. (2000) Chronic illness as Biographical Disruption or Biographical Disruption as Chronic Illness? *Sociology of Health and Illness* 22 (1) pp.40-67
- White, M., Dorman, S.M. (2001) Receiving Social Support Online: Implications for Health Education *Health Education Research* 16 (6) pp.693-707
- Wilhelm, J. (2008) *You gotta be the book* New York: Teachers College Press
- Williams, James (2011) *Gilles Deleuze's Philosophy of Time: A Critical Introduction and Guide* Edinburgh: Edinburgh University Press
- Willig, C. (2008) *Introducing qualitative research in psychology* (2<sup>nd</sup> ed.) Open University Press, London.

Wood, D., Gosling, S. D., & Potter, J. (2007) Normality evaluations and their relation to personality traits and well-being *Journal of Personality and Social Psychology* 93 (5) pp.861–879

# Appendix 1 | *Phenomenology*

Phenomenology developed originally as a philosophical approach which was then later applied as a way of pursuing scientific investigation (Giorgi, 2000). As a paradigm of its own, it developed from the naturalistic paradigm whose purpose was to understand the social reality of the individual, the experiences of those individuals and the contextual world around them (Bryman, 2004). The works of Husserl, Heidegger and Gadamer have been particularly influential in the sphere of phenomenological research.

It is widely acknowledged that Edmund Husserl is the founding father of phenomenology (Jasper, 1994; Pascoe, 1996; Walters 1995). He introduced the concept of 'life-world' (or *lebenswelt*) to describe the lived experience of the person, or individual, experiencing it (Koch, 1995). It is this ideology that underpins the philosophy for Husserl; attaching meaning to, and gaining understanding from, the experience of a phenomenon. As Walters (1995) describes, Husserl's approach focused, in part, on the pure interaction between researcher and participant. He stressed the importance of the experience being untouched by the person completing the research and he described the process used to achieve this as bracketing (or *epoche*). Often referred to as descriptive phenomenology, this requires the researcher to firstly obtain knowledge from individuals involved in the research, and then merely to provide a description of the experience (or phenomena) at a distance from the personal perspective of the participant. It is this aspect of Husserl's philosophy that attracts the most criticism (Crotty, 1996) due to its perceived links to the positivistic paradigm, given this notion of objectivity inherent in the work of the researcher. However, context is important here. Husserl was creating new philosophical theories at a time in history when the dominant approach to any scientific enquiry was fiercely positivist. It should also be remembered that he was primarily developing theory that was grounded in philosophy and was not solely attempting to create a new scientific method of research.

Any practical application of Husserl's specific philosophy has been, and continues to be, widely debated, even though it is popular with a number of qualitative researchers. For example, Gadamer (1976) suggests that attempting to concentrate solely on the epistemological inquiry of how research participants perceive or experience a particular phenomenon is worthless. He argues that you cannot remove the social constructions of the participant and therefore seek to view it, objectively, inside a vacuum. This view supports the approach I have taken in this research project by seeking to bring together my own autoethnographic contributions and the interview data from the participants. Lowes & Prowse (2001) also argue that attempting to maintain an objective stance results in the interpersonal connection and development between researcher and individual(s) participating in the research being negatively affected. This relationship built between researcher and participant is something I see as being central to the success of my research project due to the nature of the topic and the deeply personal nature of the inquiry, and for this reason Husserl's approach to phenomenology does not suit my purposes.

Martin Heidegger was a pupil of Husserl and developed his own approach to phenomenology which moved away from the Husserlian concept of bracketing (Annells, 1996). He focused on an ontological perspective which was mostly concerned with "*Dasein*", or the nature of "*being-in the world*" (Heidegger, 1962, p. 41), and requires the researcher to be integral to the whole development of the research project from design to analysis, through interpretation and presentation. His seminal work, *Being and Time* (1962), both of which are themes explored in this project, was central to advancing and developing phenomenology as a method of inquiry (Walters, 1995). His branch of the philosophy known as hermeneutic phenomenology, marks a move away from Husserl's descriptive phenomenology and towards a much more existential, or interpretative phenomenology.

Hermeneutic phenomenology assumes prior knowledge and awareness of the experience or phenomena by the researcher, and this understanding on the part of the researcher is entirely necessary for guiding and interpreting the full meaning of the research (Kock, 1995). The person completing the research naturally brings with them prejudices and life experiences of their own, which then help to interpret and

shape the understanding of the new experience being researched. Like Heidegger, Gadamer also rejects the notion of bracketing by acknowledging that preconceived thoughts and ideas of the researcher can never be truly set to one side (Gadamer, 1976). He argues that, if a researcher journeys through their own understanding and personal views of the phenomena in question whilst undertaking an active and sustained engagement with the text, this deep, interpretative analysis (known as the hermeneutic circle) will result in a fuller understanding of the lived experience had by the participants. Gadamer refers to a *"fusion of horizons"* when describing this process (Gadamer, 1976, p. 302). It is the mixing of the participant's viewpoint and that of the researcher that creates a new understanding of the phenomena under investigation. The main task for the researcher is to attempt to comprehend the personal lifeworld of the participant as they have described it from their viewpoint, and thus going beyond the immediate foreground and giving explanation (and meaning) of the phenomena from *their* horizon. From *their* narrative. Whilst this wasn't possible to the fullest extent in my project due to the limited research encounter I had with the research participants, the intention was central to what I have achieved.

When I started to consider these issues in relation to my own research project, I was concerned that attempting to fully bracket myself away would not, realistically, be feasible. I knew that my project would need to go beyond mere description. I wanted it to move towards attempting to develop a deeper understanding of the lived experience of the teaching participants (and myself), which relies on an interpretative focus. It is the notion of MS as a chronic illness, and the issue of disclosure which is the phenomenon at the heart of my study. The difficult balance to be struck was then allowing myself to be fully open, to allow real and active engagement with the data from the participants and to be fully reflexive when acknowledging any preconceived ideas and prejudices about the nature of teaching and MS that I might have as I interwove autoethnography with the findings. Some consider this process of reflexivity to be essential to the interpretative process in phenomenology (Finlay, 2011; Smith, 2003). By adopting a reflexive stance, and by accepting that any interpretations were going to be unique and subjective, the cyclical process of review and analysis of my own thoughts and preconceived ideas as well as those of the participants would become central to *"opening up of new*

*horizons*” (Gadamer, 1976, p.302), and deepen my understanding of the lived experience examined as part of this research project.

Another phenomenologist, Van Manen, whose influence is often found within educational research, stresses the importance of phenomenological reflection being retrospective and not introspective (Van Manen, 1990). This reflection on experiences or phenomena that have already passed and been lived through was a central tenet of my research project. He emphasizes the fact that this type of phenomenological research is a human science, that it attempts to uncover existential meanings. The nature, or essence, of a phenomena or experience needs to be sufficiently described (Van Manen, 1990). If it is, then that description goes some way to unveiling the importance of the phenomena and the quality of the experience in a much deeper and richer way. For Van Manen (1990), the overriding word used to describe research adopting a phenomenological methodology is *“thoughtfulness... a heedful, mindful wondering about the project of life of living, of what it means to live a life”* (Van Manen, 1990, p.12). It is this element of phenomenology that appealed to me regarding my project. To explore the meaning of the experiences, or phenomena, shared or otherwise by the participants through the first-person, subjective experiences of those teachers who have lived (or are living) through it and who can provide a rich, full description of it.

# Appendix 2 | *Participant information sheet*



## **Study title**

To disclose or not to disclose: a career in teaching living with a hidden illness

Dear.....

My name is Kit Perona-Wright and I am a doctoral student within the School of Education at Oxford Brookes University. You are being invited to take part in a research study. Before you decide whether or not to take part, 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.

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

The aim of this research is to gain a greater insight into the lived, personal experience of teachers who have a hidden illness. This will explore the impact of illness on their professional working lives, and the motivations surrounding the choice of whether to disclose or not. The research will be used to further the understanding of teachers living with hidden illnesses more broadly in the world of education by the incorporation of elements of the thesis in professional and academic journals.

## **Why have I been invited to participate?**

You are being invited to participate as you are known to fellow members of the local MS Society (that the researcher is also a member of) as a teacher with a hidden illness. Your details have not been passed on to the researcher, but you are being given this information sheet to decide whether you wish to take part. The study will involve three participants.

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

Taking part in this research is entirely voluntary and 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 along with a privacy notice that will explain how your data will be collected and used, and be asked to give your consent. 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?**

The data will be gained through interviews that will be audio recorded and transcribed. Each participant will have a minimum of two interviews, each lasting approximately an hour. These will take place at a suitable venue of your choosing (work, home or another agreed location where an audio-recorded interview can take place).

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

The time of approximately an hour given over to each interview will be agreed to suit each participant, and may take place at a location that is most convenient for each participant also. This should reduce the disadvantages of taking part as far as is possible. In addition, the sensitive issues to be discussed could potentially cause distress, and so support will be offered with regard to professional counselling services, and contact details for both MS Society services and The Samaritans.

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

The outcomes of this project will aim to help teaching staff, employers and policy makers to gain a greater insight into the experiences of fellow teachers who live and work with a hidden illness.

## **Will what I say in this study be kept confidential?**

The participants will remain de-identified, including their name and school. All information collected will be kept strictly confidential throughout the study. Participants will be given a pseudonym to retain confidentiality and safeguard their identity. All identifying information will be securely stored separately to the raw data. All raw data, paper or electronic, will be scrutinised and analysed but returned to storage and subsequently archived in a safe locked place at all times between processing. The audio recording and all raw data will be destroyed ten years after the conclusion of the project. Participants

will have the opportunity to have removed any material that they may wish to redact following review of the audio transcription sent to them.

**What should I do if I want to take part?**

If you agree to take part in the research, you should contact Kit Perona-Wright (researcher) who will be happy to discuss anything further and who will ask you to sign a consent form.

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

The project will conclude within a three-year time period, with the completion of a doctoral thesis in 2022; a summary of the findings can be made available for you to read upon request. Please note that the thesis and any professional/academic journals that utilise data or findings from the thesis are in the public domain.

**Who has reviewed the study?**

This research project has been approved by the University Research Ethics Committee, Oxford Brookes University.

**Contact for Further Information**

Please contact me (Kit Perona-Wright) for any further information. My university e-mail address is [16101978@brookes.ac.uk](mailto:16101978@brookes.ac.uk)

If you have any concerns about the way in which the study has been conducted, please contact the Chair of the University Research Ethics Committee on [ethics@brookes.ac.uk](mailto:ethics@brookes.ac.uk).

Thank you for taking the time to consider your involvement with my project.  
Date: December 2019

# Appendix 3 | *GDPR privacy form*



## Privacy Notice

**Oxford Brookes University (OBU)** will usually be the Data Controller of any personal data that you supply for this research. The exception to this is joint research projects where you would be informed on the participant information sheet as to the other partner institution or institutions. This means that they will make the decisions on how your data is used and for what reasons. You can contact the university's Information Management Team on 01865 485420 or email [info.sec@brookes.ac.uk](mailto:info.sec@brookes.ac.uk).

### Why do we need your data?

The data for this research will be the interview between the researcher and each individual participant, which is intended to provide insight into the lived experience of teachers living with a hidden illness. This will be based on the audio transcription collected from each interview so time and space can be given to the analysis of the lived experience of each participant.

### OBUs legal basis for collecting this data is:

- You are consenting to providing it to us; and / or,
- Processing is necessary for the performance of a task in the public interest such as research

If the university asks you for sensitive data such as; racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, data concerning health or sexual life, genetic/biometric data or criminal records OBU will use these data because:

- You have given OBU explicit consent to do so; and / or
- Processing is necessary for scientific or research in the public interest.

### What type of personal data will Oxford Brookes University use?

The researcher will have anonymised audio interview of consenting participants.

### Who will OBU share your data with?

The data will only be reviewed by the researcher, his supervisors and the participant. No research partner institutions or collaborators which will have access to the data. The audio interviews will be recorded onto a digital audio recording device which will be downloaded to my private computer (to which only I have access). This will only be reviewed by the researcher, his supervisors and the participants within that space.

### Will OBU transfer my data outside of the UK?

No

### What rights do I have regarding my personal data that OBU holds?

- You have the right to be informed
- You have the right of access to your data
- You have the right to correct data if it is wrong
- You have the right to ask for your data to be deleted
- You have the right to restrict use of the data we hold
- You have the right to data portability
- the right to object to the university using your data
- You have rights in relation to using your data automated decision making and profiling.

### Where did OBU source my data from?

The data is coming from individual interviews being audio recorded by research participants.

### Are there any consequences of not providing the requested data?

There are no legal or professional consequences of not providing data for this research. It is purely voluntary.

### Will there be any automated decision making using my data?

There will be no use of automated decision making in scope of UK Data Protection and Privacy legislation."

### How long will OBU keep your data?

In line with Oxford Brookes policies data generated in the course of research must be kept securely in paper or electronic form for a period of ten years after the completion of a research project.

Following the completion of the research project, the anonymised data will be filled on the password encrypted Oxford Brookes computer system for a period of ten years, in line with Oxford Brookes guidelines.

### Who can I contact if I have concerns?

You can contact the Information Management team.

Postal Address: Information Management Team, IT Services, Room 2.12, Gibbs Building, Headington Campus, Gypsy Lane, Oxford, OX3 0BP

Email: [info.sec@brookes.ac.uk](mailto:info.sec@brookes.ac.uk)

Tel: 01865 485420 in UK  
+44 1865 485420 outside the UK.

## Appendix 4 | Consent form



### CONSENT FORM

**Full title of Project:** To disclose or not to disclose: a career in teaching living with a hidden illness

Kit Perona-Wright, Doctoral Researcher  
16101978@brookes.ac.uk

|                                                                                                                                                                        | Please initial box       |                          |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|
| 1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.                                  | <input type="checkbox"/> |                          |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.                                                  | <input type="checkbox"/> |                          |
| 3. I agree to take part in the above study.                                                                                                                            | <input type="checkbox"/> |                          |
| 4. I understand that the interview will be audio-recorded                                                                                                              | <input type="checkbox"/> |                          |
|                                                                                                                                                                        |                          |                          |
|                                                                                                                                                                        | Please initial box       |                          |
|                                                                                                                                                                        | Yes                      | No                       |
| 6. I agree to the use of anonymised quotes in publications                                                                                                             | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I agree that an anonymised data set, gathered for this study may be stored in a specialist data centre/repository relevant to this subject area for future research | <input type="checkbox"/> | <input type="checkbox"/> |

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 5 | Example transcript extract

*Private vs state.*

didn't really see much of the parents but you certainly were aware of them. Whereas because it was such a different environment from my Andoversford village school....that I took my kids to and stuff....and the people I mixed with....a whole different world, so I thought I'd never fit in there....

*Less understanding? More demanding?*

**KPW**

So has that ever played a part in your thinking, your decision making to deal with the illness and or disclosing or whatever.

*Private affected disclosure because it was unknown!*

**SK**

I think it probably did back at the start because I....yeah....I mean, now I don't think Prep Schools are as....what I first thought they were (laughs)....shall we say? So maybe I probably wouldn't worry quite so much now. But at the time it was because it was all new to me, and it was all 'shall I, shan't I?', 'what should I do?'... and I just thought, yeah, say it like it is. Being that Stephen (line manager) knew from the start...

*Disclosure uncertainty.*

**KPW**

Okay. But if he....if he hadn't?

**SK**

If he hadn't known I was going for tests any everything....

**KPW**

Which he found out basically by accident....or someone told him....?

*How to disclose??*

**SK**

Yeah....because Peter's got a big mouth....(laughs)! Would I have told him...? Would I have been so open about it....? (Pause) I don't know, because it's having that first conversation. And I'm quite shy. I don't....I'd have found it quite hard to bring up, I think. So the fact that I didn't really have to make it a lot easier. And then once I told Stephen (line manager) and Nigel (Head)....the Head was my other boss. So it just made sense to fit him in as well. So. It wasn't really a biggie (problem), but I guess talking to new....new situation, new bosses, I probably wouldn't. Yeah, as I say, probably because I know that it hasn't really progressed. I wouldn't necessarily think they would need to know.

*Disclosure was forced. Might not have done....*

**KPW**

And there's....I mean to say, does it....does anything about that sit uncomfortably with you or not....?

*Because it isn't currently visible - no more disclosure....*

*Has never had to disclose from scratch. it's easier when forced.*

## **Appendix 6 | Journal Entry (Hidden Symptoms) from Chapter 4, section 4.5**

*March 18<sup>th</sup>, 2018*

*Start of the holidays. My wife, Emma, and I discussing what we should do over the couple of weeks:*

*Em: 'what shall we do then? (Jokingly) I know you don't want to do anything and would rather sit here instead, but it's not all about you...'*

*Things turn frosty, which is totally me feeling all the usual mixture of jumbled up emotions. I feel guilt. I feel embarrassment. I feel alone. I feel like crying.*

*I know she is joking and would be mortified and upset herself if she knew I was feeling like this, but therein lies the rub - I can't tell her how I feel because of how it will make her feel!*

*I feel guilty because of wanting to be a 'good dad' and a 'good husband' and wanting to try to do the right thing by everyone in the family. I don't want to burden my loved ones. My kids don't know about my MS (although there are times when I wish they did so they might understand why I'm tired all the time, why I get grumpy, why - as I fear - they don't think I'm as fun as other dads...), and Em does so much for all of us anyway I don't want to make her feel that the onus is on her to look after all three of us (rather than both parents looking after both children).*

*I'm in this strange 'zone' of feeling really tired and having just had a horrendous final couple of weeks of term and thinking that I'm 'allowed' (or should be) to have a little TLC and time for myself (for my own health and well-being) but then feeling selfish for even having that thought (and having the fear that I will be thought of as selfish if I were to say anything to that effect anyway).*

*I simply don't know what I'm 'allowed' to feel, or think or say about my MS.*

*My wife doesn't really know either, and we can't really talk about it as a result.*

*All because it's hidden...*

*If I was in a wheelchair, there would be an instant recognition that at least some of my interests come first (or at the very least, are a reasonable consideration). Part of the problem is the fear of the unknown, and unless there is an obvious problem (as far as Em is concerned), she prefers to put it out of her mind as often as possible.*

*That is not a criticism. I do exactly the same! So maybe the onus is on me to articulate how I'm thinking/feeling with greater regulatory, but that is the conflict that I constantly live. Not wanting to disclose publicly, but wanting understanding 'behind the scenes' at home (or with friends/loved ones).*

*Is it living a lie? If it is, then presumably I have no right to be selfish, to feel sorry for myself or to expect unconditional understanding (from Em or anyone else)?*

*Maybe it would be better (or at least easier) if my MS progressed, affected me more and - as a result - was no longer hidden?*

*And now, I have feelings of guilt, selfishness and embarrassment for even thinking that.*

*All because it (jokingly) 'isn't all about me'...*

## **Appendix 7 | Journal Entry (Diagnosis) from Chapter 4, section 4.7**

*May 21<sup>st</sup>, 2017*

*God. I can remember it so well.*

*It was a beautiful day. The sky was blue, very few clouds and it was warm. Not too hot, but the sun was shining and there was a lovely, gentle breeze. Such a nice day. Was I anxious? Sure. I was going for a follow up appointment at the hospital after having a series of initial tests over a few weeks with various specialists. It had all come from, well, nothing really. A strange sensation in my legs when I flexed my neck forward. It wasn't particularly painful or disabling, just a little disconcerting, that's all. Kind of a cross between pins and needles and a loss of sensation. Just enough to make me think 'hmmm, that's a bit odd', but nothing else.*

*In fact, I hadn't even been to see the doctor about that at all! I'd gone for something else, and as part of the inevitable, final, obligatory 'well, thank you for coming in Mr Perona-Wright. Was there anything else?' question – I just thought I'd mention this as it was happening more frequently and I just happened to be in front of a doctor at that point in time, so thought 'well, why not? I might as well just mention it...'.*

*So I did.*

*The first reaction from the doctor? A quizzical look, a slight pause and then a reply which was along the lines of 'I'm sure it isn't anything to worry about. Just come back if it keeps happening'.*

*In fact, I didn't need to come back, despite the fact it was still happening. The doctor rang me around a week later, which is not something I had experienced before (being contacted by the doctor rather than the other way round!). He had been looking up*

*the symptom which had puzzled him, thought that it might possibly be an indication of something (yet to be mentioned to me) and would I like to pop back in for some quick tests.*

*So, I duly went back in, he said it was probably nothing but wanted to check my reflexes and prod/poke me in various places on my body to see if I could feel it. He still looked a bit puzzled and said 'it's still nothing to be concerned about, but if you would like to explore it a bit further then I can refer you to a specialist at the local hospital'. So, whilst I wasn't overly concerned (more fascinated, to be honest, like trying to figure out a puzzle), I said that 'yes, I would'. Hey presto, a letter arrived a few days later inviting me to attend a clinic at King's College Hospital, London in the Neurology department.*

*If you haven't ever been to King's College Hospital in London, it is a monster of a hospital. A huge, sprawling estate of pieced-together buildings that have accumulated over time as it has grown into one of the UK's leading (and largest) hospitals. I found my way round the maze of corridors, attempting to follow the multi-coloured signs with arrows pointing in every possible direction and eventually checked in at the reception desk of the Neurology department.*

*Surely, I must be in the wrong place?*

*The entire hospital is busy with patients and staff buzzing round like bees in a hive, but this department had a waiting room with people that clearly had significant issues that they were living with. They were in wheelchairs, had walking aids, some so abundantly affected by whatever condition they had that they needed a carer by their side the entire time. In that slightly 'British', awkward way that you find often on public transport or in a restaurant when a disabled person comes in – you don't want to stare. But you also don't want to pretend they aren't there either, so you end up in a kind of 'no man's land' of pretending to do something else. Thank God for the mobile phone. At least we all now have something in our pockets that we can*

*pretend has our attention to help avoid the not knowing what to do or how to handle it. Anyway. I'm uncomfortable. I don't know how I should be feeling or acting (reacting) to where I am, and I'm utterly convinced this is some sort of mistake.*

*'Mr Perona-Wright?'*

*A man in a single-breasted grey suit with a white shirt and blue tie appears from a doorway. He is tall, thin and balding with remnants of some whitening hair left on his head, and glasses slightly perched on the end of his nose. He reminds me of someone really quite 'official'. Like an old-school examiner, or an inspector or school master, but most certainly someone with gravitas and authority. I feel like a child following a teacher into their office to be told off. We head into his examination room and close the door, finally quietening down some of the hustle and bustle of the busy hospital. We discuss the reason why I'm there, why I've been referred, and I reiterate that – in all honesty – I'm a little bewildered about the whole thing as I really wasn't pushing for this and certainly didn't want to waste anyone's time. How very typically British of me (again) to be apologising in that way.*

*He completes similar tests to my GP doctor – more prodding and poking, scraping the bottom of my feet with a blunt tool of some sort to see which way my toes bend in reaction, and testing my reflexes in my joints. He also gets me to close my eyes and touch my nose with each hand separately and also then walk across the room in a straight line. I have to confess to finding all this slightly amusing (again, like the naughty schoolboy in the school master's office) and almost like I imagined the police would be if I had been pulled over for drink-driving (which I hadn't ever, but these tests looked like things I'd seen people have to do in films or on TV programmes). We sat down to discuss it all again. Rather like my GP, the consultant Neurologist told me that 'it was probably nothing, but the sensations in my legs when flexing my neck forward could possibly be an indication of some underlying problem – however unlikely.' He didn't seem very concerned about it all, so neither did I! The two options were to either leave it and see if things got any worse (in which case, contact*

*them), or I could go for a scan which might possibly provide some more information. He seemed very ambivalent about it all (which I took to be a good sign and reassurance that it was, in fact, probably all just a mistake and a bit of a waste of everyone's time). Nevertheless, I shrugged and said 'well, I suppose it might be useful to find out whether it is something to worry about or not?' and agreed to have a scan.*

*I'd not had a scan before. It was an MRI scan. Magnetic Resonance Imaging – whatever that means. Sure, I'd seen scenes in TV programmes and films of people going into big, round tubes and figured it would be just like that. It was sort of like that and not at the same time. You are on your own, and you are warned that it is loud.*

*It is.*

*If they are scanning your head and spinal cord (which they do for me), then you are in the scanner for around half an hour. It is tight for space, particularly if – like me – you are relatively broad in shoulder (and waist...) width. You aren't supposed to move while lying on the sliding stretcher sticking out of the scanner or it would affect the results of the scan. To prevent that you wear ear-plugs, then additional noise reducing pads over your ears, and then your head is placed in some kind of brace device with a front part that goes over your face, locking your head in position. They give you a 'help' button to press whilst you are in the scanner as you are alone in there, and then they push you in. It is light in there, but you can't see anything other than the top of the inside of the scanner which is around 15cm in front of your face (locked into position in the head-brace), not even your hands or feet in your peripheral vision.*

*As the scanner does its thing, the whirring and clunking and buzzing is relentlessly loud. As a musician, I start to zone out a little, hear the rhythmic patterns of the machine and try to concentrate on making up little counter-patterns in my head to while away the time. There are occasional breaks. Gaps in the noise where I feel the*

*stretcher/bed thing I am on move in the machine a little – presumably to move me into a different position for the next part of the scan, and off it goes again. Eventually after one of the gaps, I feel myself being brought out of the scanner completely. I feel a sense of relief that it is over. I'm not claustrophobic by nature, but it wasn't an entirely comfortable experience. I put it down to a one-off adventure that I can boast to other people about the fact I'd had done – almost like a bucket-list type activity – and didn't think much more about it. I went home, described it all to Emma, made sure I was as nonchalant about it all as I could be (as I didn't want to cause her unnecessary worry about the whole thing) and thought 'that was that'.*

*A couple of weeks later, I had a letter inviting me back to King's College Hospital to discuss the results with one of the Neurology team. OK, I admit that at this point, my mind – and Emma's – had started to go into the realms of 'what if?', and 'but what about that?'. We were a little anxious, but it really did feel like a whole lot of fuss over nothing. My own GP and one of the Consultant Neurologists at one of the UK's top hospitals had both been so vague, not really overly fussed and, essentially, non-committal about my minor symptoms – so much so that no one really encouraged or pushed me into thinking there was much of a real problem – that I assumed it was all fine and the only thing I would have to show for it was the ability to tell a bit of a story about my experience of having an MRI scan.*

*It really was a lovely day, that day. Yes, Emma and I both felt a little anxious about the whole thing, but it was a mixture of apprehension and disbelief that anything would come of it. On the one hand it was serious enough to have had this sequence of appointments, tests and visits to the hospital. Even the word 'neurology' seemed a bit weird and over the top, to be honest. I'd never really been seriously ill in my life before. Never broken a bone or had to have any kind of operation – and here I was, returning to the neurology department for the third time in the space of a few weeks. However, on the other hand, there was nothing really wrong with me. It was just a minor, odd sensation. It didn't affect me doing anything, wasn't really causing me pain, it wasn't stopping me from going about my normal day-to-day life – so this*

*was all faintly ridiculous. I felt a little bit guilty of taking up so much time of the medical professionals away from other people who were – surely – much more in need than me. The people in the waiting area of the Neurology department with us. The people in the wheelchairs and with the walking sticks. The people who were clearly so affected by significant neurological conditions that they had to have someone there by their side to do everything for them as they couldn't do anything for themselves.*

*Surely this was all just a mistake.*

*I remember sitting in that waiting room so well. At least I had Emma next to me instead of needing to look at my phone to pretend I was doing something so that I didn't have to try to ignore the people with varying levels of disability about me. Mind you, we didn't really know what to say to each other. We didn't want to talk about the 'what if's' at that point – it didn't seem appropriate. We were surrounded by people that were living the 'what if'. Or maybe it was just that we didn't want to imagine that this could be me.*

*But, surely this was all just a mistake.*

*King's College is so busy. There are just so many people coming and going the whole time. Like any hospital, it has new bits and old bits. There are various bits of mismatched furniture. It just seemed like a bit of an odd dream sitting there. Like we were in the middle of someone else's reality, not ours. But we sat there, patiently, amongst the busyness of the waiting area, not really knowing what to say (or think) but hoping that we would be done soon, being packed off on our way having been told that there was nothing to worry about.*

*'Mr Perona-Wright?'*

*A young lady called my name this time. I took that as a good sign. The school master-type consultant didn't seem to be anywhere, so it couldn't be bad news – right?*

*We went into a very small examination room. She sat to the right of two chairs at a desk looking at what I presumed were my file notes. Emma and I sat in the two chairs next to each other holding hands, and then he came in. Not the school master, but someone else.*

*A middle aged, short-haired man who was introduced as a Consultant Neurologist. He sat, perched on the treatment bed just opposite Emma and I on our chairs. He was wearing a white shirt, no tie and with a couple of buttons undone. He was a very attractive man, I thought, like a medic out of a TV programme. The tight-fitting shirt showing his broad shoulders and muscular physique, and this was complemented by some facial stubble and a deep tan. As he introduced himself, he was quite 'no-nonsense' – courteous, but clearly wanting to get on with his busy day ahead. His voice gave away where he was from – South Africa. And this is the bit that I remember so vividly. As the female medic – sat at the desk to our right - was conveying all that had taken place from the previous few weeks, like some chronological statement of fact you would hear in a police report or court of law, this charismatic, attractive Consultant Neurologist sat perched opposite us on the treatment bed was faintly swinging his legs back and forth answering everything that was being reeled off with an impatient 'yeah, yeah, yeah...', urging her to get on with it and finish. This scenario caused Emma and I to glance at each other and giggle under our breath as I think it confirmed what we had both thought (or certainly hoped) – that this was all a bit of a mistake, that I had gone through all of this (the tests, the appointments, the scan, etc) for nothing, and that this new Consultant Neurologist was a little bit annoyed or impatient and wanted to pack us off on our way almost with a slight 'telling-off' for wasting everyone's time. Then before the female medic even got to the end of the medical report and having reached the part about my MRI scan, he interrupted her with a final 'yeah, yeah, yeah. Look, I'm really sorry my friend, you've got MS'.*

*I felt Emma's fingers tighten slightly around mine.*

*There was that moment of silence that at the time was probably only a second or two, but in that room, at that time - the whole world seemed to momentarily stop.*

*All the noise of the hustle and bustle of one of the UK's busiest hospitals just outside the door of that small treatment room vanished in an instant.*

*We both stared at him, motionless. Not knowing what to say. Or do.*

*The female medic had a sympathetic look on her face, but he was clearly the senior practitioner in the room, so it didn't seem like her place to offer any support or advice. So, she waited for him also.*

*He then quickly continued and described various next steps, which included starting treatment (that would be a course of injections). That part of the conversation, I only remember edited highlights of as – I guess – I was in a kind of mild 'shock' from the unequivocal diagnosis I had just received.*

*So many things filled my head – am I going to die? Am I going to be able to carry on working? Can I still drive? How long am I going to have to live my current, normal life? Am I going to become one of the patients outside the door of this little room stuck in a wheelchair needing Emma to push me round? Even worse, is she going to be lumbered with taking care of my every need – clothing, washing, feeding? Going to the loo, even? Christ, this isn't what she signed up to when she married me. This doesn't just ruin my life, but all those of the people around me. What about my unborn daughter currently growing innocently in Emma's womb? What if I don't have the use of my body – arms or legs – to be able to hold her, hug her, play with her? Be a normal dad?*

*So many thoughts were swimming round my head whilst he was talking. The two things I remember being told having at least asked about work, was 1) I was obliged*

to inform the DVLA with regards to my driving, and 2) I didn't currently have any legal obligation to disclose it to my employer.

Why not?

I mean, I was pleased that was the case as it gave me a modicum of control about who to tell and how/when, but I had so many questions. They gave us some leaflets with basic information on about MS, told us to go away and look at the MS Society website for lots more information, and there would be a follow up in due course.

So, out we walked of the hospital, Emma and I. Through the maze of corridors and out into that glorious day. The warmth of the sun on our faces as we stepped outside. Emma was crying. We held hands all the way, but didn't say much. We didn't know what to say. The only thing I remember saying was 'I want to know if it's hereditary'. 'Why?', she asked me. 'Because if it is, then I don't want to have any more children'. I didn't want to pass on any inadequacies of mine to any children I might be able to have.

Neither of us knew anything about MS. It was just one of those things you hear of when the hot-potato topic of assisted-suicide cropped up in the media, and there was usually an MS patient with no quality of life at all wanting to be allowed to go to Dignitas in Switzerland to die.

That day changed my life. And the lives of all those who know me and love me the most.

Forever.

## **Appendix 8 | Journal Entry (Fatigue)** *from Chapter 4, section 4.9*

*May 11<sup>th</sup>, 2018*

*I'm exhausted. Not just tired, but exhausted and entirely 'spent'. It's been a usual busy week at school (lots of extras like taking various kids to the local performing arts festival and our summer serenade, etc), and I've just spent the day in Oxford for the EdD too. I almost had to pull over the car on the way home because I was on the verge of feeling unsafe to drive I was so tired.*

*But, surely everyone is tired? Everyone who has taught all week is tired, right? All my colleagues on the EdD that have worked all week and now done a day of lectures must be really tired too, surely? Is what I'm feeling 'normal', or do I have it worse than others because of my MS? Am I 'extra' tired and have 'the right' to feel my cross is much larger to bear than others? If so, then why do I do it to myself? Why push myself? What do I hope to gain by 'soldiering on' smiling through gritted teeth?*

*I feel confused.*

*Tired and confused.*

*In some ways it has been a typical Saturday night once I get home. I have no energy to do anything (and don't want to after my day in Oxford), yet my kids are excited to see me, want my attention and don't understand why their dad appears lazy and boring and just wants to sit in his armchair. I want to shield them from the unnecessary worry and burden of knowing I have MS (how would they possibly understand what it is anyway..?), yet it perpetuates the feeling they will increasingly have that I am not as fun as other dads.*

*So I feel tired, confused and guilty.*

*I have to do my Avonex injection on a Saturday night because of the flu-like symptoms it still gives me the next day - and given I have Saturday school, a Sunday is my only non-work day to deal with the physiological symptoms (aches/pains/temperature fluctuations, etc). It means I do not get any time to 'recharge my batteries' like other colleagues at my school and is one of the reasons I do not like having to take the injection.*

*Tonight has been fairly typical. I'm exhausted so need to relax and unwind. Because of that I do not want to wait until I go to bed to take the injection (as it will be in the back of my mind and detract away from my enjoyment of the relaxing evening crashing out in front of the TV once the kids are in bed. So, I need to take it earlier. I need to take some painkillers, go upstairs to my bedroom and close the door and take it whilst I hope the kids are amusing themselves downstairs and aren't going to burst in mid-needle penetration (requiring partial or full disclosure as a result). It hurt tonight, the injection. Don't know why, I guess it is luck of the draw as to the exact spot in your leg you do it - but it was a sharper pain than usual tonight, and more sore than usual afterwards too. This is exactly why I don't enjoy it and want to get it out the way. I also dread my existing physical tiredness and the aches in my body as a result being compounded by the forced additional aches and pains from the injection.*

*I crawled into bed so exhausted I could hardly keep my eyes open around 10pm. We didn't put the fan on - don't know why when we normally do in the summer months, and so I get very restless as a result of the injection. I'm tossing and turning trying to remain asleep but gradually becoming more aware that my brain is waking because my body is unable to relax and unwind - despite so desperately needing to. Eventually, I give up. At 2am I put my glasses on, get out of bed to put the fan on, try to get comfortable again (but cannot now I've given in and woken up) so start to write this.*

*It is so utterly frustrating. I crave sleep. My body and my mind both need to rest, and the thing causing that need is also the thing preventing me from actually being able to achieve it. It is so frustrating, and makes me feel so helpless.*

*Helpless and alone.*

*But, this is simply my life. This is not an exceptional circumstance. Today is not out of the ordinary. This is just a normal weekend. I navigate work commitments, feeling like a fraud when I'm then at home with my family, I anticipate the physiological symptoms that I already feel that will be compounded by those caused by the injection I don't want to take and know that even if I end up managing to eventually sleep - my painful, aching body will wake me early needing to take some painkillers anyway. I will then spend tomorrow taking painkillers throughout the day whilst constantly feeling guilty for telling my kids that I'm feeling tired and not very well.*

*Exhausted.*

*Confused, frustrated and guilty.*

*And so alone.*

## Appendix 9 | *Journal Entry (Disclosure & Credibility) from Chapter 5, section 5.2*

October 2018

*I've just been playing in the band (on keyboard) for a local production in 'The Playhouse' of RENT. It isn't a show I knew before agreeing to play for this one – but I have grown to really enjoy it. The music is generally quite 'rocky', but with a few very tender, heartfelt moments – and a very powerful storyline focussing on a group of friends experiencing various trials and tribulations. These vary from relationships (broken or otherwise) and work, through to illness (AIDS), death and grief.*

*So much of it resonated with my own life – I guess that's why it ended up 'striking a chord' (pardon the pun) too?*

*For me, of course, it is the usual knife-edge balance of having illness (MS), disclosing to colleagues/friends and how one may or may not affect the other. For example, I am playing professionally in a band (receiving a not-insubstantial fee) alongside at least two fellow musicians who work for me at school in the music department (we were all booked separately) as well as others I know from the local music scene.*

*So, this is increasingly my quandary.*

*At the moment I can hide my MS – but I notice the symptoms (all too well during an activity like this). I'm exhausted! I'm working a busy day-job at school and then have about 10 days straight of show rehearsals and performances from around 7pm till 11pm. It is tiring for anyone, but especially for someone with an illness where 'fatigue' is a daily, common occurrence.*

*Of course, this is where a better, personal management of my illness should probably come into bear. But I want, so desperately, to cling onto as much of my musical skills*

*and abilities as I can before they get taken away from me for good. As I say, I am performing alongside both current colleagues and other professionals – and the problem with the musical world (as with the very cliquey/connected independent school world) is that it is a very, very small one! So, for me in my professional life (as both a musician and an educator), the over-riding concern is one of ‘credibility’. Can I ‘walk the walk’ as well as ‘talk the talk’?*

*Whilst I do not completely adhere to the mantra of ‘those who can’t “do”, teach’ (as there are many wonderful instances of those who do both...), there is some truth in it. As a result, having as many qualifications as I do, and a reasonably significant professional/performing musical CV – I have that all important ‘credibility’ with my large number of visiting music staff (many of whom would view me with a little suspicion and as a glorified ‘administrator’ if I didn’t have the background and experience to back up what I say and do). However, I feel that I cannot, therefore, show or reveal any weakness (musical; through diminished technical cognitive ability, or physical; through fatigue) for fear of being seen as ‘less than equal’ and thus reducing my ‘credibility’.*

*Then, during one of the final shows, I am made aware of one of my colleagues from school, Elly, in the audience. She has been absent from school – and won’t now return – because she has been diagnosed (back in August) with a terminal brain tumour. However, one of my other colleagues has told me that RENT is one of her favourite musicals, so she wanted to come to watch it. It turns out that she has specified wanting one of the songs from the show at her funeral celebration (whenever that may be over the next year). The song is called ‘Seasons of Love’ and discusses how one should or could measure a year of someone’s life.*

*Just thinking about it hits me hard.*

*Elly may only have a year (probably less) to live before her illness kills her. She and I have discussed illness a number of times. As her ‘boss’, it was my job to keep in*

*touch with her last year when receiving treatment for breast cancer (and now for her brain tumour). The HR department could do it, but it made sense for me to do it. We have ended up bonding in a way I didn't expect as a result.*

*Whilst I cannot compare MS to a terminal, life-ending illness – there are enough similarities for Elly and I to have been able to chat, discuss and convey both empathy and understanding. There is no cure for my MS, as with her brain tumour. No one can possibly know what it is like for her (or me) living as the individual living with an illness (terminal, chronic, degenerative or otherwise). Put the physical symptoms to one side, and you are left with a huge cacophony of emotions, fears, concerns and more...*

*No one can possibly know her concerns for her teenage boys growing up without their mother.*

*No one can possibly know the way my heart breaks in two every time one of my children tries to hold my hand and I can't really feel it due to the loss of sensation in my fingers and hand.*

*No one can possibly know the concern Elly has for the financial future that her boys face once she dies, or that same shared concern I have for my family if and when my MS robs me of the ability to do my job (being the main breadwinner for our family).*

*No one can possibly understand.*

*And yet, as I read through the lyrics to 'Seasons of Love', and as we play it for the show that Elly has come to watch, I am reminded of why she has chosen it for her funeral. How do you measure a year in someone's life (or any time, really)?*

*"525,600 minutes. How do you measure a year? In daylight, in sunsets, in midnights, in cups of coffee? In inches, in miles, in laughter, in strife?"*

*All of these things are true, of course, and (like illness) are measurable or quantifiable in some way. However, it is all the things you cannot measure that matter. Rather like my ever-burgeoning interest in phenomenological research due to its capacity to find out more about these individual, subjective, 'lived' experiences, the song goes on to describe what I imagine draws Elly to it:*

*"In truths that she learned, or in times that he cried. In bridges he burned or the way that she died."*

*The way that she died.*

*That's what Elly has control over. That's where she has one-up over illness. She can choose to go in her own way. On her own terms. At peace, and full of grace.*

*Of course, the point of the song (and the main line of the chorus) is what it is – or should be – to all of us: "Measure in love". That's how you measure time for someone. Whether it is a year or a life-time, you don't do it in a quantifiable way. You do it in love. Those that you love and those who love you.*

*Elly is so very loved by so many people, and that is how her life will be remembered, whenever it will come to its end. And, I suspect, that is why she is at peace with her illness. It is because she has control, and because she knows that she has lived a life full of love.*

## **Appendix 10 | Journal Entry (Relationships & Fear) from Chapter 5, section 5.4**

*September, 2019*

*Wow. Just, wow.*

*We've had a lovely weekend with my parents coming to stay with us (a very rare visit), and Em's parents came yesterday as well. It was lovely to have everyone together, particularly for the kids who hardly ever have both sets of grandparents together in the same place at the same time.*

*We decorated the spare bedroom for them, planned special meals, went to church together, and they have gone away really happy and touched by the effort we made to host them so well.*

*However...*

*Today (Sunday), I have started to feel really rubbish. My head is all over the place, I'm really achy all over (a really deep-rooted ache that doesn't go away by merely relaxing, taking pain relief, having a shower or bath, etc) and my temperature is really fluctuating. It is similar to when I was taking my injections each weekend for MS – although I stopped taking those a few months ago.*

*I just attempted to have a bath to get warm. When climbing in, I lost my balance, fell back into the bath, hurt my arm and spilt water all over the floor. I had to call for help. Emma came, mopped up the mess, gave me a hug, got me a flannel and started washing my back.*

*I dissolved into tears.*

*It's a funny time in my (our) life. I've just turned 40, don't know how MS is going to affect me and my career, am about to change medication for my MS (will be having an intravenous injection as an in-patient twice a year and have no idea how it will affect me, my work, or what the side-effects will be – so there is a real and genuine anxiety about the unknown...), and Molly is about to enter the final year of Primary School. This year will go so quickly, and all of a sudden she will be going to Secondary School. Do I continue to look for other jobs, or with so much uncertainty in my life – should I be staying put and not pursuing my career ambitions which might potentially make these other aspects of my life worse?*

*Why the tears? OK, so I lost balance and slipped. So what..?*

*It makes me feel so helpless, that's why.*

*It gave me visions of all the things that I fear the most about MS (losing my ability to be everything that makes me, 'me'). Being (or feeling) so helpless and unfairly burdening (as I see it) my wife/family into being 'carers' for me. OK. Over-reaction, maybe, but when you are feeling rubbish then everything gets to you much more.*

*My wife loves me, that much I know. But she didn't sign up to look after a husband who can't look after himself. That should be my job for her and the kids. Plus, I simply don't want it for her. It's not fair.*

*Is this becoming a turning point? Turning 40, kids growing up, starting to re-consider my career options, my MS developing and starting a new treatment?*

*So much uncertainty.*

*So much fear.*

## **Appendix 11 | Journal Entry (Control/Choice) from Chapter 6, section 6.2**

*July, 2019*

*What a few days!*

*A true mixture of emotions and experiences. I'm writing this sat on a plane, somewhere over the Atlantic Ocean, on the way to Las Vegas with my dear friend Tim. He has, so very kindly, organised for us to have this once-in-a-lifetime trip – ostensibly for my 40<sup>th</sup> birthday coming up in a few weeks' time. We are spending a few days there, looking to do all the 'Vegas' type activities you would expect; stay at the Bellagio, watch the fountains at night-time, hit the casinos (lose lots of money..!) and generally swelter in the heat of the desert, summer sun.*

*However, just a few days ago, I attended the funeral 'celebration' for my dear friend and colleague, Elly. A hugely important member of the music department at school, flute/piano teacher, consummate professional and highly talented musician – she had been diagnosed with a brain tumour (terminal) at the beginning of this last academic year. She died, finally, a few weeks ago in late June 2019 managing to get through almost a final year of her life.*

*The celebration was as expected – joyful, uplifting, sad, funny, poignant and very well attended (as you'd hope/Imagine for someone cut down in the prime of their life in their early 40s). The tragedy, beyond her young age and the fact she has two teenage sons (one of whom had to attempt GCSEs this summer...) is the fact that she had beaten breast cancer in 2017/2018.*

*As her line-manager at school, it was my job to meet with her to discuss how treatment was going whilst she was off on sick-leave. I wanted to do it, as I felt we*

*were friends as well as colleagues, so I had a very real and genuine concern for her wellbeing. In fact, this period of meeting up to discuss illness brought us closer together. She, as with many people, was intensely private, absolutely did not want fuss or sympathy, and had a very driven, can-do attitude to life. She faced illness, both the treatable cancer and the terminal one, head-on. She was determined to live her way and, ultimately, die her way too. She fought when she needed to fight, and she was accepting and made her peace with everything when she needed to do that as well.*

*Whilst she wasn't religious in a Christian sense of the phrase, she was very spiritual. She travelled widely and was particularly drawn to the humanist side of Eastern Philosophy. That being said, her philosophy and outlook on life (and death) was very much in line with the oft used Christian prayer written sometime in the 1940s by Reinhold Niebuhr (1892-1971):*

*"God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference."*

*I increasingly think finding the balance between trying to affect positive change when one is living with an illness (for well-being, general/wider health benefits, emotional as well as physical health, etc) and trying to 'let go' of the things that are beyond your control, is so important. Yet this seems to be one of the biggest issues for someone living with a chronic, invisible illness; control (or lack of it).*

*Is that one of the reasons I do not want to (or feel able to) disclose my MS to many people – particularly at work? Is it because I have no control over the illness that slowly, gradually, changes all the things that make me 'me', but I do have control over whether I choose to tell colleagues/friends/employers? Is that retention of 'control' (however small) enough of a psychological counterbalance to a sufferer (in this case, me)? Or do I simply not feel able to disclose for fear of being viewed differently? Viewed as 'less than', not on a level playing field?*

*Then I feel confused, and think to myself – ‘what would Elly do’?*

*Brave, wise Elly.*

*Illness has robbed the world of a beautiful person, and the beautiful music that she shared with it. As I sat at the keyboard playing the music she had specified that she wanted (and wanted me to play) for her funeral celebration – I was filled with an odd juxtaposition of emotion. Such deep gratitude for having known Elly in my life, but infused with heart-aching sadness that she can no longer be part of it moving forward. Then, at the same time, joy and pleasure at being able to use my musical talent as Elly had requested to contribute to the occasion in some way, whilst simultaneously having wave after wave of anxiety running through my body at every touch of a piano key in the fingers that I cannot feel and control, hoping that I get through the piece without anyone else (in a room full of musicians...) noticing so I can do justice to the musical offering for Elly.*

*Dear Elly.*

*It is the sense of loss that overwhelms. Not just losing a friend, but losing all the things (musical at the moment, but who knows what over time) that form part of my identity.*

*Illness is cruel. It takes. Only takes. And doesn't give back. And yet...*

*... would Elly view it like that? Would she use it simply as an opportunity to re-invent herself? To embrace change? To see the positives? To have the serenity, the wisdom and grace to live life regardless? That is a rhetorical question, for that is exactly what she did – right to the end of her short life.*

*Wonderful, unique Elly. Forever missed.*

## **Appendix 12 | Journal Entry (Identity)** ***from Chapter 6, section 6.4***

*April, 2018*

*I'm sitting here in our house. It's around 8.30pm, the kids are in bed and Em is out singing for a College chapel service. I stare out into the garden in the soft, dying light and listen to music whilst thoughts swim around my head.*

*The music is 'Abraham & Isaac' by Benjamin Britten. It is a piece of music I love for various reasons. It is so original in style, so powerful, so tender the way it speaks of love and trust, and it is a piece I have performed a number of times both as a soloist and accompanist.*

*It has really moved me tonight. Why..? Is it simply a piece of music I enjoy that has caught me at the wrong (or right) moment? Or is it something deeper?*

*Maybe, on some level, it is because I am reminded that my MS is gradually robbing me of my musical prowess. My fingers and thumb in the right hand are still numb from my latest relapse, which makes even writing this a challenge – let alone maintaining any kind of control at a piano or keyboard.*

*For so long, music formed part of my identity (and, I suppose, still does to a certain extent...), and yet that gradually ebbs away. Gradually diminishes like the dying light outside, and I feel that sense of loss. Of sadness. That ever-present feeling that my very 'essence' is being taken away from me over time.*

*I also 'muse' over the narrative of the bible story being sung in the music, and I am reminded of something my sister said to me yesterday about her going for ordination. She mentioned the Abraham & Isaac story with regard to the selection process for her (whether it was just God pushing and testing her to see how far she would go to*

*prove her faith). Is it similar to me with MS? Is this why I feel guilt all the time? Is that God 'testing' me? I know how great my life is in so many ways. I know how much better and blessed my life is compared to so many others. Is this a reason why (or another reason why) I don't want to disclose – and then feel guilty when I do (like I'm looking for sympathy that I don't deserve)?*

*If God is testing me – then, surely, I am failing.*

*"The aim and final end of all music should be none other than the glory of God and the refreshment of the soul". (J. S. Bach 1685-1750)*

*If this is true, and that "music acts as an aesthetic channelling of the performer's body" (Music Autoethnographies, p.251) – then my body is failing me, and my ability at music that is ebbing away surely and steadily brings no glory to God whatsoever.*

## **Appendix 13 | *Journal Entry (Career & Future) from Chapter 6, section 6.6***

*May, 2019*

*What will become of me..?*

*Things change, of course they do – that is natural. Intentions, goals, ambitions. When I was a child, I wanted to be in the SAS (!). In my teenage years, I thought I would become an orchestral conductor. As a university student I assumed I would move into professional choral music, possibly in a cathedral. Then, inexplicably, that changed to being a teacher.*

*It was a bit by accident (the Royal School of Church Music where Emma and I worked relocated to Salisbury and we didn't want to move...), but very quickly it became teaching. And not just music teaching (or aspiring to be a Director of Music), but to be a headteacher. I do little or no real music-making these days – just the odd organ accompaniment for my dad at his Parish Church. So, what prompted that change?*

*Yes, we are all good at various things – but music was, undeniably, a gift for me. It is ebbing away, slowly but very definitely, and I guess that is a mixture of lack of practice and application, but also my MS.*

*It is robbing me of my focus, my concentration, my dexterity.*

*My identity.*

*However, my identity has shifted over the last 10 years to that of being an aspirant head; I have sought promotion at school to senior leadership, do an MEd in Educational Leadership, be a Chair of Governors, be elected as a Fellow of the*

*Chartered College of Teaching, undertake work as a school inspector and now complete an EdD as well. The problem is that already I wonder about my future ability to 'do the job'. Should I temper my ambition to put my health first? But then – what does that mean? I can't just 'down tools' and wait to die..! I have a life to live, and I need to do it for myself as well as my loved ones. I just don't know at what point I become selfish by pushing too hard for what I consider to be my ambition/goal (becoming a head) over being content living the wonderful life I have in so many other ways.*

*Will I always regret not feeling like I 'made it'? Or will I ultimately regret pushing myself unnecessarily when it might be to the detriment of my health and, quite possibly, my relationships with loved ones..?*

*MS just makes me feel so uncertain. So shackled by something I don't really know what it is. A burden, yet one I struggle to articulate. It is like a black cloud hovering over my head constantly. Yet I know it will never go away. I just wait for it to get darker and, ultimately, pour down with rain...*