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poe*MS*: an exploration of poetry as a way to communicate  
lived experiences of multiple sclerosis.

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PhD in Health in Social Science

University of Edinburgh

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## Declaration

In accordance with University regulations I hereby declare that:

- (a) the thesis has been composed solely by myself;
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Georgi Gill

## Abstract

This study examines whether poetry written by people with multiple sclerosis (MS) may be a useful form for reflecting on their illness experiences. Much recent illness writing comprises prose narratives conforming to either the restitution or quest tropes (Frank, 2013), however these models may be unhelpful for people with MS because of their focus on cure or their moral imperative to personal growth. Poetry is increasingly used by social science researchers to present participant interview data and facilitate different ways of knowing than traditional prose texts. This research takes the novel approach of exploring poems written in the study by participants with MS.

Nine people living with relapse-remitting, primary progressive or secondary progressive MS were recruited to the online study through MS charity websites and social media. They participated in one initial semi-structured interview about their MS experiences, and then took part in four group poetry workshops. The researcher also has MS and the methods of data creation were designed to be collaborative. Follow up semi-structured interviews were conducted so participants could reflect on their study experiences. Four contacts of the original participants were also recruited into the study. These 'reader participants', who did not have MS, read some of their contacts' study poems and participated in one semi-structured interview about the experience.

Holistic discourse analysis of poems and spoken interview and workshop data was guided by Bakhtin (1984, 1986) and Gee (2014). This analysis identified three key themes in participants' poems and spoken data: being MS patients in relation to medical teams; MS in the workplace; and social impacts of MS. Further analysis revealed the obstacles faced by participants in these different settings and illuminated the ways in which they constructed their identities in order to negotiate or minimise these challenges. Participants' poetic inquiries incorporated phenomenological, social and political reflections in both narrative and non-narrative poems. Participants derived positive outcomes from working collaboratively together in poetry workshops and also from sharing their poems with each other, me, and a small number of their family, friends or carers. I conclude that poetry offers

a novel method for people living with MS to contribute to personal and academic discourse on health and disability.

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## Key to transcriptions and quotations

*“quotes from participants are italicised”*

*“**bold text** in participant quotes or poems indicates that I will make reference to these particular words in subsequent analysis or discussion. ”*

*“underlined text in quotes indicates the participant’s emphasis”*

“[...]” indicates text has been cut from the quote.

“mmm”, “err”, “uh-huh” etc indicate verbal inflections by participants or myself.

“ / ” in an in-text quotation from a poem indicates a line break in the poem e.g. *“I am not your subject / My life is not your case to study”*.

## Glossary of Scottish dialect

*“canny”* – cannot, can’t

*“couldnae”* – could not, couldn’t

*“didnae”* – did not, didn’t

*“ken”* – know

*“mind”* – remember

*“no”* – no, not

*“thegither”* – together

*“wasnae”* – was not, wasn’t

*“wee”* – small

## Glossary of poetic terms

These definitions of poetic terms are guided by those of the Academy of American Poets (<https://poets.org/glossary>, no date) and Poetry Foundation (<https://www.poetryfoundation.org/education/glossary>, 2024)

**Erasure poem** – a form of found poetry (See definition below.) in which the poet an existing text and erases or blacks out a substantial portion of an existing text. The remaining text forms an erasure poem which is in itself a new work of art.

**Found poetry** – created when poets use existing texts (newspapers, novels, other poems etc) and rearrange them, presenting the results as poems. The poet decides how the text should look on the page, making decisions about e.g. line breaks.

**Free verse** – often following the pattern of natural speech, free verse does not adhere to an established form, rhyme scheme, metre (See definition below.).

**Internal rhyme** – this occurs within lines of poetry rather than at the end of the lines.

**Line break / lineation** – the end of one line of poetry and the beginning of the next. A poet may choose a line break to correspond with punctuation, syntax, sound or to create or disrupt the flow of a poem.

**Lyric poem** – these poems express personal emotions but do not tell a narrative. Historically, they resembled songs.

**Metaphysical poem** – largely attributed to a group of seventeenth century poets including John Donne and George Herbert, metaphysical poems are characterised by philosophical inquiry, a colloquial voice and innovative conceits.

**Metre** – the rhythmic structure of a line or verse of poetry, measured in syllables and stresses.

**Narrative poem** – a poem which tells a story, usually featuring a plot, characters and a defined setting.

**Stanza** – several lines of poetry grouped together as a unit within a poem. Sometimes called a 'verse' in the U.K.

**Volta** – this is a rhetorical feature in a poem which marks a shift in its argument or supposition which may surprise the reader or make them aware of possible new meanings in the poem.

# Chapter One

## poeMS: An Introduction

*'the poem is an artefact  
made from words  
& the space that exists  
between & around the words*

...

*i am human  
the shape of my body  
exists within space'*

(Sluman, 2017, 19)

### 1.1 Introduction

This thesis and the research from which it derives explore poems written by people with multiple sclerosis (PwMS) about their illness experiences. Multiple sclerosis (MS) is a chronic neurological condition in which the myelin coating of nerves in the brain and spinal cord becomes damaged (Levin, 2023). It is a leading cause of non-traumatic disability in young people (Thompson et al, 2018). PwMS commonly experience difficulty in successfully explaining their symptoms, especially invisible ones, to other people (Multiple Sclerosis Trust, 2016; Uhland, 2016; MS Society, n.d.). This thesis focuses on ways in which writing poems about MS may offer PwMS new ways of exploring and understanding their experiences and communicating them to others. Through this research I examine whether writing poetry presents opportunities for PwMS to move away from dominant illness tropes and create novel and alternative expressions of their illness experiences.

In this chapter, I will provide context to the study, presenting both the relevant medical and research backgrounds in 1.2. I will also discuss my positioning as a PwMS and a poet, which has been central to my research practice and the development of this thesis. Then in 1.3 I will introduce the aims and questions underpinning the research and establish its

importance. In 1.4, I will clarify the specific meanings I attribute to a number of terms that are used throughout the thesis. Finally, I give an overview of the following thesis chapters.

## 1.2 Contexts

In this section I will make visible three contexts which are central to, and have influenced, the development and process of this research. I begin with a brief overview of the epidemiology and disease patterns of MS. Then I describe my own close location to the study as a PwMS and as a poet. Finally, in light of this location, I introduce illness narratives and the use of poetry in health in social science research.

### 1.2.1 Medical context

The causes of MS are not fully understood but they are likely to involve both genetic and environmental factors (Waubant et al, 2019). The illness is more prevalent in northern latitudes (Simpson et al, 2011), and it has been shown that the corresponding reduced exposure to sunlight, and therefore Vitamin D, is associated with increased rates of MS (Sintzel, Rametta and Reder, 2018). Around 130,000 people in the United Kingdom are currently affected by MS, with the condition being between two and three times more common in women than men (gov.uk, 2020). The incidence of MS is higher in Scotland than in the rest of the UK; estimated to be 290 per 100,000, compared to 258 per 100,000 in Northern Ireland, 190 per 100,000 in England, and 179 per 100,000 in Wales (MS Society, 2020). There is currently limited data on the prevalence of MS in different ethnicities living in the UK. However, a study exploring MS incidence in East London calculated the following rates: White (180 in 100,000 people); Black (74 in 100,000 people) and South Asian (29 in 100,000 people) (Albor et al, 2017).

MS can develop at any age, but people most commonly experience initial symptoms between twenty and forty (Romero-Pinel et al, 2022). Symptoms vary widely but can include visual disturbance, balance problems, cognitive dysfunction, pain, fatigue, walking problems and issues with bladder and bowel function. The severity of the disease can also vary

markedly across the three main recognised forms of MS. Approximately 85% of new MS diagnoses are of Relapsing Remitting MS (RRMS) (National Institute for Health and Care Excellence, [NICE] 2022), in which complete or almost complete recovery happens after episodes of illness. The majority of individuals diagnosed with RRMS will move into Secondary Progressive MS (SPMS) (NICE, 2024). In SPMS there are fewer distinct episodes of MS but symptoms gradually worsen over time. The timescale for this form of progression is contested, although it has been reported that the likelihood of an SPMS diagnosis increases as time elapses since the original diagnosis with RRMS (Fambiatos et al, 2020). Around 15% of MS diagnoses are of Primary Progressive MS (PPMS); in these cases symptoms worsen with no periods of remission. There is no cure for MS, although disease modifying drugs are available to some patients.

### 1.2.2 Personal context

This research has developed from my own lived experience of RRMS with which I was diagnosed in 2003 following repeated incidences of optic neuritis<sup>1</sup>, fatigue and numbness in my legs. I was a twenty-eight-year-old, white woman who had lived in Scotland until the age of seventeen; in other words, I am typical of the epidemiological statistics. My adaptation to life with the condition involves negotiating sudden, or gradual, often unpredictable, fluctuations in my physical, cognitive and emotional states. My illness symptoms can begin suddenly and sometimes abate quickly but often drag on for weeks and occasionally months (Gill, 2019). Bury (1982, 167), who lives with rheumatoid arthritis, has described how, for him, illness episodes do not merely lead to inconvenient cancellations or postponements of his plans, but rather they result in 'biographical disruptions'. I very much relate to this conceptualization: in my experience, MS symptoms repeatedly disrupt my sense of self, causing interruptions and disfluencies in my efforts to create narratives of selfhood. This difficulty in constructing and maintaining a sense of a stable identity has been compounded by the frustrations and isolation of trying, and usually failing, to communicate the experience of living in my body, with its woolly sensations of blurred vision, fatigue, dizziness and confusion, to family, friends and colleagues (Gill, 2019).

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<sup>1</sup> Inflammation of an optic nerve which causes blurred vision.

Throughout the following chapters, I attempt to be reflexive and open about the complexities of my location and how it influences my interactions with the research subject, the literature and my participants. 'Researchers are both involved in, and partially produced by, the same cultural practices which they study; hence, researchers cannot stand completely outside of that which they study' (Flyvbjerg, 2001, 115). This is perhaps even more evident for me given my close relation to the study themes. However, even I am not identical to my research. I am cognizant of the risks in drawing inaccurate conclusions by assuming sameness with study participants as an 'insider' researcher (Merton, 1972, 21). Accordingly, throughout the study it has been essential for me to work carefully and reflexively in order to manage my three roles as researcher, poet and PwMS in ways that respect the duties of each role but acknowledge that they are necessarily interwoven. In 3.3, I discuss my reflexive practice in detail.

Writing has always been important to me. Prior to my MS diagnosis, I mostly dabbled with fiction, but, for a couple of years, as my symptoms became more impactful, the idea of writing a novel seemed impossible. Because of cognitive fatigue, my brain was unable to hold the complexities of a plot and multiple characters. Also, at that time, I felt increasingly overwhelmed by the changes happening in my body and consequently in my social world. Living with such unforeseen uncertainty made the idea of creating a plot that culminated in resolution desirable but also quite alien to me. Keen to continue some kind of writing practice, I turned to poetry because of its shorter form, and, as I became more confident with its techniques, I began to explore my MS experiences and identities in poems (Gill, 2017, 2020). Here was a form in which I could compose brief snapshots of my life with MS. Rereading my journal, I find the following:

*'The gap is the space between what is there and what you can do/say about it. The gap is where the excitement is, my inspiration to write poems. Maybe sometimes to narrow the gap, to move closer to the experience itself, but also just to explore the gap, sit in that space of not knowing.'*

Of course, narrative prose is not obliged to present the reader with a plot that culminates in a denouement which ties up its loose ends neatly. There is flexibility in prose as in poetry to follow or reject narrative expectations: *Finnegan's Wake* (Joyce, 1999) is an incredibly

opaque text that scholars have debated for decades and failed to define its 'plot'; William S. Burroughs' (2015) *Naked Lunch* is bookended by a recognisable crime plot, but the majority of the text is comprised of surreal, abstract fantasies; and the winner of the 2024 Booker Prize, *Orbital* (Harvey, 2024), follows the journey of the International Space Station as it orbits the Earth for twenty four hours, ruminating on existence and ecology. There is very little action and therefore there is no plot to speak of – the characters literally end up exactly where we first meet them. These innovative and highly experimental novels are well-known, but not necessarily well-read by the general population. Rather, the majority of novels and certainly the novels that I was reading, and had been attempting to write, in those days, follow a conventional plot structure. In poems, however, I did not have to tell a story which presented a neat beginning, middle and end. In poems, I did not have to make bold claims to understanding what was happening to me and what would unfold in my future. Rather I could and can embrace exploration and uncertainty.

### 1.2.3 Research context

A recent meta-synthesis of qualitative research into the experiences of PwMS (Desborough et al, 2020) found existing research focused on various themes: including identity (Mozodutton, Simpson and Boot, 2011); receiving care (Riazi, Bradshaw and Playford, 2012; Rintel et al, 2012); physical activity (Dlugonski, Joyce and Motl, 2012; Smith, Fitzgerald and Whitehead, 2015; Chard, 2017; Aminian et al, 2019); 'coping' (Dehghani, Dehghan Nayeri and Ebadi, 2017, 2018); and work (Kirk-Brown and Van Dijk, 2014; Bogenschutz et al, 2016; Meade et al, 2016). Most studies featured in the meta-synthesis collected data exclusively through traditional methods: interviews (84%) and focus groups (14%).

Within the field of medical humanities there have been some more creative approaches to data collection and representation. An academic creative non-fiction case study has explored lived experience of shame and MS (Vickers, 2014). Vickers (2015) has also written two short stories derived from interviews with PwMS. Recently Shirreffs (2021, 2023) published a creative writing doctoral thesis and subsequent novel, exploring MS through fiction and drawing on her own lived experience.

Narrative may not have proved to be the best form for me to write about MS, but outside academia there is a longstanding tradition of narrative illness accounts, and there are numerous examples of people writing about their experiences of living with MS. Sir Augustus d'Esté's diary, which was written between 1822 and 1846, details his daily life and the progression of his symptoms. The diary, which is the first known documentation of life with the illness, was used by Firth (1941, 1948) to diagnose MS retrospectively. Bruce Frederick Cummings, writing as W.N.P. Barbellion (2017), published *The Journal of a Disappointed Man* in 1919. There have been many subsequent memoirs written by PwMS, including Mairs (1997), Blair (2022), and Douglas-Fairhurst (2024).

First-person narratives of illness have increasingly featured in the field of sociology of health and illness, notably in the work of Kleinman (1988) and Frank (2013). However, it is my contention that such narratives generally have a number of limitations which mean that they are not necessarily well suited to communicating life with an incurable chronic illness. The basic premise of narrative is plot and, for a plot to be understood as successful, it depends on resolution; whether through a happy ending or a sad one, a plot has to be completed. Described by Frank (2013), the restitution narrative resolves through the cure of the sick person and is therefore evidently inappropriate for someone living with incurable illness such as MS.

Furthermore, an illness narrative is produced and situated within a social world and either reflects, or occasionally rebels against, prevalent cultural and moral attitudes (Kokanović and Flore, 2017). Those with MS, or other chronic illnesses or disability, may encounter a dominant cultural rhetoric which holds that their reduced productivity and possible reliance on benefits is partly responsible for society's economic pressures (Tyler, 2020). Disabled and ill people are stigmatised (Goffman, 1990) and may be perceived to be less deserving of resources than their healthy, able-bodied counterparts (Hunt, 1966; Tyler, 2020). It is perhaps therefore unsurprising that many contemporary accounts of life with chronic illness attempt to reassert a person's worth and show them in a positive moral light. Frank (2013) also identified the quest narrative which features an ill person who is not necessarily cured but achieves social, moral or spiritual growth as a result of their poor health. In Chapter Two, I will critically discuss Frank's narratives tropes and identify the potential limitations

and ethical issues in their framing of illness experience. Then, in subsequent chapters, this critique will be further developed in relation to the self-storying of, and poems by, the research participants.

Where, then, are accounts of chronic illness which do not rely on narrative resolution or personal transcendence? There is an increasing body of poetry which explores the complex and uncertain aspects of chronically ill or disabled life (Huntington, 2003; Waller, 2010; Alland, Khairani and Sluman, 2017; Ormsby, 2017; Gill, 2017, 2020). Qualitative research embraces texts and knowledge which are messy and uncertain (Tamas, 2008), and poetry is increasingly popular for presenting such messy uncertainty in research. However, from my reading, in the social sciences, poems written directly by participants are rarely solicited in order to provide deeper or different knowledge of chronically ill life. Rather the creation of research poetry is generally reserved for academics, thus potentially reinforcing the authority of researchers over the researched.

### 1.3 Aims

This research was designed to explore how writing poetry may help individuals with MS to explore their experiences of living with the condition, and to find new ways of communicating these illness experiences to others. The study focuses on the following research questions:

- 1. What is the experience of living with MS as expressed through poetry and spoken utterances?**
- 2. How may writing poetry serve to affect or enhance the communication of PwMS with others?**

I aimed to investigate the experiences of people living with different forms of MS and in different stages of the illness. My approach has been exploratory, reflecting the novel methodology of the research and the wide-ranging themes available to participants when writing and conversing in the study.

Data creation featured both 1:1 semi-structured interviews and poetry writing workshops for small groups. In interviews, participants had opportunities to tell me about the history of their MS experience, as well as reflecting on how MS impacts their lives now, and how they communicate their illness to others. This holistic approach helped me to gain a sense of the social and biographical contexts of participants' MS experiences. Additionally, it gave me an insight into how participants understood and constructed their interpersonal relationships in light of MS. Participants also attended four group poetry writing workshops. The themes of 'MS as metaphor', 'MS and the body', 'MS and other people', and 'Dreams' were intended to be broad and create opportunities for participants to write about topics which reflected discussions in their initial interviews. I chose this method of data creation in order to increase participants' authority over the written form of their data and problematize existing power structures in the researcher-participant relationship. Follow up interviews were conducted with participants in order to reflect on their experiences of writing the poems, being in the workshops, and sharing their poetry.

A supplementary arm of the study aimed to address additional questions regarding participants' sharing of study poems with close contacts. A small number of these close contacts were recruited into the study and interviewed in order to address the following research questions:

- 3. Might the poems provide additional insights into a family member or care recipient's life with MS for the readers?**
- 4. Might the poem sharing experience have any impacts on conversations about MS between PwMS and their close contacts?**

For both arms of the study, my sense-making of participant data has been rooted in dialogic analysis as this method has allowed me to engage deeply and holistically with both spoken and written contributions (Bakhtin, 1981, 1984, 1986). Thus, I am able to show that MS is lived in ways which are both deeply embodied and socially situated for the study participants.

While it is increasingly common in the social sciences for researchers to create poems from participants' spoken data, the use of group workshops in which participants write their own poems about the lived experience of MS is a novel approach. The study data indicate that writing and reading poems can offer participants a pleasurable and emotionally safe way of exploring potentially distressing themes. This approach may be applicable to research about other health conditions. Because of this study's novelty, I have been able to make a methodological contribution to the fields of medical and health humanities and the sociology of health and illness.

#### 1.4 Note on language and terminology

##### **Person with MS / People with MS (PwMS)**

This term is used to indicate all or any forms of MS (PPMS, RRMS, SPMS). I have elected to use 'Person with MS' in this thesis rather than 'MSer', a term used by some in MS communities as a way to describe oneself as having MS. I sense that 'MSer' may carry connotations of positivity that not all PwMS experience in relation to the condition. I am also unpersuaded by the active implications of '-er'; someone could be a runner because they run, or a writer because they write. However, having MS is neither an action nor a choice. PwMS seems to me to be a more neutral term. I only use the term 'MS patient' when discussing PwMS in medical contexts.

##### **Illness / disease / condition**

Generally I use 'illness' when talking about MS and only use 'disease' when discussing medical specifics or quoting others. This denotes a distinction between illness as experienced by the sick person – the main focus of this research – and disease, which is medically defined (Leder, 2016). I occasionally use the term 'condition' to avoid repetitious writing.

##### **Sufferer / suffering**

I choose not to use 'suffer' in relation to illness and disability as it implies constant pain, discomfort or hopelessness and suggests that the 'sufferer' should be pitied. This may be

partially or entirely inaccurate and may not reflect the way in which the PwMS constructs their private or social identities. However, I do use 'sufferer' or 'suffering' in relation to MS when I am directly quoting a participant and respect their word choices as representative of their personal or social worlds.

### **Core participant**

'Core participant' refers to the PwMS who were recruited into the study to engage in interviews and poetry writing workshops with me. Most of the data and discussions in this thesis relate to core participants.

### **Reader participant**

'Reader participants', who were family or a carer of a core participant, were recruited into the study to provide their perspectives, through interviews with me, about the experience of reading a core participant's poems. Discussion and data about reader participants is mostly found in Chapter Eight.

### **Participant**

Generally, for ease of reference and when it is clear that they are the cohort that is being written about, I refer to core participants simply as 'participants'. When I am evidently discussing core and reader participants in the same instance e.g. general statements about recruitment or ethics I occasionally refer to both cohorts together as 'participants' or 'all participants'.

### **Discourse**

Health discourses and personal discourses are entangled; through dialogue, we construct, deconstruct and reconstruct our social worlds and experiences according to these evolving conversations. Within this thesis, I discuss discourses that contribute both to local, personal meaning (e.g. a participant's life experience) and theoretical discourses around chronic illness and disability.

## **Lockdown**

This research was devised and the data creation phase happened in 2020-21, when, at times, people in the UK were subject to 'lockdown' as part of the nation's response to COVID-19. During periods of lockdown, people were ordered to stay at home and, if the government did not deem it essential that they work outside of the home, could only go out in order to purchase food, seek medical treatment or briefly for physical exercise. Meeting up with people from other households was forbidden at this time. While not an official term, lockdown was commonly used by the press and in general conversation as shorthand for these restrictions.

## **Shielding**

In 2020-21, people who were considered to be extremely clinically vulnerable to death or serious illness with COVID-19 were advised to 'shield', which meant staying at home entirely, not leaving the house for essential shopping or exercise, and not mixing with other people. This cohort were encouraged to continue to stay at home and shield from others when the rules on movement and socialising were initially relaxed. Some PwMS were advised, or elected, to shield.

## **1.5 Thesis Overview**

In this chapter, I have given a basic overview of MS epidemiology and identified common patterns of the illness. Then I established the background to the research in terms of my close relation to the subject matter, the use of illness narratives, and the role of poetry in the social sciences. I went on to provide an overview of the research aims and ways in which this study makes epistemological and methodological contributions to the fields of medical and health humanities and the sociology of health and illness. I have also clarified certain key linguistic choices that I make throughout this thesis.

Chapter Two develops themes introduced in this chapter through a critical discussion of the relevant literature. I explore narrative representations of illness, with particular attention to the dominant tropes identified by Frank (2013) and their limitations. I consider how these narratives are rooted in the medical and social models of disability, arguing that both these

models and narrative tropes are inadequate for people experiencing chronic disabling illness. I go on to discuss the phenomenology of illness and consider the significance of socially located embodiment in illness writing. Then I explore poetry as a form for expressions of disability and illness, showing how poems, which may be deeply embodied and socially situated, can be exempt from the expectations of plot resolution common to illness narratives. I also consider existing uses of poetry in the social sciences and question the way in which researchers retain authorship, authority and control over participants' words when composing poems from interview data. The chapter concludes that there is scope to explore whether poems written by people with chronic illness, including MS, may produce novel forms of knowledge within the sociology of health and illness or medical and health humanities, while also problematizing power relations between researchers and researched groups.

Following on from these critical evaluations, Chapter Three presents the ontological and epistemological foundations for this research; my broadly socio-constructionist position is that every person constructs shifting identities in relation to those around them (Riessman, 2008). I discuss my reasons for developing a Bakhtinian (1981, 1984, 1986) dialogical approach to analysis, which, because it is rooted in the concept of unfinalizability, accords with the above ontology. Then, I discuss my own close location to the subject and the multiple ways that my status as a PwMS, a poet and a researcher have shaped the study and necessitated a deeply reflexive approach to the work and the study relationships. I also relate the ways in which I attempted to support ethical participation in the research, encouraging exploration of MS experiences in ways that tried not to cause distress.

Chapter Four describes the research design and the rationale underpinning my choices. I address the ways in which the study design was impacted by the emergence of COVID-19 and the subsequent change from in-person to online research. I discuss recruitment and introduce the sample with brief biographical summaries of each participant. I critically and reflexively examine the methods of data creation in the study, focusing first on participant interviews and then on the poetry workshops. The chapter also discusses the ways I tried to reduce the power imbalance of the researcher-participant relationship. Building from this, I reflect on my writing practice throughout the study and how writing has made my multiple

study selves visible in the research. Next, I reflect on transcription and the ways in which, at times, I found it to be an invaluable, if emotionally challenging, component of initial analysis. I then discuss in detail my chosen method of discourse analysis with reference to Bakhtin (1981, 1986) and Gee (2014).

After a holistic analysis of interviews, workshop utterances and poem data, I identified three key themes that ran through participants' data: the MS body; MS and occupation; MS and the social world. Chapters Five, Six and Seven explore each of those themes in turn.

In Chapter Five, I use a phenomenological lens to explore how participants spoke and wrote about their bodies, analysing their poems and our conversations about experiential embodiment. Participants were alert to their MS bodies both as locations of subjective, felt experience and as objects of an exterior, medical gaze. Some participants articulated the dissonance this caused them. I consider participants' representations of medical encounters and discuss poems in which participants variously construct themselves as 'good patients' (Sointu, 2016, n.p.) or present themselves in difficult relationships with practitioners. This chapter also discusses an instance of a participant sharing a poem with her occupational therapist which resulted in a new approach to managing one symptom of her illness.

In Chapter Six, thinking through Frayne (2019) and current sociology on work and occupation, I explore how participants' identities and wellbeing are impacted by their experiences of working with, or retiring because of, MS. Workplace experiences and attitudes are examined in the context of the dominant world view which frames work as something which everyone is morally obliged to undertake even, if possible, when ill. I also consider positive and negative utterances, presented in the interview and poem data of participants who are no longer working. There is a particular focus on various losses: financial security; recognisable position; and domestic or caring roles. The chapter also explores the experiences of participants who experienced great distress when made to take early retirement because of their health status. In addition, I highlight examples of participants finding creative outlets post-work as a positive use of their free time, and critically reflect on the study workshops as opportunities for creative occupation and relationship building for participants.

Chapter Seven explores the barriers that MS creates for participants in their public, social and family lives. Building on my work in Chapter Five, I deepen my analysis of participant data through a phenomenological lens, considering the experience of being an MS body in the social world. The chapter situates the discriminatory behaviour of others in the current UK socio-political climate of austerity. I also consider the difficulties illness and disability create in participants' close relationships, with particular attention to mother–daughter relationships in which the daughter is a middle-aged woman with MS. In light of these obstacles and changing relationships, the chapter discusses how participants construct their social and familial selves, and explores the strategies, including humour and silence, which participants use to manage their interactions with 'healthy'<sup>2</sup> people. Throughout the chapter I reflect on participants' reduced social capital as a result of having MS, although I conclude by highlighting the positive relationships and more balanced communication that occurred between participants within workshops when sharing similar experiences.

In Chapter Eight, I present and discuss data from a supplementary wing of the research in which core participants shared their poems written in the study with close contacts of their choosing, four of whom went on to become reader participants in the research. First, I discuss core participants' decisions about whom to show their poems. Then, building on the work of Chapter Seven, I examine the identities core and reader participants constructed for themselves in relation to each other and in the context of MS. This includes a discussion about the complexity of a professional carer's role who was an employee of the core participant but had a close, family-like relationship with him. The chapter considers routes reader participants took in order to engage with and understand the poems, such as recognition of similar experience; knowledge of people and places in the poems; or asking the core participant for clarification of meaning. I then consider the outcomes identified by core and reader participants. Several participants said that the poems were safe ways to access emotionally difficult themes. The skill involved in writing the poems was also remarked on by reader participants who were proud of their family member or employer. As with my findings in Chapter Six, I suggest that writing poems has been a meaningful

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<sup>2</sup> 'healthy' here meaning not having MS or significant disability.

experience for core participants who derived validation from their writing. Then I reflect on the limitations of this arm of the study, discussing ways in which it skews towards positive data.

In Chapter Nine, I provide a final discussion of the theoretical and methodological issues raised by the Poetry and Multiple Sclerosis (PaMS) study. I begin with my reflections on the impact of the COVID-19 pandemic on the research, firstly in terms of recruitment, but also the nuanced emotional effects of the pandemic on a cohort of participants and researcher who had been identified by the government as 'vulnerable'. I discuss my ethical positioning in the study and reflect on my developing understanding of co-creation and authorship. I consider the mixed results of my attempts to decentre the role of the researcher, before critically reviewing my use of poetry as a method of data creation and my process of data analysis. I also reflect on limitations which arose with the sample and the complexities of my researcher positioning. Then I collate key themes from my findings. I suggest that the research has produced useful insights, through poetry and spoken utterances, about several aspects of life with MS: somatic and medical experiences; being, or no longer being, at work with MS; and living with MS in the social and familial world. Further, I identify the ways in which power structures affect all of these life worlds for PwMS and also reflect on the strategies (compliance, silence, performativity and humour) that participants employed when confronted with changes to previous relationship dynamics. The thesis concludes with a discussion of the implications of findings for those working with PwMS and with suggestions for future research.

## Chapter Two

### Literature Review

‘Language transcends us and yet we speak.’

*(Merleau-Ponty, 2002, 456)*

#### 2.1 Introduction

This literature review has two aims. Firstly, I will critically discuss narrative and phenomenological presentations of illness, illustrating limitations of dominant narrative tropes, and considering the importance of embodiment in constructions of illness. Then I will explore whether poetry might be a suitable form in which PwMS could (re)present their experiences of living with the condition.

In 2.2, I begin with a brief review of medical narratives before discussing Frank’s (2013) illness narrative tropes in detail. I will show that although these narratives largely rely on individualistic models of illness, in reality the personal experience of ill health is situated in the social world. I will further illustrate the limitations of illness narratives by showing how their arcs and thematic preoccupations are variously embedded in the medical and social models of disability. Accordingly, these first-person narratives act to reinforce stereotypes of overcoming illness, either through cure, which is not currently available to PwMS, or through moral imperatives towards personal or spiritual growth. I will then go on to question whether narrative is necessarily always the most suitable form of illness writing for PwMS or other chronic conditions, fundamentally dependent as the majority of illness narratives are on plot resolution.

The phenomenology of illness will be explored in 2.3, and I will highlight phenomenological illness writing’s deep embodiment in relation to calls for greater attention to somatic experience in critical disability studies (Hughes and Paterson, 1997; Siebers, 2008).

Phenomenology explicitly considers the social element of embodiment and troubles collective assumptions about what it is to be ill. Through a consideration of the work of Carel (2016, 2018) and Leder (1990, 2016) I will highlight how illness can disrupt lived personal narrative in the following ways: alienation from one's own body; temporal dislocation; spatial and social estrangement. I will argue that these shifts in an ill person's relation to the world are important destabilising components of illness and may resist exploration in traditional narrative forms.

Section 2.4 will consider the use of poetry as a medium for first-person expressions of living with chronic illness. I will highlight that poems may be deeply embodied and express the ill poet's interior experiences. This discussion will observe that poetry is not expected to follow the conventional tropes of illness narrative and may be an entirely non-narrative form. Through reference to examples, I will illustrate how illness poems can also be used in socio-politically charged conversations between ill and disabled people as a way of fostering community through shared experience.

The chapter will highlight the ways in which poetry is used in the social sciences to increase researcher reflexivity and encourage empathetic responses to participant data. I will show that, although the actual words of research poems are often quoted from participant interview data, most poetry in published research is composed by the researcher, who thus exerts authorship and authority over the participants' expressions. I will argue that poems written by PwMS or other chronic illnesses may be a valuable addition to the fields of medical and health humanities and the sociology of health and illness. Furthermore, I will conclude that participant-written poetry in research may act to problematize power dynamics between researcher and participant, offering new ethical possibilities and understandings in social science research.

### 2.1.1 Methodology: finding and being with the literature

I have identified relevant critical literature for this review through an ongoing and iterative process and am grateful for reading suggestions from my supervisors, other researchers at

the University of Edinburgh (UoE), and also to delegates and presenters at conferences I have attended. My relationship with the literature of MS, chronic illness and disability, particularly the grey literature of news media, charity websites and social media by PwMS, has been a long one, in some cases going back to 2003 when I was first diagnosed. I have continued to monitor these types of text with an increasingly reflexive and critical eye. Although grey literature is not usually written with an explicit focus on narrative or disability theory, I use it to provide occasional examples, in this and subsequent chapters, of non-academic or 'lay' attitudes towards, and expressions of, MS or disability. I am aware of my location in the texts I read as well as the texts I write. As befits a chapter which will include discussion of phenomenology, I am very conscious that my reading, understanding and subsequent telling can only ever be from my unique 'zero-point of observation' (Husserl, 1952, II, 18). Accordingly, my exploration of the literature is critical and incorporates my positioning as a PwMS.

### 2.1.2 Chronic illness as disability: situating the research

PwMS and other chronic illnesses live in a diverse social world in which the attitudes of others may (unconsciously) correspond with, or do not interrogate, stereotypes of disability. Therefore, before discussing narratives, I briefly present the dominant models of disability which provide a backdrop to the social context of illness narratives.

The medical model of disability, which is very similar to the 'individual model' described by Oliver (1996, 34), 'defines disability as an individual defect lodged in the person' (Siebers, 2008, 4) and holds that atypical minds and bodies should be understood in medical terms and treated accordingly (Kafer, 2013; Linton, 1998; Siebers, 2008). This model negates or substantially reduces any requirement to consider the impact of social processes and frameworks on disabled people (Linton, 1998). Widely criticised in disability studies, the medical model is not understood to be one coherent theory, but rather it is seen as a 'discursive construct' (Hogan, 2019, 246) which represents a related set of culturally dominant assumptions about disability.

Oliver (1983) advanced the social model of disability which holds that financial inequality, poor educational provision and other barriers, including built environments, government policies and institutional practices, all contribute to the disablement of people with impairments, thus creating oppression and discrimination. According to the social model, disability should no longer be positioned as a medical problem (Barnes, 1991). Hughes and Paterson (1997, 326) observe that '[t]he social model of disability proposes an untenable separation between body and culture, impairment and disability...conced[ing] the body to medicine and understand[ing] impairment in terms of medical discourse.' They argue that the social model must evolve to include representations of embodied, experiential impairment which is socially and historically situated.

My research broadly aligns with a 'political/relational model of disability' such as proposed by Kafer (2013, 6). This relatively recent model includes social disablement as an important factor of disability but also accommodates embodied experiences including pain, fatigue and depression. Building on the work of Price and Shildrick (1998), Kafer (2013, 7) seeks to acknowledge unstable disabled identities and 'pluralize the ways we understand bodily instability'. The political/relational model does not reject medical interventions but recognizes that they are subject to ideological and political biases and as such should be consciously interrogated.

## 2.2 Illness Narratives

### 2.2.1 Medical narratives

Illness narratives have been much discussed since the final decades of the twentieth century, although a lot of this work has attended to the use and relevance of the sick person's narrative as a way of enhancing medical care (Kleinman, 1988; Mattingly, 2004; Charon, 2006; Hurwitz, Cushing and Chisnall, 2012). It has also been understood as a way of '(re)humanizing medicine' (Woods, 2014, 113) following rapid technological advances in biomedicine earlier in the twentieth century. Charon (2006) developed the concept of

narrative medicine which seeks to use patient narratives in order to increase empathy in clinicians and also improve student and clinician skills in taking patient histories (Charon, 2006). There are evident benefits for ill people in being listened to more skilfully by clinicians and in humans treating one another as more, well, human. Narratives of this type include an awareness of the patient's existence beyond the clinic; their work, family life and economic circumstances may all be taken into consideration (Kleinman, 1988; Charon, 2006; Hurwitz, Cushing and Chisnall, 2012). As described by Woods (2014), illness narratives provide further benefits for the ill person: voicing their own first-person narrative of subjective experience provides validation for the ill person and is an acknowledgement that there are plural ways of knowing illness.

However the medical location of these narratives necessarily constructs the ill person as a patient in relationship with a doctor. Thus the medics authoring such illness narratives assume the role of expert. And of course, this is to be expected; we want our clinicians to be expert and to have the requisite knowledge to diagnose, treat and offer prognoses for our illnesses. Yet the dynamics of these relationships are complicated and uneven; knowledge is not identical to power, and yet they are inextricably bound together (Foucault, 2003). Reflecting on my own experiences as an MS patient in conversations with my neurologist, the balance of knowledge and power is firmly weighted in her favour; she is fluent, not just in the medical terminology of MS, but in decoding data from my brain scans which to me are just unintelligible images. I have a niggling concern that patient narratives, recorded and edited by clinicians, are vectored by clinical priorities and ultimately translated into something other than the story of the ill person. Is there perhaps a danger that the ill person can recede into a supporting role in a story about a patient's disease and treatment while doctors become the heroes?<sup>3</sup>

There is a close and longstanding relationship between the medical establishment and charity, especially when serious chronic diseases are deemed to be (currently) incurable. It is

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<sup>3</sup> I am reminded of the television drama *House* (Attanasio et al, 2004-12) in which every episode featured a patient with a baffling and often grotesque set of symptoms. The programme's central focus was not on the patients as rounded people but rather on the brilliant medical puzzle solving of Dr House as he fought against the clock to find a correct diagnosis.

helpful, I suggest, to examine charity medical narratives in the context of the medical model of disability which conveniently absolves the state of responsibility for addressing barriers to the disabled person. Simply put, the relationship between charity and medical funding creates a loop of pitied ill and/or disabled person; medical researchers / doctors; and generous individuals who can support the medical heroes by financially contributing to their work.

When I was diagnosed twenty-one years ago, an advert for an MS charity was displayed in the London Underground. It showed a woman who had fallen on a train station platform. I no longer remember the advert's exact text, but the woman was living a regular, apparently healthy, life until she was suddenly and literally struck down by MS. I am sure after this explainer the advert requested donations to help fund research into a cure. I vividly remember the overwhelming panic this advert caused me as I tried to go about my day, while trying to adapt to the uncertainties of my diagnosis. Would I fall over and become the woman on the ground, her old life gone forever? I think the narrative implied she would never walk again, although that may have been my anxiety extending the poster's scenario. Even now from a position of more knowledge and less panic, the memory of that poster makes me feel a little sick and dizzy.

Yet, of course, the poster was not aimed at me; it was *about* (people like) me and spoke to the 'normal' healthy majority. Derived from the medical model of disability, the poster highlighted the individual tragedy that had befallen one woman, whose only hope was an as yet undiscovered cure. The poster represented an incomplete medical narrative – albeit one in which the ill person's voice does not feature – that could only be successfully resolved by the individual generosity of strangers. In order to achieve this aim, the poster, like the charity it promoted, was 'organized around the twin notions that disability is tragic and disabled people pitiful' (Clare, 2017, 8). On close analysis, although she was the intended focus of the viewer's pity, the woman lying on the station platform was not actually the focus of any charitable action; it takes years for new treatments to be theorized, developed, trialled and eventually become available to doctors and their patients. Rather, the advertisement abandoned her to an interminable present which, it strongly implied, was defined by pain and suffering. Meanwhile viewers of the advert were encouraged to look to

a distant future, thus placing greater value on a potential cure than the actual disease impact (Clare, 2017). (I will return to issues of temporality in illness presentation when discussing phenomenological approaches in 2.3.2.)

I note that MS charities' communications now avoid constructing PwMS as objects of pity. The MS Society's brand statement explicitly says that they follow the social model of disability, and they take an increasing role in campaigning as well as providing support. Their primary function remains funding research into treatment and cures because as their 'rallying cry' says 'Together we can stop MS' (MS Society, 2021, 32).

Similarly to charities' re-conceptualisation of disabling illness as socially situated, the advent of social media and the subsequent widespread online sharing of information and first-person illness experiences, has, for some, democratised the medical narrative. Activist patients are increasingly visible online and in communication with one another, expressing their (dis)satisfaction with existing medical treatment and lobbying for change in medical research and funding. This trend towards louder and more visible patient voices suggests that the medical illness narrative is evolving and that healthcare professionals should also expand 'their understanding of what "experiential-evidence" is deemed significant to patients' (Mazanderani, O'Neill and Powell, 2013, 421).

### *2.2.2 Frank and The Wounded Storyteller*

Frank (2013) attempts to locate the ill person at the centre of their illness experiences. *The Wounded Storyteller* has been understood as 'a purposeful and explicit *marginalization of the physician*' (Stoddard Holmes, 2015, 11). Rather than perceiving these first-person narratives as additional information for clinicians, Frank understands them to be 'the medium through which ill persons actively assume responsibility for constituting the personal meaning of illness' (Toombs, 1997, n.p.). Unlike Charon, Hurwitz and Klein, he is not a medical doctor and positions himself alongside his textual examples as a similarly wounded storyteller. Frank identifies three pre-existing narrative arcs through which people

explore, share and take ownership of their illness. I discuss these critically below and situate them in the context of the relevant models of disability.

### 2.2.2.1 Restitution narratives

An easily recognisable arc is the restitution story wherein a healthy person becomes sick, has treatment, and returns to a state of health. The ill person engages in battle against their bodily misfortune and usually becomes a passive protagonist in their own story, aided in their return to health by the actively heroic medical establishment. The restitution narrative aligns with the medical model of disability, locating the ill person's story as individual misfortune rather than it being partially predicated on wider societal barriers. Assumptions are made in these narratives about access to healthcare; as Frank (2013, 86) states, restitution is 'commodified'. Furthermore, the restitution narrative is fundamentally contingent on the possibility of cure and recovery, which is not possible for all and is certainly not possible for all time. In order for this type of narrative to succeed, its players and readers need to collude in denying, or 'outdistanc[ing] mortality' (Frank, 2013, 115).

Clare (2017) critiques a documentary, *Christopher Reeve: Hope in Action* (Reeve, 2007), about *Superman* actor Christopher Reeve, who became quadriplegic after a horse-riding accident. The documentary follows Reeve through rehab activities and experimental surgery, with Reeve saying he believes that he will be cured of his disability. The narrator repeatedly uses the words *overcome, fight, determination, inspirational, unwavering will, working tirelessly, amazing results* in what Clare (2017, 10) describes as 'another over-the-top story about a tragically disabled man who beats the odds, overcomes his paralysis, and through his courageous struggle gives us hope and inspiration'. Both the language of the documentary, and the framing of Reeve's experiences as a would-be restitution narrative, attempt to locate him as a brave individual who will be able to achieve cure through hard work and determination. I do not intend to deride Reeve's outlook and aims; every disabled person is entitled to their beliefs and to frame their story in whichever way feels right for them. If the macho and occasionally militaristic language (*fight, overcome, unwavering, tirelessly*) work for Reeve, well, it is his story and he was Superman after all. However, ultimately the language and narrative of the documentary reveal the 'wealth, whiteness and male privilege' (Clare, 2017, 11) that enabled Reeve to have extensive personal care,

rehabilitation, experimental surgery and a large medical team. Most quadriplegics have a very different experience (Murphy, 1987).

Narratives like this are popular and frequently understood as inspirational, yet they reinforce normative views which exclude and other those experiencing incurable or terminal illness. For an ill person who is not able to *fight* their illness or *beat* their physical limitations, the restitution story carries a strongly implied message that they are being beaten, losing, or just not fighting hard enough (Clare, 2017).

### 2.2.2.2 Quest narratives

Frank favours the quest narrative, which incorporates the existential crises that may be encountered during illness and can tell stories in which a return to health is not possible. While this form can relate more diverse experiences than a restitution narrative, it requires that the author find resolution through the course of their story. There is an expectation that the quest narrative's author will learn through their suffering and achieve positive, transformative, psycho-spiritual outcomes. Woods (2014, 121) identifies the 'strongly Christian connotations' of the quest narrative and notes that Frank considers it 'positively virtuous' to achieve personal growth through illness.

I am reminded of Holstein and Gubrium's (2000) analysis of the Alcoholics Anonymous (AA) sobriety programme. Although not aligned with any one religion, AA bears traces of its Christian precursor; its Twelve Steps programme is embedded in a search for meaning and personal growth in addition to supporting members to achieve and maintain sobriety. Writing about self-presentational stories created by individuals participating in the programme, Holstein and Gubrium (2000, 182) contend that '[t]he discourse of AA virtually "speaks" the selves interpretively constituted under AA auspices, providing the resources and directions for narrating their lives.' Members must (re)formulate their stories and experiences verbally in the AA model and adopt a conventionalized self-presentational style. Of course, people writing illness narratives have greater freedom and diversity than Twelve Steps participants in terms of structure, format and moral register. However, in a genre that has been created from, and colonized by, texts written in restitution or quest models, I feel there is still an overarching expectation that future illness self-stories will tell similar

journeys, framed in the ways which society has been conditioned to expect. To quote Holstein and Gubrium (2000, 187) in relation to AA narratives, I suggest there is a risk for authors of other illness narratives that '[t]he self is thus deprivatized, embodying an identity made apparent through the complex, socially conditioned work of putting a discourse into practice.'

The moral imperative of the quest narrative sits uncomfortably with me as a feminist and as a PwMS. I am concerned that if my health deteriorates further, then I may feel an expectation to be passive, serene and wise. I find myself thinking of Helen Burns in *Jane Eyre* (Bronte, 2006) and Beth March in *Little Women* (Alcott, 2008), dying piously, uncomplainingly and prematurely, ultimately existing as lessons in goodness for more active and healthy heroines. However, other versions of the quest narrative are emerging. In a short film (Shimano, 2023) shared on social media and his blog, Andy McKenna discusses his perceptions as a PwMS with Jonny White, another PwMS and Medical Advisor for the charity Overcoming MS. A keen mountain biker, McKenna says, '[what] I constantly get asked is, "Do you know, if you could turn back time and go back to time before MS would you?" And I would say hand on heart that I would only go back there if I could take the person that I am now and what I know about life' (Shimano, 2023). He goes on to say, 'MS can be a real bugger of a disease but I think for all of us it seems to have given us much more than it's taken away' (Shimano, 2023). He and White discuss healthy lifestyle choices they have made as a result of MS and new friends they have gained through the MS community as examples of what the illness has given them.

The word 'overcome' is very present in the film, largely because both men speak at length about how they follow the Overcoming MS (2024) lifestyle programme. Yet on this occasion, it is not being used to indicate or strive for cure in the ways discussed above. Here cure would seem to be postponed or replaced by the desire to 'overcome' by living as full and healthy a life as possible with MS, and deriving meaning and personal growth through the illness. Again, I do not intend any criticism of how these individuals are choosing to adapt to life as PwMS, and I fervently agree that each person has the right to own and present their illness identity and narrative whichever way they choose. However, the notion of overcoming sits uncomfortably with me, and for some disabled people, McKenna's self-presentation may be reminiscent of 'the inspiration-porn, "overcoming" of disability that

clutters the mainstream narrative' (Palmer, 2017, 109)<sup>44</sup>. As with the film about Christopher Reeve, I note that White and McKenna are both white men who would appear to be socio-economically comfortable. (White works as a doctor and McKenna runs a mountain bike guiding business). Additionally, although MS clearly impacts on their lives – White's wife speaks of his fatigue in the film and McKenna walks with a cane – both men are mobile, in early middle age and clearly very fit. I wonder if this more active version of the quest narrative relies to some extent on their circumstances.

### 2.2.2.3 Chaos narratives

Frank (2013, 97) identifies a third trope which he calls the 'chaos narrative'. These are deeply embodied, fragmented expressions of pain and suffering, yet, for Frank, the chaotic body is inarticulate and trapped in the present with no capacity to reflect. Frank (2013, 97) describes them as 'chaotic in their absence of narrative order', however, I would suggest that these are radical texts which do not conform to narrative requirements and cannot be easily aligned with either the medical or social models of disability. Such decontextualised presentations of suffering have the potential to unsettle a reader who desires narrative, and real-world, resolution. Frank (2013, 111) petitions for 'enhanced tolerance of chaos as part of a life story' in both clinical settings and more generally in interpersonal relations. Yet this is framed within the context of longer, quest or restitution narratives in which chaotic elements are eventually resolved. According to Frank's definition, ultimately the chaos narrative as a separate text does not meet the criteria of a narrative because 'the teller is not understood as telling a "proper" story' (Frank, 2013, 97). This statement by Frank acts as a gateway to three critical questions about *The Wounded Storyteller* which I will discuss below with reference to the literature.

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<sup>44</sup> 'Inspiration porn' (Ellis and Kent, 2016) is a term coined by Stella Young which describes presentations of disability that objectify the disabled person as inspirational to able-bodied people solely on the basis of their life circumstances.

### 2.2.3 Who is the 'teller'?

The wounded storytellers whom Frank (2013, 97) considers to be tellers of 'a "proper" story' are evidently those who have achieved personal growth and learning through their experience of ill health. For Frank, 'the moral imperative of the narrative is "perpetual self-reflection on the sort of person that one's story is shaping one into, entailing the requirement to change that self-story if the wrong self is being shaped"' (p.158)' (Toombs, 1997, n.p.).

Frank (2013, 8) defines these tellers as 'members of the remission society', a role he also claims for himself as someone who has survived cancer. Frank's remission society is heavily populated by all people with chronic illnesses as well as the disabled and the families of all sick and disabled people. Yet as Woods (2014, 119) asks, 'Are all wounds fundamentally alike?' Frank's definition conflates a wide range of people who may be materially, physically, mentally and socio-economically in very different circumstances. To suggest, as Frank does, that these differences are minimised by personal growth through narrative is potentially to ignore or erase key components of the ill person's experiences, an act which is 'politically and sociologically suspect' (Woods, 2014, 120). Not all disabled people consider themselves to be ill or recovered from illness or injury; Deaf culture is one example of this (Shakespeare, 2014). Furthermore, Frank's remission society excludes people diagnosed with a mental illness (Woods, 2014). In the afterword to the second edition of *The Wounded Storyteller*, Frank does not make space for psychiatric survivors, although he does include discussion of collaborative narratives that can be co-constructed with individuals living with dementia or brain injury (Hydén, 2011; Hydén and Antelius, 2011; Frank, 2013).

Drawing a distinction with medical narratives which objectify the body, Frank (2013, 140) emphasises the centrality of embodiment to illness narratives; 'illness stories are not only *about* the body but *of* and through the body'. However, embodiment does not exist in a vacuum, but is enacted and experienced in society (Mason and Boero, 2021). I would suggest that Frank's elision of diverse illnesses and circumstances under the umbrella of the 'remission society' potentially risks devaluing the socially embodied element of some tellers' experience.

#### 2.2.4 Who is hearing the story?

Which audience a narrative is intended for is an important consideration, as is the question of who actually hears or reads it. (Of course, these are not necessarily the same people.) Various potential audiences are possible for an illness narrative, including family, friends, work colleagues, medical teams and other sick people. Each of these audiences may gravitate towards, or respond to, different versions of the same story depending on their relation to the ill person or their illness. Some texts, such as diary entries, may be written solely for the eyes of their author, even if they are later made public. I will return to the theme of intended audiences when discussing participant decisions about sharing their poems with others in Chapter Eight.

Just as the experience of storytelling is intended to be transformative for the teller, Frank imbues illness stories with possibilities of self-growth for the listener; they too can potentially be healed by the story. Although for Frank (2013, 25), listening to illness stories is 'one of our most difficult duties as human beings', he describes it as a 'fundamental moral act'. Thus the listener of these narratives, as well as the teller, is assumed, in Frank's idealized depiction, to be someone who understands their role and relationship to the ill person to be ethically enacted in accordance with this shared aspiration to personal growth and learning. Frank focuses on the ability of the quest narrative to empower its author (Frank, 2013, Woods, 2014), however the question of power dynamics between the storyteller and listener is absent from his discussion. Similarly, although Frank does acknowledge that it can be extremely difficult to listen to illness narratives, he does not address the fact that not every intended listener is necessarily willing to hear the story. This raises questions about the ethics of encouraging people to share their stories without supporting them to manage their expectations of how the process may unfold. In Chapter Eight, I discuss an incident in the research where a participant's intended reader refused to engage with her poems.

### 2.2.5 What is a “proper” story?

As discussed above, for Frank a ‘proper’ story is clearly a morally instructive one. However, it also fulfils certain narrative criteria; it should show temporal coherence and tell, through the ill body, its journey of self-growth through suffering to a point of clarity and resolution. Put simply, there should be a plot with a beginning (*I was healthy*), a middle (*I became ill*) and an ending (*I found out something important about myself / changed for the better*). The idea of constructing selves through narrative and temporal location is popular within medical humanities; Mattingly (2004, 74) writes, ‘Most fundamentally, narrative gives us a form through which to apprehend the world, whether or not we put it into words. It places temporality at the centre of meaning’. Yet ‘some moments are “more narrative” than others’ (Mattingly 2004, 75). Both medical healing narratives and Frank’s quest narrative hinge on the ‘more narrative’ moments when the ‘healing dramas’ or impetus to self-growth occur (Mattingly, 2004, 75). However, for many, myself included, core experiences of chronic illness such as fatigue and bed rest are less dramatic. They are quotidian and dull. They may even be monotonous and wordlessly stupefying, but their dullness does not make these experiences unimportant. Furthermore, some illness events and experiences may resist sense-making even when the ill person attempts to articulate them. How might these aspects of illness be incorporated into self-storying on their own terms and for their own sake without a forced need for resolution?

There are questions over whether there has been too much emphasis on the importance of narrative (Strawson, 2004; Woods, 2014). Some have noted that the favouring of quest-type illness narratives has occurred in the context of modern biomedicine which has arguably given less space and credence to patients’ subjective and experiential expressions of illness (Woods, 2014; Leder, 2016). Might it be that the biomedical imperative to find answers through diagnosis or cure has been replicated in the medical humanities with an analogous desire for neat resolution and personal growth through teleological narrative? Furthermore, people with chronic illnesses may undergo multiple medical appointments with numerous doctors, each of whom may ask the individual to summarise their illness experience and treatment to date. In telling their illness narratives, might some people fall into the familiar, fact-seeking, chronological narrative of the case history, and thus unconsciously ignore or

devalue other important components? I consider an instance of this in Chapter Five when I discuss the ways in which a participant recounted their experience of MS diagnosis to me.

Alternative ways of exploring and knowing the ill self proliferate and some eschew, not just narrative, but speech altogether. Some argue for the recognition of silence and call to counter the noisy chatter of narrative with the wordlessness of other ways of being and (not) knowing (Maitland, 2008; Woods, 2014). For example, life with MS has variously been presented in photography by Hannah Laycock (Bolaki, 2017) and painting in Lindsay Holcomb's #ColorsofMS project (Miller, 2022). These are fascinating illuminations of experience, however, for the majority of people, putting experiences into words is an inevitable, if necessarily incomplete, mode of expression. Discussing qualitative research data, Mazzei and Jackson (2012, 747) call for attention to the ways in which 'participants give voice, not in ways that are deemed absent as silent, but in ways that are meaningful as noiseless'.

Considering the use of narrative in the social sciences, Frosh (2007, 639) cautions against 'the tendency to produce integrated "narratives" of experience and...argue[s] for the importance of maintaining the vision of a subject in fragments'. Such utterances may make possible multiple valid interpretations or understandings by both teller and listener without an urgent need for resolution, and may offer nuanced readings of what Frank terms 'chaos narratives'. Taken together with a validation of silences among words, might fragmentation be a way of enriching and deepening first-person illness expressions for both teller and listener?

### 2.3 Phenomenology

Phenomenology offers opportunities to understand the lived ill body differently and answers calls for more explicit embodiment in illness writing (Frank, 2013) and in disability studies (Hughes and Paterson, 1997; Siebers, 2008). Phenomenology, while not incompatible with narrative, offers a different approach for a person wishing to explore their illness experience. It aims to 'provid[e] a philosophical description of consciousness

and its engagement with the world' (Carel, 2018, 20). The intention and act of engagement necessarily start in, of, and from the body; Merleau-Ponty (2002, 70) describes his body not as 'one of the objects of the world' with which he might engage but as his 'point of view on the world'. Similarly, Husserl (1952, II, 18) defines the body as one's 'zero-point of observation'. Considered from a phenomenological perspective, our realities are constructed through our individual positioning in the world; they are subjective but also relational. Or as Leder (2016, 1) puts it, the body is 'not just a piece of meat, but the way we rush out to meet the world'.

Whereas Frank's narrative approaches to illness writing lead the writer towards a goal of personal growth, phenomenology offers a philosophical framework for exploring the embodied experience of illness, in which societal assumptions about being (ill) in the world can be reconsidered (Carel, 2016, Woods, 2014). An increasing number of writers with lived experience of chronic ill health are using phenomenology as a way to explore their illness or disability (Zaner, 1981; Murphy, 1987; Toombs, 1987; Diedrich, 2001; Leder, 1990, 2016; Carel, 2016, 2018). Oliver Sacks (2012), Nancy Mairs (1997), and Jean-Dominique Bauby (2023) have written illness memoirs which have also been identified as phenomenological case studies wherein the authors are motivated by their illness and disability to ask philosophical questions (Diedrich, 2001). Much illness phenomenology is written by people for whom cure, or in Frank's terminology restitution, is not possible, e.g. Mairs and MS, Murphy's inoperable spinal tumour, Carel and lymphangiomyomatosis. These authors consciously attempt to find new ways of exploring and articulating health experiences that do not align with the inaccurate and inappropriate tropes found in dominant forms of illness narrative.

Below, with reference to the limitations of the medical and social models of disability and Frank's illness narrative tropes, I briefly examine key themes that have been extensively explored by phenomenologists: the ill body as alien or dis-abled; temporal shifts in perception; spatial dislocation and social alienation.

### 2.3.1 The body as dis-abled, alien

Merleau-Ponty describes a body that works to 'create a unified, fluent, meaningful experience' whether or not the individual is paying attention to their embodiment (Carel, 2016, 30). Yet, when the body draws attention to itself through its situation, such as gender, sexuality or race, the fluidity of experience is disrupted (Young, 2005; Ahmed, 2006). Similarly pain, injury and illness insert themselves into the consciousness and disrupt the fluidity of being in the world. Carel (2016, 62) has reconfigured disruption through illness in terms of Heidegger's (1962) tool analysis which states that objects which we use as tools for tasks (e.g. pen, cup, toothbrush) only make themselves conspicuous through breakdown, unsuitability or absence. Carel advances that 'the change in the case of bodily dysfunction runs much deeper than tool breakdown...The possibility of bodily breakdown is a fundamental yet unacknowledged aspect of our being and our experience of the world.' Thus during episodes of illness, the body-as-tool-of-engagement draws attention to itself through its failures or limitations. It becomes, not a tool, but a barrier to one's being in the world in ways that unsettle our sense of self (Leder, 1990; Diedrich, 2001). This barrier to engagement in and with the world causes 'biographical disruptions' (Bury, 1982, 167) which create fractures in the ill person's attempts to create stable personal narratives.

Phenomenology encourages exploration not only of illness, but how we experience consciousness of illness. Consciousness has been located as first existing in the statement 'I can' (Merleau-Ponty, 2002, 159), but this has been reformulated to reflect disabled experience: 'I can no longer'; 'I cannot'; 'I still can'; 'I can't be taken for granted'; 'I should'; or 'I must' (Leder, 1990, 2016; Toombs, 1995; Diedrich, 2001; Young, 2005; Ahmed, 2006). Diedrich (2001, 217) writes that for Nancy Mairs, who lived with and wrote about progressive MS, 'the very ability to say "I can" is suspended, called into question. The subject loses the ability to be able, and in this loss, consciousness reveals itself.' For PwMS or other serious chronic illnesses, consciousness is not necessarily found in ability and achievement but may be derived from the recognition of persistent incremental losses through being dis-abled (Mairs, 1997; Diedrich, 2001; Carel, 2016). Reflecting on my discussion of Frank's typology, I would suggest that narrative is not necessarily the best form in which to write about biographical disruption and illness-induced losses of ability. As

discussed in 1.2.2, the majority of novels are created with an expectation of plot and resolution. Similarly, many illness narratives are also constructed according to the same expectations and are praised by Frank as examples of the restitution or quest model. However, phenomenological explorations into the developing consciousness of illness, like Frank's (2013, 97) chaos narrative, can focus on disruption and loss, without reaching resolution, or 'telling a "proper" story'.

Leder (2016, 34) writes about 'the ambivalent relationship' a person in chronic pain has with their own body. Described in Husserl's (1989) terms, pain disrupts the sensation of *being* a living, feeling body (*Leib*) and alerts us to *having* an objective, material body (*Körper*). The ill person is simultaneously hyperaware of their body and yet alienated from *it* by its strange sensations or unwillingness to follow instruction. On some levels, the painful or, I would suggest, chronically ill body is the other as well as the self, however an external other can be set down or cast aside; the painful, dysfunctional *Körper* cannot. Writing from a position of lived experience of severe breathlessness, Carel (2016, 109-110) examines this complex embodiment and explicitly refutes a quest narrative interpretation:

'Many illness narratives take on a kind of dualist flavour—the body fails, but the spirit flourishes; the body is tethered to its failing organs, but the spirit rises free. Not true. Our embodiment determines our possibilities and delineates with extreme clarity what one is and is not permitted to do and be.'

For Carel there is none of the impetus towards personal growth that is observed in Frank's quest narratives. Rather, the lived experience of illness is worthy of consideration on its own merit without any requirement to inspire the (healthy) reader. Furthermore, Carel's deeply embodied reflection illustrates how the ill person is not only disabled by society but also by the physical impairments of 'its failing organs'. Thus her words may also be understood as a criticism of the social model of disability in which, for Hughes and Paterson (1997, 329), the impaired body, as opposed to the social experience of disability, is constructed as 'a pre-social, inert, physical object, as discrete, palpable and separate from the self.'

### 2.3.2 Temporal dislocation

Chronic illness changes our relationship with time. The past may become a nostalgic world filled with lost abilities and possibilities. Although the past is always closed to us, losses accumulate, accentuating the differences between then and now; accordingly, the past may provoke grief or regret (Carel, 2016). Similarly the future may become a trigger for anxiety as the ill person anticipates painful treatments, uncertainty, progression of illness and further losses. The future, seen through the lens of ill health, may also provoke an increased awareness that life is a being-towards-death (Heidegger, 1962; Carel, 2016).

The present may be a site of deeply immersive embodiment in which time is not experienced as objective calendar time. Because of pain, '[t]he lived present may slow and expand' (Leder, 2016, 29). The past may recede in an inability to remember or reconstruct the idea of a life without pain. Similarly the future may not be perceptible as anything other than a continuation of the interminable painful present. Conversely, it could be envisioned only in terms of possible cure or alleviation; *when will my body stop hurting?* Again the ill person may feel acutely aware of their body as an other which cannot be escaped in the moment; '[pain's] felt aversiveness not only fixes us to the present but compels us to run away' (Leder, 2016, 30). I am reminded of Mattingley's (2004, 74) observation that narrative 'places temporality at the centre of meaning' and would advance that phenomenology's attention to temporal fractures suggests that non-narrative, non-chronological forms may be particularly well suited to exploring such disruptions.

### 2.3.3 Spatial and social isolation

In chronic illness a person's spatial interaction with the world can alter significantly as they try to adapt to their new personal geography of illness. What was previously a short walk to the shops can become an impossibly long hike when faced with, for example, fatigue, breathing difficulties or painful arthritis. 'The world shrinks and becomes hostile. The sense of possibility that accompanies objects disappears. A bicycle is not an invitation for an afternoon of fresh air and freedom' (Carel, 2016, 111). The social model of disability would

rightly state that, wherever possible, barriers should be alleviated by changes to the built environment (a lift instead of steps) or by access to medical aids or support staff to facilitate engagement with places and activities. And yet, such accommodations, while helpful, cannot redress all of the losses caused by physical impairment. I would argue that these losses are exacerbated by a model which does not acknowledge the centrality of the body to disabled or chronically ill life.

Working from Merleau-Ponty's position that ill health is a 'way of being in the world', Carel (2016, 114) asserts that 'the world as we inherit and organize it is less hospitable to certain "ways of being"'. What is it to feel like an unwanted guest in society? The somatic, temporal and spatial changes necessitated by illness have social ramifications. Some shared activities may no longer be physically possible if the ill body refuses to be a tool of social engagement. Spontaneity may no longer, or not always, be possible because of the amount of planning required to join in. Fun things take too long or too much effort; 'your text "sorry I'm too tired to..." becomes a staple apology, cop-out, and truth' (Carel, 2016, 111).

Just as living in and through an ill body changes self-perception, there is an equivalent 'change to social perception. How the ill person is perceived by strangers, friends, and acquaintances will shape her illness experience' (Carel, 2016, 75). As discussed in 2.1.1, both the medical and social models of disability have been interpreted as relinquishing the body to the biomedical profession. Consequently, it is perceived that '[t]he relationship of disabled people to their bodies is mediated by medicine and therapy, and has nothing to do with policy and politics' (Hughes and Paterson, 1997, 331). I would argue that this is even more the case for chronically ill, disabled people. Objectification on the grounds of illness or disability also speaks to stigma (Goffman, 1990) whereby the ill or disabled person is visibly marked out by their difference and treated by non-stigmatised individuals in ways which are shaming and reinforce normative expectations. Socially, the stigmatised person may be perceived as 'not quite human' (Goffman, 1990, 15).

As wheelchair users, Murphy (1987) and Mairs (1997) write about the frustrations of being ignored and excluded from social interactions when they are physically present. This, as Murphy (1987, 93) writes, is a conscious decision by others to ignore the 'brutally visible'

wheelchair in the room, however, the able body colludes in this selective blindness. Being at navel height to ambulatory people means being out of their automatic eyeline and thus makes it easier for them not to see. It is not only one's own 'zero-point of observation' that impacts on being in the world; just as someone cannot be compelled to hear another's story (2.2.4), it is not always possible to change someone else's literal point of view. Ignoring a visibly ill or disabled person is still a form of objectifying them, reducing them to a Körper that is not worthy of acknowledgement in much the same way that one would not expect to greet a houseplant. If it's not specifically your role to care for it/them, you can ignore it/them. I explore participants' experiences of objectification in Chapter Five (by clinicians) and Chapter Seven (in social settings).

## 2.4 Poetic Inquiry

As a poet, I have instinctively turned to poems as spaces in which to explore my relationship with MS. This section will interrogate what writing poetry about chronic illness might offer individuals and health in social science research. First I will examine what poetry is understood to do in society and briefly consider examples of poetry about chronic illness and disability, discussing ways in which poems offer different possibilities to prose accounts. Then I will discuss how poetry is used in social science research before focusing on the use of poems constructed by researchers from participant data and poems written by participants.

### 2.4.1 Role of poetry in society

Poetry is a form which people have used throughout history. There is a long tradition of narrative poetry which ranges from long epic poems such as *The Iliad* (Homer, 2003) and the *Ramayana* (Valmiki, 2000), through extended verse sequences (Carson, 1999, 2014), to shorter dramatic monologues like 'My Last Duchess' (Browning, 2000) and 'The Love Song of J. Alfred Prufrock' (Eliot, 2002). While these may vary greatly in style and motivation, they all tell a story. Yet many other types of poetry do not relate narratives at all such as the lyric

poem which expresses personal feelings.<sup>5</sup> Popular for centuries, its more noted exponents include John Clare, John Keats, Rabindranath Tagore and Sylvia Plath.

The poet and academic John Burnside (2012, n.p.) writes that ‘poetry is central to our culture, and...is capable of being the most powerful and transformative of the arts.’ Through poetry we communicate that which is important. Even those who might not otherwise read or listen to poetry may choose poems for occasions marking significant life events, such as christenings, weddings and funerals. On a wider societal level, poems are often used to mark important civic or political events such as presidential inaugurations or the coronation of a new monarch (Magsamen and Ross, 2023). The role of poems in culturally significant moments suggests that our relationship with poetry differs from our relationship with prose on an emotional or cognitive level. This premise is supported by functional magnetic resonance imaging (fMRI) research which has discovered that reading poems activates brain regions associated with introspection and emotion that are not activated by reading prose (Zeman et al, 2013). Subsequent research has found that poetry allows the reader to access strong emotions in a relatively safe way because it triggers primary reward centres in the brain, potentially rendering the experience pleasurable (Wassiliwizky et al, 2017).

‘[F]or poets “truth” is many truths, is untruths, is tales of telling and untelling’ (Tania Hershman’s comment on the cover of Barnsley, Houghton and Peter, 2018). Truth, and its counterpart, knowledge, are partial and multiple; poetry, Hershman suggests, can resist simple conclusions and embrace complexity. Others observe that the purpose of poetry can transcend reasoned understanding. Discussing the role of the reader, Padel (2007, 4) writes, ‘connection is part of what a poem is for. It needs to matter to you personally, instinctually, sensually, before there’s any question of meaning.’ Writing about representations of the self in lyric poetry, Morrissey (2019, 20) says ‘our personalities are not fixed but in flux, and subject to radical alteration at any moment.’ From my own experience, I would echo Padel and Morrissey and suggest that one of the purposes of writing a poem can be exploration; we delve into our subject and discover something of ourselves and the world. These

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<sup>5</sup> ‘Lyric’ is a contested term in poetry. I am defining it here in the most widely used modern sense, but note that some poets and scholars such as Paterson (2021, 21) use it to describe ‘that aspect of poetry which concerns itself with musical property’.

discoveries shift and are not necessarily linear. They may resist straightforward communication and understanding, hence the instinctual and sensual connection. Poetry is a liminal, shadowy form that makes new shapes on the page which offer novel ways of seeing or sharing such discoveries.

The shape of most poetry leaves blank space on the page which has been understood to represent quiet emptiness; '[s]ilence – both invoked and symbolised by the white page, and specifically insisted upon by the gaps left by lineation, stanza and poem – underwrites the status of the poem as a *significant mark*' (Paterson, 2021, 34). However, the silence of the page may do more than emphasise the poem. It has been suggested that the silent spaces around and within poems can act as a prompt to be aware of the limitations of speech; 'open space on a page...should...lead to thinking about what is (purposefully) unsaid or cannot be said' Golomski (2019, 8). In this way, poetry may, in addition to its lexical contribution, accommodate expressions of noiselessness, thus partially answering calls to honour silence (Maitland 2008; Woods 2014).

#### 2.4.2 Poetry about chronic illness and disability

Chronic illness is increasingly a theme of contemporary poetry. Jay Whittaker's (2017) *Wristwatch* is comprised of astute, intimate poems about breast cancer as is *Frissure*, a collaboration between Kathleen Jamie and Brigid Collins (2013). Poets have written about the experience of living with MS (Huntington, 2003; Waller, 2010; Gill 2017, 2020), while Frank Ormsby's (2017) poems about Parkinson's in *The Darkness of Snow* have resonated deeply with readers. It is outwith the scope of this literature review to conduct a literary analysis of any of these collections. However, reviews of some of the above texts suggest that they contain the potential for deeply embodied knowledge to be expressed, communicated and understood in novel ways. Singh (2014, n.p.) notes about Jamie and Collins' book, 'By losing the [breast cancer surgery] scar to the newly found landscapes *Frissure* charts a route for the body violated in the past to find itself again, in nature, from where it came.' A reviewer of *The Darkness of Snow* found Ormsby's 'quiet unadorned descriptions [of Parkinson's-induced hallucinations] make the experiences more real' and

easier to empathise with for a reader who does not have Parkinson's than the 'louder intricacy' of other illness writing (Pople, 2017).

Although Whittaker (2017) explores the relationship of a couple affected by breast cancer, the above collections are predominantly comprised of lyric poetry that primarily considers the interior life world of the poets. Other poets address the social/political components of being chronically ill or disabled. The anthology *Stairs and Whispers: D/deaf and Disabled Poets Write Back* (Alland, Khairani and Sluman, 2017) takes an explicitly politicised stance, springing from a manifesto 'that was ambitious and deeply rooted in a politically and socially aware approach to issues that affect the everyday lives of D/deaf and disabled people' (Alland, Khairani and Sluman, 2017, 13). The editors interpret disability widely, including poets who live with chronic physical or mental illness<sup>6</sup>.

On my reading, one of the most radical features of the anthology is its focus on disabled people writing to, and for, other disabled people. By 'refusing to seek the normative world's approval' and creating 'our own spaces' in which to share experiences (Alland, 2017, 27), disabled and chronically ill people may resist being cast as the tragic individual of the medical model of disability. Instead there are opportunities for recognition and self-validation both creatively and socio-politically. Claiming that poetry can play a unique role for disabled people, Palmer (2017, 117) states, '[d]isability poetics is a breeding ground of innovation and variety: of ruptures and chasms; poetry that performs, and is informed, by the infinite physical and neurological realities of the disabled body.'

#### 2.4.3 Poetry and qualitative research

In qualitative research, Tamas (2008, n.p) writes of a 'turn to open, messy, emotional texts, and the loss of certainties in practices of stammering knowing'. There is a growing body of 'messy' texts in social science research, rooted in attempts to articulate the tangled, ambiguous aspects of the research process and the uncertainties inherent in the process of

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<sup>6</sup> I appreciate that stark distinctions between physical and mental illness are contested and can be considered unhelpful. However, I use both terms here to reflect that people with mental illness are often excluded from the disabled community.

acquiring and relating to knowledge. Therefore it is perhaps unsurprising that poetry is playing an increasingly large role in qualitative research.

People can automatically reach for clichés in conversations about ill health, however in poems people may create expressions that are powerful representations of individual experience. Prendergast (2009, 551) says: 'Language is always inadequate. We dance with impossibility each time we put words on the page. It is far better to dance with impossibility than to accept the first ordinary word that comes to mind, the easy cliché.' Similarly Richardson (2000) advises against the use of hackneyed everyday metaphors which can lead to clichéd writing. These cautions imply literary judgement. While this conceptualisation of good writing as avoiding or transcending cliché resonates with the poet in me, I worry that, in a health in social science context, such judgements may result in important participant data being undervalued or omitted from the research because it is perceived as clichéd. When participants speak in interviews, they do so more quickly than they might compose poems and choose language for its ability to communicate clearly rather than for its literary merit. I suggest that it is unfair to judge data poems according to the literary merit of participants' word choices. Both when writing and speaking, participants may feel that clichéd phrases accurately represent their voice. Alternatively, participants may have varying linguistic resources, and the notion of trite language may not occur to, or concern, them. Familiar words may feel like a safe way to express sensitive or emotionally difficult experiences and accordingly participants' linguistic choices should be respected (Breckenridge, 2016). In Chapter Seven, I will discuss an instance of clichéd language in a participant's poem and its potential significance.

Leggo (2012, 7) suggests that rather than asking, 'Is this a good poem?' we should instead inquire 'What is a poem good for?' In the case of data poems, I would argue that the purpose of creating the poem is not to make a 'good' poem but a good representation of participant data which stimulates deeper or different responses in the researcher and the reader. Furthermore, regarding both researcher-created and participant-authored poems, the poet may not necessarily know much about poetry or poetic technique. Piirto (2002) and Leggo (2012) have both argued that researchers who intend to use poetry should learn about the art and techniques of poetry just as they might learn to use statistical or analytic

tools. A greater understanding of the craft of poetry may be of benefit, but I would suggest that the research purpose of the poem should be uppermost in the researcher-poet's mind in order to prioritize the data and the ethical responsibility towards participants.

#### 2.4.3.1 Types of poetic inquiry

Prendergast (2009) presented a bibliographic analysis of 182 instances of poetic inquiry in social science literature, updated to include a further 129 examples (Clement and Prendergast, 2012). Prendergast (2009, xx-xxi) found multiple ways that poetic inquiry was being used and delineated by researchers including 'poetic representation', 'poetic transcription', 'poetic narrative', 'research-generated poetry', 'autoethnographic verse, autoethnographic poetry', 'performative autoethnographic poetry' and 'investigative poetry'. Prendergast (2009, xxii) divides social science research poetry into three categories: 'Vox Theoria' (poems written in response to literature or theory); 'Vox Autobiographia / Autoethnographia' (poems that reflect on the researcher's life or field experience); and 'Vox Participare' (poems that are created by the researcher from interview transcripts or poems that are written by the research participants themselves). For the purposes of this literature review, I briefly comment on Vox Autobiographia/Autoethnographia poems below before a fuller discussion of Vox Participare poems in 2.4.2.2.

Nursing students who wrote reflective poems fitting the definition of Vox Autobiographia felt they developed more compassion and a greater sense of connectedness to patients (Coleman and Willis, 2015). Furman (Furman, McDaniel and Campbell, 2004) wrote autobiographical poems about his father's lung cancer as ways of representing the qualitative data of his experiences. Richardson (1993, 705) suggests that '[p]oetry is...a *practical and powerful* means for reconstitution of worlds', because its particular engagement with technical features such as form, repetition, and rhythm 'let us see and hear the world in a new dimension'. It would appear from the findings of the researchers mentioned above that they have been able to explore and know their work differently through the prism of poetry.

### 2.4.3.2 Vox Participare

Within the broad umbrella category of Vox Participare, Prendergast (2009, 545) has identified three types of poems: those which are co-created with the researcher in ‘an action research model’; those which are solicited directly from participants; and those which researchers create from participant interview data, often called ‘data poems’. These three distinct sub-categories incorporate a wide range of participant contributions to, and control over the poems, and as such the sub-categories are substantively different. Data poems are particularly popular, offering a concise method of (re)presenting important data from long transcripts. Some researchers’ experiences with data poetry confirm Leggo’s claim, quoted above, that poems offer alternative ways of knowing (Clarke et al, 2005).

Hill (2005, 104) used a combination of transcript data and her own field notes to create ‘poetic portraits’ of Black women educators and found that they added ‘depth and detail’ to the presentation of subjects, while also being a way of acknowledging her own location in the research. Feedback on data poetry has been seen to promote empathy in nursing students and conference audiences (Macdonald, 2017), although I would suggest that there is scope for future research to explore what exactly contributed to a perceived increase in empathy. From my reading, data poems tend to be very concise distillations of much fuller participant data. I wonder whether their brief intensity contributes to a greater sense of empathy or compassion than more traditional data presentations. Increased empathy or compassion also raises questions about authorial intent: did the use of poetry lead audiences to interpret the data differently for themselves, or were they responding to the researcher’s poetic interpretation of participants’ words?

Incorporated into the process of data analysis, data poetry ‘helps to engage researchers in a process of reflexion-in-action’ (Breckenridge, 2016, 457), whereas Stenhouse (2014, 434) found ‘re/presenting’ participant data in verse ‘allow[ed] individual, rather than the collective, voice to be heard’. Kendall and Murray (2005, 749) found (re)presenting patient transcript data as poems to be a mindful act which uses the patients’ own language and imagery and serves as a prompt to consider data differently. However they write that there is always potential for researchers to ‘mis-take’ participants’ meanings when working with data. They also caution that poetry alone cannot solve all of the challenges inherent in the

relationship between interview data and original experience. In these examples the usual narrative prose of qualitative research data has been adapted to allow new types of response through poetry. However, the researcher retains both authorship and authority over the voice of the participant as they shape and edit the participant words into poems. Thus, I would suggest that both ethical possibilities and responsibilities need consideration in data poetry.

Additionally – and this may seem a slightly odd point to make in a literature review – creating poems can be fun. I would suggest it is likely that researchers who make poems from their participants' transcripts enjoy the process. Creative acts can be fulfilling in and of themselves, and, in the discussions or conclusions to the research referenced above, researchers all state that the use of poetry gave additional insights to their work. Foster (2012, 543) states that '[a]rts-based research has the potential to involve participants in an enjoyable and meaningful way and to equip them with vision and new skills.' So, why not recruit participants into the potentially enjoyable and instructive process of poem writing? When creating co-constructed or entirely participant-written *Vox Participare* poems, the participant has partial or complete authorship of the resulting work, thus partly addressing the above ethical concerns. This approach may act to acknowledge or problematize the power dynamics between researcher and participant. However, participant-written poetry does not seem to be as prevalent as researcher-written poems. Two major collections of essays about the use of poetry in social science are *Poetic Inquiry: Vibrant Voices in the Social Sciences* (Prendergast, Leggo and Sameshima, 2009) and *Poetic Inquiry II – Seeing, Caring, Understanding* (Galvin and Prendergast, 2016). Yet, only three of the fifty-two chapters feature research including poetry that might be perceived as participant-written, rather than wholly researcher-written or compiled by researchers from participants' spoken data. I suspect that, in some cases, researchers may feel that participants might not wish to write poems about the research theme. Alternatively, researchers may lack confidence to guide participants through the process of poem composition. Furthermore, creating a found poem from spoken data as part of the analytic or representational process is a different process from using a participant poem as original data to be analysed. It is possible that some researchers do not feel confident in knowing how to analyse the technical features of poems when considering them as raw data.

Below I briefly detail three research examples that use participant-written or co-written poetry. These examples are not straightforward; however, they do give some insight into the potential purposes of this type of Vox Participare poem and the methodological decisions of the researchers.

Spiers and Smith (2016) investigate the experience of living with end stage renal disease through an Interpretative Phenomenological Analysis of the autobiographical poems of Jon E. Seaman. The poems were not written specifically for the study but found by the study's first author online. She contacted Seaman, who gave 'his full blessing for the analysis to go ahead' (Spiers and Smith, 2016, 240). The researcher and Seaman communicated multiple times through the course of the research, including for a clarification of meaning when the two researchers interpreted a poem differently. The researchers found a key theme of agency and struggle for agency within the poems. In the study discussion, they approached these findings in tandem with more traditional interview-based research about dialysis and renal disease.

A participatory action research project conducted in the U.S. recruited incarcerated women as peer-researchers working alongside a university researcher and a volunteer to investigate ways of improving the health and wellbeing of incarcerated women (Ann et al, 2009). The university researcher and volunteer recorded and transcribed an 'inaugural meeting designed to initiate the participatory action research project' (Ann et al, 2009, 306). The research team then had conversations about the transcript. The recordings of these secondary conversations were transcribed by the university researcher and volunteer who then selected from and rearranged the transcription into found poetry. All participants read and gave approval to the final version of the poetic text, and all members of the research team were listed as authors in the resulting article, with only first names being used in order to preserve anonymity and not privilege any individual over the others.

West worked together with a family in the U.K. to explore their experiences of being in a Deaf-hearing family (West et al, 2009). The family of four initially communicated their stories through speech and/or British Sign Language (BSL). The researcher transcribed the

stories, an intricate act which incorporated the complex features of sign language. The transcripts were then used as a foundation for 'co-edited poetic re-presentation[s]' of the BSL and spoken conversations (West et al, 2009, 335). Individual poems, although co-edited are attributed to the participants who had the original conversations, and the family members were given first name author status in the resulting paper. The co-creation of these poems suggests greater creative agency for participants than in the preceding study, although both honour the participants in ways which give them authorship and authority over the final poems.

My analysis of the existing uses of poetry in health in social sciences, has confirmed to me that there is scope for research, which specifically explores the methodological and data implications of participant-written poetry created in settings facilitated by the researcher. I acknowledge that my experience as a poet and workshop facilitator has given me pertinent skills for conducting this novel research, both in terms of guiding the workshops and analysing the resulting poems.

## 2.5 Review summary

In this review, I have critically examined medical and illness narratives with particular attention to Frank's (2013) conceptualisations of the restitution, quest and chaos tropes. My reflexive discussion, which acknowledges my personal location to the subject, has used lay examples to illustrate how these narratives both derive from, and reinforce, the medical or social models of disability and their limitations. This analysis has shown that the dominant narrative tropes can lead to stereotypical and morally questionable constructions of ill selves who either *beat* their illness through cure or *overcome* poor health through personal or spiritual growth. I have argued that these constructions along with popular narratives' perceived expectation of plot resolution can be incompatible with the non-temporal, fragmentary elements of chronic and/or incurable illnesses, such as MS.

Having noted the calls for greater embodiment in illness writing (Hughes and Paterson, 1997; Siebers, 2008; Frank, 2013), I subsequently discussed how phenomenology's concepts

and language make it possible for the chronically ill person to reflect on their experiences of disruptive embodiment. The analysis also illustrated how the phenomenology of illness permits exploration of temporal dislocations, not simply as a failure of narrative, but as a key component of chronically ill life. I have also argued that, in addition to being deeply personal, phenomenological illness writing is socially situated and can lead to new understandings of ill bodies that do not automatically default to medical interpretations.

Then I considered ways in which people use poetry to communicate their narrative and non-narrative experiences of chronic illness and disability, showing that it is a form which may be deeply embodied and personal, yet also socially and politically engaged. This discussion also examined the use of poetry in health in social science research, identifying that, although poetry is increasingly popular in qualitative research, the poems are usually written, or assembled from spoken participant data, by researchers. I found this lack of poetry written by participants about their own health experiences raises ethical questions about representation, and conclude that there are epistemological and methodological gaps in the use of poetry within health humanities and the sociology of health and illness. I conclude that my research into poetry as a form for PwMS to (re)present their health experiences has the potential to add to knowledge of living with MS through its novel method. In the following chapter I discuss the methodology that underpins my study.

## Chapter Three

### Methodology

*'Reflexivity...demands that we interrogate each of our selves regarding the ways in which research efforts are shaped and staged around the binaries, contradictions and paradoxes that form our own lives.'*

(Guba and Lincoln, 2008, 279)

In this chapter I critically describe the aims and methodology underlying the study. Section 3.1 is a discussion of the aims and motivations of the research design. In Section 3.2, I establish my ontological and epistemological positioning. Section 3.3 reflects on my multiple roles within the research and my self-reflexive approach to them. In Section 3.4, I consider the ethical responsibilities of working with vulnerable participants. Finally, the concluding section briefly summarises the chapter's key points.

#### 3.1 Study Background and Aims

As discussed in Chapter Two, poetry may have a role in helping people to explore, articulate and communicate complex, fluctuating perceptions and states; that which we know through lived experience but cannot necessarily claim to understand. Subsequently I determined to examine further the possibilities of this approach by researching with participants who, like me, have MS. The resulting research questions are inductive and open-ended, speaking to the exploratory nature of this novel research theme:

- 1. What is the experience of living with MS as expressed through poetry and spoken utterances?**
- 2. How may writing poetry serve to affect or enhance the communication of PwMS with others?**

In the supplementary reader participant wing of the study I also sought to address the following questions:

**3. Might the poems provide additional insights for the reader into a family member or care recipient's life with MS?**

**4. Might the poem sharing experience have any impacts on conversations about MS between PwMS and their close contacts?**

## 3.2 Theoretical Foundations

### 3.2.1 Through an ontological lens

This study is about the intersection between identity, experience and communication. The ability of individuals to communicate their MS experiences partly relies on the self-perceived identities of PwMS and also on how others apprehend PwMS. Ontologically, I adopt a socio-constructionist stance, understanding our perceptions and communications to occur in social realities which are themselves 'interpretive nets woven by individuals and groups' (Marshall 1994, 484, quoted by Crotty, 1998). In order to function, these realities are necessarily negotiated and agreed as 'real', yet our identities and interactions are multiple and relational, 'dynamically constituted in relationships and performed with/for audiences' (Riessman, 2008, 137). We are plastic in our capacity to shift, deconstruct and reconstruct our 'selves' differently.

Cultural institutions and discourses form and inform our individual attempts at sense-making and self-making, which we reformulate over time in response to our changing relationships with our environment. Yet our access to the prevailing systems of sense-making is not uniform and equal. Individual and communal attempts to participate in society are constructed and interpreted through various, and often intersecting, standpoints of power, race, gender, socio-economic status, education and (dis)ability (Collins, 1990; Garland-Thomson, 2005; Smith, 2012). This is particularly evident in relation to the individual experience of chronic illness, which is shaped not only by symptoms, but by medical institutions, care provision and society's prevailing attitudes to ill health. The socio-constructionist perspective challenges Western society's emphasis on the objective and clinically observable 'facts' of disease as presented in medically recognised signs, symptoms

and results of clinical investigations, which tend to be valued over first-person narratives of illness (Leder, 2016). However, we know about our bodies by and through the subjective experience of living in them (Husserl, 1952; Merleau-Ponty, 2002). Embodiment tells us we are 'here', thereby giving us a perspective from which to engage with the world which is necessarily 'over there' (Ahmed, 2006, 8). As a researcher and particularly as a PwMS, I am confronted by these contradictory ways of knowing. Within the methods, findings and discussion of this thesis, I represent my participants' and my own attempts to engage with the complexity of these apparently contradictory interpretations of what we can know about ourselves as ill people.

### 3.2.2 Dialogue and discourse

When choosing an analytic approach, I was mindful that it should be applicable to the different kinds of spoken and written data created in the study. Therefore I explored Bakhtinian dialogical methods, as these have been applied by others, including Bakhtin (1981, 1984, 1986), to both literature and social sciences data. Furthermore, as discussed in Chapter Two, this research is alert to phenomenological expressions in, and interpretations of, the data. Rockwell (2011, 8) identifies congruity in the positions of Bakhtin and the phenomenologist, Merleau-Ponty:

'Bodies belong to the world of the subject. Both Bakhtin and Merleau-Ponty take subjectivity as the starting point for all social life. For Bakhtin, social existence is not possible without processes of dialogue, and for Merleau-Ponty, existence is itself a process of perpetual incarnation of subjectivity.'

This compatibility further confirmed to me the suitability of a Bakhtinian approach to analysis. Here I elaborate on my understanding of discourse and dialogue and how this forms the foundation for my study design.

Gee argues that people attempt to explore, know and communicate their experiences and their selves through language, which 'does allow us to inform each other. But it also allows us to do things and to be things, as well' (Gee, 2014, 2). So, in and through language we can live, act, construct and perform identities. Yet we cannot do this in isolation. 'Life is dialogic

and a shared event; living is participating in dialogue. Meaning comes about through dialogue at whatever level that dialogue takes place' (Coghlan and Brydon-Miller, 2014, 73). Meaning is socially constituted, dependent on who participates in the dialogue, what has already been said, and what is said later. Everything that we say carries the language and echoes of a wide array of influences. We inhabit the dialogues that precede us and carry them with us in our own dialogues (Coghlan and Brydon-Miller, 2014). Alertness to the positioning of new or current dialogue in relation to previous utterances is applicable to the various forms of data in this research. Not only do study conversations about MS evolve from earlier dialogues on the theme, but the poems generated within the study are located within MS dialogue and are influenced by preceding poems.

Inherent in my analytic approach is Bakhtin's idea of unfinalizability. In dialogue, interlocutors aim to create complete, or *finalized*, specific utterances in which they have said all that they want to say about a subject on a particular occasion (Bakhtin, 1986). Of course, other speakers, or indeed the original interlocutor, may go on to say novel things and make new meanings about the original theme. Retrospectively, this can change our understanding of the original utterance. Thus, discourse on a personal, local level and discourse in the wider societal sense can never ultimately be finalized (Bakhtin, 1984). Accordingly, identities, constructed relationally through dialogue, can never be finalized. Through a Bakhtinian lens, we can construct knowledge while simultaneously being aware that both ourselves and the knowledge we create are 'always partial – committed and incomplete' (Clifford and Marcus, 1986, 7).

The principle of unfinalizability means that for the researcher, '[n]o one fixed analysis is possible'. (Frølund, 2012, 188). This has ethical as well as epistemological implications: I believe that I do not have the right to the last word about my participants. Rather it is my responsibility to acknowledge that the most I can say about a participant is, 'This how I see this person now, but I cannot know what she or he will *become*.' (Frank, 2005, 967). Dialogic analysis foregrounds the context in which data is co-constructed and in which participants and researcher constitute their research identities. Thus, it makes space for the 'active presence' (Riessman, 2008, p.105) of the researcher, important in this study where my own positioning and contributions influence and co-create data along with participants.

### 3.3 Self-reflexivity: so many Georgis

Following logically from my ontological position regarding the multiple, shifting selves that we construct in and through our experiences and relationships, I have reflected on the different selves that I bring to this research: including researcher, poet, and PwMS.

Conscious engagement with the significance and effects of these roles and subjectivities is good qualitative research practice (Stanley and Wise, 1993). Furthermore, reflexivity is a core element of this study, driving and underpinning my aim of troubling the distinction between researcher and researched.

Disclosure of my status as a PwMS has been an essential, if complicating, component of the study. From an ethical perspective it would have felt dishonest not to disclose this to participants and I suspect it would have been practically impossible given the close and sustained nature of our engagement. My research relationships with participants are undoubtedly influenced by my also having MS, yet this is not straightforward. Merton's (1972, 21) definition of 'insiders' as 'the members of specified groups and collectivities or occupants of specified social statuses' has felt overly simplistic as a categorisation of my positioning in this research. Participants and I have MS in common but the type and severity of our symptoms vary, and of course, many other factors contribute to our identities. We vary in terms of socio-economic status, geographical location, family circumstances, education, gender, age and so on. Put simply, similarity is not sameness. Many of the factors in which we differ from one another are not fixed but shift with time and context. By making explicit and exploring these areas of divergence as well as those of similarity I hope I am creating research that is both more nuanced and robust (Stanley and Wise, 1993).

Of course, within research relationships, my positioning is not only constructed by me but also by individual participants (Teusner, 2020). My status as a PwMS was mentioned in the Participant Information Sheet (PIS) and on the study website, so, although I have no way of knowing, it is possible that some people may have been deterred from participating if this blurring of the traditional research relationship was problematic for them. Within interviews and workshops, I told participants that I was very happy to answer any questions that they

may have about my MS experiences. As appropriate, I volunteered information where it felt relevant and the participants often seemed eager for me to do so. This helped to create an atmosphere in which participants felt safe and comfortable to share information with me, and it also enabled us to navigate and explore our points of similarity and divergence. This had a permissive action, particularly in workshops where my openness may have encouraged participants to share their experiences with one another.

Participants generally appeared to value my status as a researcher with MS; Saskia told me it was *'a really important thing to know...because I know you can relate.'* Memphis said, *'You'll ken. You'll understand that.'* Because of shared experiences, there is a risk in qualitative research that participants and/or researchers may make assumptions during data collection which result in insufficiently rich or inaccurate data (Berger, 2015). As the above comments show, some participants possibly did assume too much similarity in our MS experiences and took for granted my understanding of their experiences. In order to mitigate this without shutting down the developing trust and ease of the researcher–participant relationships, I responded to participant remarks like those above with questions and comments designed to elicit more information or reflect back to them with relevant personal experience of my own. At times I also stated explicitly that we all had different MS experiences although it felt less suppressive to do this within activity instructions or feedback in workshops than in one-to-one interviews.

In practice, these attempts at openness and transparency around our commonality did facilitate more sharing and deeper conversations than might have taken place otherwise; *'I wouldn't say this to my friends but I can say it here'* (Philippa). Frequently in study interactions, we found ourselves laughing at difficult subjects which may have seemed inappropriate subjects for humour in other contexts. Like other researchers with personal experience of their research themes (Galvin, 2005; McKenzie, 2015; Chandler, 2016), I found these instances of in-group humour helped us to establish atmospheres which felt safe and light-hearted, while simultaneously facilitating conversations on potentially dark or uncomfortable themes.

Thus I approached these study encounters similarly to Galvin (2005, 395-6) who writes of 'a space in which to share our stories and to reflect on the various ways in which disability had

affected our identities.’ It became apparent in analysis that some of my contributions in these free-flowing conversations had influenced what and how participants talked and wrote, much as the prompt poems we considered in workshops gave us nudges to explore certain themes. Our dialogues resulted in participatory and co-created experiences of spoken data and written poems which reflected us as individuals but also as small research communities. I will discuss these processes and outcomes more fully in later chapters.

Disclosure in the study was generally a very positive experience for me as a PwMS. Like many people with invisible chronic illness, previously in social or work situations I had felt obliged to hide or minimise symptoms. However, in study interviews and workshops I was always met with empathy when I lost words or conversational threads and elected to explain my mild cognitive dysfunction. This had a profound impact on my sense of wellbeing and belief that two of my selves – PwMS and researcher – could both be visible in my professional milieu. However, although there was ease in disclosure with participants, it has been more problematic in academic conference settings. As my MS status is a central feature of my research, I routinely and briefly disclosed it in when presenting papers at academic conferences. Sometimes, rather than engage with the themes and findings of my emerging research, conference delegates responded with attempts at sympathy for my health status. Some spoke of my ‘bravery’ which was inappropriate, inaccurate – I am not brave – and akin to inspiration porn (Ellis and Kent, 2016) in that I felt othered and invalidated within the research community. While I acknowledge and am grateful that postgraduate conferences are spaces in which researchers-in-training (myself included) can make mistakes and develop our skills and understanding, I did find these experiences frustrating.

Within the study design, provisions were made to support me both as a PwMS and a researcher, if I experienced any distress resulting from the research themes or experiences. There was potential for me to engage with the UoE counselling service for four sessions if required. I made use of this in the fourth year of study but generally found it more helpful to reflect on any concerns or strong emotions in my study journal and field notes and then to discuss any remaining worries with my supervisors.

As mentioned above, multiple Georgis are present in the study and I have considered deeply how this might have influenced the emerging data. My role as researcher is itself made up of multiple facets; Georgi-as-facilitator operates in different ways to Georgi-as-interviewer. When conducting initial interviews, I was aware that in addition to gathering data, I was establishing a rapport for the workshops ahead. This was important for me in terms of future data creation but also to the participants, most of whom had no prior experience of creative writing workshops or classes. While I tried to be responsive to participants' questions and emotions about the forthcoming workshops, possibly on occasion, I may have given over too much of the available interview time to discussing this.

Georgi-as-poet is a role that is often present in conjunction with Georgi-as-facilitator when leading workshops. Throughout the study, I was often self-deprecating about myself as a poet which gave opportunities for humour within the groups. I intended to establish an atmosphere in which everyone's creative endeavours were equally valuable. Also I hoped this would help participants to create reasonable expectations about what and how much we might write in our relatively brief drafting sessions. This, alongside conversations with my supervisors, served as a reminder to me that I should set aside any inclination to judge the 'quality' of participants' writing. While critical judgment is an essential component of my non-research role as a poetry magazine editor, it was irrelevant and potentially harmful to the study where the focus was on participant self-expression and not any critical poetic measures.

### 3.4 Whose work is it anyway? Supporting ethical participation

It is crucial that researchers be attentive to possible unintentional harms to vulnerable participants (de Laine, 2000; Melrose, 2002; Sin, 2005; Liamputtong, 2007). In research with vulnerable groups, there is a particular risk of psychological and emotional distress or anxiety (Barnard, 2005; Sin, 2005; Liamputtong, 2007). I was mindful throughout the study design process that provisions were necessary to minimise and mitigate any participant distress during the research. However, the key activity of this study involved engaging with upsetting life events, an act which can itself be distressing! Liamputtong (2007, 40) has

asked, 'Ethically speaking, how far can researchers probe their participants?' I believe that engagement with, reflection on, and discussion of the research themes, even if upsetting in the moment, have the potential to be a positive or neutral experience rather than a harmful one. Consequently, on occasion I made an ethical decision to protect participants' wellbeing, and the trust that had been established in the research relationship, by not probing too deeply into a subject if I felt that the participant was becoming distressed. I discuss one such decision in 6.6.

Throughout this aspect of the study design, I was aware of an implicit tension between academic institutions' fear of distress and the aim of much qualitative health research – to create knowledge and understanding about lived experience of illness. I reflected in my study journal and in meetings with my supervisors that much of what is involved in the actual experience of negotiating participants', and researchers', emotions was far more nuanced than the legal ethical framework for research. The ethical considerations of this research are embedded in its design and my practice, informing every stage up to and including the present writing.

When designing the study, I tried to be attentive to the different roles that participants may inhabit in their research contributions. Participation involved both talking in interviews, and talking and writing poems in workshops. By attending two interviews and four workshops, health- and energy-compromised participants would be spending around 8.5 hours in the study over a period of 8-12 weeks. This was a substantial commitment and I decided against including participants in formal checking of my analysis. To do so may also have been an unreasonable cognitive load for some participants. I did, however, decide to ask participants to suggest topics for discussion as a way to facilitate their shaping the research and to trouble the accepted roles of participant and researcher. My attempts at this are discussed in Section 4.3.2.

Some feminist researchers have made found poems from participant interview data as a way of problematizing their status as authors (Clarke et al, 2005; Hill, 2005; Stenhouse, 2014), however I was concerned that by troubling my authorship as a researcher in this way I would assert poetic authority over my participants' words. Therefore a crucial element of

the study design was that participants be invited to write their own poems exploring their MS experiences, thus making their own creative decisions about how their words should be (re)presented. In interview-based data collection, it is standard practice that the researcher/university is the 'author' of all study data, including that spoken by participants. This is unsurprising: the 'giving' of words and ideas between interlocutors is the very act that brings equitable conversations into being. However, a poem is the product of a creative effort and therefore is distinct from a conversational contribution. It was ethically important for me that participants would be recognised as poets, able to assert themselves as the authors and legal owners of their poems. I was concerned that not doing so could result in the unintended exploitation of participants. If they ever wanted to publish their poems after study participation, they should be free to use them in any way they saw fit. It transpired that this was an unusual stipulation to be included in a Participant Consent Form, requiring advice from the UoE Legal Services department. They devised a statement for the Core Participant Consent Form which confirmed participants would own copyright in their poems and would grant a licence to me and the University to reproduce the poems here in the thesis and in any other reports or publications connected with the study. (See Appendix A for Core Participant Consent Form.)

### 3.5 Chapter Summary

In this chapter I have described how the PaMS study has evolved from a desire to explore my own lived experience of MS through poems. I have laid out the ontological and epistemological theory which underpin my thinking and practice and have discussed the multiplicity and plasticity which is at the heart of this research. My positioning within the research has been made explicit, and I have explored the complexities of my various study selves with attention to how they impact on: each other; participant–researcher relationships; data creation; and all stages of the research up to and including now as I write this thesis from my situated perspective.

It is, of course, *my* thesis: I am the author of this work, and yet, as discussed, I have attempted to decentre the privileged role of the author and researcher in several ways: my disclosure and openness about my status as a PwMS; inviting participants to write their own poems rather than my creating poems from their spoken data; and insisting that participants be legally acknowledged as the owners and copyright holders of their poems. As I have acknowledged, this attempt at transparency has been complex and has required watchfulness for the possibility for misunderstanding and assumptions between myself and participants.

I have further considered the roles of the participants and described how the study was designed to be ethically informed and attentive to their needs. I have tried to make explicit the tensions between the theme of my research – exploring experiences of ill health – and not causing distress to participants. Furthermore, I have explained how I worked to create an appropriate environment for them to explore upsetting incidents without experiencing further harm.

Dialogue is simultaneously how we communicate our selves and how we create those selves; it is both the process and the product of living. Dialogue in Bakhtin's conception can be finished but is unfinalizable and therefore so is this thesis. Everything I have written above and in the chapters to follow is provisional, a pin stuck in a map of space and time. This thesis represents my best attempts to say that which I can know, or gesture towards, about the research and its participants up to now. Like all sense-making, I create these meanings in the act of becoming; the participants' becoming and my own. We are always becoming, and these words are part of an unfolding and evolving dialogue.

In Chapter Four, I will describe and evaluate my research methods and study design, including how I attempted to be consistent with the ontological and epistemological values identified above.

## Chapter Four

### Method

*'What else than a natural and mighty palimpsest is the human brain? Such a palimpsest is my brain; such a palimpsest, oh reader! is yours. Everlasting layers of ideas, images, feelings, have fallen upon your brain softly as light. Each succession has seemed to bury all that went before. And yet, in reality, not one has been extinguished.'*

De Quincey (1985, 119)

In this chapter I describe my research methods and practice in the study. In section 4.1, I address the research design impact of the emergence of COVID-19. Section 4.2 describes my recruitment strategies and sample. Section 4.3 is a discussion of the data creation process and Section 4.4 considers my own writing practice during the research. I go on to discuss my transcription choices and experiences in Section 4.5 and in Section 4.6 I present my chosen analysis methods. In Section 4.7, I summarise and offer concluding thoughts on the chapter.

#### 4.1 Switch to online research

Originally the PaMS study was designed to take place with support from the Anne Rowling Regenerative Neurology Clinic (ARRNC) in Edinburgh. The main research question focused on whether poems written by PwMS could impact on communication with their neurology teams and recruitment was planned to take place at the clinic from a pool of eligible PwMS attending routine outpatient appointments. UoE sponsorship had been obtained and a favourable opinion had been given by the National Health Service (NHS) East of Scotland Research Ethics Service. A temporary NHS contract had been issued to enable me to work on site at the clinic. However, shortly after recruitment commenced in February 2020, it became obvious that the newly emerging COVID-19 virus would make the study impossible in its current form. Accordingly, the research was halted and I developed a new study design

which focused on communication between PwMS and their close contacts (friends, family members, carers) rather than their clinical practitioners.

With the advent of lockdowns and the designation of PwMS as a COVID-vulnerable group, it became clear that all study activities would have to take place online. Initially I felt resistant to this and was concerned that conducting interviews and workshops online would be awkward and off-putting for the participants, resulting in a minimal sample and limited or inhibited data. Writing about this in my study journal, I realised that, while these concerns were valid, my lack of experience with online workshop facilitation was causing some of my anxiety and reluctance. Before formulating the study design, I learned about online data collection (Salmons, 2016) and attended a webinar with Dr Janet Salmons. This encouraged me to consider relevant practical and ethical implications for online research.

Subsequently I formulated a new study design. The table below briefly summarises the new design and the ways in which it differs from the original planned study.

*Table 1: Summaries of PaMS Study and pre-pandemic planned study*

New PaMS Study	Pre-pandemic planned PaMS study
Online recruitment of nine PwMS via social media and MS charities websites.	Face to face recruitment of nine PwMS at The ARRNC, Edinburgh.
Online 1:1 initial participant interviews to find out about their lives with MS.	1:1 initial participant interviews at UoE to find out about their lives with MS.
Online group poetry writing workshops, (planned for three groups because of online format).	Group poetry writing workshops at UoE (anticipated two groups depending on availability and support need of participants).
Participant poem sharing with personal contacts via face-to-face or online methods.	Participant poems to be shared with clinicians at ARRNC, Edinburgh.
Follow up interviews with participants.	Follow up interviews with participants
Recruitment and interviews of reader participants.	Recruitment and interviews with selected clinicians from poem sharing event.

The new study design and protocol obtained sponsorship from the UoE College of Arts, Humanities and Social Science and a favourable opinion was given by the Counselling, Psychotherapy and Applied Social Science Research Ethics Committee.

## 4.2 Recruitment

### 4.2.1 Recruitment of Core Participants

#### 4.2.1.1 Core Participant inclusion criteria

It was determined that participants should:

- **Be aged 18 or over.** Thus, I avoided the additional ethical and procedural restrictions specific to working with under 18s in a group setting where other adults are also participants. It was also possible that participants may have wished to discuss adult themes of their MS experiences (e.g. sexual dysfunction or financial hardship), and they may have felt inhibited from engaging with such themes if under 18s were also participating.
- **Have had a diagnosis of RRMS, PPMS or SPMS for a minimum of one year.** Newly diagnosed PwMS may be at greater risk of experiencing acute stress and possibly distress or depression. By excluding them from the study, I aimed to minimise potential emotional harm. This strategy was also intended to reduce the risk of attrition as newly diagnosed participants may have been overwhelmed with the recent change in their circumstances.
- **Be resident in the UK.** This avoided ethical and procedural restrictions specific to working with participants from other countries and allowed a focus on the particular cultural and societal elements of living with MS in the UK.
- **Be sufficiently fluent in English that they felt able to participate fully in the reading and writing aspects of the study.** Participants' poems were intended to be shared with the researcher and other members of the workshop group and therefore needed to be written in English. By excluding poems written in languages other than English, the

study avoided potential disruption of workshop dynamics caused by the presence of a translator. It also avoided the further complication that a translated poem is in itself an act of interpretation and distinct from the communication of the original poem (Szirtes, 2014).

The research Protocol also made provision to exclude potential participants who did not have the capacity to give informed consent at the point of recruitment. I judged this on the basis of email and video conferencing conversations that I had with potential participants. The only participant for whom this might have been an issue was Saskia<sup>7</sup> who was in the early stages of dementia, however she was competent and confident in all of our interactions, and adjustments were made to support her slowed communication (small workshopping group, interview questions emailed in advance).

In order to support the wellbeing of potential participants, it was also stated in the PIS that the process of reflecting on MS experience might prompt emotions that participants were not expecting. Therefore in the PIS, I said that participants might choose to 'take a break or have a chat' with me if feeling upset and that I may suggest additional avenues of support, such as contacting their GP or MS telephone helplines if appropriate. I recognised that it was essential that any potential risks or disadvantages to participants were made explicit in advance and therefore contributed to their informed consent to participate. (See Appendix B for PIS.)

#### 4.2.1.2 Sample size

When determining sample size, I took into account the fact that participant engagement would be both deep and relatively long-lasting (a maximum of two interviews and four workshops over two or three months). Yet there was potential for substantial attrition because of the extended nature of the participation and possible health complications of the participants. The issue of data saturation did not arise as it felt inconsistent with the creative approach of my research in which each poem represented a new and unique item of data. Therefore, I sought to ensure data sufficiency, although I acknowledge that

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<sup>7</sup> All participant names used in this thesis are pseudonyms chosen by the participants.

'sufficiency' in creative qualitative research may vary widely and may depend in part on the practical limitations of an individual study. For example, in this research it was imperative that I be mindful of both my participants' and my own potential for fatigue, and I tried to set data expectations accordingly. I was guided by Malterud, Siersma and Guassora (2016) and Morse (2010) who state that in qualitative health research which involves multiple interactions with participants and results in a large amount of data, a sample size of 6-10 participants can generate sufficient project data. In conjunction with my supervisors, I decided that a minimum of six rising to a maximum of nine participants would be recruited, allowing for potential attrition. Nine was chosen as the maximum, rather than ten, because initially I planned to allocate participants to three workshop groups of three participants each.

The only attrition that occurred was Eleanor who attended her first interview and all four workshops but did not reply to invitations to attend a follow up interview. She did not contact me to say she was withdrawing from the study and she did not retract permission for her data to be used. Accordingly her data was analysed and is discussed within this thesis.

#### 4.2.1.3 Core participant recruitment strategies

I created a study-specific website, a Twitter account, @StudyPoetry, and a Facebook account, all of which I used exclusively for the purposes of recruitment. (See example screenshots in Appendix C.) Tweets and posts directed interested people to the study website where I displayed the PIS. The website also explained the Study aims and structure in lay terms across several short pages on the site, including an 'FAQs' section so that information could be found easily and in whichever order seemed most relevant to potential participants. In order to maximise engagement and understanding, I also made a short film for the website in which I spoke about the study. (See Appendix D for film transcript.) I felt this was a way for me to be a visible and approachable researcher from the outset.

I wrote blogs outlining the research for the websites of several MS charities. (See example blog in Appendix E). These blogs directed potential participants to the study website and

invited them to contact me via my university email address. In addition, MS Society Scotland invited me to deliver an online poetry workshop for their service users at which I was able to share brief details of the study. Via my poetry networks, I also disseminated information about the study in a blog which I wrote for StAnza Poetry Festival.

#### 4.2.1.4 Core participant recruitment timeline

*Table 2: Timeline of Core Participant Recruitment*

June 2020	Recruitment begins.
August 2020	Recruitment paused. Workshop Group One (three participants) and Workshop Group Two (two participants) begin.
September 2020	Recruitment resumes.
November 2020	Recruitment completed when maximum of nine participants reached.  Workshop Groups Three and Four begin.

#### 4.2.2 Recruitment of Reader Participants

As stated in 1.4, the purpose of recruiting reader participants was to explore the experiences of the poem sharing experience from the readers' perspectives. However, as the primary focus of the study was the core participants' experience, recruitment of reader participants was supplementary. Accordingly, I decided that a sample of 2-4 reader participants would provide sufficient data. I recruited reader participants informally via core participants. In their follow up interviews, I asked some core participants whether they would be happy for me to speak with any of the people with whom they shared poems. If they agreed, I invited consenting core participants to approach these people to ask if they might be interested in speaking to me about the experience. My contact details were then given to the potential reader participants by the core participants so that they could find out more and read the Reader Participant Information Sheet (Appendix F). People who went on to choose to participate then completed the Reader Participant Consent Form (Appendix G).

### **Reader Participant inclusion criteria**

- **Be aged 18 or over.**
- **Be resident in the UK.**
- **Have read one or more poems by a core participant.**
- **Be fluent in English.**

### **4.2.3 Sample**

Below I give a brief biographical summary of each of the recruited participants. This information is given in the order that I first interviewed them. Demographic data (age, location, profession) were collected informally, with participants often volunteering information in their introductory emails to me or during their initial interviews. Occasionally, I requested clarification during, or after, initial interviews if, for example, a participant had not told me where in the country they were based. The information given about reader participants is less detailed than for the core participants. This reflects the level of personal information disclosed in the two different categories of participation.

#### **Core Participants**

Nina (35) was diagnosed with RRMS seven years before her study participation. Her symptoms at the time of participation were mostly limited to numbness and tingling in one hand, although she had previously experienced brain fog and numbness in her feet and legs. She lived in a town in Scotland's central belt with her husband. Nina worked full-time in marketing and communications for a large public sector organisation. She had previously worked for an MS charity. Nina had written prose in her professional roles but had not written poetry prior to her participation although she had studied some for Higher English at school.

Ellen (59) was living in the Southeast of England with her husband, adult son and adult daughter. She had been diagnosed nineteen years earlier with RRMS. Her symptoms included fatigue and debilitating pain. Her walking and balance were impaired and she used

a wheelchair when outside her home. Ellen had stopped working because of her MS symptoms but she had gone on to train and work as a counsellor for a short time before retiring. Shortly before the first COVID lockdown she had attended a local poetry writing class and had written a poem.

Tilly (60) lived alone in a Scottish city and had been diagnosed with RRMS for thirteen years. Her initial symptoms included weakness and pins and needles. As her symptoms progressed, Tilly used a wheelchair at home and a wheelchair or scooter when out. At the time of her participation, Tilly had been “*on bedrest*” for over a year because of complications from two fractured vertebrae. She also had very limited use of her right hand and experienced fatigue. Tilly had two adult daughters and one grandchild. Prior to retiring through ill health, Tilly was a social sciences lecturer. Since then she had taken up art and writing poetry.

Saskia (58) had been diagnosed with MS five years earlier. At that time, she had been living overseas for almost twenty years but she returned to England because her MS symptoms (difficulty walking, nerve pain, cognitive problems) were getting worse and she wanted to be nearer to family. Saskia lived alone but her adult sons, grandchildren and elderly mother lived nearby. Prior to her participation, Saskia had also been diagnosed with early onset dementia which may be connected to MS. Dementia was impacting on her verbal abilities to find words and remember the thread of conversations; however she remained very articulate in writing, an activity which she enjoyed. Before retiring, she had been a nurse and had also completed a Bachelor’s degree in an unrelated subject.

Philippa (50) lived in a small town in a rural area of Scotland with her husband and teenage son. Her older son was also living at home because of COVID restrictions. She had been diagnosed with RRMS five years prior to participation and experienced left-sided weakness, bladder issues, fatigue and brain fog. Her walking was impaired and she used a wheelchair if an excursion involved a lot of walking (e.g. around shopping centres). When younger, she had trained and worked as a nursery nurse but then stayed at home to raise her sons. Philippa enjoyed writing and had written poetry as a teenager.

Memphis (58) had been diagnosed with RRMS eleven years before his participation in the study but had since moved into SPMS. His initial symptoms were pain and weakness in his ankle. Since 2014 he had used a wheelchair and now had a personal assistant to help him with self-care and accessing leisure activities. Before retiring, Memphis had worked as a plumber and an insurance salesman. He lived with his wife in a town in the East of Scotland. In his introductory email he described himself as “*an amateur poet*”. Memphis also undertook fundraising and awareness raising for a respite centre that he visited regularly.

Claudia (50s) lived in a small town on the South coast of England with her husband, adult daughter and her daughter’s boyfriend. She first experienced MS symptoms twenty-three years before her participation. She had subsequently been diagnosed with SPMS and had used a wheelchair since 2016. To manage a pronounced leg tremor, she had brain surgery which resulted in awkward handwriting and changes to her voice which she described as “*difficult*”. (Claudia’s speech was slowed and she spoke in a monotone which did not reflect her mood or personality.) She worked as an art teacher for twenty-two years before giving up work because of the impacts of MS. Claudia continued to make art after retirement. She had written a few poems prior to her participation in the study.

Eleanor (50s) was diagnosed with PPMS in 2012, having experienced optic symptoms and fatigue. The diagnosis was later changed to RRMS. Her symptoms at the time of diagnosis included left-sided weakness and fatigue. She lived in a village in Southeast England with her partner and worked four days a week in the NHS. She had recently completed a second Master’s degree and brought a very inquiring and philosophical disposition to her participation. Although Eleanor enjoyed reading poetry, she had not written any prior to this study.

Alex (48) was diagnosed with PPMS three years before her participation in the project. Her symptoms included issues with balance and coordination, and walking was becoming increasingly challenging for her. She lived in a city in the North of England with her husband and two school-aged daughters, and she worked fulltime at a university library. Previously, she had completed a Bachelor’s degree in English Literature but had no experience of writing poetry.

### **Reader participants**

Matilda – adult daughter of Tilly.

Timmy – aunt and godmother to Claudia.

Peter – youngest brother of Saskia.

Aurora – personal assistant (carer) to Memphis.

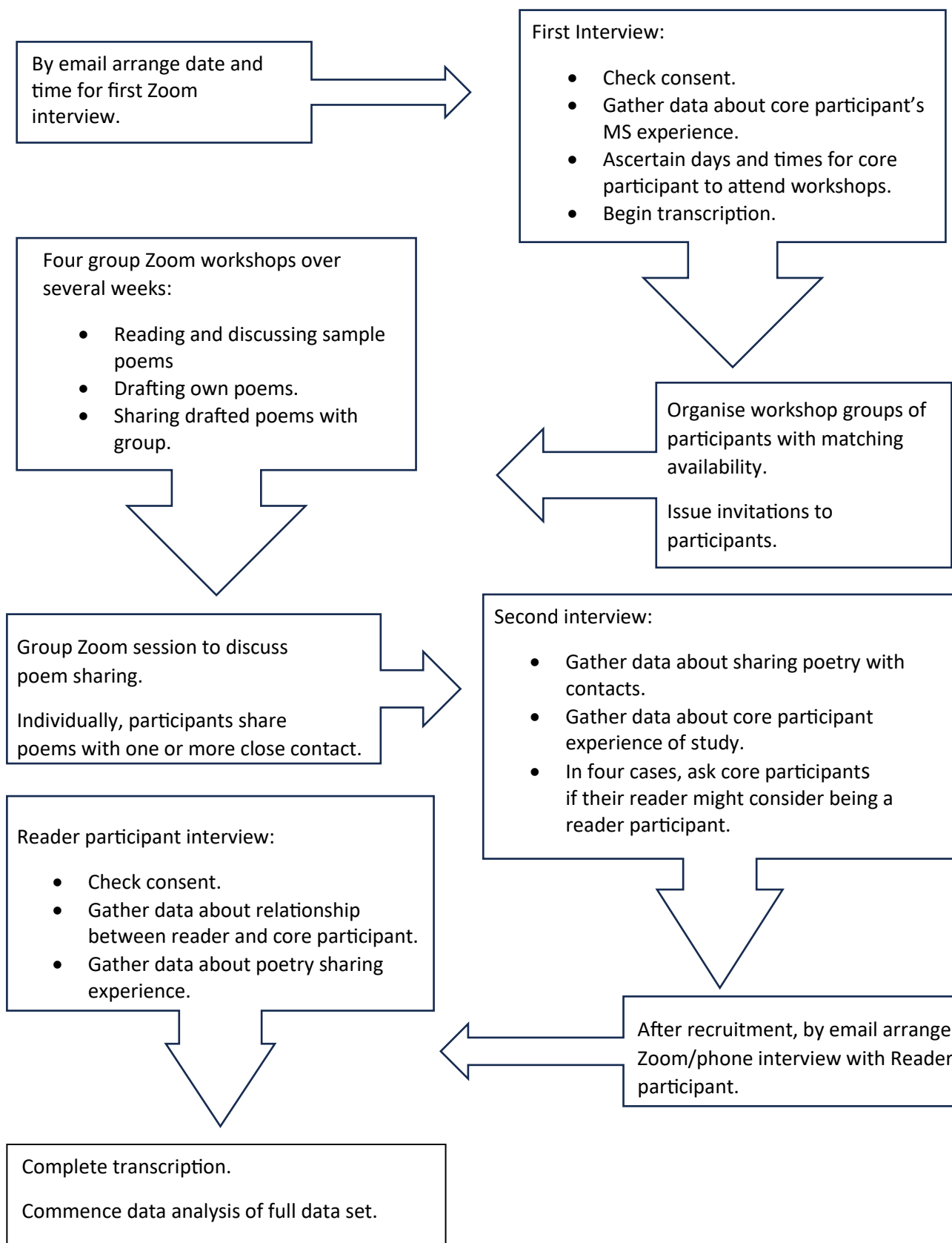
The sample of core participants shows a range of types of MS (5 RRMS, 2 SPMS, and 1 PPMS). Saskia did not specifically disclose to me with which form of MS she had been diagnosed, however her increasing dementia symptoms indicated that she was in a progressive phase of disease. A wide range in symptoms and disability was evident in the participants who had a diagnosis of RRMS. This may reflect the highly active nature of some forms of RRMS. However two of the more severely disabled participants (Tilly and Ellen) both told me that they believed they had moved into SPMS and had not been informed by their doctors. Because many younger people with MS are still able to work fulltime, I had not expected to recruit many participants below the age of 40. However, the sample shows some diversity in terms of age with one participant, Nina, aged 35. The majority of participants were in their 50s, with the oldest, Tilly, aged 60 at the time of recruitment. While the internet is traditionally thought to be a resource used mostly by younger people, this has been changing over the past decade and at the time of recruitment, many older people were increasingly turning to the internet as a means of communication during COVID lockdowns. However some older people may have been discouraged from participating if they were not familiar with the technology used in the study.

A significant number of men are diagnosed with MS in the UK; 106 per 100,000 population (Gov.uk, 2020). However, prior to starting recruitment for the original planned study, I was told anecdotally by other MS researchers that I would not ‘get any men’. They said that in their experience of medical trials, they struggled to recruit men and felt that poetry and the personally discursive aspects of my study would further discourage men from participating in my research. Memphis was the only exception to this anticipated trend. Similarly, the sample lacks diversity in terms of nationality and ethnicity. All recruited participants were white British (5 English, 4 Scottish).

I include information on participants' current or previous occupation to indicate their level of education. While in some cases, this also suggest their socio-economic status, it is not always indicative; one of the participants had worked in a low-earning profession but their spouse worked in a well-remunerated role.

### 4.3.Data Creation

Figure 1: Timeline of Data Creation



#### 4.3.1 Context of data creation

I use the term 'data creation' rather than 'data collection' as it accords better with my epistemological position in this research. Evidently the poems were written in conscious creative acts by participants in the study workshops. However, I hold that the interview data is also co-constructed between the researcher and participant in dialogical attempts to make meaning, even if some of the influences (intonation, body language) may be unconsciously made by one speaker and similarly received by the other. Thus by using the phrase 'data creation', I aim to be transparent and mindful about my active role in the dialogues.

In most cases, data creation was arranged and conducted during periods of government-mandated lockdowns in Scotland and England. Anxiety and isolation were evident across UK society, and this was especially present in the disabled and chronically ill communities who were deemed to be at greater risk of severe illness or death from COVID-19 than the general population. Although at various points in data creation these restrictions were temporarily eased, some participants were either officially shielding at home on medical advice or had decided to shield because of their increased susceptibility to severe illness with COVID-19. This had two impacts on the study: firstly, people who may previously have been reluctant to engage with unfamiliar technology such as Zoom, the platform for the interviews and workshops, were prepared to give it a go. For some participants, video conferencing was the only way that they could see their friends or family during this time so it quickly became normalised as a method of communication. Via email, I offered support to participants who were using the technology for the first time or were finding it difficult to negotiate. Also, in a couple of cases, participants' family members helped them to join the Zoom meetings. Secondly, the interviews and workshops represented a rare opportunity for social contact during this time of enforced isolation. It is very possible that this bolstered the level of participant attendance in study activities.

### 4.3.2 Interviews

Initial interviews were designed to explore core participants' experience of MS and how they communicated this to others. The interviews were conducted 1:1 from our homes via Teams or Zoom. Because of her dementia-related speech issues, I sent Saskia the questions in advance and she emailed me her responses before our Zoom interview. We then used the interview to talk through her answers and as an opportunity for relationship building. This allowed us to assess whether Saskia was able to manage the Zoom interaction. She seemed to cope well and was happy to proceed. Sometimes she wandered from the topic or had word finding difficulties but we were able to negotiate a path round these. I also experienced occasional word finding problems and Saskia seemed more confident knowing that she was not the only person in the study with that symptom.

The length of interviews was dictated by the participants, as I had told them that we could stop at any time if they were tired or unwell. As a guide, in the PIS, the interviews were described as lasting 'around an hour, but can be longer or shorter to suit.' With participant consent I made audio-recordings of the interviews. Through the semi-structured format of the interview, I attempted to increase the participants' agency and control over the experience, and I encouraged them to approach the questions in any way they chose. This format gave them the opportunity to tell me as much, or little, as they wished about any topic. Memphis, Nina and Alex's initial interviews took about one hour whereas the longest interview with Philippa lasted over one hour and forty minutes.

In most cases it took me and participants a little time to settle into the interview. I reflected in my study journal that the edges of a digital meeting are less flexible than those of an in-person meeting. You are either in the Zoom meeting or not, whereas if the interviews had taken place at the university, there would have been the fuzzy borders of moving together from the lobby to the meeting room, valuable time for small talk and getting used to one another's voices, mannerisms and self-presentations. Accordingly, I encouraged general chat at the beginning of the digital sessions to put both parties at ease. Lots of talk about pets, hair styles, weather and COVID case rates ensued, but I maintain that this was an important step towards relationship building between myself and the participants and, in

workshops, between participants. I was acutely aware that participants were committing to engaging with me, not just as a researcher conducting interviews, but also as a creative workshop facilitator; it therefore felt important to build ease, trust and informality from our first meeting.

The interviews proper were bookended by procedural and practical elements. After the initial chat, I asked participants to verbally confirm the consent forms which they had already signed and emailed to me. I also reconfirmed participant consent to audio-record the interview and subsequent sessions. Then, at the end of each interview, I asked about any accessibility requirements which would facilitate their workshop participation.

In interviews I encouraged participants to explore the following themes with me: thoughts and feelings about their lived experience of MS; how they talk about MS with others; and any existing relationship they may have with poetry. I used the questions below as ways to introduce the themes.

- Can you tell me a little about how you see yourself as a person with MS?
- How do you talk about your illness to family and friends?
- Do you use any particular words or images to talk about your experience of MS?
- How much do you feel that others understand what you are trying to tell them about MS?
- What role, if any, does poetry play in your life?

Obviously, it is not possible to negate the power disparities between researcher and participant, however by making space in interviews for participants to ask me questions, I hoped to acknowledge and possibly begin to trouble the accepted dynamics of the research relationship. Several participants asked me whether I have MS even though this information had been disclosed in the PIS. People variously asked which type of MS I have and how long I have been diagnosed. Overall there was a sense of similar experience which may have led to increased sharing by participants or them feeling more at ease.

In the first few interviews I invited participants to suggest questions that I should ask them. None of the participants took me up on this offer to overtly shape the interview and some

looked confused by my invitation. In retrospect, I realised that participants are not necessarily interested in or disconcerted by power imbalances in the research relationship. Indeed, the very structure that I found concerning, my having sole responsibility for deciding the themes of inquiry, may well have given them confidence in their roles as participants. Accordingly, in later interviews I stopped inviting participants to tell me what they thought I should ask. However, I always inquired if there was anything more they wanted to tell me after they had answered all the questions.

My own primary intended outcomes for the study were, I felt, transparent and universal among PhD students: as a post-graduate researcher, I hoped to make a novel contribution to knowledge in my discipline and thereby gain a PhD. However, I was keen to understand, and potentially facilitate participants' aims, so, if time allowed at the end of the interview, I asked what they hoped to achieve from taking part in the study. Responses included increased confidence in writing poetry (Memphis, Claudia); new ways of talking about MS (Alex, Claudia, Saskia); insights into their relationship with MS (Eleanor); opportunity to do something different (Alex); "*a wee bit of enjoyment*" (Memphis); social interaction (Alex); meeting others with MS (Alex, Claudia); and "*sharpen my mind*" (Saskia).

#### 4.3.3 Workshops

There were four workshop groups: one of three participants (Nina, Philippa, Tilly) and three of two participants (Ellen and Saskia, Claudia and Memphis, Alex and Eleanor). Although initially I had planned to conduct three workshops of three participants each, in reality some participants could only attend on particular days or at certain times because of prior engagements, established care routines or energy patterns. Therefore, as recruitment continued, it became practical to create smaller groups. Also, being in a smaller group had benefits for Saskia as there was more space and time within those workshops for her to collect her thoughts and express herself whereas a larger group may have overwhelmed her. The small group setting may also have been advantageous for Claudia because, although her cognitive capacity was not an issue, her speech was slow.

An inherent risk in any workshop made up of participants who do not know each other is that people may not get along. This can be a particular problem with small workshop groups where participants can't be put into different sub-groups for discussion activities. However, all of the participants found common ground on which to build their relationships and treated one another with kindness, respect and good humour throughout. I am grateful for this commitment that they showed to creating a positive and supportive creative environment.

Each participant was invited to attend four workshops in their group. Workshops were held approximately weekly, although occasionally, there were some longer gaps between sessions e.g. for Christmas holidays and participant or facilitator illness. I designed the number and frequency of the workshops so that if participants missed one or more sessions, they would still have sufficient opportunities to make a meaningful contribution to the study. However, whenever a participant contacted me to say that they were unwell and wouldn't be able to attend the next session, their fellow group participant(s) always elected to postpone the session so that their peer would not miss out. This allowed participants to receive feedback from as many people as possible about their workshop poems, but also was indicative of the mutual understanding and support that they displayed towards each other and me.

Workshops were planned to last 90 minutes and a break was included halfway through every session. Additionally, I told participants they could take as many additional breaks as they needed and there was flexibility so that if participants felt unwell, workshops could be shortened, or individual participants could leave early. In practice, these accommodations were not used by any of the participants, and, in some cases, workshops ran over 90 minutes as there was so much talk in the groups, both in terms of social chat and poem discussion. This informal chat also fulfilled a need, identified by participants, for social interaction during COVID-19 lockdowns.

The main purpose of the workshops was for participants to explore and express their health experiences through writing poems. Each workshop was designed around a theme relating to MS experience:

1. **MS as Metaphor:** this introduced the idea of using metaphor to describe individual experiences of MS and encouraged participants to reflect on the ways MS impacts their lives.
2. **MS and the Body:** exploring symptoms and somatic experience of MS.
3. **MS and Other People:** considering how MS impacts or constructs our relationships.
4. **Dreams:** a loosely themed workshop, encouraging participants to consider their sleeping dreams or their hopes and aspirations and how these are impacted by MS.

The basic structure of each workshop and approximate timings were:

- Hellos and informal catch up (10 minutes, often more)
- Prompt poem reading and discussion (20 minutes)
- Idea generation activity e.g. list making, visualisation, free writing (10 – 15 minutes)
- Break (10 – 15 minutes)
- Poem drafting (20 minutes)
- Poem sharing and feedback (10 – 15 minutes)

### **Prompt poem reading and discussion**

The prompt poems were all by published poets and I chose them because they were variously: clear examples of metaphor; about an ill body; about a disabled or ill person in relation to others; and a retelling of a dream. They represented a range of poetic styles, although all were in free verse, because I did not want participants to be put off or confused by the complex 'rules' of some stricter poetic forms. Also, given the relatively short length of workshops, I did not feel that I had adequate time to explain the technicalities of metre and rhyme. None of the prompt poems were about MS because I wanted the participants to feel free to create their own MS writing rather than thinking that their poems had to converge with or mimic that of 'proper MS poets'. I used the same prompt poems and activities across all the workshop groups with the exception of Workshop 3, discussed below. Prompt poems are reproduced in Appendix H, however here I give brief details of their titles, poets and main themes.

Workshop 1: excerpt from 'Grief' by Matthew Dickman (2008, 54). This 23 line passage from a longer poem imagines grief in the surreal form of a purple gorilla. The grief gorilla visits the reader who must accommodate her. I chose this poem in order to show a metaphorical representation of a difficult state or experience.

Workshop 2: 'Migraine' by Kitty Coles (2017, 204-5). This poem describes having a migraine. I chose it because Coles' writing is deeply embodied and, for me, represented her direct experience unmediated by medical interpretations.

Workshop 3: 'What Can You See?' by Holly Magill (2017, 48). This short poem is about a sighted person questioning a blind or partially sighted person about their vision. I chose it because of its potential to prompt participant conversations regarding their interactions with others about MS, particularly in terms of unwanted attention from strangers, which several participants had mentioned in their initial interviews.

Workshop 3 (additional poem with groups 1 and 4): brief excerpt from 'Homage to Clotho: A Hospital Suite' by L.E. Sissman (2009, 128). I used an eight-line segment of the poem in which a hospital patient considers the behaviour of a nurse preparing him for surgery. With Group 1 in Workshop 3, I introduced this poem in addition to 'Migraine' in order to encourage discussion of clinical interactions. On reflection after the workshop, I noted that this had weighted the workshop too much towards writing by others and had the potential to overload and confuse participants. Additionally, participants in all groups seemed eager to discuss medical interactions regardless of the poem's inclusion. Subsequently I only used 'Migraine' in workshop 3 with Groups 2 and 3. However, with Group 4, who were more experienced and confident readers of poetry, I reintroduced the second poem as both Alex and Eleanor seemed to gain particular pleasure and benefit from discussing prompt poems.

Workshop 4: 'In close' by Kristiina Ehin (2013, 61). This poem describes a dream in which the voice of the poem buys a ticket for a bus journey. I chose this poem because its understated, surreal quality had an openness which I hoped would encourage participants to approach their final workshop poem with a spirit of enquiry and write about whatever felt right for them.

### **Idea generation activities**

These were designed to start us thinking of possible topics or phrases to include in our poems. One of the most popular idea generation activities, frequently mentioned by participants in their follow up interviews, was freewriting. I set a timer for five, seven or eight minutes, and we would write whatever came to mind about the workshop's theme in prose or notes. Participants could then use these freewrites to scaffold their poem drafting by incorporating phrases or ideas from the initial activity. This was a shorter and targeted version of Natalie Goldberg's (2009) timed writing exercise.

In my teaching experience, freewrites are very helpful. I often tell students that freewriting is creative writing's equivalent of stretching before a run, but they had additional benefits in the PaMS workshops. Freewriting allowed participants to work through stuck or unprocessed thoughts: *"I like that idea of just blurbing out a lot"* (Philippa); *"I couldn't believe that out of, you know, all the jumbled thoughts in your head and then you would be able to construct something out of that"* (Nina). It also reduced creative anxiety, especially for those participants who had little or no experience of writing poetry: *"You haven't got a blank page because you've just spent twenty minutes filling it with stuff so that, you know, then it was a lot easier to pick bits out and put a poem together so that was really helpful"* (Alex). In advance I told participants that I would not ask them to share their freewrites with anybody. This was so that they could view them as safe and private spaces to record their thoughts and ideas without fear of judgement from me or their fellow participants.

### **Poem drafting**

After the break we returned to our freewrites or notes and used them as the basis to draft poems. I was available to support individuals as required during any of the idea generation or poem writing activities, although once people had settled into activities, I was rarely called on to do this and so I usually also wrote in response to the workshop prompts alongside participants. In my experience of attending and leading creative writing workshops, this is standard practice when time and circumstances allow. In this way, we established small 'communities of practice' (Peary and Hunley, 2015, 190) in which I, as facilitator, evidenced that I place value on the workshop activities and am willing to take on

the same creative risks or challenges that I ask of participants. Rather than adopting a teacher's role and waiting for participants to finish their writing, I immersed myself in the activities, deepening the sense of shared experience. While the balance of researcher-participant power was not entirely subverted – I chose the prompt texts and writing activities – by writing alongside participants, I identified as a member of our writing community. I also used some of this time to write brief field notes about the workshops.

These notes, generally short phrases scrawled during gaps in workshop conversations and poem drafting, were far less detailed than my journal writing in which I undertook more deeply reflexive consideration of the data creation and analysis processes. My in-workshop field notes were generally aides memoires designed to capture details of the workshops that the audio recording would not pick up, e.g. a participant's expression or gesture. I also attempted to record my sense of the mood or atmosphere of the workshop e.g. '++ laughter again today, more easeful than last week. Getting comfortable w. each other?' These notes were also a way for me to record if something had come up in a workshop that hit me sharply or deeply, especially if this was unexpected – 'E's mum like [person in my life]? The MRI conversation. Feel angry-sad.' Notes like this would be unintelligible to anyone else, but they allowed me to quietly acknowledge my own heightened feelings and increased awareness of my very human vulnerability during some workshop conversations (Gadamer, 1995). Then I was able to respond to participants in ways which prioritised their experiences. Later, when I returned to analyse the workshop data with these notes alongside the transcripts, I was better placed to assess whether and how my own feelings had impacted the workshop interactions.

### **Group poem sharing**

After we had completed the writing activities, I invited participants to share their poems with the group and/or to feedback about that workshop. It was my intention that, by sharing their work with one another in a supportive and confidential group environment, participants would begin to develop an awareness of how sharing their work affects them and whether they might be comfortable sharing their poems with others later in the study. Participants were told that sharing their work with one another was voluntary. In Workshop 1 of Group 3, Claudia did not want to share her poem as she felt that it wasn't finished and

was uncomfortable with what she perceived as the uncharacteristically negative mood of her poem<sup>8</sup>. In all other workshops, all participants shared their poems. (See Appendix J for all participant poems.)

At the end of workshops with Groups 1 and 4, I usually shared my own workshop poem, or an excerpt from it, and the groups briefly commented on my writing too. Again this corresponds with standard creative writing workshop practice. It was also, I felt, a way of demonstrating that, even though some participants viewed me as the expert, my own workshop writing could be unfinished, unpolished or even unsatisfactory to me as its author and still be a valid outcome. Thus, I hoped to challenge expected researcher–participant power dynamics and also create reasonable expectations of what we might achieve in a relatively short workshop. However, with Groups 2 and 3, I didn't share much of my own writing. This was because I was aware that conversations in these groups moved more slowly so I was reluctant to make the workshops unnecessarily long.

With participant consent, all workshops were audio-recorded in order to support me in planning subsequent workshops and as a way to record any comments participants made that illustrated their creative processes.

#### 4.3.4 Follow up interviews

Prior to conducting any follow up interviews, I conducted Zoom sessions with the workshop groups in order to discuss what sharing their poems outwith the workshops might involve and also to encourage participants to think about which of their workshop poems they might want to share. These sessions also gave participants opportunities to ask any questions they might have about the sharing process and to celebrate the poems they had written during our time together. I did not record these sessions. Then I stayed in occasional email contact with participants until after they had shared their poems with at least one other person. The length of time this took varied between participants but was generally between a couple of weeks to a month. Once poem sharing had taken place, I arranged follow up interviews with core participants. The purpose of these interviews was to explore

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<sup>8</sup> Claudia's reluctance to share on that day and the fruitful conversation that followed between Claudia and Memphis are discussed in detail in 6.5.

participants' perspectives of their workshop experiences and to gather data about the process of sharing poems with their chosen readers.

These semi-structured Zoom interviews generally lasted around an hour, although in a few cases they lasted longer and included a lot of social chat. The longest, Philippa's, lasted for approximately 1 hour and 50 minutes. As with Saskia's initial interview, I sent her the questions in advance by email and she answered in writing, ahead of our Zoom meeting. Although in many cases questions were modified in order to reflect the specific circumstances of participants, the following questions represent the foundations on which we built our follow up interview conversations:

- How did you find the workshops?
- Do you feel that your writing changed or developed through the course of the workshops? Tell me about that.
- Do you feel that you expressed anything new about your experience of MS? Tell me about that.
- Tell me about sharing your poems with [friend/family/carer]?
- Has taking part in the study affected how you see yourself as a person with MS? How?
- More generally, have there been any changes in how you express your MS experiences when talking with others? Can you tell me about those?
- What, if anything, do you feel you've gained by taking part in the Poetry and Multiple Sclerosis study?

Overall, the questions opened up fruitful conversations, in which participants reflected deeply on their experiences of talking about, writing and sharing poems. With the first question, while I had been aiming for a very general inquiry which encouraged participants to respond with whatever felt most relevant or important to them, in most cases, I followed up with specific prompts about the reading activities, writing activities and interactions with other people in the group. In retrospect, given the importance of the workshop interactions that emerged in analysis, I may have devised questions which were more specific.

There was space in the follow up interviews to have detailed conversations about participants' poems which had been particularly meaningful or important for them. This allowed me to further my understanding of the participants' writing and to pick up on aspects which may not have been evident in the workshops. This gave me greater confidence when analysing participant poems. Occasionally however, I did not have a poem at hand when a participant mentioned it, and once, it took me several minutes to find the relevant poem on my computer in order to screenshare it in the Zoom meeting. While the participant was understanding, I felt if I had been better prepared for that interview, I would have appeared more professional.

When talking about the workshops, I also asked participants if they would have liked me to do anything differently. Although I tried to reassure them that I viewed any critique as constructive and valuable information, I was aware that participants did not want to offend me or damage the close research relationships we had built. Only a few participants suggested any modifications: Saskia "*would have loved longer [workshops] but appreciate fatigue may have been an issue*"; Alex would have liked more information about the technical aspects of poetry; Tilly would have liked "*some critical feedback but that wasn't really the point of the workshops*". She also said that she realised that type of feedback would have been difficult to manage with a new group who didn't know how receptive one another were to criticism.

#### 4.3.5 Reader participant interviews

Three of the four reader participant interviews were conducted via Zoom. Timmy requested a telephone interview. These interviews were shorter than core participant interviews lasting between 25 minutes and 53 minutes. The semi-structured interviews were structured around the following prompts and questions:

- Can you tell me about your relationship with X in terms of their having MS?
- Tell me about the poem sharing with X.
- Did this provide any additional insights into X's experience? If so, can you tell me about them?

- Did the poem(s) or talking about the poem(s) lead to any changes in the conversations you have with X? If so, how?
- Are there any other impacts of the study that you'd like to tell me about?

In these interviews I was aware of a strong desire in reader participants to support and care for the PwMS in their lives. Participating in the study was a novel way for them to enact this support and focus on a recent achievement by their relation or care recipient. In three cases, the reader participants spoke of their perceived inadequacies in dealing with the impact of MS for the other person: both Peter and Timmy spoke of being unable or uncertain how to do more for Saskia and Claudia; Aurora talked at some length about her desire for further specialised training in order to support Memphis better. The depth of emotion shown by these reader participants took me by surprise and, although I listened and made space for their feelings and experience, I feel I might have better anticipated this aspect of their interviews. In Chapter Eight, there is a detailed discussion of the data, outcomes and limitations of this arm of the study.

## 4.4 Thinking through writing

### 4.4.1 Reflexive journal

Throughout the research I have kept a reflexive journal where I think through my ideas and study experiences in prose and poetry. Very often this has functioned as a space where I can write out any concerns on either theoretical or practical themes. I have recorded field notes in my journal, brief phrases scribbled during interviews or workshops and longer notes written afterwards, in which I have reflected on the events of the session and the developing research relationships. Because of my close involvement with the research subject, on occasion, after interviews or workshops, I have recognised similarities between my own MS symptoms and those that a participant experienced at an earlier stage in their disease progression. Sometimes, as a result of (over)thinking this, I have felt very anxious about the potential directions that my own health may take. Writing about these feelings has been helpful in a number of ways. Converting sweaty-palmed panic into words on the journal page has allowed me to name my monsters and articulate my fears. That act of

verbalization has created a distance. This distance is not objectivity, but, like time, it allows me a space to reflect on my anxiety, to pick at the illogical seams of my panic, and to emerge calmer.

Looking back over my journal writing, it is a curious, at times discordant, combination of academic and very personal writing. Initially I was concerned, even embarrassed by the tone and theme of some of my journal entries; they were not reasonable or profound, but raw and exposed. They were not, I worried, the notes of a researcher. However, by writing through my writing, and reflecting on my reflections, I have come to realise that the journal represents an assemblage of my writing selves that are present in the study: Georgi-as-Researcher meeting Georgi-as-PwMS meeting Georgi-as-Poet. Each of these intersectional constructions of me are intrinsic to the research and the relationships and co-creations facilitated within the study; as Stanley and Wise (1993, 157) state, 'there is no method or technique of doing research other than through the medium of the researcher.'

My more personal journal writing is perhaps akin to participants' experience of the freewriting activities that we did in workshops. These were opportunities for me, like Philippa, to "*blurb out a lot*" of emotion and tangled thoughts which we could then tease out when writing something that would hopefully be more cogent and audience-directed; in Philippa's case poems and in mine this thesis. The image of a palimpsest comes to mind; a manuscript on which text has been effaced and replaced by later writing, yet the traces of the earlier words remain. I realise that all of the texts of this research (poems, transcripts, field notes and this thesis) are to a greater or lesser degree palimpsests, carrying the sense-making of those that have gone before them. Returning to the idea of multiple and shifting constructions of self that I laid out in Chapter Three, I realise that I am, that we are all human palimpsests.

#### 4.4.2 Poems

As mentioned above, I wrote poems alongside participants during the workshops and also wrote poems in my reflexive journal. The decisions to write poems in the journal were instinctual, a reflection of whether I was in the mood to write poetry or prose. Around the

time of data creation, I started to experiment with how poetry can interact with academic and research texts, writing found poetry that used my own words from workshop transcripts as their basis. Unlike the workshop poems where I wrote discretely on the given theme of the session as a PwMS, these poems gave me opportunities to sit with data differently and made space for reflections on the complexity of my location in the study. Through writing reflexive poems, I felt I could be 'accessible, visible, and present...in ways that traditional writing forms discourage' (Denzin, 2014, p. 86). Additionally I wrote some erasure poems, using as a starting point, dictionary definitions of terms including *symptom*, *anamnesis* and *multiple sclerosis*. By removing letters from key given words of the definitions, I problematized the readers' efforts at sense-making by attempting to create for them an experience similar to the slowed cognition of brain fog or optic neuritis. These pieces did not necessarily result in satisfying poems; rather they were intended to frustrate the usual reading experience and were therefore difficult to understand. However, they were an interesting experiment in trying to recreate one person's phenomenological experience for another. When transcribing, I also made a found poem from things I had said in interviews and workshops as a way of exploring the visible impacts of MS on my functioning as an interviewer and workshop facilitator. (See Appendix K for samples of these poems.)

## 4.5 Transcription

A transcription of a verbal exchange is not identical to the conversation but is a representation of it; therefore transcription is itself part of the interpretive, or analytic, process (Mishler, 2003). In this way it is not dissimilar to a poem which has been translated from a different language and is itself an original work. I made decisions about what and how to transcribe recorded interviews with this in mind.

### 4.5.1 Interview transcription

I attempted to transcribe all speech, including my own, within the interview exchanges. In this way, as far as possible, I hoped to create a representation of the whole verbal exchange,

making it easier for me to analyse how our speeches impacted one another during the interview. This representation, however, is limited and not identical to the conversations that happened in the interviews. Mostly, I have not included facial expressions, gestures or other visual information. Rarely, I have included a description of a gesture or facial expression used by a participant when they used this rather than words to make meaning e.g. when Ellen set her face in a particular expression to show me how her son responded to one of her poems. On these occasions, I noted the expression or gesture in my field notes during the interview and stated to which question or utterance it related. Within the definition of speech as dialogue, I include false starts and para-linguistic utterances such as pause-fillers (*umm, er*), interjections (*ah, oh*), laughter and crying, all of which contribute to sense-making and also give a sense of individual participants' communication style. I attempted to transcribe all of these.

I elected to take a new line for each speaker, even if this was just an interjection, like *yeah* or *uh huh* midway through the other person's utterance. On a practical level, this made it easier for me to distinguish who was speaking at each point, but it also served as a visual reminder of the space between us in the dialogue, the relational space where meanings were created. One exception to this was non-verbal emotion. I recorded "(laughing)", "(crying)" etc if someone laughed or cried during their own speech. If a speaker laughed or cried during the other person's speech, I did not take a new line, but recorded it in the midst of the speech and marked it with the laughing person's name, e.g. "(Georgi laughing)" or "(both laughing)".

Researchers often transcribe pauses and interpret them as indicative of conscious hesitation and that pauses therefore carry meaning (Gee, 2014). However, I elected not to include pauses in core participant data transcription for two reasons. Because all of the interviews and workshops were digital, there were often glitches or pauses in the Wi-Fi speed for either me or participants. This could account for brief silences which might, when played back, seem to be a hesitation on the part of a speaker. Secondly, two core participants told me early in their study involvement that they had speech issues which slowed their spoken communication. In addition, a number of participants and I experience occasional word finding difficulty or take longer to organise our speech because of cognitive fatigue.

Therefore I did not feel that pauses could be reliably interpreted in the ways mentioned above. Also, while it is unlikely that participants will choose to read this thesis or see the transcripts, they have the right to do so, and I feel that transcribing their pauses may be perceived as a judgement on their cognitive abilities.

#### 4.5.2 Workshop transcription

Initially I had not anticipated that audio-recordings of workshops would be transcribed, however after transcribing the follow up interviews and rereading participants' poems, it became clear to me that workshop discussions were important data in their own right and core components of how we co-constructed our selves and our poems during the project. Accordingly, I created what I termed 'running records' of each workshop recording, in which I transcribed prompt poem discussions, feedback about activities and discussions about one another's poems. I also transcribed informal chat where it was relevant to the study themes and did not include details which would compromise participant confidentiality. Workshop activity instructions and my reading aloud the prompt poems were consistent across the different groups and were not transcribed. I used the same transcription conventions for the workshop running records that I describe above for interviews.

#### 4.5.3 Poems

Participants sent their poems to me as Word documents or in the body of emails so for the most part I did not have to transcribe these from workshop recordings. This was preferable as it preserved the participant's creative choices regarding line breaks and punctuation. One exception to this was Ellen's poem, 'This is me', which she tried to email to me but did not attach the document. I only realised that this was the case later in Ellen's participation at a point when she was experiencing a severe exacerbation in her pain symptoms. Not wanting to burden her at a difficult time, I elected to transcribe 'This is me' from the workshop recording. I used the audio of Ellen reading her poem aloud and her other poems to guide me in choices about punctuation and where to break lines, however I acknowledge that my transcription of her poem may differ from the poem itself.

#### 4.5.4 Personal impact of transcription

Transcription was an important opportunity for me to engage deeply (and slowly given my typing speed!) with participant data. Yet, as has been identified by others, transcription of sensitive data is not an unemotional experience and may lead to secondary distress (Butler, Copnell and Hall, 2019; Smillie and Riddell, 2023). During the interviews, several participants told me of circumstances or events that were upsetting or difficult for them and disconcerting for me: Claudia and Tilly losing their jobs as a result of ableist discrimination; the way some of Saskia's family ignored the impact of her illness; Ellen's experience of harassment by a stranger. I found it harder to sit with this information during transcription than I had on first hearing in the interviews. The interviews were dynamic situations, unfolding in real time. While the information being disclosed to me sometimes made for uncomfortable or upsetting listening, I had a responsibility in the moment to respond to participants appropriately and with due regard for their wellbeing. Accordingly, while listening, I was also assessing if they were emotionally OK at that point in time. From there I was formulating what to say next. While the interviews could carry a lot of emotion, they were busy, and participants moved relatively quickly from relating one distressing event to telling me a different, and often happier, one. Transcription on the other hand was a slower and more solitary experience; just me with the words in my ears and on the computer screen. It was easier for me to get stuck.

Exploring as it does issues of illness and disability, my research is in a sensitive subject area (Liamputtong 2007), however I had not perceived it as potentially traumatic. After all, my study does not approach war, violence, sexual abuse or suicide. Consequently, I had not anticipated that I would find it distressing to engage with some data on multiple occasions. Yet I experienced distress for a number of reasons during the course of the research. Study relationships with participants unfolded and deepened over a period of months; their negative life experiences, once transcribed, are not merely items of data but are aspects of people whom I know and wish the best for. The emotional impact of distressing data on transcriptionists has been noted (Darlington and Scott, 2002; Liamputtong, 2007; Dickson-Swift, James and Liamputtong, 2008). My close relationship to the research and the uncertainty about my own disease progression likely made me particularly susceptible to, or

aware of, the emotional impact of this work. Although it would have benefited me to have read more widely and known about the possibility of such a response before I started transcription, discussing this with my supervisors and exploring my feelings in my study journal has helped me to manage this experience.

Transcription allowed me to identify themes that ran through individual participants' contributions or emerged across different workshop groups. Accordingly, I started to think about how I might proceed with formal analysis in terms of either tracking individual participants from beginning to end or whether to analyse thematically across workshop groups. In the next section I discuss my choices and reasoning.

#### 4.6 The analysis framework

Early on, I decided that I did not want to use computer-assisted qualitative data analysis software (CAQDAS). While I acknowledge that this would have saved time, I was concerned that it may have resulted in a disjointed analysis of data excerpts that had been taken out of the dialogical context in which they were created (Ritchie, 2013). I was also mindful of Coffey and Atkinson's (1996) caution that CAQDAS is not best suited to discourse analysis as it would not facilitate close attention to the ways that language in data is used to construct meaning. Below I discuss how I developed the framework for my data analysis.

##### 4.6.1 Utterances: units of meaning

Following transcription, my next step was to decide how to organise the data into units of meaning for analysis. As my epistemology is guided by Bakhtin, I explored his definition of 'utterances'. For Bakhtin, an utterance is a complete written text (e.g. a poem), but in speech it is bounded at the beginning by a person starting to talk and at the end by a change of speech subjects (speakers), which allows for the agency of the speaker. Bakhtin (1986, 76) holds that the speaker stops speaking because in that moment they 'have said (or written) everything [they] wish to say at a particular moment or under particular circumstances'. Yet, in reality, a speaker may be interrupted or in some way be prevented

from completing their intended utterance (Barker, 2023). Thus in dialogue, the bounds of the utterance may also shine a light on the change of speaker and the co-construction of meaning.

Organising the data according to utterances felt appropriate to the different types of study data (spoken interview conversations, workshop discussion, poems). It also helped me to be mindful of various questions which were important to my consideration of spoken dialogue and co-construction: what does the first speaker anticipate or desire from the second speaker? How does the second speaker respond? What meaning is made by and between the speakers? Has one speaker interrupted another? Has a speaker abandoned an utterance? What meanings may be underlying interruptions or abandoned utterances?

In practice, when working with spoken interview data, I observed that an utterance is not necessarily the same as a narrative. While often a participant completed a particular anecdote or narrative within one utterance, sometimes a narrative unfolded over several utterances across an interview, or in some cases, across more than one interview or workshop. These extended narratives were constructed within and influenced by contemporaneous utterances from either me or a participant. For example, having spoken about a medical incident in response to an early question, a participant might go on to answer a question about communication, only to return later to the medical narrative because they felt they had more to tell me about it. However, for the purposes of the research, I have maintained the utterance as a manageable unit of analysis and have considered utterances in the context of the dialogues which produced them, while also paying attention as far as possible to any prior influences on the utterance of which I was aware (e.g. earlier texts or conversations).

I numbered a speaker's utterances in each interview or workshop dialogue. The boundaries of the utterances were generally straightforward and corresponded with the change to a new speaker in transcripts. However, there were exceptions; sometimes an utterance continued beyond an interruption by a new speaker. In these cases, the new speaker, usually me, interjected with a brief comment like *OK* or *Mhmm*, and the original speaker continued as though the interruption had not occurred. These interjections were largely

evidence of listening, particularly on glitchy Zoom connections where screens froze not infrequently and sound was often slightly delayed. They also perhaps functioned as encouragements to participants to keep on speaking and did not appear to materially change the tone or content of the utterance.

#### 4.6.2 Colour coding data

The exploratory nature of the research led to a large number of possible themes for analysis. Some themes, such as COVID-19, arose because of the specific circumstances in which the study was conducted and were outwith the intended scope of the study; they were therefore not analysed. My theoretical interests and personal experience meant I was particularly alert to the themes of communication, poetry, embodiment and clinical interactions when they came up in participant data. However, other themes also became evident in initial interviews (family, work/loss of work, social interactions) and these then guided me in choosing workshop topics. Workshops added to the richness and complexity of the data, further illuminating these themes. Thus, analysis was a pervasive and iterative process throughout the study (Coffey and Atkinson, 1996) rather than being restricted to a discrete, formal activity.

Once the formal analysis process was underway and I had numbered the transcribed study data as utterances, I read through all transcribed data (speech and poems) and colour coded the utterances manually according to the themes that I had seen emerging throughout the period of data creation:

- Body
- MS (generally)
- Identity
- Family and friends
- Work
- Healthcare
- Speech & communication

- Poetry
- Society

The colour coding was essentially organisational, allowing me to find more easily particular passages of text in lengthy transcripts, however it was also a heuristic, providing me with a range of ways to engage with the data (Coffey and Atkinson, 1996, 30). Through colour coding, I was able to start tracing common themes across the sample (e.g. Memphis, Claudia and Tilly all spoke at length about their former working life in their initial interviews). Also, some utterances spoke to multiple themes e.g. the body *and* society or family *and* identity. By manually colour coding the utterances with both colours, I could see how participants felt that multiple themes interacted in their lives and also observe how they spoke about these intersections.

As my reading of the data continued, I also added in a colour code for 'Georgi as PwMS' for speech in which participants spoke about my having MS and what that meant to them. When looking at the workshop transcripts I also added colour codes for 'response to other participant's poem' and 'participant talk about own poem'.

#### 4.6.3 Working with Gee

Exploring different types of discourse analysis, I was drawn to Gee's (2014) framework for analysis. His focus on figured worlds seemed particularly apposite to this research. Similar to a discourse model or a cultural model, '[f]igured worlds are simplified, often unconscious and taken-for-granted theories or stories about how the world works that we use to get on efficiently with our daily lives.' (Gee, 2014, 95). They are received ideas that usually we do not question. Attention to how participants automatically used figured worlds to help them construct meaning could potentially deepen my understanding of their contributions. Also, and of particular interest to me was what happens to dialogue and meaning when a participant's figured worlds of illness and disability are at odds with their personal lived experience. How might this cognitive dissonance between societal and local knowledge play out in the conversations and poems of the study?

I decided against re-transcribing the data in accordance with Gee's notations and stanzas. Because of some participants' issues with speech, I felt that Gee's attention to intonation could not be fairly applied to everybody's data. Similarly, I wanted to look at the spoken data and the poems with the same analytic framework and it would not be appropriate to re-transcribe the poems in such a way as to change their lineation.

The research was exploratory and I wanted to make space in the analysis framework for a range of findings to emerge around the foci of MS, identity, experience and communication. I was guided by Gee in my formulation of the framework and a specific set of questions with which I could interrogate the data. For each utterance I considered as appropriate:

- the Genre of the utterance (e.g. poem, casual conversation, answer to interview question)
- its Style (including word choice, narrative structure, rhetorical or performative features)
- Grammar
- Intertextuality (actual text references, but also references to prior conversations and discourse)
- the Emotions of speakers

I determined to explore these features through the following questions:

### **Initial interview**

1. What figured world(s) is the participant invoking/creating?
2. What identity does the participant construct for themselves as a PwMS?
3. What experiences are they expressing? (e.g. personal, physical, social, political)
4. What intertextualities are present? (other texts, earlier conversations, discourse)
5. What relationships are present in the participants' utterance? (e.g. researcher, fellow participant(s), others in described narratives, society, MS)
6. How are these relationships constructed by the participant?
7. How do these relationships impact on the participant, or how are they impacted by the participant?

8. What connections is the participant making?

### **Workshop**

The initial interview questions and also:

1. How are participants interacting with one another?
2. What is being co-constructed in workshop conversations?
3. What are the effect of the prompt poem?
4. What are the effects of the idea generation tasks?

### **Poem**

The initial interview questions and also:

1. In what ways is the poem (dis)similar to the participant's interview utterance on the same theme?
2. Have the interactions of the workshop affected the poem? In what ways?

### **Follow up interview**

I applied the same questions as for initial interviews but when considering the presence of intertextualities, I paid particular attention to how the utterance was (dis)similar to initial interview utterances on the same theme.

### **Reader participant interview**

Reader participant interviews were analysed after all of the core participant analysis was complete. I applied the same considerations, but using the questions below:

1. What figured world(s) is the reader participant invoking/creating?
2. What identity does the reader participant construct for themselves?
3. What identity does the reader participant construct for the core participant?
4. How does the relationship between the reader participant and core participant impact on the participants, or how are they impacted by the participants?
5. What experiences are they expressing? (e.g. personal, physical, social, political)
6. What intertextualities are present? (textual, earlier conversations, discourse)
7. What other relationships are present in the participants' utterance? (e.g. researcher, others in described events, society, MS)

## 8. What connections is the participant making?

Initially I planned to analyse the data of each core participant throughout their participation before moving onto the next person. I did this with Saskia's data, but then decided to analyse all first interviews in turn – identifying different themes – then followed each group through its workshops, individual poems after each workshop and then the follow up interviews. Practically this prevented some duplication of workshop analysis. It also made it easier to explore the workshop relationships and interactions.

Interrogating the data with the analysis questions facilitated the emergence of a number of key themes which featured across the interview and workshop data. Broadly, these themes resolved into the categories of embodiment, being a patient, work or occupation, and multiple kinds of social interaction. There was also an additional strand relating to core and reader participants' experiences of sharing study poems. The identified study themes are complex and often intersect with one another; for example, when talking about encounters with strangers, participants also reported a heightened awareness of their embodiment as PwMS. With an awareness of potential intersectionality and correspondence among different themes, I organized the research findings into four chapters which are briefly summarised at the end of 4.7 below.

### 4.7 Chapter Summary

In this chapter I have shown how the research design evolved in light of the COVID-19 pandemic. As discussed, this has necessitated fundamental changes to the study question and method. I have presented the practical steps I took in order to conduct the research online and have considered the changing social needs and behaviours of participants during the UK lockdowns. These changes, I feel, have largely benefited the study, creating conditions which encouraged participants, who were otherwise isolated from many of their usual social interactions, to engage with one another in positive and meaningful ways.

Also, I have reflected on the data creation processes for the study and how I attempted to minimise the power balance of the researcher–participant relationship in workshops by writing alongside participants in order to create communities of practice. A consideration of my own writing practice throughout the study has led me to perceive a correspondence between the multiple, constructed selves ontology underpinning the research and the intertextual, palimpsestic way that texts evolve, are edited or erased and then resurface in later writing.

I have explored the difficulties I encountered when being present with difficult data for long periods during transcription. Although I now feel prepared to work with personally challenging data in future, I think that it would benefit early career researchers and PhD students who are in close relationship with their study themes if there were generally more awareness of the potential for distress and challenging emotions during transcription. However, as I note above, even though it was at times a deeply uncomfortable experience, transcription was very valuable in terms of initial analysis. Finally, I described how I established an analytic framework inspired by the work of Bakhtin (1981, 1986) and Gee (2014).

In the following four chapters, I discuss the research data, considering poems and spoken data from both interviews and workshops. In Chapter Five, I use a phenomenological lens to present and reflect on ways in which participants spoke and wrote about their MS bodies. Chapter Five also explores participants' experiences of medical interactions. Chapter Six comprises an examination of participants' experiences of occupation, both in terms of professional employment, or loss thereof, and leisure activities. This examination also includes reflections on the role of participation in poetry workshops as a validating form of occupation for participants. In Chapter Seven, I focus on the social interactions and experiences of participants in light of MS, with particular attention to: casual encounters with strangers; interactions with friends; and the impact of MS on familial relationships. Chapter Eight is a presentation and discussion of data and findings from the supplementary reader participant wing of the study; it explores the impact of participants sharing study poems with close contacts, and examines data from both core and reader participants.

## Chapter Five

### There and not there: constructions and absences of the MS body

*'The most prosaic of us betray a belief in the inward life every time we talk about "my body" rather than I. We feel it as absolutely part but not at all part of who we are.'*

Winterson (2009, 102)

#### 5.1 Precis

This thesis explores how participants constructed their bodies in three intersecting ways: *phenomenologically*, as living tools through which they experience MS; *biomedically*, as objective, institutionalised sites of medical interventions; and *sociologically* as incarnations of interaction with the wider world. In this chapter, I consider ways in which participants spoke, or chose not to speak, about their bodies in conversation and also in their poems.

I begin, in Section 5.2, with a brief discussion of the body in terms of the German words *Lieb* and *Körper* and show how these terms are useful lenses through which to view participants' self-constructions of their bodies. In 5.3, I explore two poems and participant conversations that present experiential embodiment. The concepts of the 'good patient' and the 'good doctor' are introduced in the following section. I go on in 5.4 to consider two poems in which the participants represent themselves as 'good patients' in medical encounters. In Section 5.5, I turn to two poems written in the context of difficult neurologist–patient relationships. These poems consciously rebel against the medicalised objectification of the MS body, choosing instead to present the holistic impact of the condition. Then I consider how Saskia shared a poem with her occupational therapist and how this led to new strategies for helping her manage one of the impacts of dementia. Finally I summarise the key threads of the chapter and offer concluding thoughts.

## 5.2. The Lieb and the Körper: being both bodies

People may instinctively understand their bodies as their animated, sensory selves: we live in and through our bodies or Lieb (Husserl, 1989). We know we are alive because we detect breath in our nostrils, sunlight on our skin or uneven ground beneath our feet. However, engagement with the medical profession introduces us to a different way of constructing our bodily experiences and subsequently ourselves. We may begin to view our bodies as exterior, medicalised objects or Körper (Plessner, 1975; Husserl, 1989; Bendelow and Williams, 1995). In actuality, these are not mutually exclusive definitions of the body: the Körper is an aspect of the Lieb; bodies exist in society and cannot escape the objectifying gaze of others. However, Western medicine prioritises this exterior institutionalised body to the extent that it dominates the doctor–patient discourse and the animated, felt elements associated with Lieb can be ignored (Baron, 1985; Leder, 2016).

The initial interview question, ‘Can you tell me a little about how you see yourself as a person with MS’, was purposely open-ended, giving participants an opportunity to respond in ways that might give me an insight into how they construct and present themselves to others. I, perhaps naively, anticipated participants would focus predominantly on their phenomenological or socially mediated life with MS (current symptoms, impact on daily life). However, five of nine participants began their responses at the point of diagnosis and then went further back to describe their diagnostic journey in more detail.

### 5.2.1 Memphis and Ellen

The following utterance from Memphis shows how his understanding and self-representation features both Lieb and Körper:

*“Memphis: Erm I was diagnosed in 2009. Erm, I was playing badminton and I went over on my ankle and it just never healed. It just – it was limp. I thought I’d snapped a tendon or something, so I went to the doctor. The usual tablets and putting in surgical stockings and that. Tried everything and it wasnae working so I then developed a really, a pain at the top of my spine and at the base of my brain where the brain stem and the spine joined. It was **like somebody had their fist in there constantly.***

*GG: Aie aie!*

Memphis: It was **a gnawing ow! pain** so I went back to the doctor for that and co-codamol, everything from aspirin, paracetamol, co-codamol. Went through the full gambit and **eventually she said, 'I'm going to have to send you to a neurologist.'** So **right away panic sets in. I've got a brain tumour, that's me. Six months to live.** So I went to the doctor – he's still my neurologist, brilliant guy and erm MRI scan came back in two weeks. 'You've got MS, I'm 99.9% sure. In order to be 1000% sure what I'll do is I'll check.' **They done a spinal tap, whatever they call that again. I canny mind.**

GG: A lumbar puncture?

Memphis: **A lumbar puncture – that's the boy.** They done a lumbar puncture so he says, 'I'll check with that, but your symptoms, all your previous' – because I had Bell's Palsy, I had erm neuralgia and I had weakness in my right hand so all these sort of things, they all added up..."

Here Memphis gestures to the complex ambiguity of living in a body with MS. He starts by describing his somatic experiences, detailing the sensations of his original symptoms in descriptive language which escalates as his pain increases: "*like somebody had their fist in there constantly*"; "*a gnawing ow! pain*". Because the bio-medical model is prevalent in our society and therefore his lifeworld is 'saturated with medical meanings' (Leder, 2016, 99), Memphis attempted to find a plausible explanation for his pain, "*a snapped tendon or something*." Then when he speaks about his consultations with the GP and neurologist, his vocabulary becomes more prosaic. He lists prescribed medication: "*everything from aspirin, paracetamol, co-codamol*" and diagnostic tests: an "*MRI scan*" and "*a spinal tap, whatever they call that again. I canny mind*." In contrast to his self-presentation as an ill person, Memphis is less confident with the medical terminology surrounding his diagnosis as a PwMS. The increasingly active role of the doctors and his own physical passivity are evident grammatically: "**They done a spinal tap**"; "**They done a lumbar puncture**". In this utterance he constructs himself in the roles of Memphis-as-Lieb, the embodied ill person focusing on the sensations of unexplained pain, and also Memphis-as-Körper, the compliant patient whose body becomes a puzzle for the doctors to solve.

A skilful raconteur, Memphis enacts conversations with his doctors which further show the entanglement of himself as an ill person and a medicalised object: "*eventually she said, 'I'm going to have to send you to a neurologist.'* So **right away panic sets in. I've got a brain tumour, that's me. Six months to live.**" He contrasts his fear of mortality with his doctor's objective perspective by creating a humorous version of himself and simultaneously makes

space for the reader's empathy. He adopts the role of entertainer, constructing his narrative with pace, humour and patter: "*A lumbar puncture – that's the boy.*" It was apparent to me during the interview that Memphis enjoyed performing this role. The consummate ease with which he told me this narrative made me aware that it is one which Memphis has probably told on numerous other occasions. From my own experience, I recognise that people living with chronic illness are frequently expected to explain or discuss our health in a range of non-medical situations. A selective precis presented in an upbeat fashion can create boundaries and provide a sense of safety and comfort while describing a difficult personal experience. This is possibly what Memphis and some other participants did at the beginning of our first meeting.

Participants sometimes consciously wrangled with the dissonance of making sense of their illness through body–mind dualism while also perceiving themselves to be unified, holistic beings. Ellen repeatedly turned to this theme in interviews and workshops: "*Well really, you're not your brain are you when you think about it? I always thought you were but you're not really your brain...Your brain is an entity that controls your body like a computer but something greater – that is you.*" She constructed her essential self as distinct from her brain and also from the MS which impaired her brain's functioning:

*"I am me and erm, this thing inhabits my body and misbehaves and er I just to have to er get on with it. That's all I can say really. (laughing) It isn't me but people, other people look at you and define you more. That's what we learn but you learn not to define yourself, and I don't really – it's really weird. It's like there's me and there's that, d'you know and it's just there... It's a bit like an unwanted lodger, isn't it? (laughing)*

*GG: Yes. Ellen, I think we've found the title of your first poem. (both laughing)*

*Ellen: The Unwanted Lodger."*

Ellen repeatedly asserts herself as separate from MS : "*I am me*"; "*It's like there's me and there's that.*" By referring to MS as "*this thing*" and "*that*", she constructs the condition as both concrete and vague. She then goes on to characterise it as an "*unwanted lodger*", a personified entity which "*inhabits my body*". In this construction MS is still separate from Ellen but she has to coexist with it at very close quarters, a complicated relationship as MS "*misbehaves*" and she cannot control it entirely.

As Ellen makes clear, she has felt judged and defined by others because she is visibly disabled by MS, however she has learned “*not to define*” herself through the condition. Perceiving MS and its symptoms as separate to her own identity enables her to maintain an intrinsic and continuous Ellen-ness in the face of a society which others her. Her metaphor of “*an unwanted lodger*” worked well in our conversation to neatly encapsulate Ellen’s conception of MS, and, as I joked in the interview, poetry would be a good place to experiment with metaphor. In 7.2.1, I will return to Ellen’s experiences of being judged because of her disability in the context of her interview and workshop utterances and a poem.

I have a heightened awareness of my body through its dysfunction and I feel the exile of living in and through this body (Leder, 1990). Yet, midway through the initial interviews, I reflected in my study journal that I usually only experience my body through a clinical lens and assume the role of MS patient when I attend annual neurology check-ups. However, for some participants who were attending more frequent appointments, their MS bodies were not always separable from their status as patient. I now realise that their focus on the medical process is not surprising and I would argue that there is a semantic reason behind the decision to begin their responses at diagnosis. Although a person experiences MS symptoms beforehand, it is not until diagnosis occurs that the body’s malfunction is identified and labelled. Leder (2016, 14) writes that ‘our experience of illness is often vectored by clinical interpretations’ and this is certainly the case with MS. It is through engaging with doctors and diagnostic processes that someone is defined as having MS and can then begin to develop new understandings of their body and construct an identity as a PwMS.

## 5.3 Exploring the Lieb and the Körper in poetry

### 5.3.1 Claudia

During the second workshops, the majority of participants wrote about their bodies from an animated, experiential perspective. In each group, prior to writing, we read and discussed a prompt poem, 'Migraine' by Kitty Coles (2017) (Appendix H.b) which is a vivid description of experiencing a migraine. In her initial interview, Claudia had told me that generally she was reluctant to talk about MS with friends and family: *"we all know MS is horrible and what it does but I don't want to be dealing with that."* Instead she said, *"my whole thing is to be very positive."* Yet, she responded enthusiastically to Coles' poem, which identified both positive and negative aspects of migraines: *"she's written it...without being obvious. It's not like an NHS description, is it? It's more a feeling of what [a migraine] is like. It's good."* After discussing Coles' poem, we did a visualisation activity in which I invited Memphis and Claudia to focus quietly on the sensations, or lack thereof, in their bodies. Claudia found this made her *"angry and cross that I can't do what I used to do. That my legs don't work like they used to...I'm not the person I was and so it's trying to find that bit of me that's still me without the MS on top."* Memphis replied to affirm her identity: *"it's there, I'm looking at it. You are you."* He went on to share that he also gets *"cross and upset and angry"* about no longer being able to do certain simple things *"but I'm still me."* After the workshop break, Claudia wrote the following poem:

*"My Legs*

*encased in my head the feelings rise from the deep  
black exploding firework colours  
emanating from cringing frustration*

*my brain is firing orders to the sergeant major who barks instructions to deaf recruits  
trapped by bad wiring*

*my legs are a massive disappointment  
it is profoundly sad  
my mind races ahead soaring on warm thermal currents  
quietly gliding above the patchwork squares"*

*I am dragged back with violence to earth  
struggling with the energy sapping heaviness*

*I'm scared of my legs  
fighting a memorable battle to stop me slipping  
into the quicksand I clear my head and*

*breathe."*

On one level, this poem is about the moments when Claudia tries and fails to move her legs; her brain, "*the sergeant major*", sends signals to her legs, "*deaf recruits*", which cannot act on the instructions because MS lesions, "*bad wiring*", prevent the message from getting through. However, Claudia asserts her embodied experience and, throughout the poem, focuses on the emotional impact of disability; for her this is the heart of the experience, not the dry details of "*an NHS description*". A former art teacher and a textile artist, she uses colour to articulate her strong feelings about having limited use of her legs: "*from the deep / black exploding firework colours*". The first half of the poem is filled with energy and activity; "*exploding*", "*races ahead soaring*", "*gliding*", yet this is contradicted by a sense of imprisonment; "*encased in my head*", "*trapped by bad wiring*", "*slipping into the quicksand*". Here Claudia speaks to the dichotomy of being mentally alert and wanting to be more active, while being "*dragged back*" by her legs which are no longer able to support her to do the things she wishes, a state that she finds "*profoundly sad*". In contrast to her initial interview response which, like Memphis's, focused on the experience of engaging with doctors, this poem is solely about Claudia in an unmediated relationship with her MS body: no one else is present, but "*my*", "*I*" or "*me*" feature in every stanza as she explores the frustration and disappointment of her particular situation: Claudia's legs are part of her and one of the ways she experiences the world, and yet because they can no longer follow the brain's commands, they appear to her through their dysfunction, becoming alien or other (Zaner, 1981; Leder, 2016).

Engaging with the prompt poem and discussing it with Memphis and me seems to have encouraged, or perhaps emboldened, Claudia to write about her own somatic experiences in a creative and descriptive, non-medicalised way. Through writing '*My Legs*' she began to explore her feelings about the impact of MS without being burdened by an expectation of

artificial positivity. The ending of the poem achieves equilibrium: *“I clear my head and / breathe”*, but it does not attempt to deny the distress she has articulated or force a happy resolution. At the end of the first workshop, she had chosen not to read her poem to Memphis and me as she was concerned that it was *“too negative”*. However, she offered to share *‘My Legs’* in the second workshop. Memphis responded enthusiastically and emphatically: *“Wow! Thumbs up”; “I’m blown away with that poem, really.”* Although Claudia was then self-deprecating – *“but, it’s only a bit [of a poem]”* – she was visibly buoyed by our responses. This felt like a significant moment for Claudia in her participation; she continued to discuss and share her poems, even writing and sending me an extra poem that she wrote in between workshops.

### 5.3.2 Alex

In her initial interview, like Claudia, Alex identified herself as reluctant to talk about MS with friends and extended family: *“I’m not sure I do it terribly well, if I’m honest”; “I tend to shy away from that”*, preferring instead to *“move on to something more interesting”*. However, she was keen to find new ways of speaking about MS and was very engaged in the workshops. In Group 4’s second workshop, she wrote the following:

*“Machine*

*Old machinery whirring*

*The guarantee expired or lost.*

*Cogs stick and rub, movements jerk and stop.*

*Toes curl into tight balls unable to separate.*

*The engine coughs and splutters.*

*Limbs dead weight, blood collects in stagnant pools. Sensations lost.”*

In this short poem, Alex represents her MS body as a malfunctioning machine in a way that is simultaneously embodied and objectified. As I read *“Toes curl into tight balls”*, I notice that I have clenched my own toes as I trace the breakdown of the poem’s body-machine. Similarly, in the workshop, Eleanor was very struck by Alex’s image *“blood collects in stagnant pools”*. She noted the juxtaposition of the machine with pools of blood and used it as way to consider her own experience of numbness: *“for me, when my fingers go numb, they are still a part of me but they could be a machine.”* Here Alex writes about, and Eleanor

recognises, a very specific phenomenon of illness: displacement from one's body. Leder (1990, 84) writes compellingly of how in pain or sickness, by preventing us from being and acting in the ways we wish, 'the body *appears* as thematic focus, but precisely as in a *dys* state' i.e. a state of dysfunction. For Alex, as for Claudia, this dys-appearance has resulted in the body becoming 'other'. Yet this othering is complex: as well as feeling alienation, simultaneously, because of the body's dysfunction, "*the cogs [that] stick and rub*", the ill person is hyper-aware of their uncomfortable, perhaps painful, embodiment.

Often participants and I recognised our own experience in each other's poems and went on to discuss these experiences more fully. I responded to Alex that as a result of her machine metaphor, I was thinking about how "*the body betrays [us] in that way by not doing the task or making the task convoluted or difficult or painful.*" Eleanor commented that I was bringing an "*emotional connotation*" to my reading of the poem. She phrased her remark as a neutral observation, but it prompted me to reflect on my response to Alex. Others have written of the chronically ill body as 'betraying' the ill person (Kleinman, 1988; Williams, 1996) and it is an interpretation that resonates deeply with me. For a long time I had been frustrated about the limitations of my own life with MS and I too had often reverted to a dualist framing of my body, blaming it for disloyalty, even though this interpretation was illogical and inconsistent with my conscious world view. During the workshop conversation, I realised that I had incorrectly assumed that Alex felt a similar sense of betrayal to me. She went on to explain that she had been "*thinking more, you know, of the frustration... You know that whole, it's not working as it should and that's annoying and frustrating and I'm not sure how to fix it.*" This is an example of how workshop conversations provided informal opportunities for me to check my interpretations of participant data and for us to construct new meanings together about the nuanced differences in our attitudes towards our MS bodies. Also on this occasion, there was an outcome that, for me, was personally significant: following the workshop, and for some time afterwards, I have continued to consider my own sensations of betrayal and what effects this may have had in my evolving relationship with MS.

## 5.4 The Good Patient and the Good Doctor

Participants frequently spoke and occasionally wrote about their interactions with neurologists, GPs, physiotherapists and occupational therapists. The patient–doctor relationship is socially and culturally enacted and is dependent on:

‘the cultural health capital...the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviors, and interactional styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal health care relationships.’

(Shim, 2010, 1)

Accordingly, the power dynamics of the patient–doctor relationship are weighted in favour of doctors and those patients who share the same cultural values and skills as their medical team. I acknowledge that the constructions of the ‘good patient’ and ‘good doctor’, discussed below, derive from, and exist within, exchanges that are determined by the cultural health capital of patients and their doctors. The ‘good doctor’ is a construction that while also socially and culturally mediated, is enshrined in professional standards and ethics. The independent regulator for doctors in the UK, the General Medical Council (2023, 7) states that in order to conduct good practice, registered medical professionals:

‘must make the care of patients your first concern...

- Provide a good standard of practice and care, and work within your competence.
- Keep your knowledge and skills up to date.
- ...
- Listen to patients and work in partnership with them, supporting them to make informed decisions about their care.
- ...
- Treat people with respect and help to create a working and training environment that is compassionate, supportive and fair, where everyone feels safe to ask questions, talk about errors and raise concerns.’

The commonly recognised perception of how a patient should behave reflects this construction of a ‘good doctor’. Sointu (2016, n.p.) states that a ‘good patient’ is seen by

medical staff as one who is 'active, compliant and knowledgeable'. Here 'active' is defined as making lifestyle choices which support the patient to preserve or regain their health. It also involves engagement with the doctor by asking questions and being enthusiastic about the prospect of cure. In this context, 'knowledgeable' means having a good understanding of one's own medical history and communicating it well to the medical team. However, the good patient's activeness and knowledge do not lead to their challenging the doctors' reasoning or recommendations. Compliance, or a certain amount of passivity, prevents the good patient from questioning the knowledge of the doctor and thus morphing into a bad patient (Sointu, 2016).

#### 5.4.1 Alex

Frequently in conversations and poems, participants were very aware of the time constraints of medical appointments and referred to the steps that they took to be good and efficient patients. Alex presented herself as a resilient and capable person who was determined to seek answers to her predicament. In "*The List*" she wrote:

*"Filling up the page,  
Preparing your approach,  
Tactics  
Tactics*

*Get through the initial small talk,  
The pleasantries.  
Hit them with the questions that matter."*

Here Alex shows how she constructs herself as a good patient, preparing her questions in advance of the consultation and indulging in the politeness of "*pleasantries*" before asking "*the questions that matter*" to her. She is active, compliant and knowledgeable, and yet:

*"Too soon you're waiting at the bus stop,  
Watching as it comes round the corner.  
You stare out the window,  
Listless  
Deflated*

*The door did not unlock  
Nothing was found."*

The energy and focus of the initial two stanzas have been replaced with listlessness and deflation. She is now passively waiting for, and then carried by, the bus. In her initial interview, Alex spoke of the uncertainty she had experienced since her PPMS diagnosis three years earlier and how this was a factor in interactions with doctors:

*"what's the future? That's a big question mark as I suppose for all MS sufferers really. Erm, so there has been, you know, a marked deterioration in that three years. GG: Right.*

*Alex: So, you know, it's kind of steadily becoming more challenging if you like. Erm, and yeah there, there is the constant kind of, erm, dunno. **It's a strange situation that you're diagnosed with this illness but nobody has any idea, you know, what caused it? Erm, what's gonna happen? What's the deterioration gonna be like? What you'll be able to do in six months or a year?** You know, so there's **absolutely no, erm, help in that way, no structure I suppose, erm, which, I'm sure there are other illnesses which have the same problem but I think that's one of the more difficult aspects. It's, you know, you could, you can say, oh right, well it's like this so this is how it's going to be and I know. I'll adjust accordingly but you don't know that this is how you're going to be. You don't know how you're going to be in six months' time, for example.**"*

Her utterance is characterised by the sorts of unanswered questions that she may have prepared in "The List": "what's the future?"; "but nobody has any idea, you know, what caused it? Erm, what's gonna happen? What's the deterioration gonna be like? What you'll be able to do in six months or a year?" This uncertainty about her future prevents Alex from knowing how best to adapt. As she says, there's "no structure, I suppose". She frequently says, "you know", a common discourse marker that is used as a filler while the speaker prepares what to say next. It unconsciously seeks to find agreement and build a harmonious relationship between interlocutors. However, in this utterance, "you know" resonates with a particular poignancy; a heightened awareness of what Alex and I cannot know, specifically her future.

Doctors and scientists are noticeably both present and absent in this utterance as "nobody": "nobody has any idea" so "there is absolutely no, erm, help...no structure", similar to the

brief mention of “*them*” in her poem. There is a strong sense of isolation and abandonment in both the poem and her spoken utterance; even the expert neurologist cannot answer her questions, and in spite of her efforts, Alex’s sense of frustration and helplessness are reinforced at each appointment. She is highly motivated to be a good patient and, as her poem shows, is adept at performing that role. However, it would only be advantageous for Alex if scientific understanding permitted the doctor to fulfil the role of the ‘good doctor’ that *she* wants him to be; one whose knowledge is sufficient to enable a defined prognosis for her disease progression. Without answers, Alex is trapped in an interminable present, akin to a chaos narrative (Frank 2013), where she lacks the resources to create a temporal structure for a future MS self.

#### 5.4.2 Eleanor

As someone who had worked in a senior non-clinical role in the NHS, Eleanor approached medical interactions confidently and had a professionally guided sense of how good medical practice should unfold. She was comfortable critiquing her medical team, referring to one consultant as “*surprisingly rude. I’m used to working with doctors. He was surprisingly – well, he’s quite old fashioned*”. She described another as “*really lovely...we talked about all kinds of things.*” In Workshop 3, Eleanor wrote about a difficult interaction with a neurologist:

*“How Strange*

*It’s probably just mild MS, he said.  
Friendly, smooth and smiling.*

*Months later, in the underground room,  
where two others were having eye tests  
He sat opposite me and said  
It was definitely MS.  
The other patients heard.  
The line of medical students  
behind him heard.  
Through the open door,  
The people in the corridor waiting room heard.*

*How strange, I thought,  
that something so human was not.”*

In this poem, Eleanor subtly raises questions about issues of consent and power in the doctor–patient relationship. She does not directly address the neurologist but focuses on his words which are detached and abstract: “*It*” – his diagnosis of her symptoms – is “*probably*” and then “*definitely*” MS. “*It*” lends both a concrete and a vague quality to the neurologist’s construction of MS. Reminiscent of Ellen’s designation of MS as “*this thing*”, “*It*” is other and remote. Both Eleanor and her MS body are strangely absent from the conversation. I wonder if the consultation might have proceeded differently if he had said, “You have MS,” thus acknowledging the impact of the diagnosis for Eleanor and drawing her into the conversation. The poem focuses on the neurologist’s different enactments of his role in the two appointments. In the first he is “[f]riendly, smooth and smiling”: he sounds unconcerned and therefore reassuring, while “smooth” is reminiscent perhaps of a ‘good doctor’ in a television drama. However, when describing the follow up appointment, Eleanor does not mention any further friendliness or attempts at relationship building. The second encounter is clinical, both in its medical nature and its sterility. It is transactional and lacks compassion.

Eleanor does not focus overtly on her own presentation as a patient, although it can be inferred from her silence that during the consultations, she is compliant. It is unclear whether she was given the opportunity to have the appointment in a more confidential setting or without the presence of the medical students, however, as the poem details, she was very aware of, and uncomfortable with, the lack of privacy. Her discomfort is derived from the fact that the other patients, the “*line of medical students*” and the people in the waiting room, all heard the neurologist tell Eleanor she has MS. Her repetition of “*heard*” is forceful, emphasising how impactful this public occurrence of a private experience was for her. Plus, although the poem is not explicitly emotional, the simplicity of its language and the clarity of its chronological structure enable the reader to step into Eleanor’s shoes and map their own discomfort, whether anger, fear, embarrassment or something different, onto the poem. The poem concludes with Eleanor’s reflection, neatly echoing the title, that it was “*strange...that something so human was not*”. This lack of humanity could be read as relating both to the neurologist’s abruptness and the lack of privacy which led to several strangers hearing her diagnosis.

When Eleanor shared the poem with Alex and me in the workshop, we both felt that it was very relatable and Alex praised the power of her imagery: *“the line of students...that’s really quite a powerful image, I think, because, yeah, you can definitely visualise that but also it’s quite intimidating”*. She went on to elucidate: *“as I imagine soldiers stand in line silently, you know, the students are standing in this line silently.”* Eleanor replied that was *“exactly what they were doing. Thank you.”* Through the composition and sharing of this poem, Eleanor succeeded in representing her complex and discomfiting experience in a creative act that was understood and responded to positively and empathetically by others. I would posit that, on this occasion, the audience simultaneously validated both what had happened to Eleanor and the creative endeavour through which she explores it.

Reflecting on Eleanor’s poem and our workshop conversation, I am reminded of *The Birth of the Clinic* (Foucault, 2003) as I visualise her acute awareness of the medical gaze of numerous, silent trainee doctors. The consultant here occupies multiple forms of power in relation to both his patient and his students. Certainly, although he was ostensibly speaking to Eleanor, his remarks were also directed to the students, and this extended audience impacted how she received and experienced the diagnosis. I would suggest that it is possible to interpret Eleanor’s choice of ‘human’ as implying a desire for, or expectation of, empathy from her consultant. Clinical empathy is increasingly considered to be an important component of healthcare, although training in the skill is not currently mandatory in UK medical schools (Winter et al, 2023). It would appear that Eleanor’s consultation was an opportunity for the neurologist to model clinical empathy for the medical students, which may have also made the difficult experience of diagnosis more *“human”* for Eleanor. Clinical empathy has been seen as dependent on the physicians’ emotional labour (Larsen and Yao, 2005), but it has also been understood to derive from the organizational context of the medical encounter (Vinson and Underman, 2020). I cannot help but wonder whether the busy, public setting of *“the underground room, / where two others were having eye tests”* and *“a line of medical students”* may have impacted on the consultant as well as Eleanor, limiting his ability to interact in a more human way with her on this occasion.

## 5.5 Dis-ease and Disconnect: fractures in the neurologist–patient relationship

Some participants were acutely aware of their lack of status in the neurologist–patient relationship as a result of information being withheld from them or miscommunicated. The General Medical Council (2024) framework for ‘Good Medical Practice’ emphasises the importance of effective communication. Paragraph 28 of the framework states ‘You must give patients the information they want or need to know in a way they can understand.’ (General Medical Council, 2024, 13). However, in her initial interview, Claudia told me that her neurologist had not informed her about her MS progression: *“it’s only in the last sort of five, ten years that I’ve realised that I’ve got secondary progressive MS really...Only because I saw my form but nobody’s ever actually told me. **It’s weird.**”* Claudia seemed frustrated by this but gave no indication that she felt entitled to raise the matter with her medical team.

### 5.5.1 Tilly

Tilly spoke to me about how she discovered that she had been diagnosed with MS:

*“It wasn’t until I had a second relapse that I got the diagnosis and **that whole process was really weird because no one actually gave me a diagnosis.** I only found out about it when I read a letter in my HR file at work that my GP had written to say that I had multiple sclerosis and needed accommodations. So, I called my neurologist and said, ‘You know. Do I have MS?’ **He said, ‘Oh yes, I think you do, yeah.’ Really strange, totally bizarre. Yeah.**”*

Her language prior to this had been clear, objective and focused on describing her early symptoms, but she gave a greater sense of the emotional impact when she told me about the lack of information from her doctors. Like Claudia, Tilly used the language of unreality in her utterances about diagnosis – *“weird”, “Really strange, totally bizarre”* – when referring to the communication failures of her doctors rather than MS itself. Even now, years later, Tilly’s word choice and the fact that she disclosed this incident at a very early stage of our interview show that she was still shocked by the negligent behaviour of her neurologist and GP.

Finding out by reading her HR file at work caused Tilly further harm; at that time her employers were refusing to make reasonable adjustments for her increasing disability and were encouraging her to retire early from a job that she enjoyed and had done for a number of years. Unaware that she had been diagnosed with MS, she had asked her GP to send a letter confirming that her symptoms entitled her to workplace accommodations.

Information about Tilly's health, to which she was not party, was then shared with the employers who were being obstructive and discriminatory towards her. In recreating her telephone conversation with her neurologist to confirm the information, Tilly assigns him casual and tentative language – “*Oh, yes, I think you do. Yeah.*” There is no suggestion that he apologised or acknowledged the inappropriacy of the manner in which her health information had been handled. Tilly told me it is likely that this situation arose accidentally, rather than because of a deliberate decision to withhold information from her. However, the result is that Tilly was excluded from conversations about her health between, and within, two large institutions, the NHS and the university where she worked. Both as a patient and as an employee, she had been disempowered. This information about Tilly's diagnosis gives important context for the discussion of her poem below in which she withholds information from her neurologist.

In workshop two, Tilly was dissatisfied with her freewrite about her MS body, saying that it was “*boring...the sort of thing I might say to my doctor.*” This statement reminded me of a line from the session's prompt poem, Kitty Coles' (2017) 'Migraine': ‘Then the pain, / considerably less interesting.’ For both of them the most commonly recognised physical aspects of their medical conditions, although painful and disabling, were not interesting creative subjects. It struck me as compelling that Tilly, an articulate woman who wrote poetry frequently, instinctively approached writing about her body in what she felt was the dry “*boring*” style of a medical consultation. Had the medicalisation of her MS body prevented her from writing about it in a more personal, animated way? However, Tilly went on to author the following poem:

*“Left-side weakness in a left-handed woman with multiple sclerosis: A case study*

*I don't tell my neurologist  
I am not your subject*

*My life is not your case to study*  
*I dutifully present my symptoms, in carefully curated soundbites*  
*Digestible by medical professional and family-member alike*  
*Trim off the excess heartbreak of losing my ability to*  
     *write shopping lists*  
     *sign my own name*  
     *draw doodles*  
     *sketch faces*  
     *knit ugly christmas jumpers*  
     *spend just one day without pain*  
*The physio is hopeful I'll walk again*  
*I am appropriately upbeat about my chances*  
*Leave out mentioning the aching void left by*  
     *Schiehallion*  
     *Bennachie*  
     *Balmedie beach*  
     *Lochnagar*  
     *Arthur's seat*  
*Stolen from my landscape,*  
*filled instead with wheelchairs,*  
*walking frames*  
*two-minute daily standing practice"*

The title of Tilly's poem presents her in concise medical terms: she has MS and left-sided weakness. The words "case study" establish an expectation that the poem will discuss her as an exterior institutionalised object. Like Alex, Tilly has learned techniques and behaviours to adopt in consultations: "I dutifully present my symptoms, in carefully curated soundbites / Digestible by medical professional"; "am appropriately upbeat". She is aware of her performance of the role of patient and the duties that she is expected to fulfil. She chooses not to tell the neurologist or physiotherapist about the emotional impact of her lost abilities, instead "Trimming off the excess heartbreak". Tilly knows that she is participating in a relationship which is predicated by a world view that 'sees illness as an objective entity that is located somewhere anatomically' (Baron, 1985, 606) rather than as something which happens to people who experience life in manifold nonmedical contexts. Plus, as we have seen, it is not a relationship in which she has been made to feel valued or important; withholding information about her emotional vulnerability may be an act of self-preservation. Although the poem makes it clear that she chooses to be a compliant and dutiful patient, it is also apparent that she is uncomfortable being objectified in this clinical manner. By placing "I am not your subject / My life is not your case to study" on their own

indented lines of the poem, Tilly draws the reader's attention to them and offers a provocation: she doesn't say this to her neurologist, but what if she did? Could a different type of patient–clinician relationship be possible?

The poem continues to subvert our expectations that Tilly will present herself as Körper, by focusing on the other 'fact' of the title, her left-handedness, and the devastating impact that left-sided weakness has therefore had on her life. She lists activities that she can no longer do, some of which are practical frustrations in her everyday life: "*write shopping lists / sign my own name*". Others are more creative acts, "*draw doodles / sketch faces / knit ugly christmas jumpers*", which may seem frivolous or insignificant but brought her pleasure and creative occupation. Tilly implies that these losses of creative and enjoyable activities are equally distressing, if not more so, than the physical symptoms themselves. She makes brief reference to the physical pain she experiences – "*losing my ability to...spend just one day without pain*" – but saves the emotive language of "*the aching void*" for the loss of her ability to go hillwalking. The "*void*" here represents both the loss of activity and also the geographical gaps caused by the loss of landscapes from her accessible world. "*Schiehallion / Bennachie / Balmedie beach / Lochnagar / Arthur's seat*" are listed memorial-like in the poem.

When Tilly shared her poem in the workshop it had a profound effect on the participants and me, particularly Philippa, who started to cry and said she:

*"really, really resonated with the loss of landscape...It's hard, it's hard. It's also hearing someone else write what you're feeling because so often you feel on your own...and it's not often that you get somebody put into words kind of just what you can really click with."*

In this recognition of shared experience, Philippa felt a sense of togetherness whereas she habitually felt isolated by the physical and social limitations of living with MS. Tilly reflected that she "*almost started to cry too*" when she was reading her poem aloud even though she "*wasn't feeling it when I wrote it. That's the weird thing. 'Oh, I'll put this down. Ah, this'll do.'* And then when I read it, I was like, '*Oh crap. That's really real.*'" In spite of Tilly's self-reported slapdash, unengaged process of writing the poem, she was surprised by the deep emotion that she went on to feel. The act of sharing, rather than that of writing, was the

emotional stimulus for Tilly, perhaps because on this occasion she was telling us *“all the things I don’t say”* when speaking to family or medical professionals. The circumstances of the workshop as a creative space inhabited by people with similar health experiences seems to have emboldened her to greater openness about her situation and to access her feelings about it.

### 5.5.2 Ellen

In Group 2’s second workshop which was ostensibly about MS bodies, conversation largely focused on Ellen and Saskia’s medical interactions. They were both very engaged in this topic and spoke at pace with a lot of non-verbal agreement when the other was talking. Ellen described the difficulties of dealing with a GP and two neurologists, one an MS specialist and one a migraine specialist, all of whom gave her different explanations for her symptoms. Her frustrations at her encounters with her medical team became apparent: *“I don’t know if you guys feel the same – and another bit for poetry – is that you feel a burden to keep asking your flipping doctor.”* Saskia strongly agreed with this and told us both how the doctor who diagnosed her dementia said that one of her MS medications could be contributing to her cognitive decline: *“So I thought, well, OK, so why hasn’t somebody said, ‘Let’s try and wean you off of it?’”* The lack of communication between different members of their medical teams caused a great deal of frustration for both participants. Although the discussion had quickly moved far from the prompt poem, it was evident that Ellen was thinking about the subject in terms of writing: *“don’t you both feel – and this is a bit poetry – that we have to be detectives?”*; *“and another bit for poetry”*. If anyone were expected to be a medical detective, it would usually be a doctor, but here Ellen is again aware of how she uses metaphor in everyday conversation to introduce a different or unusual perspective.

She went on to talk about having a *“good relationship with my [GP] now. I’ll say, ‘I’ve researched this. These are the links,’ so she can see it’s proper information...she responds quite well.”* At the time of the workshop, Saskia was a former nurse with thirty years’ experience although her specialism was not neurology. Ellen had been living with and managing MS for nineteen years. In this conversation, they rejected the figured world of

'doctor always knows best.' Both Ellen and Saskia referenced the increased role they felt they had to play in managing their own health; they were now expert patients who monitored possible contraindications and potential side effects of their prescribed medications. Accordingly, they would prefer to have a more collaborative approach to their healthcare in which their professional and/or experiential knowledge were taken into account in a process of shared decision making. Although this would amount to a partnership like that described in the GMC (2023) good medical practice guidelines, it is clear that Ellen and Saskia felt their knowledge and opinions did not increase their status in the neurologist–patient relationship. Plus, as disabled, chronically ill women approaching sixty, one of whom experienced significant cognitive impairment, it is likely that they felt further diminished by the unequal power dynamics of the medical relationship (Jackson, Hackett and Steptoe, 2019; National Institute for Health and Care Research, 2022). The quantity and complexity of labour in being a patient can be unsustainable. From lived experience, I can attest that the occasions which have demanded me to be a strong advocate for my health or MS-related accommodations have often coincided with my feeling particularly weak physically or cognitively. Ellen expressed anxiety about this: *“you have to take on this responsibility and when you stop having the ability to research it yourself, then what?”* Saskia responded that she was at the point *“of not being able to do that now. That’s hard for me.”*

When engaging with neurologists, the most senior members of participants’ medical teams, the discrepancies in cultural health capital was particularly apparent. Philippa said in her initial interview that her neurologist was *“quite abrupt and quite – I think he’s very clever. He’s quite a boffin but he’s not really a people person.”* In the workshop conversation quoted above, Ellen, who spoke passionately and unambiguously on several topics, was more guarded when making a distinction between the attitudes of her GP and neurologist: offering her own research *“doesn’t work so well with the neurologist because they think they’re – they do think, don’t they?”* Given the context, it would be reasonable to infer that she meant something like they think they are smarter than the patient or that they are above listening to the patient. It is interesting that she chose not to complete her sentence here, instead leaving Saskia and me to fill the gap. By saying *“don’t they?”* Ellen makes it clear that she expects Saskia and me to understand and agree, which as people who had

also experienced problems with medical care, we felt we did, and yet she still censored her remarks. Possibly the neurologists' senior status in the medical team inhibited Ellen from being overtly critical? After the session, I reflected in my journal that in study conversations it felt almost taboo for PwMS to criticise their neurologists. However, Ellen went on to write the following poem during the workshop:

*"This is me*

*I am not you  
I stand in my shoes  
be it wobbly  
be it stubborn  
I am free  
I am not chained by my disease  
be off with your drudge  
I can decide, not you  
They offer me poison  
It may dampen the devil  
but it does not discriminate  
and treat me in parts  
I am fond of my liver  
I think it's fond of me  
I'll treat it with kindness  
I'm careful with the gym these days  
Hey, another loss with this disease  
So why is it OK for you to say,  
I'm only interested in your disease  
Well, I'm interested in me  
all the parts of me from my webbed toes  
to my tender head  
I will decide how I will nurture me  
I am not you  
I am not a statistic  
I am a partner a mother a lover  
I am passionate about this world  
I love the beauty of the world  
I see it through my eyes  
not the glazed drugged eyes  
ones that I get prescribed  
I am whole  
Please see me this way."*

Ellen presents herself as a complex individual, encompassing many “parts” from her “webbed toes to [her] tender head”, who fulfils several roles in a society in which she is deeply engaged; “I am a partner a mother a lover / I am passionate about this world”. She confronts the neurologist directly in the poem, contrasting herself with him: “This is me / I am not you”. She questions why the neurologist is “only interested in your disease” and wishes to prescribe “poison”. While Ellen acknowledges that the intended medication may alleviate some of her symptoms, it “does not discriminate” and will therefore have side effects on her liver or cognitive function: “glazed drugged eyes / ones that I get prescribed”. This highly emotive language is tempered by “I’m careful with the gym these days” in which Ellen represents herself as a responsible patient who makes adaptations because of her illness. This behaviour is shown as a negotiating tool: she has made this concession so why doesn’t the neurologist perceive her as a “whole” person who is affected both by MS and its treatments? The flat, objective language which Ellen assigns to her practitioner conflicts with her preferred construction of the doctor as a medical caregiver for sick bodies. In contrast, she describes her own relationship with her body as one that is actively rooted in self-care: “I am fond of my liver”; “I’ll treat it with kindness”; “I will nurture me”. As in Ellen’s earlier conversation, there is no collaborative approach to her healthcare or shared decision-making. This is very much a poem of “you” and “I”, although unlike the real-world consultation that she has described, Ellen makes much more space in the poem in which to assert herself.

Towards the end of the poem, she states her phenomenological experience of the world and how this is impacted by medication: “I see [the world] through my eyes / not the glazed drugged eyes / ones that I get prescribed”. This neatly encapsulates Ellen’s predicament. Only she can directly know what it is to experience the world through her eyes, drugged or not, and yet, as a patient, she is reliant on the understanding and compassion of her medical team. The poem ends with a plea to the neurologist: “I am whole / Please see me this way.” Implicit here is an acknowledgement that Ellen has less power than her neurologist in their relationship. Yet, she seeks to her improve her status and therefore the care she receives, by asking him to perceive her as an animated person with agency rather than as merely an objectified locus of disease.

## 5.6 Going public: using poetry in a healthcare interaction

Saskia wrote an 'extra' poem between workshops which she shared with me and then, on her own initiative, shared with her occupational therapist:

*"Did I Boil The Kettle?*

*It's Monday today.  
It's probably not but hey who cares.  
It's a new day which of course starts with a pot of tea.  
I fill the kettle.  
What now? Not sure.  
Maybe I should wash the few bits in the sink.  
All done. Did I boil the kettle?  
It feels hot but I will boil it again.  
While I am waiting I will clean the hob.  
It doesn't need much cleaning as I do it most days -  
After washing the few bits in the sink.  
It's nice and shiny now. Hang on,  
Did I boil the kettle?  
It feels hot but I will boil it again.  
I rinse the teapot and add the tea.  
I am getting there now. I think.  
Did I boil the kettle? I'm sure I did but I will boil it again.  
I need milk. The fridge is behind me.  
I gaze inside the fridge wondering why I have opened it.  
I guess I need to prepare lunch and dinner for today.  
I need to check my meal planner on the computer for that.  
It's not far, in fact it is on my desk next to the fridge.  
As the screen opens I spot I have 3 emails.  
I note on my daily planner to read the electric meter.  
Planner says today is actually Wednesday –  
Today I am scheduled to do the washing.  
As I turn back to the kitchen counter, I spot the teapot.  
You can't miss it, its bright yellow. Now did I boil the kettle?  
I must have but I will boil it again."*

Here Saskia recreates her early morning internal monologue for the reader. She starts making tea by filling the kettle but also begins the washing up and then cannot remember what she had been doing: *"Did I boil the kettle? It feels hot but I will boil it again."* She is frequently distracted, a consequence of dementia. At key points in the poem, she

remembers her intention to make tea and repeats a variation on: *“Did I boil the kettle? I’m sure I did but I will boil it again.”* In the poem’s final line, Saskia and the reader end where they began; the tea is still unmade. In writing, Saskia is able to show the self-awareness and continued focus with which she struggles while trying to complete this basic domestic task. The poem’s reader gains an insight into the frustration and confusion that she experiences on a daily basis.

In the poem, Saskia mentions the aids that she uses to try to focus her day: the meal planner and daily planner which alerts her to the fact that the Monday we greeted at the beginning of the poem is actually Wednesday. So, although her planners do help her to self-correct and complete some tasks, they do not support her to make an early morning cuppa. However, by writing her efforts with the planners into the poem, she shows that, as a responsible, active patient, she is keen to engage with therapeutic strategies, and indeed, two of the positive outcomes of sharing this poem have been targeted resources to help her in the kitchen:

*“It has helped even my OT and my Physio to apply strategies that help me to focus on one thing which have been invaluable. (OT with memory laminated sheets to list all of items needed for recipe and Physio to do exercises holding onto kitchen sideboard to keep me near the kettle...)”*

I can understand how this poem would have been an effective way to explain the impact of her cognitive struggles to her occupational therapist, especially for Saskia who can struggle to retain the thread of spoken conversations. As she wrote to me after the workshops were complete, *“Did I Boil The Kettle has helped so many people understand the beginning and in fact my whole day especially as I live alone and so no one experiences how MS affects me.”* I suggest that there is a further benefit for Saskia in using this poem within her occupational therapy appointment. In her initial interview, she emphasised her pre-MS achievements, writing to me that she had been:

*“a Nurse for 36 years with an abundance of experience...who would hit the ground running every shift and all the while finishing a degree in [an unrelated subject]. (I was given an award for academic excellence coming in the top 5% of [the country where I lived at the time].)”*

She felt that MS and the accompanying early onset dementia had “*robbed*” her of many of her abilities and that she was “*not the same person as before.*” Nonetheless, sharing the poem with members of her healthcare team enabled Saskia to present herself as capable of contributing effectively and with humour to her developing healthcare plan and also as a creative person. In this way, I would argue she was able to boost her self-confidence and perception of her status within the patient–practitioner relationship.

## 5.7 Summary and concluding thoughts

Through a discussion of spoken and written data, this chapter has explored how constructions of MS bodies are nuanced and shift according to context. Participants variously discussed and wrote poems about: their bodies as locations of felt experiences of living with MS; those MS bodies as the objects of an impersonal, medical gaze; and the challenges of representing, and being acknowledged as, an animated holistic self during medical interactions. Early in the chapter, poems and study conversations showed some participants grappling with dissonant constructions of their MS bodies. For some, this related to their pre-MS and current MS selves, resulting in bodies which were losing or had lost strength and motor skills, impacting their sense of coherent identity. Thinking through Young (2005) and Leder (2016), this sense of ‘I can’ is transformed for these participants to ‘I cannot’; specifically to ‘I cannot’ *any longer*. This lessening of ability is common to everybody as they approach old age, however, as participant poems showed, it is particularly shocking and destabilising for PwMS, or similarly disabling conditions, who can experience these losses in physical or cognitive ability at a far faster rate than their peers.

Later in the chapter, participant poems and dialogues considered how their consciousness of their animated, sensory selves was not always in concord with the exterior view of their medicalised bodies. In some cases, this resulted in mind-body dualism as a way to reconcile the two experiences. For other participants, the dissonance resulted in poems which partially or thoroughly rejected the dominant medicalised construction of their bodies. I suggested that, by writing poems about their various somatic experiences, participants were

able to consider these themes more deeply than they usually did. Some seemed empowered to examine uncomfortable emotions or attitudes that they felt they would not otherwise express in conversations with family, friends or medical teams. This was particularly apparent in poems exploring sadness about the disabling effects of MS and those expressing anger or dissatisfaction with neurologist interactions. Across the study, participants were very aware of power relations within patient–doctor interactions and the lack of status that they felt in these encounters. I considered these poems in relation to the constructions of ‘the good patient’ and ‘the good doctor’. Through poems and spoken utterances, participants identified neurologists as the most senior actors in their medical teams, representing the apex of a medical hierarchy where they were more powerful than GPs, nurses and therapists. Some participants explored how the particular power imbalance between themselves and their neurologists affected what they felt able to discuss during consultations and hinted at how the patient–neurologist relationship might be improved.

The experience of being a body is necessarily a private one, resulting in sensations and feelings that cannot be directly known by another. Similarly, medical consultations are usually private experiences between doctor and patient. People rarely speak with one another about the holistic experience of a visit to the doctor; it is more common to report back only those details which are most salient from a bio-medical perspective, such as scan results or changes to medication. Writing the poems afforded participants access to a confidential space in which they could reflect on their own somatic experiences of MS and medical encounters. Sharing and discussing those poems with others in the workshop groups was, I believe, also valuable in a number of ways. Because to some extent we shared similar experiences, participants and I were sometimes able to recognise ourselves in one another’s writing. I would argue that that this led to feelings of validation and (temporarily) reduced some of the alienation and exile of chronic illness. The dedicated space and time in workshops to write and discuss our somatic experiences was very different than in medical appointments which are usually marked by time pressures and privilege information prioritised by doctors. These were opportunities for ill bodies to speak and be heard with compassion and not be dismissed as irrelevant.

Finally I discussed a poem which Saskia wrote and shared with her occupational therapist as a way of explaining a problematic symptom and asking for strategies to deal with it. I suggested that sharing her poem in this way had additional benefits for her self-esteem. Sharing a poem with her occupational therapist is likely to have been a less intimidating prospect than sharing with a neurologist: the interaction took place in Saskia's home; it focused on maximising Saskia's independent abilities; and she had previously said in a workshop that she finds it difficult to influence neurologists' opinions. Nonetheless, her positive experience of sharing a poem with one of her healthcare team has possible implications for future avenues of research. (See discussion in 9.4.)

In the following chapter, I explore participants' utterances and poems about occupation, discussing the impact of MS on their workplace experiences. I also reflect on the role of the study's poetry workshops as purposeful uses of participants' leisure time and how in some cases this presented a different kind of occupation.

## Chapter Six

### Occupation

*'I put thirty-four years into this firm, Howard, and now I can't pay my insurance! You can't eat the orange and throw the peel away — a man is not a piece of fruit!'*

(Miller, 2015, 181)

#### 6.1 Introduction

In Chapter Six, I will discuss the theme of occupation which, for much of the chapter, I will define as paid or unpaid labour, however I will also explore another meaning of occupation: something people do to *occupy* their leisure time. Below I briefly establish the parameters for the chapter's discussions, prior to examining relevant interview, workshop and poem data.

##### 6.1.1 Occupation as labour

My interpretation of labour is a feminist one and includes unpaid housework, childcare and eldercare in addition to paid employment. After all, a stay-at-home parent raises the next generation of workers, while also, if co-parenting, easing the other parent's care responsibilities and making them more available for paid work. As Frayne (2015, 14) notes, the United Kingdom, like other affluent countries, is a 'work-centred society.' On one level, non-domestic work is experienced by most as an economic transaction, making it possible for the worker to pay for life's essentials and, one would hope, to facilitate other interests like sport, culture and travel. However, work is also expected to be fulfilling; it is generally held that we should derive meaning and personal satisfaction from our jobs. Through work we may seek social connection, personal growth and social status (Frayne, 2015). Thus, when a person becomes chronically ill, much more than their income can be threatened.

'Work' or 'Occupation' was not an explicit theme of any of the workshops, although participants were free to include it whenever the topic seemed appropriate or relevant to them. It was a subject that was broached by participants in their interviews and informed some poems and workshop discussions. Section 6.2 will consider the impact on identity and wellbeing for those participants who were still in employment and explores ways in which they had chosen to assimilate MS into their work identities. In 6.3, I will discuss data pertaining to participants who had chosen early retirement as a direct result of MS symptoms. Others told me how they felt they had been forced to leave their jobs through discrimination because they have MS; these data are discussed in 6.4. Across the aforementioned sections, I discuss data in relation to current sociological thinking about work and post-work, including that written and edited by David Frayne.

#### 6.1.2 Occupation of leisure time

In 6.4.3, I consider how Tilly, who had been very distressed by having to give up work, found positive, creative fulfilment through art and writing. These activities were not only ways to spend her free time but enabled her to find meaning and satisfaction. Analysis of this data prompted me to consider ways in which the study workshops may be understood to have functioned as sites of creative occupation. I present these methodological reflections in Section 6.5, which culminates in a discussion of co-creation and intertextuality in the study, and examines how a conversation between Memphis and Claudia in Group Three Workshop One contributed to Claudia's poem. It is, I acknowledge, perhaps unusual to combine data discussion and detailed methodological reflections in the same chapter. However, I would posit that in creative participatory research such as this, it is fruitful to explore the deep entanglement of data creation methods and the resulting data in a way that makes their interrelation explicit.

#### 6.2 In work

In 2016, PwMS, aged 16-65, were estimated to have an employment rate of 55%, whereas the employment rate in the general population was 75% (All-Party Parliamentary Group for

MS, 2016). MS is classed as a disability within the Equality Act (gov.uk, 2010). Accordingly, an employee with MS is legally protected from discrimination by their employers or colleagues. However, as with other protected characteristics including race, gender and age, discrimination towards PwMS can and does happen in workplace settings (Vickers, 2017). Transparency about one's health status when applying for jobs does not necessarily feel safe. Even when a chronically ill individual is able to work, they risk being construed as more likely to take sick leave, a concern that is borne out by statistics; in 2022, the UK sickness absence rate for people with a long-term health condition was 4.9%, compared to 1.5% for people without a long-term illness (Office for National Statistics, 2023). Employers may be wary of their legal obligation to make reasonable workplace adjustments so that disabled workers are not 'substantially disadvantaged' at work (Gov.uk, 2010a). Similarly, PwMS may be reluctant to inform their existing employer when they are diagnosed with the condition. Maintaining employment can be a complicated process of negotiating occupational health services and disability services.

Nina and Eleanor told me about their workplace MS experiences: Nina spoke and wrote about her construction of a professional identity; and Eleanor discussed with me her long-held attitudes to work and how MS had caused her to reflect on her working self.

### 6.2.1 Nina

Nina, who was in full time work, spoke of her previous concerns about how employers might react if they knew about her MS diagnosis:

*“when I joined [current workplace]...erm, I don't know why, I decided not to tell them about the MS. Erm, I don't know why...but for whatever reason, I think it was that, you know, I **didn't want people to think, 'Oh maybe she can't do the job or maybe she's really poorly** and it is like I suppose such a great theme of individuality and **not fitting everyone in the same box**...I suppose that years ago...that's the way people would see it as well, like, you know, that it would be a **rapid decline** and you'd be in a wheelchair and that was it. Erm, but I decided not to tell the organisation about the MS until then I had to last year because I got quite poorly. And it was one of the best things I'd done because they were **absolutely incredible** and they continue to be.”*

As someone with relatively mild RRMS, Nina wanted to resist the 'sick role' (Parsons, 1951) and therefore avoid the pervasive stereotypes associated with MS; the PwMS's inevitable "*rapid decline*". Nina's feelings are not unusual; research shows employees with MS can feel that disclosure of their health status at work is a dangerous strategy which may result in misperceptions of their abilities or discrimination (Kirk-Brown et al, 2014). It was important for Nina not to be fitted "*in the same box*" as everybody else with MS. This utterance suggests that, by not disclosing her MS status, she may have been able to establish a professional identity which was implicitly based on an understanding of her as healthy and therefore capable. Thus, when she did tell them about MS, her "*absolutely incredible*" employers may have continued to see her as a fully participating team member rather than as any of the MS stereotypes.

In Workshop 3, Nina wrote the following poem:

*"Her mask glitters gold in the sunshine,  
She wears it all of the time.  
But not always the same one.  
**She tips her mask to acknowledge  
Its presence, but does not remove it.**  
Her mask, whichever one she chooses, is **her protector, her strength.**  
**Just like her shoes she has one for each occasion.**  
Sometimes, just **sometimes, the mask slips.**  
**But that's okay too."***

Like Nina's other workshop poems, this manages a balance between openness and self-containment, similar to Nina's self-presentation in Group One. The masks are metaphors for her range of social behaviours and identities. The quantity and variety of masks suggest they are used in both workplace and social settings; "*just like her shoes she has one for each occasion*". The glittering gold of the masks allows Nina to present a positive image to others, although the mask is also "*her protector, her strength*", enabling her to present a certain image but also to defend herself from revealing too much. The poem suggests that Nina wears the masks knowingly and playfully; "*She tips her mask to acknowledge / Its presence*". This could be perceived as a reference to the fact that many people in Nina's life, including her employers and colleagues are now aware of her having MS, but, as someone who is relatively well, she appears to retain the mask with relative ease and continues to maintain

choice and control over her self-presentation. Indeed, Nina's choice to write this poem in the third person could be interpreted as a further mask, a way to create distance between herself and the reader.

However, *"sometimes, the mask slips"*. At this point the poem could have a volta and change mood to something darker but it doesn't because *"that's okay too."* This signals that on occasion, MS, or an aspect of herself which Nina would prefer to keep private, will be revealed, but the informal word choice of *"that's okay"* reassures us that these *"slips"* are slight and recoverable. Thus, through this poem, Nina constructs herself as a PwMS who is coping, thriving and in control of her self-presentation in various aspects of her life. She is able to acknowledge the difficulties of life with MS obliquely without making direct reference to the condition in the poem, which was well received in the workshop. Tilly commented, *"It's like you're in charge of the mask. For me, it often feels like the masks are taking over and I don't have any control but, in your poem, you're in charge and I really like that. I really like that."* By contrasting Nina's interpretation of masks with her own, Tilly prompts me to consider the difference between her position and Nina's. Nina looks and appears well to others most of the time; in Goffman's (1990, 58) terminology, whether consciously or subconsciously, she 'passes' for healthy. She has found a way to negotiate her 'dual citizenship, in the kingdom of the well and the kingdom of the sick' (Sontag, 2002, 7). It is therefore perhaps easier for her to maintain autonomy over others' perception of her in the workplace than for Tilly who was perceived by her employers to dwell entirely in the land of the sick (discussed in 6.4.2).

### 6.2.2 "Are you ill enough?" – Eleanor

Eleanor, who had switched to working part-time as a result of MS, spoke in her interview about her attitude toward work around the time of her MS diagnosis:

*"So I was diagnosed back in 2012. I was on a sabbatical at the time. I'd been working in the health service at a **senior** level for a while and thought I didn't want to do my job what I'd been doing and just the things that happened in life, and now I can understand that was the MS. I got exhausted. I was **working crazy long hours**. I have a **very strong natural work ethic** but I just thought I was **flaky**. I thought it was a psychological thing and I didn't bother to go to the doctors because I just thought,*

*you know, in the realm of [the health trust where she works], [senior staff members] all had heart problems and you'll know, it's not always a healthy environment to work in, even though it's rather splendid."*

One might hope that if numerous employees were ill in the same working environment, an organisation would look at how their workplace might be creating conditions in which illness, rather than employees, would thrive. Yet it would appear from this utterance that in Eleanor's organisation, the high incidence of illness became normalised. Therefore she was able to compare herself unfavourably to colleagues with "*heart problems*", serious medically recognised conditions, unlike her vague, "*flaky*", undiagnosed MS symptoms. Also, it is perhaps noteworthy that she and the ill colleagues to whom she refers were all "*senior*". Sick managers feeling compelled to continue "*working crazy long hours*" reflect the findings of a pre-pandemic NHS England staff survey in which 56.6% of staff reported going to work when ill partly because they felt obliged to cover for sick colleagues and vacant posts (Copeland, 2019). Around the time Eleanor was diagnosed with MS, the overall rate of sickness absence in NHS England was 4.5% between October and December 2012, significantly higher than in the rest of the economy (NHS Digital, 2013). Frayne (2015, 149) writes:

*'In a society with such a powerful moral emphasis on being a working and economically active citizen, perhaps the more conventional response to physical and psychological distress is to ignore or suppress symptoms, rather than interpret them as signals of social and environmental disharmony.'*

Frayne's focus on society's moral obligation to be a productive worker resonates, I think, with Eleanor's and my discussion about our attitudes to work. Her initial remark about having a "*very strong natural work ethic*" chimed with me in terms of my own experiences around work and diagnosis. I told Eleanor this, referencing my family's tendency to a Calvinist work ethic where work is valued above all other (in)activity. I recognised that this had not been helpful for me as my health deteriorated. In turn, Eleanor was also aware of constructing her professional identity under the influence of familial and societal expectations, and she spoke of her mother having "*a very strong Calvinist flavour*". She said,

*"my mother's words are, 'Are you ill enough?' – well, it goes right back to school but I'm sure my mother said it, and I'm sure the Scottish voice comes through the ages,*

*and sort of, 'If you're well enough to sit on the sofa, you're well.' 'I'm not quite OK, thank you.'*"

Eleanor and I had both understood work as granting us validation in society, a perception which may have been more deeply entrenched by the social usefulness of the public sector work we did around the time of diagnosis; Eleanor in the NHS and me in education. According to this unconsciously absorbed dogma where work is morally 'good', sickness can be seen as indicative of shirking or laziness: "*If you're well enough to sit on the sofa, you're well.*" Eleanor attempts to refute this gently at the end of the utterance with "*I'm not quite OK, thank you*", which could relate to the childhood conversation with her mother or to her mother's understanding of Eleanor's health now.

Underlying this conversation were the notion of "*ill enough*" and "*well enough*". Who has the power to decide when we are ill enough to rest or well enough to work? In one respect, the MS diagnosis may have helped Eleanor to regain her professional confidence; she now has a valid explanation for what she had assumed was "*a psychological thing*" or her being "*flaky*". Now that her condition has been medically and socially recognised, she can officially assume the 'sick role' (Parsons, 1951). However, the compulsion to work (too much) does not fade easily in the light of lifelong conditioning. Also, the need to rest is complicated by the need to continue employment; both Eleanor and I are well enough to work some of the time and, certainly in my case, are financially compelled to do so. So, when are we "*ill enough*"? Workplaces can make adjustments and accommodations, but tasks and deadlines all need to be met according to the rhythms and demands of our employers.

Research that I located on disabled people working from home focuses primarily on the positives. Working from home increase chances of the disabled or chronically ill worker remaining in the workforce. Disabled home workers have more opportunities to rest, have greater flexibility around medical appointments, and are able to avoid inaccessible environments (Holland, 2021). However, the same research also highlighted greater job insecurity and isolation for the disabled home worker and highlighted the socio-economic inequity of working from home opportunities and supportive work environments.

Xiao et al's (2021) research on working from home during the COVID-19 pandemic lockdowns considered the experiences of general populations, rather than those of disabled or chronically ill people. It highlighted issues with work-life boundaries but concluded that these were likely a result of specific pandemic circumstances. From Eleanor's and my experiences, I would suggest that, although we are able to rest more when working from home, sometimes, whether by choice or necessity, we continue to work when we are sick. We discussed the blurring between work and rest as people who were working from home; I stated that the couch in my flat was often both my work and rest space. Eleanor said, "*I sit on the sofa which is generally when I'm tired and do work.*" As I type this, sitting on the living room floor, leaning against my couch, I wonder if Eleanor is more likely to think about work when she sits on her sofa watching TV in the evening, because earlier that day she sat on the same sofa typing emails to colleagues? Do our accommodations of working from home and incorporating rest into our daily schedules lead our jobs to leak into our non-professional lives? Are we inadvertently more absorbed into the world of work by consciously trying to work less?

### 6.3 Post-work

In championing the rights of disabled people, Oliver (1999, n.p., quoted in Introna and Casagrande, 2019, 217) has said: 'To be constantly and consistently denied the opportunity to work, to make a material contribution to the well-being of society...is the root cause of us [disabled people] being labelled as "other" or "useless".' This is not, I feel, a contentious statement, and the movement for disabled workers' rights has made it possible for many PwMS to remain in employment for longer and more easily than they may otherwise have done, as shown by the experiences of Nina, Eleanor and me. However, this movement largely ignores those chronically ill or disabled people who become too physically or cognitively impaired to remain in the workplace. Thus PwMS who have no alternative but to take early medical retirement can face further alienation. They are not othered or useless merely because they have MS but because they have MS *and* are not gainfully employed. Memphis, Saskia and Philippa spoke and wrote in the study about the loss of identity and future plans that they had experienced as a result of no longer being employed or 'useful'.

### 6.3.1 “Is ambition a dream?” – Memphis

During his initial interview, Memphis reminisced about his previous work as a plumber: “...it was specialist work. It was great. I loved it anyway.” At the time of his diagnosis with MS, he was working in recruitment and, like Nina, he reported a positive experience with his employers: “my work did everything they could...They were brilliant. They were absolutely amazing. They got access to work and they got me everything that I needed.” Over several years, symptoms progressed until “I couldnae do it anymore. I got trigeminal neuralgia on the right-hand side of my face which is the worst pain I’ve ever experienced and that just knocked me out the park.” Memphis appeared quite sanguine when he talked about having to take early retirement and soon switched to talking about treatment for the neuralgia. However, the theme of work resurfaced in Workshop Four, when we considered the theme of Dreams. In the session, Claudia was confident with the prompt poem, ‘In close’ by Kristiina Ehin (2013)(Appendix H.d) which was surreal and, as the title suggests, dream-like. She said that from her experience as a teacher, art could be mysterious and she didn’t feel the need to understand it. Memphis, on the other hand, was more uncomfortable with the poem’s uncertainty:

*“...I’m the exact opposite of you, Claudia. I would have to open up a clock and take all the bits out of it **and find out how it works**. I was brought up like that...I’ve got to **get the meaning**. Where’s that coming from? Why did she say that? And that’s why I get, not upset with myself – a wee gr – angry with myself at things. How are you no getting that? Are you thick? I mean I ken I’m just a daft plumber...but this doesn’t add up for me.”*

Here, Memphis asserts his practical, problem-solving nature: “I would have to open up a clock...and find out how it works”. In previous workshops, he had occasionally said that the prompt poet’s style was “totally alien to me in how I write poetry”, but he had always presented it as a positive opportunity to further his learning. Yet this poem and conversation caused him to consider his identity in terms of his prior education and employment, and his comments, including “I ken I’m just a daft plumber”, suggested a deeper insecurity about poetry and his ability to “get [its] meaning”.

Ultimately, these reflections seem to have been useful for Memphis whose Workshop Four poem focused on dreams as aspirations:

*"Dreams can come true*

*Is ambition a dream?*

***do your wants and needs have an arrival or expiry date?***

*Where am I going and where have I been, recalling memories of things that I have seen there was a time when all of that was a dream*

*when and how did it happen? **Was the plan achieved?***

*Can I, will I, did I, are all questions that I've asked*

*in a dream to take me to the future and deliver me from the past*

***Dreaming of retiring early, of being financially secure***

*dreams from my youth that were **innocent and pure.***

*An aspirational dream, that was well on its way, until that fateful day*

*I was diagnosed with MS **what more can you say, but life for me is not over***

***I have plenty things still to do and wish you health, wealth and happiness in everything that your dreams bring to you."***

In addition to his work as a plumber and his role in Human Resources, Memphis had also previously worked as an insurance salesperson. He said that the language of this poem was inspired by the jargon of that profession: "*do your wants and needs have an expiry date?*"; "*Was the plan achieved?*"; and "*Dreaming of retiring early, of being financially secure*". Certainly the sales patter of insurance is present, but Memphis uses these questions to create a more reflective tone, considering his previous ambitions while prompting the reader to do the same. He explores the figured world, dominant in our society, that enough planning and fiscal management will provide certainty and security. Yet, as Memphis discovered, his aspirations to financial security were part of a long-term plan that could not be achieved when he became too ill to continue working. By rhyming "*financially secure*" with "*innocent and pure*", I would suggest, for him, financial security had been a precarious dream that assumed continuing good health and employment until the point that his pension would reach maturity.

Following the mention of his MS diagnosis immediately with "*what more can you say*" acts as a thought-terminating cliché; the implied answer being that there is nothing more to say, that the MS diagnosis was an instance of terrible individual misfortune. Thus Memphis shuts

down the personal finance thread of the poem and with it the wider fiscal context of ill workers and ex-workers. This may be because he does not want to discuss the complex relationship between self and society in a poem; I imagine that would take more time, energy and reflection than was available to him in the remaining five minutes of our workshop drafting time. However, it is possible that Memphis did not perceive a correlation between his personal circumstances and the government position on financially responsible employment. Or, if he did, this may have been at a nascent stage and not something that he felt able to discuss.

Memphis seeks a positive conclusion to the poem by asserting his individual resilience and positive outlook: *“life for me is not over / I have plenty things still to do”*; and *“wish you health, wealth and happiness in everything that your dreams bring to you.”* Here he focuses on a sunny, if indeterminate, future which, it might be inferred, will be enjoyed and valued through non-financial measures. In the workshop, Memphis joked after he read his poem aloud that he should write text for greetings cards, a sense that he perhaps got partly from the strong rhyme of *“...still to do”* with *“...bring to you.”* Certainly this neat resolution is an abrupt shift from his insightful comments on the impossibility of his former financial aspirations. I do not want to impose a definitive interpretation of the shift in stanza three to incorporate *“you”*; after all, the final line may have been chosen purely because of its strong rhyme and easy, unchallenging conclusion. However, it is possible to infer a comparison between the projected, indeterminate future for *“me”* and the *“health, wealth and happiness”* wished for *“you”*. Health, wealth and happiness here are implicitly connected as in much positivity and personal development discourse, and they may be understood to be, to some extent, interdependent. While Memphis can still aspire to do *“plenty”*, the poem makes clear that the successful outcomes which he wishes for the healthy reader are no longer necessarily possible for him. In this reading of the poem, he has shown, perhaps inadvertently, that the health–wealth–happiness triad, which trips so neatly off the tongue, is rooted in social inequality and is not an attainable *“dream”* for everybody.

### 6.3.2 “I don’t recognise myself” – Saskia

In reply to the first initial interview question, ‘How do you see yourself as a person with MS?’, Saskia sent me the following via email:

*“I don’t recognise myself since only as far back as 2016 when I was diagnosed. If I just go back to 2015, I can sum up who I was simply as: a Nurse for 36 years with an abundance of experience...who would **hit the ground running every shift** and all the while finishing a degree in [a social science]. (I was given an award for academic excellence coming in the top 5% of [the country])...**[MS] has robbed me of being able to care for other people and having to accept that it is I that needs the help now.** Along with the cognition issues that I also have, meaning I could not process a piece of research or recall many things (it is much more detailed than that) I am not the same person as before in so many ways and **I resent MS** for it. I look exactly the same until I talk or move. However (and here is **my strength and positive attitude**), **I will adapt, I will accept, and I will look for the positives in who I am now as a person living with MS...**There are things I can no longer participate in but there are so many other activities where I can. **I have learned to ask for help** and I will take it when I can to conserve my energy...I am stubborn and determined...Some days I will grieve for the person I was. but I think that is natural. **In truth, I am blessed to be who I am now, even if it is totally different to who I used to be.**”*

By beginning with an abrupt negation of identity, “*I don’t even recognise myself [since diagnosis]*”, Saskia structures her reply to show just how much of herself she feels she has lost because of MS: her successful career has been cut short, and future academic success is no longer possible for her. Her list of achievements prior to MS is reminiscent of a CV, invoking a figured world in which ability, skill and competence are valued and rewarded with opportunities; a world in which success is a key component of the identities we construct; a world in which healthy Saskia nursed other people. By parenthesising her academic award in brackets, it seems to me that Saskia acknowledges this as supplementary information while simultaneously drawing attention to it, and thus implies that this additional detail is important in her construction of selfhood. I am mindful that Saskia, who has evidently derived much validation from her professional and academic success, may have wanted to emphasise these achievements to me, the academic researcher, in hope of further affirmation.

The phrases “*having to accept*” and “*learned to ask for help*” suggest that the mental transition from carer to person who needs care has been challenging for Saskia. Her word

choices, “[MS] has robbed me” and “I resent MS”, speak to the extent of her anger at what she perceives as the theft of her identity. As the utterance continues, she talks about her “strength and positive attitude”, again reinforced by bracketing. Thus the focus moves from loss to personal resilience and adaptability as she begins to construct a future self: ‘I will adapt, I will accept, and I will look for the positives.’ Acknowledging that she will continue to experience grief, Saskia nevertheless concludes with a positive outlook; “In truth I am blessed to be who I am now, even if it is totally different to who I used to be.” For me, the use of “In truth” acts as a conscious attempt to emphasise this new positivity and Saskia’s authenticity in claiming it.

On first reading this utterance, I felt a little sceptical; “hit the ground running every shift”. Really? Surely not every shift. I would suggest that Saskia is being a little nostalgic. Taken as a whole, her utterance is, to me, reminiscent of both Frank’s (2013) quest and chaos narratives; she seems to fervently desire movement from loss to acceptance and adaptability. Yet her present self-identity seems to be in limbo, stuck between who she was and who she hopes to be. In spite of her (self-)assurances, Saskia’s identity is tentative and contingent on various factors outwith her control.

In the first workshop, Saskia wrote the following poem:

*“Her life was as **perfect as a rosebud**  
**Ready to blossom** and reveal her intricate layers  
Surely, in time, she became colourful and bold  
And **her life was magical**.  
Gradually her petals began to age and she knew change was coming  
But she did not expect it to change as quickly  
And so painfully.  
Everything she knew her life to be was changing.  
As the first petal floated to the ground, **a part of her was lost too**.  
**But she was still the amazing, magical bloom as she started as**.  
As each petal dropped and the rose changed  
So did she.  
She could see her life changing before her,  
**Tearing away possibilities** and replacing them with **challenges**  
**Unlike any she had anticipated**.  
But she is strong and while her rose will wilt over time  
She is determined to maintain **her magic**.”*

With its romantic central image of a rosebud and floating petals, Saskia’s poem could be read as a metaphysical love poem to her life and identity pre-MS. The poem conjures an idealised existence very similar to that which she constructed in her interview: *“her life was magical”* and *“perfect as a rosebud”*. It emphasises great opportunity in Saskia’s pre-MS life, implicit in the rosebud that is *“[r]eady to blossom”*, until MS arrived *“[t]earing away possibilities”*. Saskia does not directly name MS and her associated dementia in the poem which may perhaps create too harsh a contradiction with her romantic imagery. She presents an identity which has been partially deconstructed by MS: *“a part of her was lost too”*. However, the poem soon speaks of *“challenges”* which although acknowledged to be difficult – *“Unlike any she had anticipated”* – are to be met and overcome. Yes, the rose will inevitably wilt but she intends to retain *“her magic”*, the ineffable component of Saskianess because *“she was still the amazing, magical bloom as she started as.”* Read simply, there is loss, followed by determination that Saskia is, and will be, the same person. Yet, for me, this poem raises an ontological question: how can we maintain a consistent identity in the face of disease progression? Returning to the data, I am left with a lingering concern that, for me, Saskia’s switch from loss to determined positivity feels a little too easy, possibly because I do not see in either utterance a suggestion of *how* or *what* Saskia might retain of her existing identity as her petals drop away. I do not intend this as criticism of Saskia. I am not surprised that, as with Memphis, the route to her ambitions remains undefined; this is perhaps a sign of a wider societal problem, namely the lack of evident social recognition in the UK for those who cannot work (Frayne, 2019). How can Saskia or Memphis envision the specifics of a future valued life when they don’t see similar people being validated in society?

### 6.3.3 “I was a busy person” – Philippa

In Philippa’s initial interview, she told me about a key change she perceived in her identity because of limiting MS fatigue:

*“Phillipa:...I’m a doer. I’m a busy person. I’m a busy erm – I’m a busy person. Erm, I **was a busy person** and I find it quite frustrating and quite hard. It’s been a really difficult transition to try and – I’m the person everybody came to for help. I’m, I’m the one that was at home. I was at home with my boys. I was a **nursery nurse***

GG: Right

Phillipa: so it was really natural to stay home and be with the boys when they were little erm but as the **stay-at-home mum** often the other mums or friends of mine that are working would often say, could you pick my one up from childcare or could you have her for half a day or, you know, whatever. I was always the one that was at home and around so, yeah, **I was always the one that everybody asked for help**. Erm, and so it's been really hard to put myself – because I'm very bad at asking for help myself (laughing). Funny!"

Philippa makes repeated assertions of busyness before correcting from present to past tense; "I'm a doer. I'm a busy person. I'm a busy erm – I'm a busy person. Erm, I was a busy person". This shows how the reduction in her abilities has been difficult for her. She spoke with pride about her role as a homemaker and mother which was an intrinsic component of her pre-MS identity. As a "stay-at-home mum" and former "nursery nurse", Philippa construed herself as the person in her community "everybody came to for help" with their own childcare needs. Later in the interview, she repeated again how busy she had been, reinforcing that occupation and usefulness to others had been an essential component of her identity. In this respect, she is like Saskia; they have both struggled to reconcile that it is they who now need help.

In Group One Workshop One, Philippa wrote the following poem when I asked the group to find metaphors for their individual experiences of MS:

*"A Plate In The Washing Machine.*

*It's not where one would usually find a plate  
It was a shock – unexpected  
Knocking around in the washing machine  
The wrong machine – **how did that happen?**  
**Scooped up** by accident with the bedclothes  
**Battered bruised – looking old now and used.***

*A **pretty** little side plate, **fine china** – Granny's side  
**Little scrolls around the edges**  
Little chips now too.*

***It's a miracle it didn't break**  
**It must have come quite close**  
I can relate  
To the plate*

***Still useful but not to be given to guests  
Who wants cake from a chipped old plate?***

*It's ruined the whole set now!"*

Philippa told the workshop group that this poem is based on an actual incident when she inadvertently added a plate to the washing machine because it had become tangled up in laundry. The plate and washing machine situate Philippa's MS experience in the domestic setting, which feels apt and resonant given her role as homemaker. She begins the description of the plate by focusing on the damage it has sustained with some neat internal rhyme; *"Battered bruised – looking old now and used"*. She then goes on to describe the plate's quality and attractiveness; it is *"pretty"* and made of *"fine china"* with *"[l]ittle scrolls around the edges"*. Clearly the plate has been loved and is cherished. The plate, and by association Philippa, is passive, *"scooped up"*, *"battered, bruised"*, reflecting, I think, the turbulence and hurt she has experienced because of MS and the subsequent destabilization of her identity. She uses questions in the poem to indicate her frustrations but also her bewilderment: *"how did that happen?"* and *"Who wants cake from a chipped old plate?"*

Philippa does assert the plate's and her own resilience; *"It's a miracle it didn't break / It must have come quite close"*. The plate is *"still useful"*, yet its status has been compromised as it is *"not to be given to guests"*. By extension, Philippa has been damaged and compromised as a hostess. She presents a figured world in which the damaged, in this case chronically ill, can still be useful but are limited in their role and less socially presentable. *"It's ruined the whole set now!"* is an interesting line for the poem's conclusion, suggesting that the impact of MS extends beyond Philippa to her family. By implication, this reflects back again to Philippa, potentially causing further distress, since raising and caring for her family had been Philippa's primary role for most of the previous two decades.

#### 6.4 Forced out of work

The movement for ill and disabled people to remain in work has coincided with increased financial austerity from the UK government. Thus it has become increasingly difficult for ill

and disabled people to claim out-of-work benefits (Frayne, 2019). If out-of-work, they are seen as a drain on the public finances, yet such people may require intensive, and therefore expensive, support to stay in the workforce, support which is seen by employers as a drain on *their* finances (Southwood, 2019). I contend that this situation creates a social and financial abyss into which severely disabled or chronically ill people may fall. Saskia and Memphis had construed their medical retirement as resulting entirely from the physical or cognitive impacts of MS; put simply, they just could not work anymore. However, in Claudia and Tilly's narratives, both the medical and social models of disability were at play. Their physical health was deteriorating and would ultimately reach the point where they were unable to work, however they both felt that their employers could have supported them to work longer or differently.

#### 6.4.1 "I was made to leave" – Claudia

Early in our initial interview I made a comment referring to Claudia as 'retired' which led to the following conversation:

*"Claudia: I didn't retire. I was made to leave.*

*GG: Oh right, OK.*

*Claudia: Because (inaudible). Well, I thought I was alright but they didn't. They thought I was a risk to the children. Don't know how but they, they just wanted. They got me, um, invite – what is it? The health person?*

*GG: Occupational health?*

*Claudia: Occupational health to come in and she said I should leave. Yeah, it wasn't easy.*

*GG: No.*

*Claudia: I didn't want to go but I can see now, but I thought I could do it in a wheelchair or something.*

*GG: Yeah.*

*Claudia: No. No that wasn't very good and I had to leave within the week she told me because of health and safety at school because she'd written this report, I had to leave. I just walked out. I'd been at the school for twenty-two years and with the kids. Yeah.*

*GG: Oh, Claudia.*

*Claudia: So that wasn't very nice.*

*GG: No.*

*Claudia: I'm understating it but that was about five years ago. Yeah."*

Claudia emphatically corrected my error about retiring in two stark sentences: *“I didn’t retire. I was made to leave.”* She structures her utterance to show the lack of clear communication from the school which resulted in confusion and opposition: *“I thought I was alright but they didn’t. They thought I was a risk to the children. Don’t know how”*. The repeated use of *“I”* and *“they”* suggest that her position at the school had changed. From feeling, and being, part of a team with a collective duty to nurture young pupils, Claudia had become an outsider who was perceived as *“a risk to the children”*. She no longer represented a ‘normate’ (Garland-Thomson, 1997, 8), a person unmarked by disability or difference who can easily ‘align with the rhythms and rigours of waged work’ (Introna and Casagrande, 2019, 214-5). It appears that Claudia’s request for accommodations, *“I thought I could do it in a wheelchair or something”*, was either not considered by the occupational health officer or was quickly dismissed: *“I had to leave within the week”*.

In this utterance, the local authority seem to hide behind bureaucratic procedures: *“health and safety”*; *“she’d written this report”*. Now a ‘deviant other’ (Garland-Thomson, 1997, 8), Claudia appears to have been dehumanised by her employers, who do not seem to understand the huge impact that their decision had on her, an employee who had *“been at the school for twenty-two years”*. Her long-term professional identity was dismantled within a week and collegiate relationships were abruptly severed as were the relationships with the children that she had taught. She was rendered ‘an unemployable other...viewed as damaged goods, insufficiently resilient’ (Southwood, 2019, 41). Although health and safety is given as evidence that the local authority fulfilled its legal duty of care to the school’s pupils, there is no suggestion that anyone considered their duty of care regarding the emotional wellbeing of Claudia, her colleagues or her pupils. It was not clear from our conversation which symptoms or effects of MS had caused her to be deemed a risk, although her mention of a possible wheelchair implied that her mobility was reduced at this time. It is not my role to make claims as to whether or not Claudia *could* have continued longer in her post; Claudia herself possibly suggests that leaving was ultimately the correct decision: *“I didn’t want to go but I can see now”*. Nonetheless, whether she was fit for her position at the school or not, perhaps especially if not, the local authority might have displayed greater compassion and sensitivity. This may have permitted a smoother relationship with Claudia and, together, perhaps she and the school could have found a less

traumatising way for her to transition into a different role or conclude her twenty-two-year tenure at the school.

#### 6.4.2 “make sure that they kick you out” – Tilly

Tilly spoke cogently and at length about how MS had impacted on her working life:

*“Erm, when I first became ill I was very focused on staying in work. I was working full time as a university lecturer...in (a Social Science) and I loved it and **it was such a big part of my identity, who I was**. Erm, I loved everything about it, **I loved the teaching, the research, collaborating with my colleagues**. The only thing I didn’t like was marking (Georgi laughing). Other than that I loved it all. And I – **my immediate boss was very unsupportive; my immediate colleagues were very supportive**. And the head of school was also unsupportive. It basically felt like they just wanted to get rid of me because **it was going to cost too much to support me**. Um and very fortunately, the GP, who was the GP for the students, was also involved in assessing me and he gave me some really good advice and he said, ‘Just don’t go. Whatever you do, don’t volunteer to go, **make sure that they kick you out** because they’ll have a much harder time not giving you your pension if they do it – if you do it that way.’ And **it was horrible** because I had to stay on while I, I had a meeting with the members of, with the sort of, my bosses and they were trying to get me to volunteer to leave and, I, because I’d got his advice, I was like, ‘No, I’m going to stay. I don’t agree. I need – I’m still competent.’ Anyway so that was really sort of **soul destroying** to be in that kind of **conflictual** relationship with people who I’d always thought of as being **on my side and being part of their team** and suddenly I just wasn’t, and **it made me feel rotten about myself and about the way the world approached people with disabilities and chronic illnesses** and it was, it was a not nice place to be in, um, and **I was devastated** when I did have to retire, but I retired with my full pension so that felt good. **I’d sort of won that fight but it was a fight and it – I didn’t like that**. Erm, and I thought it would be really, I would be really lost and I just wasn’t. It was like, ‘Oh, this is great! I love this. **I love being retired.**”*

Tilly was very clear about the importance of work in her life: “*it was such a big part of my identity, who I was.*” In addition to the academic components of her work, “*the teaching, the research*”, she spoke fondly of its relational aspects; she also “*loved*” “*collaborating with my colleagues*” and “*being part of their team*”. However, although her “*immediate colleagues were very supportive*” in the wake of her illness, she described how her relationship with management became “*conflictual*”. Tilly was very aware of the socio-political dimensions of her workplace situation; she was the only participant who had left work because of MS who explicitly referenced finance as a reason why her employers

wanted her to leave; *“it was going to cost too much to support me”*. The process for Tilly to take early retirement with her pension intact became a tactical battle in which she had to *“make sure that they kick[ed] [her] out”*. Unsurprisingly, she found this *“soul destroying”* and *“horrible”*. Like Claudia, she experienced harms that impacted much more widely than the sadness she felt at no longer being allowed to fulfil work tasks. Having to *“fight”* people who had previously been *“on [her] side”* *“made [Tilly] feel rotten about [herself] and the way the world approached people with disabilities and chronic illnesses”*. Her self-esteem was damaged and she became alert to the ways in which society now viewed her as unemployable, damaged and other (Garland-Thomson, 1997, Southwood, 2019). When she was ultimately forced to retire, Tilly *“was devastated”*.

Although Tilly *“love[d] being retired”*, she was acutely aware of the inaccessibility and discrimination which had increased as she became more disabled. She went on later in the interview to tell me her feelings about the UK government in light of the COVID pandemic and her experience of shielding:

*“I mean I’ve always thought it was terrible – society’s attitude towards people with disabilities and elderly people but the feeling I get from the Johnson Conservative government is that we’re **beyond expendable**. He actively wants to get rid of us...I think...that was the underlying core idea in his head when the care homes were abandoned because it would just be better if these people all died.”*

During this utterance, Tilly sounded both angry and scared to be living in a society which had forced her out of the workplace only to perceive her as *“beyond expendable”* because she was no longer economically productive. Because of the helpful advice of the university GP and her own determination, she had been able to maintain financial security, and, unlike some other participants, she had the discursive resources to construct her experiences through a wider socio-political and cultural lens. However, this does not seem to have lessened the trauma she personally experienced regarding her position in society as a disabled person.

### 6.4.3 Finding occupation in the arts

As discussed in 6.1 above, for many people work 'operate[s] as a main axis of identity' (Frayne, 2019, 27). So, how might people who cannot, or can no longer, work create and perform those aspects of identity which are conventionally found through employment or unpaid domestic occupation? PaMS study participants told me about other forms of occupation in which they engaged, and from which they had derived fulfilment since medical early retirement. Memphis said, *"I paint, I read, I'm doing poetry now. Ha! Like wow!"*. He also spoke about activities he did with his carer; *"we do the garden thegither, we go shopping thegither so it's great. I've got a cinema card, got a library card."* Saskia spoke of how she enjoyed photography, while others talked about pursuits including art and writing: Claudia made *"seascapes on the sewing machine"* which, for her, was a positive and creative link to her previous profession as an art teacher. Tilly had written *"angry wheelchair poems"* which gave her an opportunity to express some of her socio-political frustrations. Philippa also *"put quite a lot down in writing"*, especially about *"bleak"* things which kept her awake at night. She derived ease from this catharsis: once something was written down, *"I didn't have to think about that again and then you kind of, you're freed up again."* Thus, even though six of the participants were no longer economically active, they were taking steps to construct identities that were creatively productive.

Although participants enjoyed creative activities, these were very often solitary pursuits which they did not share with others. In some cases, this was because family members or friends were busy or uninterested in participants' hobbies; for example, Saskia said that her son was not interested in her writing and did not want to read her poems. Participants sometimes found physical barriers to engaging in their creative interests; in her follow up interview, Ellen spoke of the frustrations of having discovered writing and then having periods where she felt too unwell to write; *"Because you find something you can do at home, don't you, (crying) and this bastard thing stops you doing it, you know, because all you can do is sit in a chair."* Tilly told me that she used to attend spoken word and poetry events in the city where she lived. However, since *"using the wheelchair fulltime"* she had been excluded by the inaccessibility of venues:

*Tilly: It's just awful and um like **nobody cares**, like **it's just not a thing**, it's not a – look, you know, **this is a clear inequality**. People who, you know, they're writing poems about inequality for other groups and just don't – **they just give you a blank look** when you say well, what about my group?*

*Georgi: Yeah*

*Tilly: Where's my toilet? Where's, you know?...It's (sigh) – I didn't like the place that that put me because I became resentful and angry and bitter and like, I don't want to be that person,*

*Georgi: Yeah*

*Tilly: but **why the fuck** can't people address this issue?...I never really found a way to come to terms with the lack of accessibility. Um, I wanted to continue doing the things I had done before but found it just so frustratingly difficult."*

Tilly's vexation at the "clear inequality" she experienced at local poetry groups is apparent in the strength of her word choice; "why the fuck". For me, what comes across most powerfully is that she feels her experiences are unacknowledged by others: "nobody cares"; "it's just not a thing"; "they just give you a blank look". She is barred from many venues by their inaccessibility, but even at those events where she can gain access her experiences are disregarded. Vivek Murthy, quoted by Magsamen and Ross (2023, 220), identifies different types of loneliness, including '[c]ollective loneliness' which he defines as 'the hunger for a network or community of people who share your sense of purpose of interests.' I would suggest that this is what Tilly was experiencing. She had not been writing poetry in the months immediately before her participation in the PaMS study and had "maybe written one or two poems" in the previous year. She had been injured during that time which was further hampering her mobility and may have contributed to her writing less. Tilly did not explicitly say to me that she was writing less poetry as a result of the inaccessibility and "blank looks" of her local poetry scene. However, I wonder whether she had been discouraged by the isolation she experienced when engaging with other poets and poetry fans.

In Workshop Three Tilly wrote a poem about a new creative interest, drawing on her iPad:

***"Weak tired  
Lockdown mired  
Count the cost  
Left-hand lost  
Paints, pens  
All dried-out***

**Heart, tears**  
**All cried-out**  
Neighbours caring  
Me despairing  
Nothing doing  
Just angry stewing  
**No more knitting**  
**Just Vacant sitting**

**100 days**  
100 days  
**Right hand works**  
**Right hand plays**  
Makes a mark  
**Has a lark**  
Draws a face  
A cat, a hand  
Beavers, bears,  
Dragons, hares  
Hurdler, sprinter  
Owls, fish  
Old photographs  
Elephant, flowers  
Cubes, cones  
Spheres, domes  
A fox, a mouse  
Newts, bees  
My best pal's dog  
Fanciful fish  
A pig, a goose  
A mallard duck  
Magpie, snails

**Post on instagram**  
**I've got it back**  
**Like a gift**  
**A sudden shift"**

The poem begins with Tilly in a state of despair which she was experiencing because of increasing MS disability, "*Left-hand lost*". She was also isolated; "*Lockdown mired*". As a left-handed person, it was particularly difficult for her to lose strength and mobility in her left arm and hand, and, as the poem states, she was unable to do the creative activities she had enjoyed. The strong rhyme of "*Paints, pens / All dried-out / Heart, tears / All cried-out*" emphasises the emotional toil this had taken on Tilly, while "*No more knitting / Just Vacant*

*sitting*” shows the stark contrast between her former nimble hobbies and this inertia. The poem moves into curiosity and persistence as she embarks on “100 days”. 100 Days of Sketching is an internet challenge in which people draw for at least six minutes every day for one hundred days, <https://www.100daysofsketching.com/>. During Workshop Three, Tilly told Philippa, Nina and me that a friend was doing the challenge so she had decided to join in to see whether she could learn to draw with her right hand. In the poem, it is evident that learning to draw with her non-dominant hand is effortful, “*Right hand works*”, but Tilly enjoys the process; “*Right hand plays*”, “*Has a lark*”. As she lists twenty-nine of the objects and animals that she drew on the challenge, the poem slips out of its tightly rhymed pattern, thus highlighting the momentum and freedom she felt during the challenge. The poem concludes, “*Post on Instagram / I’ve got it back / Like a gift / A sudden shift*”. Certainly, this speaks to her satisfaction at getting her artistic “*gift*” back by learning to draw with her right hand. However, by undertaking the challenge with a friend and by sharing her creative output on social media, she has also re-engaged with other artistic people and shown herself to be one of them as opposed to someone who is predominantly “*Weak tired / Lockdown mired*”. I would suggest that through online sharing Tilly has found some of the artistic and personal validation that she sought at local poetry groups.

## 6.5 “the words that are on the page and in the air today” – the workshops

Contemplating Tilly’s positive experience of taking part in the sketching challenge prompted me to explore the study data from new perspectives: might the participants have derived a sense of creative community from the workshops? In what ways might the workshops have given participants a new form of occupation? How might the workshop environments contribute to participants’ poems? Below, I examine participant data in terms of these questions and reflect on the complex interaction between the research methodology and resulting data. I conclude the section by demonstrating how the workshop conditions contributed to the completion of Claudia’s first workshop poem.

### 6.5.1 “There’s nobody the odd one out” – the workshop communities

The PIS described potential benefits of the workshops: ‘Some participants may also enjoy the social aspect of the workshops and value the opportunity to spend time with others who have similar illness experiences to their own.’ However, in their initial interviews several participants told me that they did not know any other PwMS and had consciously chosen not to engage with MS support groups. They gave varied reasons for this but generally it resulted from a reluctance to engage with people who were more disabled or ill than themselves. In her first interview, Eleanor said, *“I haven’t joined any local MS societies because I didn’t want to meet people who were ill. I think maybe that links to the future.”* Similarly, Philippa said, *“there was a really mixed group so, for a start, I got a fright seeing people in a lot, lot worse state than I was in which I wasn’t prepared for.”* She persevered with attending that support group but *“but then it seemed to just become a let’s see who’s got the worst story to tell about how they were treated or how they got the news...and I just thought, no, this isn’t supportive. This is just making me feel really sad.”* Before beginning the workshops, I was hopeful that their structured, task-based format would create a different and more positive atmosphere to the one reported by Philippa at the MS support group.

Each group developed a mood or ‘personality’ according to its individual participants. For employed participants, the workshops functioned to some degree as a break from the day job. Group Four was comprised of Alex and Eleanor, both of whom were in paid employment. We joked that their Friday afternoon workshops were a way to ease into the weekend. Both were proficient with Zoom and appeared confident in the workshop; for example, Eleanor suggested extensions to activities, such as offering to share a word list that I had asked participants to write. In Group Two, Saskia sometimes focused on practical matters and treated Ellen and me as ‘experts’ on MS and related matters, asking if we had experience of arranging lasting power of attorney documents. Memphis, on the other hand, told Claudia the recipe for a Rusty Nail cocktail in Group Three. Nina, Philippa and Tilly in Group One seemed to forge deep connections from the first workshop and continued to stay in touch after the conclusion of the study. These varied examples speak, I think, to how participants took ownership of ‘their’ groups and shaped them.

I had intended the workshops as a safe space for discussion and the sharing of experiences, opinions and poems, and I explained this intention to participants both in their first interviews and in the first workshops. In my previous experience of teaching poetry workshops in both formal education settings and community groups, in the heat of a strongly held opinion, participants would occasionally need reminders about listening or being respectful to one another. However, reminders were never needed in the PaMS study workshops. As time went on, participants shared deeply personal information and poems with one another in ways that I found to be always respectful, patient and empathetic. This springs in part, I would suggest, from the similar experiences they had as PwMS. Certainly, everybody in the workshops, including me, was considered to be an MS ‘insider’ by everyone else in the group. In Workshop One, Philippa said, *“If you’re in a group of normal people kind of thing you feel like the flaky one because you need that wee bit of extra time...but here I think everybody gets it...There’s nobody the odd one out.”*

#### 6.5.2 “the focus of what to do, that was good” – the workshops

The ease that participants demonstrated with one another led to collegiate atmospheres in which poem discussions seemed to flow naturally. They seemed comfortable to offer their own interpretations of poems, but also to express uncertainty or request clarifications. For example, Tilly expressed uncertainty about an aspect of ‘Grief’ by Matthew Dickman (2008) (Appendix H.a) in Workshop One:

*“Tilly: Everything about it makes sense to me but **why a purple gorilla?**...it’s so **random**.*

*Philippa: It might be the randomness is there because there’s so many random aspects that sometimes occur to you when you’re grieving that don’t seem to make sense, **things that trigger you** and things that you think about.*

*Tilly: Yep.*

*Philippa: And I think there’s a **ridiculousness** as well about a purple gorilla...*

*Tilly: And the gorilla is so big and purple and scary but then it’s purple so it’s **ridiculous**.*

*Nina: I think it’s maybe **the volatile nature of grief** and the volatile nature of the gorilla. I suppose purple **might be a sad colour** as well to some people.”*

Tilly picks up on Philippa's mention of "*ridiculousness*" and uses it to consider specifically what is "*random*" about the gorilla; for her, its purpleness. Nina then volunteered a possible different effect of the colour purple which "*might be a sad colour*". Thus in this example, and across different groups and workshops, participants expanded one another's understanding of, and engagement with, prompt poems. Tilly's question, "*why a purple gorilla?*", was ostensibly about the poet's literary choice, yet it prompted the group to gesture towards their own experiences of grief; "*things that trigger you*" and its "*volatile nature*". For some participants, perhaps the abstract nature of the prompt poem discussions were a way of sounding their capacity at that time to share or engage with potentially emotional and affecting themes and experiences. I would suggest that the poetry workshops gave participants both a novel, creative route to access their MS experiences and a way to do so in relative emotional safety. This sense of security came, I think, from the occupation offered by the workshops; Claudia, who expressed her reluctance to talk about MS in her first interview, said the following in her follow up interview when I asked how she had found the workshops:

*"I really enjoyed the workshops. I really did and I think because it was **structured**, it was good and because you had a poem to start with and **the focus of what to do, that was good**. So it sort of, **it gave you a reason to really to think about and write about** and yeah it was good. I really enjoyed them."*

It is apparent that Claudia valued the "*structured*" nature of the workshops and the fact that it was purposeful and task-based with a "*focus of what to do*" and "*a reason to really think about and write about*". Emotional labour and exploration was undertaken in the workshops, but I contend that, for Claudia and some other participants, the creative or literary work of reading and writing poems gave a more recognisable (and respectable?) purpose to our time together.

### 6.5.3 'Echoes and reverberations' - intertextuality and co-creation

Although, as described above, discussion was a key element of the workshops, they also contained dedicated time for quiet reflection and independent writing. Yet, when, after the break, participants settled to the individual work of writing their poem drafts, they were scaffolded by the poems and talk that had happened before. Thus the conditions and

structure of the workshops created an environment in which both intertextuality<sup>9</sup> and co-creation flourished. Participants sometimes felt inspired to echo the themes or stylistic strategies of prompt poems. For example, influenced by Holly Magill's (2017) 'What can you see?' (Appendix H.c), Ellen chose to write a short poem about an encounter with a "Rude Man" in which she felt othered (discussed in 7.2.1). Similarly, Claudia's poem "My Legs", discussed in 5.3.1, was evidently influenced by Kitty Coles's (2017) poem 'Migraine' with both featuring bold, varied metaphors and a combination of short and long lines.

Participants were also inspired by the writing, conversations and suggestions of others in the group. Nina spoke in her follow up interview of having been influenced by Tilly and Philippa's writing style as the workshops continued:

*"I suppose, I actually learned from yourself, Phillipa and Tilly that there was, I suppose, especially with Phillipa and Tilly there was almost a storytelling point style to their writing...And I really liked that because it brought it to life, erm, so much...And I was like, yeah, and that kind of struck a chord with me, so I think I did take that on board a wee bit and tried maybe more of a story style as kind of the weeks went on."*

These are not instances of participants copying one another or the published poets who had written the prompt poems. Bakhtin (1986, 91) wrote,

'Each utterance is filled with echoes and reverberations of other utterances to which it is related by the communality of the sphere of speech communication. Every utterance must be regarded primarily as a response to preceding utterances of the given sphere'.

Considered in this light, I contend that the participants were working individually and together to develop their own understanding and experience of the craft of poetry, and in doing so, they added their voices to the existing discourse of poetry about disability and chronic illness. Maria Rosario Jackson says, 'That ability to delve into the past, present and future individually and collectively and without external judgement is so important' for

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<sup>9</sup> Post-structuralists Kristeva and Barthes understand texts and their meanings to emerge in relation to pre-existing texts, language and discourse (Allen, 2019). It can take the form of a conscious compositional strategy on the part of an author to allude to, quote directly, or use a stylistic device favoured by another writer. Alternatively, the dialogue with prior texts can be more thematic.

marginalised communities (Magsamen and Ross, 2023, 213). I would contend that such acts of 'delving' were undertaken and mutually supported in the PaMS study workshops.

In spite of the workshops' supportive and encouraging atmosphere, the work undertaken by participants was not always entirely comfortable or easy for them. In Workshop One, Claudia told us that she was finding it difficult to complete her poem because she felt it was stuck in a negative mood; *"It's just me because I don't like to not be positive but I'm rather trapped in this. I suppose I could use these feelings. At the moment I'm sort of trying to sort it out. Oh God."* Memphis replied that he also did not like being negative *"but it is what it is. It's what you're feeling at the time...no rights and wrongs in it."* He went on to read his poem and said, *"Darkness has crept in over the years. Sometimes I do go there a bit. No all the time. Something like that is good for us."* Following this acknowledgement that he, a very upbeat, jokey member of the group, allowed darkness to creep in sometimes, Memphis and Claudia moved into a frank discussion about how they hid *"negative"* emotions from people close to them. This was done under the aegis of commenting on Memphis's poem and was therefore, I would argue, an easier way to approach a topic that Claudia found uncomfortable. Although she elected not to read her poem aloud in that workshop, Claudia did explain to us that it was about MS as a thorny bush. Memphis made a joke on wordplay between horny and thorny which Claudia and I laughed at. Claudia replied that she *"won't say I'm a little prick but!"* and after more laughter from everybody in the group, Memphis suggested she could put that in the poem, and we spoke about the benefits of an intriguing title. After the workshop, Claudia continued to draft her poem before sending me the completed version, called *"Little Prick"*. The title of the poem is arguably at odds with some of the darker subject matter of the poem in which MS *"invades and smothers / all that's normal and steady"*. However, Memphis's suggestion provided Claudia with a way that she felt she could present her darker emotions while also showing the humorous side of her identity. The co-constructed elements of *"Little Prick"* remind me of something Eleanor said about our writing in Group Four's first workshop, a comment that, for me, encapsulates the co-construction work that happened across the different groups: *"There's something about our community efforts, because we all had conversations that would have shaped our poems, and our conversations will shape what we do or don't do next...it's the words that are on the page and in the air today."*

## 6.6 Summary and Concluding Thoughts

In this chapter, I have explored participants' experiences of working or stopping work because of MS and I have considered ways in which MS, and society's attitudes towards it, have impacted on their professional identities and wellbeing. I discussed the ways in which Nina spoke and wrote about withholding or disclosing health information at work to retain autonomy and her use of 'masking' to create a confident, successful workplace persona. Eleanor's workplace experiences and attitudes have been considered in the context of a wider socio-political position which frames work as a moral obligation which one should attempt to meet regardless of illness. Additionally, I have explored issues of post-work identity through the interview and poem data of Memphis, Saskia and Philippa, who variously revealed losses of financial security, recognisable identity, and caring or domestic roles. Memphis and Saskia both presented positive visions for their futures but these were vague, suggesting perhaps the lack of suitable role models for medically retired PwMS. I have also discussed Claudia and Tilly's experiences of being made to retire from work and the ways in which they felt this process was made deeply distressing by their employers.

In addition, this chapter has considered the ways in which participants found creative occupation and the barriers they encountered. Then, I reflected on the study workshops as possible sites of creative occupation. From participant data and my own impressions in workshops, I would suggest that MS groups with creative activities give group members a purposeful focus for their co-engagement and that, for some people, this is preferable to traditional MS support groups which may feel unstructured. This chapter has also explored how participants worked with one another and me to build collegiate relations with one another and write poems. These poems, while undeniably authored by individual participants, displayed co-creative and intertextual elements deriving from the workshop conversations, resulting in unique records not just of participants' MS experience but also of the workshops themselves.

During the composition of this chapter, I have reflected on why I decided not to include 'Work' explicitly as a workshop theme. Following interviews, I was struck by Tilly and Claudia's seeming vulnerability and deep grief at having been "*made to leave*" jobs that they loved. This, along with Saskia's grief and confusion at her loss of professional identity, made me concerned that further probing the topic in a focused ninety-minute workshop could cause unnecessary distress to some participants (Liamputtong, 2007). Accordingly, I decided to assign Workshop Four the more general theme of 'Dreams' which participants could interpret however they chose.

While analysing data for this chapter, I have been very aware of how participants' talk about work seemed less embodied than their discussions and writing about medical or social interactions. It is possible that this reflected the fact that work was not a poem theme for most participants. However, participants tended to speak about other aspects of MS with attention to their lived somatic experiences. Marx (1990) posited that the bodies of workers are constructed as tools of productivity, and, as a result, pain, tiredness or illness are suppressed. I wonder whether a sense of disembodiment, springing from (subconscious) suppression is widespread in the workplace for disabled and chronically ill people. Like Nina and Eleanor, I have certainly experienced difficulties reconciling my felt experience of MS symptoms with my professional self. These invisible symptoms of blurred vision that does not resolve with glasses, weak memory, and fatigue have gone unseen by numerous employers, and I have struggled to find a way of assimilating this aspect of myself into my professional identity. It should perhaps come as no surprise that the narratives and analytic work of this chapter have tapped into anxieties that I am currently experiencing as a PwMS who, on completion of this thesis, will be attempting to re-enter the job market.

Considering the concerns of participants who were still working, the difficult experiences of those who had stopped working, and my own anxieties around my employability, I am reminded of Abberley's (1997, 39) assertion that society would benefit from a different paradigm which 'rejects work as crucially definitional of social membership'. On a small scale, participants were able to find validation and worth through writing and sharing poems in the workshops. How might this be replicated or expanded? Later, in Chapter Eight, I will

be exploring participants' sharing of poems beyond workshops through both core participant and reader participant data.

## Chapter Seven

### Being with Others

*'It is in writing – engaging with the difficulty of matching words to experience, of finding new words for old wounds – that we learn to speak our own language rather than that only of our culture, parents or peers.'*

Kureishi (2019, 70-71)

#### 7.1 Introduction

In this chapter I explore data about what it means for participants to live with MS and participate in the social world. Socialising and public life was explicitly approached in the third workshop, 'MS and other people'. However, this topic also arose naturally in other conversations and workshops, reflecting how we continually (re)construct ourselves in relation to those around us as our environment and relationships shift. When I told Claudia that we would be exploring ways in which MS changes how people interact with us, she replied eagerly, *"There's plenty to say!"* She and the other participants spoke openly and thoughtfully about incidents and interactions which they might otherwise 'keep in the family'. Rereading transcripts as I write this chapter, I am deeply grateful for the willingness of all participants to share deeply personal and sometimes difficult or uncomfortable information with me.

In Chapter Five, I incorporated the theory of 'dys-appearance' (Leder, 1990, 84) into my explorations of participants' relationships with their MS bodies. Leder expands his theory to encompass 'social dys-appearance' which occurs when an observer perceives another's dys-appearance and consequently objectifies them, often in ways which are hostile or antagonistic. Leder contends that this causes disruption in the usual pattern of communication and interaction, potentially leading to a sense of social isolation or inadequacy for the objectified person. Here I use Leder's theory of social dys-appearance as a phenomenological lens through which to focus on the participant data about their own

public and social interactions. Where relevant I also reflect on the data from a sociological perspective with reference to Tyler's (2020) work on stigma.

As a researcher who has a close relationship to the study themes, sometimes I have felt that participants' words hold up a mirror to my experiences with family and friends, prompting me to reflect on challenging aspects of my own relationships and interactions around MS. Conversations with core participants about these experiences were an important element of our study interactions, in which we thoughtfully discussed our similar threads of experience with an awareness that our similarities incorporated multiple differences. My personal reflections in my study journal stitched and unpicked these threads in ways that have facilitated my data analysis in this chapter. However, in order to establish some boundaries between my private and professional roles, and also to maintain confidentiality for family, friends and myself, I have mostly elected not to discuss my personal relationships within this thesis. The discussions in this chapter represent my best efforts to walk the tightrope of illuminating the data while protecting myself and others.

## 7.2 Being in public

Several participants, whose MS disabilities meant that they could not 'pass' (Goffman, 1990, 93) for able-bodied, spoke about their experiences of participating in public life and how strangers interacted with them. In this section, I discuss participants' perspectives of being in public, considering data about how PwMS can be made to feel hyper-visible or invisible because of their dys-appearance. Attitudes to disabled people of individual members of the (able-bodied) public do not arise in a vacuum: from my own experience, participant data and academic literature (Morris, 1992), for disabled people, the personal can be wearily and sometimes alarmingly political. Accordingly, I explore the data in the context of recent and current political and media rhetoric about disability and economic worth. Although the section is primarily about encounters with strangers, for people with substantial physical impairments, public interaction is often practically enabled or prevented by carers or family members. Therefore the role of family in facilitating such interactions is explored in Claudia's data and in my subsequent discussion.

### 7.2.1 “What’s wrong with you, like?”

In the Workshop Three prompt poem ‘What can you see?’ (Magill, 2017), the poet experienced unwanted questioning about her blindness. This reminded Memphis of an incident that had happened to him several years before when parking in a disabled bay:

*“I had the blue badge but I was still walking on crutches and this guy **out of nowhere** just tramps up and, ‘**You’re parked in a disabled space.**’  
‘Aye, I’ve got M.S.’  
‘**Aye, so you have!** What’s wrong with you, like? You’re walking alright.’  
I said, ‘I’ve got **multiple sclerosis.**’  
‘Aye but **there’s nothing wrong with you.**’ **And it just – that will stay with me forever.**”*

Memphis begins the utterance by justifying his parking in the disabled bay: he “*had the blue badge*” and also he was “*walking on crutches*”. There is a strong sense that he felt ambushed or attacked by the sudden approach of “*this guy out of nowhere*”. The language attributed to the other man is accusatory: “*You’re parked in a disabled space.*” Memphis phrases this as a statement of fact rather than a question and the power dynamic of the encounter is evident; the other man felt he was entitled to an explanation for a stranger’s parking decision. Memphis reports his own speech as short and to the point, implying that this was a conversation he would have preferred not to have: “*Aye. I’ve got MS*” which is later expanded for clarification to “*I’ve got multiple sclerosis.*” This is very personal information to feel obliged to disclose to a verbally aggressive stranger in a public place. There are inconsistencies in the stranger’s response; he says “*You’re walking alright*” although Memphis has stated that he was using crutches. The man uses “*Aye*” aggressively to imply disbelief and then rejects Memphis’ explanation. It is highly unlikely that this member of the public had any medical education – if he had, he would not have assumed that a PwMS could not walk – and yet he felt entitled to accuse Memphis of lying: “*there’s nothing wrong with you.*’ The damage of MS is compounded here by the harmful behaviour of strangers. Memphis is not judged solely on his physical limitations, for which he would have had to offer extensive evidence to his local council in application for the concessionary parking badge (mygov.scot, 2023), but also on what the stranger insinuates are moral failings and fraudulent behaviour. When telling me about this incident, Memphis broke off

speaking in order to gather his thoughts before completing the sentence “*And it just – that will stay with me forever.*” He has become conscious of the opinions of others towards his MS body. His Workshop Three poem included the line, “*People’s perceptions means the world to me, but when you look at me, tell me what do you see?*” Rereading his words, I am reminded that we never construct our body-images in a vacuum but rather our understanding and awareness of our corporeality is an intersubjective social act. For Memphis as for Leder (1990, 92), ‘My self-understanding always involves the seeing of what others see in me.’

Memphis has understandably become self-conscious in public as a result of this personally directed verbal attack, however the behaviour of his antagonist is not an isolated case of rudeness. Rather it can be seen as developing from the wider socio-political forces of twenty-first century life in the United Kingdom. As Foucault (1979, 25) has written, ‘the body is...directly involved in a political field; power relations have an immediate hold upon it.’ The poor, chronically ill and disabled – often intersecting groups – have long been blamed for economic pressures, and disabled people in particular can be perceived as useless or abnormal and therefore less deserving of rights and resources than able-bodied citizens (Hunt, 1966; Tyler, 2020). Since 2010 there has been a marked increase in political discourse that stigmatises those citizens deemed to be ‘unproductive’ and over-reliant on state benefits, (Tyler, 2020, 4). MPs speak arbitrarily of ‘the really disabled’ (Ryan, 2018) and the ‘bogus disabled’ (Walters, 2013) with no medical definition of what constitutes either category. Propelled by government rhetoric dehumanising poor and disabled people, the press have focused on ‘welfare cheats’ and the ways in which people are undeserving of benefits (Daily Telegraph, 2012; Leathers, 2022; Marsden, 2023). Such political and media contributions to the discourse would appear to have affected public attitudes; a recent YouGov poll (Smith, 2023) found that only 39% of respondents believed that people on out-of-work benefits (a category which includes a significant number of disabled people) should be able to afford a non-active hobby such as playing a musical instrument. The same survey found that only 27% of respondents believed that people in receipt of out-of-work benefits should be able to afford to socialise outside of their homes, e.g. in pubs or restaurants. The public have been encouraged to be suspicious of people who present as disabled and to report suspected cases of benefit fraud anonymously to the Department for Work and

Pensions (Newton Dunn, 2012). It is therefore unsurprising that in this climate of austerity and stigmatisation, some individuals feel entitled to accost disabled strangers in public places.

Similarly to Memphis, Saskia spoke with Ellen and me about her discomfort when parking in disabled bays:

*“Saskia: I get looked at in ways that to me **make me feel guilty** because I get out of the car. It takes a while but I get out. I use...that thing that slots into **that little bar thing so you can lift yourself out and then I get my cane and then I have to wait for my legs to kind of stabilize and then I can wobble off** but because I am not **an elderly person in a wheelchair**, it’s almost like, you know, the question would be, ‘Why do you need a disabled spot?’ You know? Because I think **people judge**.  
Ellen: They do. They do, Saskia. They really do.”*

Saskia would appear to have internalised the suspicious judgements and stares of others and feels “*guilty*” even though, like Memphis, she needs, and is entitled to, the accommodation of a parking space close to her destination. Also like Memphis, she detailed and justified her parking choices, talking Ellen and me through her process from parking the car to “*wobbl[ing] off*” on foot. This process is composed of a number of steps and is time-consuming, which is emphasised by the very long sentence structured with repeated use of “*and then*” to introduce each action. Getting out of the car and walking necessitate multiple mobility aids for Saskia: the “*little bar thing so you can lift yourself out*” and her “*cane*”. Nevertheless she feels that she does not look disabled enough for people to accept her entitlement to this modest but important accommodation. She is not “*an elderly person in a wheelchair*” and therefore thinks “*people judge*” her. Ellen, who had spoken in her initial interview about being “*verbally really abused*” for parking on double yellow lines with a blue badge, strongly agreed with Saskia. She said that people who have no personal or familial experience of disability “*perceive you as public property*”. This phrase speaks to how strangers can feel entitled to challenge or judge disabled people who may be in receipt of publicly funded accommodations and benefits. While the strangers in Ellen and Saskia’s discussion do not know any personal details about them, for me, their attitudes seem to reflect the suspicious mindset of people who might telephone the government benefit fraud hotline mentioned above.

Ellen uses a wheelchair when on shopping trips and excursions and yet she too finds that although she is disabled enough for people to pass comment on her appearance, she is harassed and judged for not acting in line with the stereotypical image of a wheelchair user. In her initial interview she told me about a strategy that she and her adult son employed to defuse her fear and vulnerability in public settings:

*“Ellen:...when I was first sometimes using the wheelchair or the scooter and then I got off of the wheelchair or the scooter, and people would look, because **people do look** if you get out of a wheelchair, and he would say, ‘**Woo! It’s a miracle! She rises! She rises!**’ (both laughing) ‘Hallelujah, she rises! God sent a miracle!’ If **you were really scared**, he would do that. You know that is how we dealt with it and **we would just burst out laughing**.*

*Georgi: Yeah. (both laughing) Because it’s nobody else’s business.*

*Ellen: No, it’s **nobody else’s business** because, yes, you can walk but you might need to use a wheelchair because you can’t walk that far.”*

Here Ellen speaks about trying to manage both her medical impairment and social disability: not only is she learning to use and safely transfer from a wheelchair and mobility scooter, but she is having to do so under the intrusive, othering gaze of strangers. By performatively mimicking a religious miracle – “*Woo! It’s a miracle! She rises! She rises!*” – her son acknowledges the strangers’ curiosity by sarcastically pretending that their stares are justified and thus protects his “*really scared*” mother. I am reminded of Garland-Thomson’s (2005, 35) work on disabled performance artists choosing to draw attention to their physical difference as way of ‘control[ling] the terms of the encounter’, essentially inviting the starers to keep on looking but not in a way that is victimising, rude or intrusive. Although Ellen and her son would hope that the strangers are embarrassed into discontinuing their staring, by “*burst[ing] out laughing*”, they assert that all is well and that they are managing the situation. Even if the strangers did continue to stare, they would be highly unlikely to challenge Ellen and her son for information that is “*nobody else’s business*”.

Ellen also spoke about other instances when she felt particularly uncomfortable in public:

*“I tell you what I get a lot when I’ve been swimming over the years. I get people saying to me, ‘**Oh you’ve got a hip problem, have you?**’ because my leg’s a bit bent ‘Or a knee problem?’*

*‘No I don’t have either of those’, and then they’re waiting for me to explain what’s wrong with me...It’s **intrusive**, isn’t it?*

*Saskia: Yeah*

*Ellen: Especially for women and you're there in a swimming costume. 'Can you not stare at me, please?'"*

The “intrusive” stares of strangers make Ellen feel doubly objectified and vulnerable as a woman with a visible disability. This othering is emphasised by the setting of a swimming pool, which is associated with healthful activity, and her therefore wearing a swimming costume which makes her impairment more visible. Here the disabled body fascinates and unsettles the non-disabled starrer; if the observed body is different or disabled, might the observer’s body become different or disabled? This prompts inappropriate questions from strangers seeking ‘a narrative that puts their disrupted world back in order’ (Garland Thomson, 2005, 31): “‘Oh, you’ve got a hip problem, have you?’” While this type of questioning would not appear to derive from the same suspiciousness and accusations that Memphis experienced, Ellen is still stigmatised by the encounter which transforms her from an active person swimming into a disabled female object of surveillance. To paraphrase Berger (1972, 47), non-disabled people act, disabled people appear. Or as Garland-Thomson (2005, 32) asserts, ‘[t]he male gaze produces female subjects; the normative stare constructs the disabled.’

Ellen went on to write the following poem during Workshop Three:

*“Rude Man*

*Please don’t stare*

*I am not your property*

*I’m like you*

*I belong to nobody*

*I might be in a chair, but how very dare*

*I rise!!*

*I can walk! Take a look,*

*Integrate me with your eyes.*

*You will not find out*

*What is my curse ?*

*It is not for you to know.*

*I do not wish to share*

*I’d like to say ‘piss off’*

*And you’d think, how does she dare.”*

Here Ellen imagines an assertive challenge to the unwanted attention and accusations that she receives. Although the poem is written in free verse, i.e. with no set pattern of rhyme, rhythm or stanza length, Ellen does make striking use of rhyme across the poem with the words '*stare*', '*chair*', '*share*' and '*dare*'. These four words encapsulate the central premise of the poem: the man *stares* at her because she is sitting in, and then gets up from, a *wheelchair*, an act which he presumably thinks she should not be able, or *dare*, to do and thus she should *share* with him the reasons for her actions. Writing of his own experience of going 'a bit blind', Lenard Davis (2022, n.p.) writes: 'You are either disabled or not, and, like pregnancy, you can't be a little disabled. That black or white definition provides a false comfort to "normal" people so that they can push the prospect of being disabled comfortably behind a definitional wall.' Evidently Ellen is more than 'a little disabled'; MS has significantly impaired her mobility, yet she can still stand and walk for short distances. However, the various "*rude*" men that she has encountered would seem to apply a very limited definition to mobility: either a person can walk or they cannot. This definition may be applicable to some wheelchair users, but it leaves no space for the large proportion who retain some ability to walk or self-transfer from a chair. The application of such a blunt, inaccurate definition erases Ellen; her lived reality as a disabled person is doubted by the stranger who, I would contend, is a synecdoche in the poem. He represents several "*rude*" people whom Ellen has encountered and, by extension, embodies the widespread prejudice that Ellen and other disabled people are faced with regularly in the media and political rhetoric. Furthermore, this attitude which erases her, paradoxically makes Ellen hyper-visible; the stranger feels entitled to stare at that which to him is strange, and this makes Ellen self-conscious. Consequently she is aware, not only of that which has *disappeared*, namely much of her previous mobility, but also has a heightened sense of her *social dys-appearance*; how the objectification of her dysfunctional body by another has caused a rupture in the usual pattern of social behaviour (Leder, 1990).

Although the stranger wants an explanation of her actions, Ellen does not wish to "*share*" her medical status with him. Initially she makes polite but assertive requests which reassert her humanity over his objectification: "*Please don't stare / I am not your property*". As the encounter continues, she states that her reason for using a wheelchair "*is not for you to know*" and attempts, through this definite emphatic construction, to set appropriate

boundaries for him. At the poem's conclusion, Ellen says that she would like to tell him to "piss off" but this would also be construed as her *daring* to step outside of the accepted role of submissive disabled person by being "rude" to the passerby. Of course, this riposte is only imagined; in Ellen's utterance about intrusive attention from strangers, she made it clear that she can feel "really scared" and avoids engaging the strangers directly in conversation. However, through her imagined conversation in 'Rude Man', she is able to challenge the disruptive and aggressive, politicised discourse that others force upon her.

### 7.2.2 "people overlook you"

In Workshop Three, Claudia spoke about her experience of public encounters:

***"people overlook you when you're in a wheelchair. They sort of look beyond and the other thing is that quite often my husband will stop to chat but he'll put me facing the wrong way so I'm having to lean around...and he's finished chatting by the time I get there, so it's things like that."***

Here she is explicit and detailed about how others behave around her as a wheelchair user: they "overlook" and "sort of look beyond" her. Claudia's husband chats with others but does not angle Claudia's chair so that she can join the conversation. By the time she has shifted in her chair, the conversations are over and she has been completely excluded. In this utterance she focuses almost entirely on the actions of others: "people overlook", "they sort of look beyond", "he'll put me", "he's finished chatting". This example of 'ocular evasion' (Garland-Thomson, 2009, 84) in the face of something as undeniably present as a wheelchair, goes beyond the politeness of not staring and suggests that some people, including Claudia's acquaintances, feel so socially uncomfortable about interacting with a wheelchair user that they actively avoid doing so. Similar to Murphy (1987) and Mairs (1997), discussed in 2.3.3, to all intents and purposes she has been made to disappear from the social encounter. This 'refusal to communicate, however, is still a form of communication' (Merleau-Ponty, 2002, 420), which can contribute to feelings of low esteem and partial erasure of selfhood in the ignored disabled person (Murphy, 1987; Leder, 1990).

In interviews and workshops Claudia rarely referred to her own emotional state, but instead would leave Memphis or me, to extrapolate how she felt. For example, here she makes brief

reference to “*the other thing*” and “*it’s things like that*” but doesn’t specify how these instances affect her. In her initial interview she told me how family members “*park*” her outside shops or in an out of the way corner of a shop: “*It’s the idea that you’re in the way almost...so I’m left out in the cold or I’m left outside while they’re in shopping and that irritates me.*” The repetition of “**left out**” strongly suggests that by being physically excluded from the shopping trip because of her wheelchair, Claudia feels she is being ignored and her needs neglected. She went on to explain that “*to park me makes more sense than trying to wheel me round*” shops that didn’t have sufficient room to manoeuvre the chair, yet this collusion between non-disabled businesses and family members meant that “**you just feel a bit, it makes you feel a bit like, you know redundant.**” Here, even though her comment is couched in the relative safety of the second person, Claudia began to be more explicit about how the behaviour of others made her feel. She took a while to settle on the word “*redundant*”. While this could simply indicate her trying to find the most correct term for her emotion, for me it evoked Claudia’s forced early retirement from a job she had loved, discussed in 6.4.1. Now she was routinely being made “*redundant*” again by family and others when trying to participate in basic activities of daily living (shopping, communication).

In the third workshop Claudia went on to write the following poem in which she continued to explore the social impact of being a wheelchair user:

*“The invisible*

*I’m the invisible person  
I sit here in my chair  
on a different eye line to others*

*confined in wheels  
dependent on others’ good will  
I turn to talk and am facing the opposite way*

*left outside, foxed by mountainous steps  
I face a minefield of clothes and dummies*

*my racetrack around confectionery and body wash  
bored*

*all well-meaning and earnest  
I am a question mark  
people don't know how to answer*

*so I disarm with a smile and openness  
honesty and lack of embarrassment  
I have a reason for being here"*

Here Claudia gives the reader a sense of the impact of being ignored and excluded because of her wheelchair: she is "*foxed by mountainous steps*" and then faces "*a minefield of clothes and dummies*". Both "*foxed*" and "*minefield*" imply that others are purposely trying to deceive her or place hazards in her way; thus we can discern her exclusion and subsequent isolation. Her vulnerability is also made clear: "*dependent on others' good will / I turn to talk and am facing the opposite way*". It is perhaps unsurprising that rather than experiencing the wheelchair as an aid which facilitates her mobility, Claudia feels "*confined in wheels*". For her, the chair is a very visible symbol of both disability and inaccessibility.

Claudia alludes to erasure of the self in her poem, constructing herself as "*invisible*" and "*a question mark / people don't know how to answer*". However, in the conclusion of "The Invisible" she claims her right to be present and included in the social world: "*I disarm with a smile and openness / honesty and lack of embarrassment / I have a reason for being here*". On one level this is an upbeat and assertive resolution to the problem of being ignored by family or strangers; Claudia smiles and is not embarrassed even if others appear to be awkward and uncertain of how to behave towards her. Her smile and active friendliness might even be perceived as an act of resistance or a gentle challenge to discrimination. However, for me, what comes across most strongly is how much labour Claudia undertakes just to be acknowledged and put others at ease during public interactions.

In her initial interview, Claudia described how she didn't want to complain or make a fuss and this inhibited her from talking about MS with family and friends:

***"My attitude is I don't like to bother them with my problems. I'm on my own. I have to get on and cope so I just get on and cope. I don't want to go on too much to them because I feel they don't need that, yeah, which is very much a sort of looking out for them but not looking out for me."***

Here Claudia constructs herself as a concerned wife and mother who doesn't "*like to bother them with [her] problems*" as she "*feel[s] they don't need that*". Yet there is a dichotomy implicit in this attitude: in order to "*look out for them*" and be the good family member that she aspires to be, she has to erase part of herself and her experience from the relationships; "*I'm on my own. I have to get on and cope so I just get on and cope.*" This tautological statement appears to be definitive and pragmatic; it asserts that her strategy for getting on and coping by not bothering people is inevitable; the only way of coping while also protecting others. Yet, as Claudia has described above, she is only able to go shopping or engage in public encounters with the support of her family. The figured world that she is subscribing to here is one in which a wife and mother should avoid burdening her family with her own troubles. I would suggest that Claudia has internalised the inherently sexist and ableist views which are prevalent in society, striving as she does to minimise her needs as an ill and disabled wife and mother in favour of the needs of other family members. Claudia does acknowledge the disparity of this figured world at the end of the interview utterance: she is "*sort of looking out for them but not for me*", although she does not present any alternative ways of negotiating the situation.

I believe it is likely that there is a gendered element in how people understand the needs and rights of disabled and chronically ill men and women and how disabled people perceive their own needs and responsibilities. The study's only male participant, Memphis, told me in his initial interview that he tried to avoid sharing difficult information with his wife, because he tried to "*shield*" her:

*"I try and **be more gentle** with the missus...Like when they told me I had secondary progressive, I went home and I didn't, didn't just say, 'Oh I'm secondary progressive now.' I sort of went back and **sugar-coated it a wee bit**. 'Things have got a wee bit worse'... and blah blah, so we went through a lot of that and at the end of it, I sort of said, 'So it's now called secondary progressive. We've moved on from remitting relapsing but it's fine.'"*

It is possible to infer from Memphis's language in this conversation, "*shield*", "*be more gentle*", "*sugar-coated it a wee bit*", that he felt it was his duty as a husband to protect his wife from potentially upsetting information where possible. As the sample size of this study is very small, eight women and one man drawn from a variety of socio-economic and

educational backgrounds, it is not possible to make any definitive statements about gender and MS attitudes and behaviours. However, I suggest that a wider consideration of this issue could be a fruitful avenue for future research.

### 7.3 Being with friends

In this section, I explore participant data on the subject of friendship and socialising. Participants shared very different experiences about friendship and how this was impacted by MS. Nina told me about *“four close, close girlfriends that are pretty much always there and can talk openly about [MS]...they’re there for the laughs but they are there for the hard times as well.”* As the youngest participant at 35, and the least disabled by her symptoms, Nina presented herself as participating fully in a meaningful social life in which MS was not usually spoken about but could be discussed with humour if there was *“something going on”*. However, some participants with more significant impairments spoke about adaptations and fractures in their friendships and social encounters. In 7.3.1, I consider conversations about friendship and how it is affected by the prevailing model of illness as curable and recoverable. In 7.3.2, I explore a participant poem and subsequent discussion about attending social gatherings. This includes consideration of how PwMS can experience unintended harm from the performance of compassion by others and, conversely, how it was positive and validating for participants to discuss these instances of isolation or othering with other PwMS.

#### 7.3.1 Philippa and “a really strong group of friends”

Philippa was a chatty and engaging participant. As discussed in 6.3.3, her busy pre-MS identity had incorporated the role of useful and dependable member of the local community. In her initial interview she said that she was *“relatively open”* with her friends about MS. She told me how supportive some of her friends had been around the time of her diagnosis: *“my bestest pal had chatted to physio friends of hers”,* and *“a lot of [my friends] read chunks from the MS Trust and the MS Society and would send me the safe things, the non-scary things to read.”* This speaks to the value accorded to practical support in

Philippa's friendship group. Furthermore, it is suggestive of a pattern of reciprocity within the friendship group where *"everyone rallies round"*; just as Philippa had helped others by providing childcare when needed, they were now able to help her.

Speaking about her current situation, five years after diagnosis, Philippa said that she saw herself as *"pretty lucky"* to have a *"really strong group of friends"* who *"can come in and see me sitting on the sofa, in a mess with no makeup on and sobbing and they can see me kind of with makeup on and looking really well and that's fine as well."* She feels comfortable and emotionally safe with these close friends: it is *"fine"* on good or bad MS days. She also told me that she had *"got into quite a comfortable place with a lot of my friends where they're really, you know, 'Do you need to go and lie down? Do you want a comfy seat now?...Do you want to put your feet up?'"* It seemed clear that Philippa appreciated this nuanced and thoughtful care that was offered spontaneously by friends who knew her well. She did, however, also talk about the difference between having a recoverable illness and MS and how this had impacted her social relationships:

*"My...friend had...cancer. For about a year her life was completely upside down and we all rallied and there was mummies doing her school run for her and friends doing [inaudible] food and we, you know, everybody was just, it was all over the place, everybody was just there. But she's completely recovered...and back to normal and cooking and doing and, and I think, I think the hard thing for people is to recognise that, erm, I can do all the right things and I can take my medicine and, but I'm not going to have an operation then get over this. You know, you're not, I'm not going to get well. I'm not going to get my life back, kind of thing, and erm, and I think I'm very aware of not, not kind of using up the good will, if you know what I mean?"*

Philippa knows that MS will always be present in her life: she is *"not going to get well"* and *"get her life back"* even if she is an exemplary patient who does *"all the right things"*. She is concerned that her friends do not understand this; it is a *"hard thing for people...to recognise"* and that their *"good will"* may be finite. She knows that the compassion and practical support of the friendship group continued for *"about a year"* while one of them lived with and recovered from cancer. Extrapolating from average life expectancies for women in Scotland and PwMS in the UK, Philippa, who is 50, is likely to live at least into her early seventies (National Records of Scotland, 2022; NHS, 2022). Looking through this long lens, I can understand why she is concerned that the tap of friendly *"good will"* may run dry.

When discussing the uncertainty around her prognosis, Alex also spoke about the frustrations of communicating this to family and friends in her interview:

*“but also for friends and family as well because **they want answers**. They ask you and you go, ‘There aren’t any answers.’... ‘**Well, there must be. There must be answers. You know - medical science** et cetera, et cetera.’ I’m like, ‘Yeah. No.’ (both laughing)...So that’s quite difficult, managing that.”*

Of course, it is to be expected that Alex’s friends and family are eager for her to be cured and regain health and mobility, but more than this they seem unable to accept that the “answers” to her illness do not exist: “Well, there must be. There must be answers. You know – medical science.” For me, in these utterances, both Philippa and Alex are gesturing towards the inadequate ways in which illness is perceived within Western culture. Two models still prevail in non-medical communities: curable illness in which a person becomes sick and then returns to health; and terminal illness in which the ill person cannot be cured and dies. While one of these models entails a happy outcome and the other very definitely not, they are both time limited. Neither is useful in cases of those chronic illnesses which are incurable but not terminal. A large number of conditions, including MS, and some cancers, can result in the ill person inhabiting a ‘liminal’ existence; ‘an in-between state, a kind of nether region characterized by “ambiguity, paradox, a confusion of all the customary categories”’ (Leder, 2016, 40, quoting Turner, 1967, 97). Put simply, the chronically ill person may no longer be able to inhabit the well world and similarly does not inhabit the world of the dying. Their social circle may equally be at a loss as to how to reintegrate their sick friend. This is reminiscent of the limitations of Frank’s (2013) identified illness narratives, discussed in Chapter Two. Neither Alex or Philippa spoke of seeking to be morally or spiritually transformed by MS as in a quest narrative. Rather they and, it is implied, their friends would all prefer for life and friendship to proceed as it did before the MS diagnoses, hence Alex’s friends’ foci on cure and both Alex and Philippa’s heightened awareness that cure is not possible for them. This impossibility of cure disqualifies them from the restitution narrative and the remaining narrative – chaos – is unhelpful, giving no examples of a functioning life with positive relationships. Thus Philippa, Alex and their friends continue their efforts to negotiate successful friendships in the face of MS without guidance or precedent.

I would suggest that these efforts can lead to some PwMS minimising aspects of their illness experience in order to fit in with the established patterns of friendship. Philippa was keenly aware of the expectations and behaviours on which she feels her friendships are contingent. She spoke about how, as her energy and mobility have been increasingly compromised, she has become concerned about appearing negative or talking about MS too much with friends:

*“I find the whole people being radiators or drains – and we’re all attracted to those who radiate the – erm, but I don’t want to be a drain either. I don’t want people to say, ‘Oh, I have to go and see this bint again and she’ll be whining on about her rubbish life and how she can’t get out,’ and, do you know what I mean? And I think there has to be a certain point of, you know. So, I tend to probably be a wee bit more jokey.”*

The radiators and drains analogy is one that is sometimes attributed to Oprah Winfrey (Pylas, 2016) and has been popularised by positivity websites, workplace training and life coaches. It holds that radiators ‘exude positivity and warmth and are people you want to spend time with because they make you feel good, energised and happier’ whereas ‘[d]rains are people who have the power to suck the life out of you. Time spent with them is exhausting and leaves you feeling worse about the world and the people in it’ (Quealy, 2019). I suspect I am not alone in finding the analogy at best reductive and unrealistic, focusing as it does on a stable, implicitly healthy and wealthy life experience in which the protagonist can easily set aside any problems in order to be relentlessly positive. Philippa herself seems ambivalent about the concept; she discontinues the first sentence twice, ultimately not saying what she “*find[s] the whole people being radiators or drains*” to be and not explaining what it is that radiator people radiate. However, the concept does hold some meaning for her and she is unequivocal that she doesn’t “*want to be a drain*”. She goes on to imagine a scenario in which a friend talks negatively about being obliged to visit her: “*“Oh, I have to go and see this bint again and she’ll be whining on about her rubbish life and how she can’t get out”*”. Philippa delivered this imaginary criticism of herself in a light-hearted manner. It is possible that she was being “*a wee bit more jokey*” within our conversation, exaggerating for comic effect, and thereby managing the tone of our interview in a similar way to her strategy for managing other social interactions.

Nonetheless, her word choice, “*bint*”; “*whining*”, was pejorative and, I suggest, indicates genuine underlying anxiety about the long-term security of her friendships were she to speak more freely with friends about her MS experiences.

### 7.3.2 Philippa and parties – “I steel myself”

Philippa told me that she tries to “*keep it quite light and quite erm upbeat*” when interacting socially with people she doesn’t know well:

*“Philippa: Again because you’re at a party you don’t really want to stand there...and be the, you know, Dilly Downer and [laughing] everybody’s crying.*

*Georgi: Yeah, yeah.*

*Phillipa: But also I think, yeah, if you can poke fun at yourself and, you know, erm – I always if I wobble, I can, I can fall over from standing still is **my kind of party trick**. I’m not actually doing anything (laughing). **I just have a wobble or I do a funny walk and I do a – because I use a stick – and er, erm, I have a funny walk and I just start singing** (singing like an elderly, drunk Scottish man) which is what we used to sing when people were, you know, the drunks walking down the street.*

*Georgi: Yeah, yeah, uh huh (laughing)*

*Phillipa: And then **everybody kind of starts laughing and stuff.**”*

Here she describes how, by comparing herself to the jolly, unsteady drunk, a Scottish stereotype recognised by her peers, she consciously enacts the role of comedic ill person to put others at ease. Like Ellen’s son (“*Hallelujah! She rises!*”), Philippa asserts control and explicitly foregrounds her disability in an attempt to defuse any potential tension that she or others are feeling about it. In Leder’s (1990) terminology, it could be said that she is aware of her dys-appearance, both through the evident limitations of her body and also through the disruptions in communication that can occur in social interaction. She co-opts the visual markers of disability, her walking stick and tendency to “*wobble*”, as props in her comic performance. No longer signs of weakness, they are used to showcase Philippa’s comedic and imitative talents, both at parties and in this utterance to me. Thus, pre-empting social disruption, she attempts to subvert it, by creating the conditions for a positive response from the other party guests, rather than one based on pity or avoidance.

In this interview, Philippa appears to be socially confident and has techniques for managing friendly party interactions. In workshop three, she wrote the following poem which uses her customary humour, but also shows a different type of party experience:

*"Such a lovely time!*

*I wear my role as party guest  
I put it on as I put on my dress  
Over my head.  
I steel myself – warm, friendly smile  
I've got lots of make up on so I wait for the first,  
'But you're looking so well!'  
Yup, £70 worth of Touche Eclat will do that!  
If I wash my face right now you'd call an ambulance.  
But I'm too polite to say that  
I say, 'Thank you'*

*I am pigeon-holed - most kindly done –  
With the elderly – seated in the chair near the fire  
Assisted – waited on – fussed over lovingly  
Everyone takes turns at keeping me company  
I'm always polite – I smile  
I am brought a plate from the buffet  
'A little bit of everything?' questioning head tilt  
I'm too polite to leave anything on my plate  
So often I eat food I do not like but  
I say, 'Thank you'*

*In my head The Grandma turns into the Toddler!  
I WANT to roam the room  
I WANT to help with the dishes  
Gossip in the kitchen and pour my own wine  
I DO NOT want to leave early – before I get tired!!  
Foot stamp – pout!!!  
'I'll fetch the car to the door'  
Have you got your bag? Stick? Scarf?  
Politely I say, 'Thank you'  
And, 'Goodnight'"*

From the beginning of *"Such a lovely time!"*, and similarly to her interview utterances, Philippa makes clear that being a guest at a party is a performative *"role"* which *"I put...on as I put on my dress / Over my head"*. Her *"warm friendly smile"* is part of the costume

which she uses to “steel” herself for social encounters. Thus she contrasts the softness of the polite part she plays and the effort that it takes her to do this. Philippa’s makeup functions as a mask to help her fit in but the flip side of “£70 worth of *Touche Eclat*” is that she feels her illness and effort to participate are unacknowledged: “*But you’re looking so well!*” This could be politeness on the part of the other guests; after all it might be considered rude if an acquaintance told Philippa that she looked ill or exhausted. However the use of “*But*” might indicate that the other guest is implying that Philippa looks so well that she cannot really be ill. Again we see dissonance between how people relate to Philippa’s physical appearance (make up, party dress) and her felt illness experience.

However, although others at the party may not recognise Philippa’s illness, they cannot ignore her disability, and it is their behaviour in response to this that is at the centre of the poem: “*I am pigeon-holed – most kindly done – / With the elderly – seated in the chair near the fire*”. Here Philippa uses punctuation to emphasise how she is “*pigeon-holed*”; by using dashes, she literally places her poem-self in parenthesis as carefully and firmly as the hosts relegate her to sitting with elderly guests by the fire. In this second stanza, Philippa has switched from the active voice of the first stanza’s party preparation to a more passive and subdued one: “*Assisted – waited on – fussed over lovingly*” as others enact their roles of compassionate partygoers. She acknowledges that their actions are well meant: “*most kindly done*”, “*lovingly*”, yet they result in unintentional harms. She lists what others do for her, “*keeping [her] company*”, bringing her “*a plate from the buffet*”, and goes on to say what this actually does to her: “*I’m too polite to leave anything on my plate / So often I eat food I do not like.*” By assuming that she wants to sit by the fire and eat “*A little bit of everything*”, others feel that they have integrated Philippa and taken care of her but in reality they have removed her agency over how she participates in the party. Some of the actions of Philippa’s friends described in the poem seem to me to be polite variations on the social evasion experienced by Claudia when using her wheelchair and encountering strangers. By avoiding discussion of her health and solicitously relegating her to an out-of-the-way seat by the fire, the other partygoers have found ways of displaying care and positive intentions but also of evading a deeper or more authentic interaction with their ill friend. “[*L*ooking so well” and yet “*pigeonholed*” “*with the elderly*”, Philippa is aware that she occupies an ambiguous and disempowering social limbo.

In the final stanza, Philippa introduces other constructions of herself; her role as compliant party guest is named "*The Grandma*", reflecting how she is treated in a way that is inappropriate for her age. Yet the polite and passive Grandma metamorphoses into the similarly inappropriate "*Toddler*". Marked by capital letters and sprinklings of exclamation marks, the Toddler is an outburst of Philippa's frustration and desires. She would like to "*roam about the room*", "*Gossip in the kitchen and pour my own wine*", things which her non-disabled peers can all do freely at the party. Philippa's frustrations in the poem reflect the multiple barriers to her social participation, speaking both to the medical and social models of disability. She *could* participate much more if others accommodated her needs differently; for example, she could eat food she enjoyed if she were asked for her preferences. Similarly, if there were a chair in the kitchen, she might be able to gossip there. However, MS directly prevents her from doing some of the things that she would like; because of her energy limitations she probably could not help to wash the dishes *and* roam about the room. Ultimately, while the expressions of the Toddler are energising and cathartic within the poem, they do not change Philippa's party experience because social convention and politeness dictate that these words remain "*in my head*". Throughout the poem the only words that she actually says are "*Thank you*" and "*Goodnight*", words that are in keeping with her role as grateful, disabled guest and show a passivity and compliance that speak to her lack of status and self-confidence at the party.

### 7.3.3 A poem shared – effects of Philippa's poem in the workshop

Philippa read her poem to Tilly, Nina and me in a very animated and performative way; she affected a patronising, artificially cheery voice for the words of other partygoers and tilted her head at the line "*A little bit of everything?*" questioning head tilt." Similar to her impressions of drunks when wobbly at parties and the frustrated irony that is present in 'Such a lovely time!', Philippa's reading used humour to illustrate her point and possibly as a self-defence mechanism. Her observations were praised by Tilly:

*"That was just a perfect, perfect description of what it's like (others laughing) and the voice that you said – what was it? There was one line and you said it in a – 'a*

*little bit of everything'. How many fucking times have I heard that in that exact same voice? (others laughing)"*

Philippa seemed pleased that her words and experience were recognised by others and said, "I'm glad it's resonating." She went on to say, "I feel like my granny sometimes", and quoted illustratively from her poem: "'Have you got your bag? Stick?'" Again Tilly recognised her own experience and spoke about always being seated with her dad at family gatherings, making clear that her displeasure wasn't about her father: "I loved him. I loved sitting next to him", rather "it's just other people, the way they responded to us." Thus, through this poem and our discussion of it, as a group we scrutinised how, as PwMS, some of us feel obliged to be quiet and passive while the able-bodied around us perform compassion in ways that can make us feel more objectified and excluded by our peers.

In addition to the validation that Philippa and Tilly felt through recognising and discussing their similar social experiences, there is, I think, an additional important outcome from the sharing of this poem in the workshop. Although the poem and subsequent discussion considered ways in which Philippa has been socially disempowered through disability, her poem and performative reading of it gave her an opportunity to be entertaining company. This wasn't Philippa as complaining or ungracious guest. Similarly she didn't construct herself as an object of pity. I am not suggesting that the well-received reading of her poem in a workshop compensates for uncomfortable interactions with her peers at parties. However, Philippa was able to be the 'life and soul' of the workshop, making effective use of her comic and imitative skills and hopefully she derived some esteem or wellbeing from the experience.

#### 7.4 Being a family

I now return to the topic of family relationships and MS. In Group Three's third workshop, as discussed in section 7.2.1, Saskia and Ellen's conversations prior to writing were largely about interactions with strangers in public places. Yet during the subsequent writing activity, they both wrote poems about the care and understanding that they crave from their mothers but do not feel is given. (Ellen, a fast writer, composed both "*Rude Man*" and

“Ostrich” during this twenty-minute period.) Below I discuss Saskia and Ellen’s mother poems in the context of their interview data. Then, although I usually discuss the impact of sharing poems in workshops after individual poem commentaries, in section 7.4.3, I consider the sharing of both pieces together. This is because the poems, which were written and shared in the same workshop, are so closely linked thematically and acted as a springboard for a detailed discussion about mothers and MS between the participants.

#### 7.4.1 Saskia Says Nothing

During her initial interview, Saskia told me that previously she had been seriously scalded when washing up because, having lost sensitivity in her hands, she had not realised that the water was extremely hot. She also spoke about the support and advice that her mother offered in terms of these physical MS symptoms: *“I’ve told mum about it and she’s, you know, made sure that the gloves are there and...never to wash up again without gloves.”* However, in this poem, titled *“I Say Nothing”*, she explored her mother’s refusal to acknowledge the cognitive effects of Saskia’s early onset dementia:

*“I Say Nothing*

*She’s 80 and spritely  
She’s 80 and quick minded*

*She looks at me and sighs impatiently  
‘You must know where you are going by now’ she says.  
I don’t. I need help with navigating these days, as she knows.  
I say nothing.*

*‘What’s taking you so long?’ sounding irritated.  
I can’t do things as fast as I used to, as she knows.  
So I say nothing.*

*‘Are you stupid?’ she asks  
I want to cry now because I’m not  
But to others I may seem to be.  
I say nothing.*

*She’s my Mum and she’s 80  
I know she loves me unconditionally  
So I say nothing.”*

In this poem, Saskia immediately establishes her mother's character. The reader is told that "She's 80" and therefore possibly vulnerable or frail, however she is also "spritely" and "quick minded". This presentation of the strong and capable mother is soon contrasted with Saskia's own vulnerabilities that result from MS and early onset dementia: "I need help with navigating these days" and "can't do things as fast as I used to". The repetition of "as she knows" makes clear that this is not their first conversation about Saskia's cognitive impairment. Yet, her mother fails to recognise or acknowledge this, instead appearing irritated and "sigh[ing] impatiently". The repetition of "I say nothing" emphasises Saskia's silence in comparison to her mother's three statements. From this we can infer that saying nothing is routine, an established technique in Saskia's efforts to manage the relationship.

Saskia shows opposing sides and how they are balanced against one another, reflecting the difficulties inherent in her attempts to maintain a cordial relationship with her mother. The seesaw between "I" and "you" throughout the poem serves to demonstrate their opposition and attempts at balance. Hearing "I Say Nothing" in the workshop, I sensed dissonance between the assertion of the mother's unconditional love and what appeared to be her refusal or inability to process the facts of Saskia's progressive cognitive impairment. Although passive silence protects the mother from conflict and the painful reality of her daughter's cognitive decline, it results in distress for Saskia. At its conclusion, both the poem and the mother–daughter relationship are at a stalemate: Saskia's impairment remains unacknowledged and her needs remain unmet.

#### 7.4.2 Ellen – "Hear me, hear me, hear me"

Ellen said in her initial interview that she has a complex relationship around MS with both of her parents and one of her siblings and also that she has felt unsupported by her parents since diagnosis nineteen years before. In recent years, one of Ellen's family members has become severely disabled and another close relative has become seriously cognitively impaired. Ellen described a relationship with her mother in which she, as an adult daughter, is expected to give support to others while her own health problems and increasing

disability are minimised. She said that she had tried to discuss this with her mother: “My mum says to me, you’re where you are because you’ve never given in on any day...she’s sort of taught us a bit like you ignore the things that happen. Just don’t take any notice of them and get on with life.” In the figured world that Ellen ascribes to her mother, serious illness and disability happen if someone “gives in”. According to this view, retaining mobility and wellness in the face of MS is not down to luck or medical management but mental determination alone. It can be inferred from this perspective that, on some level, people who get chronically ill do not really want to be well. Thus, Ellen is in a difficult situation: if she were to convince her mother of the severity of her symptoms and disability, she could be perceived as having “given in” and thus lose status with her mother.

In Workshop Three, Ellen wrote the following poem:

*“Ostrich*

*Dear Ostrich*

*It does not help me to pretend that all is well  
Help you it may, shield you from the pain  
That I seem to be not me*

*Look closer, I am me*

*See through your pain to see mine  
It is a lonely place when the ones who say they love refuse to see your pain*

*I am not my illness, but it’s part of me  
I am not the person down the road with MS  
I am not the neighbour’s nephew  
We share the shared diagnosis  
We are each unique  
As are you*

*Hear me, hear me, hear me*

*Do not change the subject when I tell you I may drown  
In sorrow, in loss, in pain and loneliness  
By denying my illness you deny me  
Accept and set yourself free.*

*It is not about you  
It really is about me  
Set me free”*

As with Saskia's poem, "*Ostrich*" is predominantly written in everyday conversational language. It is not explicitly stated that "*you*" represents her mother, although Ellen explained this during the workshop. In the poem, she would like her mother to acknowledge the specific impacts that MS has on her as opposed to "*the person down the road*" or "*the neighbour's nephew*". She states that what helps the mother – "*shielding*" from her daughter's MS – is not helpful for Ellen. The poem is written in a forceful voice and uses numerous imperatives, instructing her mother to "*look closer*"; "*accept*"; "*do not change the subject*". This, combined with the repetition of "*Hear me, hear me, hear me*", emphasises how important and urgent it feels for Ellen to have the reality of her illness recognised. There are similarities with "*This is Me*", discussed in 5.5.2, Ellen's poem to her neurologist which appeals to be seen as a complete and complex individual: "*I am whole / Please see me this way.*" Just as she resisted being reduced to a set of symptoms in that poem, here she resists being ignored or stereotyped as an MS hero who never gives in.

In both poems Ellen expresses her frustration at not being perceived holistically: first by the neurologist who she feels "*treat[s] her in parts*" and is "*only interested in [her] disease*"; and now by her mother, who sees Ellen's wider self and role in the family, but ignores the impacts of MS. I would suggest that in both relationships Ellen feel partially erased by the others' inability to acknowledge the complex totality of her self.

As the poem continues, the word choice switches to more emphatic and emotional language: "*Do not change the subject when I tell you I may drown / In sorrow, in loss, in pain and loneliness*". She implicitly queries her mother's love: "*when the ones who say they love refuse to see your pain*". Yet at the end of the poem she attempts to find a route to resolution by asking her mother to "*accept and set yourself free*" by acknowledging the facts of her daughter's illness. She argues that this would also "*set [her] free*", allowing Ellen to be herself rather than being stuck between her lived reality and her mother's imagined perspective of her MS. Yet, the impassioned words of this poem form an imagined dialogue and do not represent what Ellen actually says to her mother. Like Saskia, in reality she finds it hard to challenge her mother's opinions of MS.

#### 7.4.3 Sharing within the workshop: “I get that. I get that completely.”

Leder (1990, 94) writes of how being-with-others can be a mutually positive, affirming experience in which neither person objectifies the other but rather they expand each other’s perspectives: they ‘are co-subjectivities, supplementing rather than truncating each other’s possibilities.’ This could be the sort of constructive and supportive relationship that people might wish for with close relatives. Yet both Saskia and Ellen describe evasion by their mothers who refuse to acknowledge either specific symptoms of their MS experience (Saskia’s dementia) or the extent and severity of their symptoms (Ellen). This inability to accept the cognitive or physical losses that their daughters are experiencing, has created ruptures in the mother–daughter communication, meaning that it is not possible for them to be co-subjectivities, leading to frustration and alienation for both Saskia and Ellen who feel trapped by the inaccurate versions that their mothers persist in projecting onto them.

Given the similar theme of these poems, I was particularly pleased that both Saskia and Ellen volunteered to share their poems during the workshop. This speaks, I think, to their developing ease with one another; their discovered similar experience; and also an understanding that poetry represented a more comfortable way to approach challenging themes. Immediately after reading her poem, Saskia began to cry. Ellen responded to say she sent “a hug” and “I understand that...I get that. I get that completely.” When Ellen then read “Ostrich”, Saskia commented, “It’s a hard relationship” and “Mums are difficult.” Although both Ellen and Saskia describe similar issues in their poems, it became clear during our conversation that they experience and construe their maternal relationships differently. Saskia said, “as they love us unconditionally, we love them the same way”, however Ellen replied:

*“I think my relationship with my mum – I wouldn’t ever say that she – I don’t think really as I grew up, she loved me unconditionally...she does love me but I suppose my childhood was always with conditions and **one of the conditions was that I was never sick as a child. I wasn’t allowed to be sick.** Erm, you know, it was a sign of weakness and that’s sort of gone on through the adult years.”*

Ellen made three false starts before finding the words to phrase her statement about (un)conditional love; I wonder if it was difficult for her to say this and thus diverge from

Saskia's idealized assumption that all mother–daughter relationships are rooted in unconditional love. By describing the “*conditions*” on which she felt her relationship was contingent, “*I was never sick as a child. I wasn't allowed to be sick*”, Ellen encouraged us to explore the wider and pre-existing family dynamics that may have contributed to the ways MS impacts maternal relationships<sup>10</sup>. Saskia said:

*“being the eldest daughter in the family comes with a lot of responsibility...and expectations and when suddenly you are struck down and **you can't fulfil those inverted commas responsibilities anymore**, it's hard for anybody to accept. **I think my mum, and rightly, always thought I would be the one to look after her** when she got old but she's still the one looking after me and it's hard.”*

Here Saskia appears to subscribe to a figured world in which the role of the adult daughter is to acquiesce and take care of elders. She finds it difficult that she “*can't fulfil those inverted commas responsibilities anymore*”. Thus the expected, or idealized, relationship has been compromised in multiple ways: Saskia and Ellen's mothers are not listening or being compassionate in the ways that their daughters crave; and the daughters are physically, and in Saskia's case cognitively, unable to care for their mothers. In the workshop, both women were at a loss as to how they might resolve the dissonance in their maternal relationships and did not feel that they could approach the subject directly with their mothers:

*“Ellen: I don't know whether I would be brave enough to read [“Ostrich”] to my mum.  
Georgi: You don't have to be.  
Saskia: Yeah, I had the same thought. I think it would upset her and that's the whole point of “Say Nothing” because I don't upset.”*

It seemed to me that in their roles as dutiful daughters, neither Ellen or Saskia felt comfortable with disrupting the peace and potentially failing in their “*responsibilities*” as adult daughters. I intend no judgement of those participants who tried not to destabilise existing patterns of family behaviour. Frequently, I also choose not to rock the boat in interactions with certain family members in order to manage my fatigue levels and negotiate our complex relationships. Yet as I write, the words of Audre Lorde (1984, 41) ring in my ears: ‘My silences had not protected me. Your silence will not protect you.’ I acknowledge that the silences employed by Saskia, Ellen and me do not help us to mend the

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<sup>10</sup>These remarks remind me of Eleanor's comments about her mother's inability to accept illness when Eleanor was a child, discussed in 6.2.2; ‘*If you're well enough to sit on the sofa, you're well.*’

fractures and dissonances that can appear in some of our close relationships. These can be uncomfortable, even painful, silences. Lorde makes a good point, but to what extent is it realistic to expect chronically ill individuals to challenge entrenched societal views of family roles and responsibilities? Much of the time, negotiating symptoms, medications, medical appointments and the business of daily life is challenging enough. As shown by Saskia and Ellen, co-existing with MS can be a highly emotive issue for families to navigate. Any attempts by them to address the problems they identified in their relationships with their mothers may be ignored or misunderstood, potentially leading to further distress. Silence does not fix the problems we face, but maybe it can, or can seem to, offer some short-term protection for our relationships and familial identities.

## 7.5 Summary and concluding thoughts

This chapter has shown that for the majority of participants, MS creates obstacles to their negotiation of public, social or family life. Considering data in light of Leder's work on social dys-appearance, I have discussed how participants experienced strangers reacting to their MS bodies with avoidance (Claudia), outright hostility (Memphis) and inappropriate curiosity (Ellen and Saskia). I have argued that these suspicious, objectifying acts spring in part from wider socio-political attempts to stigmatise disabled people as less economically productive or useful in the current UK climate of austerity (Tyler, 2020). Also, I have suggested that avoidance or evasion was also evident, if more subtly, in participant narratives of friends' behaviour. While unlikely to be directly rooted in socio-political prejudice, these instances of polite evasion and performative compassion may be indicative of the lack of a satisfactory social blueprint for relationships between chronically ill and healthy people. Similarly, avoidance and evasion was a feature of close family relationships, as described in participant poems and narratives. Saskia and Ellen's words about their mothers' inability or refusal to engage with key aspects of their MS experience spoke to their families' challenges in expanding or adapting existing figured world views of parent–adult child roles to accommodate the condition.

In this chapter I have also explored how participants construct their social selves and behave in relation to others; Saskia to some extent has internalised strangers' attitudes which *"make [her] feel guilty...because [she is] not an elderly person in a wheelchair."* Some participants have developed different strategies for coping with various social interactions: Memphis's positivity; Claudia's concerted efforts to be friendly and *"disarm"* people; Philippa's use of humour; and Ellen's comic double act in which she plays the 'stooge' to her son's more flamboyant joker. These strategies and behaviours allow participants to utilise their existing strengths and talents: Ellen spoke with pride about her close relationship with her son, whereas both Memphis and Philippa presented themselves as entertaining raconteurs who enjoy telling, or performing, incidents from their past. Participants' coping strategies appeared to make social interactions more comfortable for them and their able-bodied, healthy interlocutors as well as creating or reinforcing their social identities. Garland-Thomson (1997, 13) recognises 'charm, intimidation, ardor, deference, humor, or entertainment' as strategies that disabled people adopt in order to put non-disabled people at ease and hopefully be treated as 'fully human'. She continues; '[t]hose of us with disabilities are supplicants and minstrels, striving to create valued representations of ourselves in our relations with the nondisabled majority' (Garland-Thomson, 1997, 13). I recognise this striving in myself and in study participants, however, I would tentatively argue that such supplicant minstrelsy is also an attempt to fit in with pre-existing social dynamics, rather than challenging them in order to maintain an authentic ill self in relation to others. Cheyne (2019, 122) highlights the negative elements of such emotional labour with reference to Liddiard's (2014, 125) argument 'that the obligation for her participants to perform emotion work in their intimate lives constitutes "a form of psycho-emotional disablism".' I found participants' anecdotes of their strategies in social interactions to be often funny or charming and genuinely entertaining. Furthermore, I could see that participants derived worth when they felt valued in these interactions. Yet, I also find them to be uncomfortable reminders of the discrimination that they face and, in some cases, possibly internalize; after all, the good fortunes of the supplicant and the minstrel are always dependent on those in positions of greater power and status.

Also I have explored participant silences with family about MS, both by avoiding or minimising the subject (Memphis and Claudia) and also by not challenging assumptions

about their health (Saskia and Ellen). I noted in my study journal, 'Feeling raw after [Saskia and Ellen Workshop Three]. Who is deemed worthy of family love and support? Am I worthy of love and support from [my family]? What the hell does "worthy" mean anyhow?' I do not believe that there are definitive and fixed answers to these questions. More importantly perhaps, I do not feel that they are helpful questions to ask of ourselves, although, as PwMS, many of us frequently do. Maybe a better question to consider in future might be, 'How can we dismantle the conflation of health and worthiness?'

Thus, this chapter has illuminated the lack of power and communication that some participants experience socially in terms of their illness. Yet, I have also discussed the effects of poem sharing within the workshop groups. As seen in Chapter Six, sharing poems together has given participants opportunities to reflect on their experiences with others in similar circumstances. I suggest that this process has been particularly emotionally resonant when discussing social life and family. Concurrent with reporting their sense of isolation or social dys-appearance, participants established new social bonds within which their experiences were recognised and their feelings validated. While these bonds may have been temporary, it is my hope that in some small way they facilitated voices where before there was uncomfortable silence. Perhaps they also formed a gentle rebuttal towards the more negative social interactions that participants and I have encountered. Chapter Eight will explore data from both core and reader participants about their experiences of poem sharing, or not, outwith the workshop environment and will focus on the potential, and limitations, of poem sharing to bring about change in existing relationships.

## Chapter Eight

### Poem Sharing

*'A good poem helps to change the shape of the universe, helps to extend everyone's knowledge of himself and the world around him.'*

(Dylan Thomas, 1992, 61)

#### 8.1 Introduction

In this chapter, I will present and discuss data from reader participants and core participants about their experiences of sharing poems written in the PaMS study. As stated in 4.2.2, the reader participant arm of the study was supplementary to the main research focus, which considers the core participants' experiences of exploring MS through poetry writing. My intention, when working with reader participants, was to gain the perspectives of people who did not have MS but had a meaningful relationship with a core participant:

- **Might the poems provide additional insights into a family member or care recipient's life with MS for the readers?**
- **Might the poem sharing experience have any impacts on conversations about MS between PwMS and their close contacts?**

Firstly I will establish the basis for this data discussion by exploring the relationships between core and reader participants. As discussed in 3.2.1, this research is underpinned by the ontological position that everyone constructs identities in relation to others (Riessman, 2008), and then performs these shifting identities within the accepted social reality of the relationships (Marshall, 1994). Therefore I will consider how both reader and core participants constructed their selves and their relationships to one another in interviews with me. Then in 8.3, I will present data about sharing poems and, in 8.4, I will develop this discussion by exploring outcomes identified by reader and core participants as emerging from the sharing experience. Finally, I will present my reflections on the reader participant component of the study, including its limitations. This chapter is shorter than other data

chapters in this thesis and is different in tone; participants’ utterances in the post-sharing interviews frequently took the form of synopses and evaluations. As such they were more matter of fact linguistically than many other data presented in this thesis. Accordingly, my analysis is focused less on particular word choice and more on agreement, and occasional dissent, between participant utterances.

## 8.2 Relationships between core and reader participants

For ease of reference, the relationships between core and reader participants are glossed in the table below.

*Table 3: Relationships between Core and Reader Participants*

<b>Core participant</b>	<b>Reader participant</b>	<b>Relationship</b>
Tilly	Matilda	Matilda is Tilly’s younger daughter
Saskia	Peter	Peter is Saskia’s youngest brother
Claudia	Timmy	Timmy is Claudia’s aunt
Memphis	Aurora	Aurora is employed as Memphis’s carer

### 8.2.1 “on the same wavelength” – Choosing readers for the poems

While I acknowledge that the relationships between core and reader participants are enacted among myriad other relationships in a wider social world, the practical and ethical scope of this research is such that I can only explore them as dyadic. They were sustained, close connections in which both people made efforts and were emotionally invested in the success of the relationship (Simmel, 1950). Tilly, Saskia, Claudia and Memphis are all people who experience extensive MS impacts physically and in Saskia’s case also cognitively. As discussed below, MS has materially affected the three pre-existing familial relationships. In contrast, Memphis and Aurora’s relationship is entirely contingent on his having MS; this professional connection, situated in a domestic setting, is a close and complex one which will be explored below. I would suggest that MS sometimes resembled an additional

character or presence in all these relationships, analogous perhaps to Dickman's (2008) 'Grief' as a purple gorilla (discussed in 6.5).

Saskia told me that she had initially chosen to read a selection of her poems to her mother and sons. However, she reported that her mother did not want to see or hear the poems, and her sons told her that "*they had no comment on whether poetry was another way of communicating [her] life with MS, saying they already know this stuff so they didn't see the point.*" Poetry is not for everyone; its mention may provoke uncomfortable memories of school lessons that focused on poems only as objects of academic analysis rather than a potential source of pleasure (Wassiliwizky et al, 2017). Yet, as I noted in my journal, I felt very frustrated on Saskia's behalf. Her mother and sons might not enjoy poetry generally, but Saskia had explained to them that poem writing had become important to her, offering some validation of her creativity and intelligence in the face of early onset dementia. 'Surely', I wrote, 'twenty minutes of allowing Saskia to bask in the glory of her writing is not too much to ask?' But also, I worried. Had I encouraged participants to make themselves too vulnerable? Had the mutual support and acceptance of the workshop groups lulled participants into a false sense of confidence? Prior to sharing, I had discussed with participants the importance of feeling emotionally safe with the people to whom they chose to read their poems as it could potentially be exposing or awkward. I had cautioned them against unrealistic expectations, yet, we had not explicitly discussed what it would be like to be rejected by someone close.

Before her illness, Saskia's construction of herself as a capable professional who cared for others extended to her familial self-presentation; "*I am the person in the family that everybody goes to so I am the strong one.*" Saskia had previously spoken in interviews about the reluctance of her mother and sons to engage with MS on an emotional level and had written "*I Say Nothing*" about her mother's denial of her cognitive difficulties<sup>11</sup>, as discussed in 7.4.1. I suggest that by attempting to share some of her poems with them, Saskia was possibly trying to influence these relationship dynamics so that she could receive the engagement and understanding that she craved. Reflecting afterwards, she told me that she

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<sup>11</sup> Saskia did not attempt to share "*I Say Nothing*" with her mother or sons, having decided in Workshop Three that it might be too upsetting or provoke an argument.

had *“realised [her sons and mother] are always going to have their heads in the sand in relation to my MS.”* She also said that she thought her sons were *“both terrified of the future and don’t want me to remind them of what’s happening”*. Although she was disappointed, she seemed to have re-evaluated her expectations of these relationships and was prepared to think instead about other people who might better fulfil her emotional needs around MS.

Saskia went on to approach other potential readers; *“I deliberately targeted two people who I believed would one, appreciate poetry, and two, would be completely honest with their response. I asked them both to focus on the content of both poems rather than whether I was an amazing poet lol.”* It seemed to me that in this second attempt, Saskia thought carefully about what outcomes she wanted and who would be best to help her achieve them. She chose a close friend from overseas and her youngest brother, Peter, telling me, *“I had to think twice about asking him as he is a very sensitive person and hates to hear about me struggling or changing in relation to my MS.”* She had told me in her first interview that, regarding MS, *“[Peter] will just fall into a heap and cry so I limit what I tell him and when I do I am deliberately upbeat”*. I would suggest, although Saskia was initially reluctant to share poems with Peter, she recognised that his sensitivity might equip him to respond to her writing. Also, I wonder if she was beginning to shift from her perception of their relationship as protective big sister and emotionally vulnerable little brother to one which also permitted her own vulnerability.

Tilly told me that she had also been concerned about upsetting her daughters with her poems; *“there was a little voice in my head that said, ‘Do I really want to be sharing this with them? Do I want to protect them from it?’...it was just kind of floating around out there, it wasn’t really a strong voice.”* Tilly said that she knew it had been difficult for her daughters to see her *“suffer”* with MS and reflected on her instincts to manage their responses:

*“Yeah, I think it is, it is hard and I do have that maternal – I want to protect people and manage their emotions for them but I don’t – I try not to act on that...and I don’t think it’s difficult for me to resist, erm, but I mean I know a lot of women sort of embrace that. That’s their role within the family. It’s like, nah, no. I don’t wanna be the emotional head of the family.”*

It seems to me that Tilly has alighted here on a theme common among the middle-aged female participants; in addition to Tilly and Saskia, Philippa, Claudia and Ellen all spoke in interviews or workshops about shielding younger members of the family from the emotional impact of MS. The tension between taking care of others and having one's own needs met has been a recurring thread of the PaMS study and I was interested to see whether, and how, poem sharing might affect it.

Claudia described clear reasons for sharing poems with her aunt Timmy:

*"[I] relate more to her than to my mum in some ways...My mum is very stoic and you sort of get – she used to say to me when I was young, 'You're only ill because you're not positive enough'...She's sort of, 'You don't dwell on things...You get on with it.' Whereas my auntie is more emotional like me, I suppose. She's more along my, my wavelength."*

Claudia's reference to her mother's insistence that her illness is a result of "*not [being] positive enough*" is reminiscent of Ellen (7.4.2) who said her mother believed that Ellen retained some mobility because she had "*never given in*". It can be inferred that Claudia and Ellen felt that, to some extent, their mothers blamed them for being ill. Here Claudia confirms, as did Ellen, that her mother's attitudes were indicative of, or were responsible for, obstructing their relationship; they were not on the same "*wavelength*". I think that it can be inferred from Claudia's utterance that, in contrast to her relationship with her mother, she felt accepted as an "*ill*" person by Timmy and was therefore more able to be vulnerable as a PwMS with her. Claudia's sense of emotional closeness with her aunt was closely mirrored by Timmy who also described their relationship in similar terms; "*we're on the same wavelength, definitely, yes, emotionally, I think, because not all our family are very – I want to say emotional – they don't always feel the same way that perhaps Claudia and I look at things.*" I am also mindful that in choosing to share her poems with an older family member, Claudia was, perhaps unconsciously, seeking a way to have her feelings and experiences acknowledged without "*bothering*" her husband or adult children.

Memphis chose to share his poems with his wife and also his carer, Aurora. He did not explain why he had chosen them but he was evidently very close to them both and saw them in person every day. Aurora was sometimes present but off-camera in Memphis's

interviews, helping him to get set up technically, and I felt I detected mutual warmth and ease in their interactions. She worked directly with Memphis for thirty-three and a half hours per week, and, in addition to her personal care role, Aurora told me she also provided social care *“like the cinema or going for a coffee”*.

### 8.2.2 “you feel so useless” – Impact of MS for reader participants

In their interviews which took place after poem sharing, all the reader participants referred to the constant presence of MS in their relationships; Matilda told me, *“...there’s not an end point. There’s not a thing to tackle or fight or overcome...it’s just there and it’s gonna keep being there.”* Similarly, Aurora said of Memphis, *“he’s trapped with [MS]. It’s not going anywhere.”* Here both Aurora and Matilda reject the restitution-type narrative as unsuitable for Memphis and Tilly. Additionally, Matilda could be interpreted as rejecting the quest narrative or, certainly, its terminology of ‘overcoming’. Thus these well-rehearsed tropes are found to be inappropriate or unsatisfying in these instances.

Tilly told me that she felt Matilda was more able to process the emotional aspects of MS than her older daughter, however, Matilda said the following about MS’s impact on her relationship with her mother:

*“I think in terms of our relationship I think there is – I think it’s a tricky thing to navigate because it’s painful for me seeing that loss, that loss for her. I think she experiences a lot of it as like grieving or loss, but then I also, I feel, I feel a bit like – I don’t think I feel guilty but I feel a bit like I don’t know exactly where, like what **right** I have to – it’s harder for her but it’s still hard for me...I find it difficult to know what is **legitimate** for my pain when I know it’s so much less than hers.”*

Here, Matilda speaks about her difficulties, not just in sharing her emotional pain with Tilly, but also in feeling that she has a *“legitimate” “right”* to feel pain compared to her mother. This is reminiscent of the work of Carling, Nilsagård and Forsberg (2020) which found that close relatives of PwMS can suppress their own emotions about the impact of the condition on them and may de-prioritise their needs in favour of the PwMS.

Peter told me how Saskia, who was living overseas at the time, had told him about her diagnosis in a video call:

*“...finding out about it was **catastrophic** to me. It really, really was so, yeah. I remember sitting right here where I am now when she first told me so (sharp intake of breath) erm yeah **but you’ve just got to accept it and live with it and get on with it.** So, **what could I do? What could I possibly do apart from worry?** And that’s (short laugh) that’s all I’ve ever done.”*

Peter appeared to still be shocked by the “catastrophic” news of Saskia having MS. It seemed to me that with his sharp intake of breath he was experiencing the jolt of distress all over again. His comment, “you’ve just got to accept it and live with it and get on with it”, reminded me of an earlier utterance by Saskia; “I will adapt, I will accept, and I will look for the positives”. Yet her remark was an active statement of her ambition whereas Peter’s comment sounds as if he is repeating what someone else (Saskia?) has previously told him; “you’ve just got to...”. I was particularly struck by a profound sense of helplessness in Peter’s utterance; “what could I do? What could I possibly do apart from worry?” This impotence in the face of MS was echoed by Timmy; “It’s just you feel so useless. What can I do to help her really? I mean the practical stuff, yes.” Matilda also said that she found “helping her [mother] with practical stuff” much easier and said, “I prefer to do that and often when I go and visit her I’m quite busy, sorting things out and doing practical things, but the bit that I find difficult is engaging with her emotional pain about it.”

In their research about family members who care for chronically ill older adults, Monin and Schulz (2010) discuss Gross’s (2001) process model of emotion regulation. The behaviours of Timmy and Matilda might be seen as situation modification, one of Gross’s strategies for modulating emotional responses. By doing something practical to support Claudia and Tilly, they were easing the care recipients’ situational suffering and also minimizing their own negative emotional response to MS. I wonder if, necessary and beneficial as it may be for both the caring relative and their recipient, such practical support may sometimes mask the awfulness of being unable “to help her really”<sup>12</sup>. ‘Real help’ is likely to be constructed

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<sup>12</sup> During their participation, Peter, Timmy and Matilda, who did not live with Saskia, Claudia or Tilly, had been unable to offer practical assistance to them because of UK COVID-19 restrictions. While we did not explicitly discuss the impact of these circumstances, it is possible that reader participants’ frustration and sadness at their “helplessness” was exacerbated.

differently according to the specific contexts of each relationship and the stage of MS with which their relatives were living. Saskia, Tilly and Claudia were not going to recover from MS so help intended to cure was impossible. Also, family dynamics may have made it difficult to offer emotional support, especially in these relationships where Saskia presented herself as the capable older sister and Claudia's family did not talk about MS.

Aurora spoke about the complexity and emotional involvement of being a carer; *"they say, 'Don't get too close. Don't get too invested.' But these people are like my family."* Aurora does not specify who *"they"* are, although, because in other parts of the interview, she discussed her training as a carer and her previous professional appointments, it is possible that she meant her trainers or former employers. Certainly, *"they"* and their advice not to *"get too invested"* sound objectively distanced and very remote from the circumstances in which she worked closely with Memphis and his wife in their home. Aurora gave the following example of how Memphis's experience of progressive MS had impacted her emotionally:

*"Aurora: We helped him decorate the Christmas tree and it was a bit hard for me because Memphis always used to be the person who put the star on the top of the tree.*

*Georgi: Right. He couldn't do that this time?*

*Aurora: And for all Memphis can stand for a moment, he needs to have something to balance around him, and as you know when you're dressing a tree, there is no balance there. You have to lean...but you know, it's even in my house, the man puts the star on the top of the tree or your kid does, you know, and that kind of really struck a chord with me that Memphis isn't able to do that anymore."*

Aurora is employed by Memphis to facilitate his participation in daily living, offering support where needed and taking on aspects of tasks that he can no longer accomplish independently. However, in a domestic setting this can include nostalgic and emotionally resonant family activities such as decorating the Christmas tree, and in this case it starkly emphasised the progress of Memphis's impairment. In her interview, Aurora disclosed to me that she experiences anxiety and has associated physical tics, although she did not attribute this to her job. Nonetheless, I wonder about the cost to Aurora of the emotional labour involved in this blurry aspect of her role in which she both is and is not a member of

Memphis's family. She is a lone worker, employed directly by Memphis to fulfil his care needs. What recourse does she have to support for her own emotional burden from MS?

### 8.3 "intimate, gentle" – Sharing the poems

Core participants chose different ways of sharing their poems. In some cases these were determined by UK COVID-19 rules which prohibited mixing with people from different households. Memphis read his poems to Aurora and his wife at home whereas Tilly shared her poems with Matilda on a video call. Claudia and Saskia emailed their poems to Timmy and Peter. Then Saskia and Peter "had a very long conversation on the phone" about the poems. At the time of their follow up interviews, Claudia and Timmy had not discussed the poems but were planning to do so. Some participants spoke about the atmosphere of the sharing experiences, with Tilly saying the process was "intimate, gentle" and Aurora describing it as "personal", an interesting word choice which I suggest gestures towards the personal-professional interplay of her relationship with Memphis.

#### 8.3.1 "That's really cool. What does it mean?" – Routes into the poems

Reader participants found different ways to find meaning in the poems. Peter spoke to me about recognising the setting of one of Saskia's poems:

*"I can relate to [the ocean poem] really, really quite well because the spot that she was standing in, erm, I've either stood in it myself or I know exactly where it is...So to me it was quite personal. I could envisage her actually being in this spot...I could relate to it. **I could relate to where she was.** I could relate to what she was looking at. **I could also relate to the point** that she was trying to reach, erm, in that, why had this happened to her and trying to find a way to, I guess, accept it and live with it and not, not let it overrun her daily life...the first poem, it made me, it made me cry at the end of it, erm because **this is my big sister who I absolutely adore** and she's going through this...But it was very – I could relate to it so strongly which with a lot of any poetry that I've, erm, that I have read **sometimes leaves me a little confused** what this person's trying to get across which is probably why I don't pursue it. And knowing that it was written by my sister, knowingly possibly where she was standing on that beach...made it **very personal.**"*

I would suggest that because Peter “*could relate to where she was*”, he felt more confident that he “*could also relate to [her] point*” about trying to come to terms with her MS and dementia diagnoses. Here Peter implied that he did not usually read much poetry as it “*sometimes [left him] a little confused*”. This is contrary to Saskia’s perception of him as “*the kind of person who would sit down and read poetry*” because he was “*very sensitive*”. Regardless of his general relationship to poetry, Peter was able to relate to Saskia’s poem because it was “*very personal*”; “*this is my big sister who I absolutely adore*”. For me, this suggests plural meanings: Peter could understand and relate to Saskia’s poem because he had prior understanding of her and her circumstances; also he was willing to engage because the poem was by his much-loved older sister. He cried during the sharing, an acknowledgement of both the impact of Saskia’s MS and his distress about it. In turn, his emotional vulnerability gave Saskia an opportunity to do what she described as “*lift[ing] his emotions [with the positive conclusion of the poem] and I’m so glad that I gave him that*”. It seems to me that through the poem sharing, “*big sister*”, Saskia, and “*youngest brother*”, Peter, found a way of interacting which incorporated the existing dynamic of their life-long sibling relationship while being open about Saskia’s experience of MS.

Timmy, who described herself as someone who had “*always read poetry*”, seemed to engage deeply with Claudia’s poems in both thematic and emotional ways:

*“Georgi: ...I think you made the point that [Claudia] doesn’t seek sympathy or pity. Timmy: No, and in fact she doesn’t want it. Looking at this [poem, ‘The Invisible’], she doesn’t want it. **She wants people to acknowledge what’s happening to her. It’s like getting old. When you’re old, people just ignore you and I think she feels the same. People just ignore her. Erm, she’s sitting in a wheelchair and she’s on a different level. Because she’s in a wheelchair she sees things on a different level, doesn’t she?”***

Like Peter, Timmy drew on her existing knowledge of Claudia to assert that her niece doesn’t want sympathy and then confirmed this message through reference to the poem; “*[s]he wants people to acknowledge what’s happening to her*”. Then Timmy explicitly acknowledged Claudia’s position as expressed in the poem; “*People just ignore her*” and “*[b]ecause she’s in a wheelchair she sees things on a different level*”. Pondering ‘The Invisible’, Timmy felt that she could identify a similar experience between herself and

Claudia; *“It’s like getting old. When you’re old, people just ignore you and I think she feels the same.”* I would suggest that Timmy’s position here is not one of sympathy but empathy.

Aurora explicitly discussed the difference between sympathy and empathy when telling me about her experience of listening to Memphis’s poems; *“When he started reading, I just – I was just **so emotional** inside and I was trying to keep it in there because I didn’t want him to think his poem was upsetting me or I don’t like it if people think you’re feeling sorry for them because it wasn’t that. It was empathising.”* I felt that her understanding of the poem was embedded in the particular personal–professional relationship between them; she felt *“so emotional”* but tried to withhold this from Memphis. Also, she showed her professional knowledge by identifying two potential audiences that she felt could benefit from this prompt to empathy: *“[the poems] need to be heard because one, it gives people who are blind to an illness like MS a very good insight, but also for other people that are living with MS or a similar Parkinsons, MND type of thing, I think for them, they could relate.”*

Matilda initially found an intellectual route into Tilly’s poems, discussing their meanings with her mother:

*“...the first couple she read it to me and I thought it sounded really nice but I didn’t – some of them I think, sometimes when I hear poetry I appreciate it as being beautiful but I feel like I don’t quite get it and I feel like that happened with a couple of them where I was like, ‘**That’s really cool. What does it mean?**’ (both laughing) and then she had to talk me through and I think that as a process...it was like a way to be **able to talk about that** without rea- sort of **without directly looking at it**. So it sort of facilitated that, that **bridge**, I think. And I think we were both, or I was in that space anyway of, like this is interesting, kind of intellectually, thinking about it with my head.”*

Here Matilda appeared comfortable with not knowing and did not seem embarrassed about asking Tilly for clarification. Being *“able to talk about [MS]...without directly looking at it”* seems to have been a safer way of approaching the theme for Matilda. The intellectual *“bridge”* into the poems appeared to have put her at ease and she spoke of how she went on to have a more emotional response to a later poem:

*“and then one of the poems that she read to me at some point in the middle...was about loss, about grief and there was a list of places that she couldn’t go anymore,*

*places in Scotland...and that just really got to me and we were both crying about it. I think it was an **amazing** poem. It's **really powerful** and I know I could fully understand what it was about as well (laughing). So yeah,...I think it opened up a space for us to talk about her pain about it which I find **really hard** like I was saying before....just yeah, just have **a bit of a cry** (laughing) **which is quite important sometimes about things that are really hard.**"*

Later in her interview, Matilda and I reflected together on why it may have been easier to be emotionally open through the poems than in her more habitual interactions with Tilly. I suggested that the process may have felt easier because the conversation had a specific focus on the poems. Matilda replied, "Yeah it's quite boundaried, I think...or bound up so it feels safe in that way, I think."

### 8.3.2 "really powerful" – Impacts of beauty and emotion

Matilda described one of her mother's poems as "amazing" and "really powerful". Other reader participants also expressed appreciation for the core participants' skill, with Peter characterizing Saskia's ocean poem as "eloquent" and "beautifully written". Timmy said about Claudia's poems, "That one about the bramble pulling her down, that was **brilliant**, I thought... and stopping her legs from walking was **wonderful**, that sort of relentless advance on her body and yet again she's trying to look on the bright side". Aurora had a similar response to Memphis's poems:

*"The leg tremors for example, I experience that with him every day, every morning, erm, but to – also for it not also be a negative for him but **for him to turn it into a positive**, like the waves and the laundry drying in the wind. Like to hear him take it from being something **so cruel** that's nobody should have to go through to something **so beautiful** was just amazing. Erm, I cried the whole way through...I had **tears streaming down my face**. I was actually, at the end I **was sobbing**. I was like (mimes gasping). I couldn't actually catch my breath."*

Here, both Timmy and Aurora show appreciation of Claudia and Memphis's choices of literary metaphor; "brilliant", "wonderful", "so beautiful". From Aurora's utterance, I would infer that the beauty of Memphis's writing was one of the reasons that she started crying although she had initially tried not to do so.

Also it seems to me that Timmy and Aurora are commending Claudia and Memphis's determination to be seen as upbeat; *"trying to look on the bright side"*, *"for him to turn it into a positive"*. As discussed in earlier chapters, both Claudia and Memphis present themselves as people who *"get on and be positive"* in spite of the significant impact of MS on their lives. Initially, I felt some concern that these poems might be perceived simplistically as examples of their 'overcoming MS' or being 'MS champions'. (See discussion of 'overcoming' in 2.2.2.2.) However, the responses of Timmy and Aurora suggest subtler interpretations of the poems, which make space for MS as *"relentless"* and *"so cruel"* alongside a conscious striving for beauty and positivity.

As well as acknowledging the emotional pain experienced by the core participants, all four reader participants spoke of engaging with their own grief during the poem sharing experience. Above, Aurora spoke of *"sobbing"* and *"tears streaming down [her] face"* while Peter and Matilda both mentioned crying when listening to the poems or discussing them with Saskia and Tilly. Timmy had not spoken with Claudia about the poems by the time of her interview, but she cried when speaking to me about the emotional impact of her niece's illness and the resulting poems. Nobody represented their tears as unfortunate or uncomfortable. Rather it seemed that they perceived the flow of emotion to be beneficial; as Matilda said, *"a bit of a cry...is quite important sometimes about things that are really hard."* In their research on how poetry affects the brain, Wassiliwizky et al (2017, 1239) conclude that 'poetry is a powerful emotional stimulus capable of engaging brain areas of primary reward'. Put simply, listening to or reading poems allows us to access strong feelings while also deriving pleasure from the experience. I would suggest that is what happened to Aurora, Matilda, Peter and Timmy during poem sharing.

#### 8.4 "this poetry has certainly made me think" – Outcomes

Towards the end of their interviews I asked reader participants to reflect on whether the poems had given them new insights into the MS experience of their relative or employer. Peter told me that *"Did I Boil the Kettle"* *"made me understand a little bit more about [Saskia's] day-to-day life"* and he felt that her intention in writing and sharing the poems

was “to make people understand what she goes through because I don’t think people do”. Peter’s comments largely converged with Saskia’s own summary; “In particular ‘Did I Boil The Kettle’ has helped so many people understand the beginning and in fact my whole day especially as I live alone” and “poetry has given me a new way of expressing my feelings”. Although not generally a poetry fan, Peter appreciated the experience and said that he would be open to Saskia sharing poems with him again in future; “Anything that can stimulate a conversation between my sister and I will be welcomed with open arms.”

Timmy told me that the poems had increased her understanding of Claudia’s feelings and also increased her awareness of her own attitudes to disability:

*“Reading some of her poetry has made me realise that erm that I haven’t really known how [Claudia] felt about [having MS]. Erm, obviously, she didn’t want me to feel – she didn’t want pity or for me to feel sorry for her but that’s, erm, to start with that’s what you do feel, erm, and you do treat people slightly differently when they have a **disablement**, erm, but you don’t realise that you’re doing it, I think, and this poetry has certainly made me think about that.”*

Timmy was a very articulate interviewee, but in this utterance I was very aware of her hesitations and what I perceived to be a lack of confidence. This may have been because she was taking time to choose her words carefully; “*disablement*” is a precise term, not just for being disabled, but for the experience of becoming disabled which is the specific focus of Claudia’s poems. However, I wonder if Timmy felt a little awkward about saying that she had initially felt “*pity*” for her niece and that she had unwittingly treated disabled people “*slightly differently*”. I am also curious whether any discomfort about this was exacerbated by the fact that she was telling it to me, a PwMS. Timmy went on to say that the poems would “*lead to [Claudia and her] talking about things a bit more... We will have a good conversation about it as well.*”

Some reader participants spoke of observing benefit to the core participants’ sense of wellbeing and confidence during their participation, and specifically through having a purposeful and creative use of their time. For example, Aurora said,

*“I mean for somebody who used to like writing a bit of poetry here or there like before the MS but it’s gave him such a new lease and outlook. He’s not only writing*

*about the MS....I think it's been wonderful for his MS mental health side because he's not only having to talk about his MS side. He can talk about whatever he wants, so it's actually gave him a new passion so I think the impact's been massive."*

Aurora went on to talk about ways in which Memphis was sharing his poems more widely within the MS community. Timmy said, "[Claudia] would never have, she would never have done this [poem writing] and shown me...you've given her confidence to do that."

In their follow up interviews, some core participants did not really speak about any emotional impacts of poem sharing. Rather they predominantly focused on the literary validation of the process. I wonder if I inadvertently led them towards this theme by asking them, in the preceding question, if they felt their writing had developed during the study. To this end, Saskia sent me detailed, effusive comments from the friend with whom she had shared. She seemed very pleased with both Peter and her friend's appreciation. Memphis said he was "actually quite astounded at how well they thought I'd written because I thought it was alright but they were all like, (enthusiastically) 'AWWWW!...That's brilliant.'" Likewise Claudia echoed Timmy's comments when I asked her what she felt she had gained from the study; "definitely confidence and the belief that actually what I was writing was good...and is worth sharing with people really." She also spoke about the ways in which poetry allowed her to communicate her feelings about MS without having the difficult and overtly emotional conversations that she preferred to avoid; "the poetry was a way of telling people how I felt without having to be there almost...sort of removing yourself in a way, although the words are very personal but I don't actually have to stand and talk to someone, you know."

Like Matilda, Tilly spoke about the poem sharing as a route into talking about emotions and MS:

*"I think it's hard to find time to talk about your emotions in a way that is not **draining** on the other person, especially around something as difficult as chronic illness...and I think that's what this was. It **was nurturing** for all of us and it was like they both thanked me for doing it, in a way that they wouldn't if I'd just called them up and said, 'I'm so fucking fed up with this bloody MS.'...so, yeah, it was like I was giving them something as well as just having them listen to me."*

Rather than “*draining*” them, the experience “*was nurturing*” and gift-like for her daughters. I would suggest that being heard and understood, both as a writer and as a PwMS, was affirming and supportive for Tilly.

## 8.5 Concluding thoughts

Below I discuss the limitations that I have identified with the reader participant arm of the PaMS study. Then I offer summary reflections on the main findings of this chapter.

### 8.5.1 “Am I being biased?” – Limitations

There are several evident limitations to this wing of the study. The first is with regard to the recruited reader participant sample. Speaking about his overwhelmingly positive response to Saskia’s poems, Peter volunteered, “*Am I being biased? (laughing) Yeah, probably.*” I suggest that in this situation a certain amount of bias was unavoidable. Core participants had to feel sufficiently confident in, and safe with, the people who ultimately became reader participants in order to trust them with deeply personal poems. Thus, they were likely to select people who would approach the experience with a kindly outlook. Even if they were not usually poetry readers, these relatives and one employee all identified themselves as emotionally close to the core participants. Furthermore, the core participants all felt that the sharing experience had been positive enough that they were confident for me to approach their readers in hope of discussing it with them. The only negative sharing experiences reported to me by any core participant were those Saskia had with her sons and mother who did not want to engage with the poems. It is not surprising that Saskia suggested I contact Peter rather than her sons, and indeed, if she had suggested that I speak to her sons, I very much doubt that they would have consented to participating. Therefore the resulting data skew towards positive interpretations of the poems and the sharing experiences. While I do not think that this invalidates the above data, they should be read and understood in this context.

During the reader participant interviews, I became aware that there were both benefits and limitations in my being the person to conduct them. On the positive side, I had spent numerous hours with the core participants by the time I spoke with the reader participants. Accordingly, I knew the core participants reasonably well and would suggest that we had built up a degree of trust over that time. This meant that I was recommended to the reader participants by the core participants who likely felt that speaking with me would not be unpleasant or difficult for their chosen readers. That possibly helped to ease our conversations a little, however reader participants were aware that the poems had been written in workshops facilitated by me, and this knowledge may have inhibited their responses. If reader participants actually disliked elements of the poems, I think they would have been unlikely to tell me, perhaps because of their loyalty to the core participants but also because of my close involvement in the poems' genesis.

As mentioned in 8.4, I was concerned that my having MS may have inhibited Timmy or made her feel more awkward when speaking about her previous "*different*" treatment of Claudia, and I wonder whether this may have also been a factor for other reader participants. I was aware on occasion of consciously performing the role of a well ill person, partly because I wanted reader participants to feel able to speak about the impacts of the core participants' more severe MS impairments without worrying that they might make me feel uncomfortable. The 'well ill' role was not a misleading self-presentation for me; the nature of RRMS is such that I often feel well and that was the case during those particular interviews. However, the fact that I felt so conscious of enacting it suggests that I may have been amplifying this aspect of myself.

During Peter and Timmy's interviews it became apparent to me that they both experience a lot of grief about Saskia and Claudia's declining health. I felt unprepared for the depth and rawness of their emotion, expressed through Timmy's tears and Peter's repeated rhetorical questions, "*What could I do? What could I possibly do...?*" Listening again to the interview recordings, I think that I was able to hold space and compassion for their sadness and frustration, but my study journal reflects that mentally I was preoccupied with having MS rather than the experience of knowing someone with MS. Perhaps if this had been a bigger and differently funded study rather than a self-contained doctoral project, it may have been

better for the reader participant interviews to be conducted by someone else. I wonder if an interviewer who was a relative of a PwMS or other neurological condition could have created a dynamic analogous to that between core participants and myself.

#### 8.5.2 “it opened up a space for us to talk” – Summary reflections

This chapter has explored the experiences and impacts of poem sharing between core participants and reader participants with a primary focus on reader participant interview data. Firstly, I considered core participants’ choices of readers for their poems, including the difficulty that Saskia had when she approached her mother and sons. Then I briefly examined how core participants and reader participants constructed their selves in their existing relationships with one another. This included the emotional impacts which reader participants experienced as a result of the other person having MS. Notably these included: a sense of uselessness or helplessness as expressed by Timmy and Peter; and practical help, or situation modification behaviours, such as shown by Matilda and Timmy, whereby they could be helpful while also minimising their emotional discomfort. Another key theme which emerged was uncertainty about the legitimacy of pain on the part of Matilda and the tendency of relatives to minimise their own distress in comparison to the PwMS.

Data also emerged about the complexity and blurriness of Aurora’s role as an employee of people who were “*like my family*”. As Aurora was the sole professional carer in the study, there is only a small quantity of very specific data about her emotional labour and personal involvement in her role. I would suggest that there is scope for future research looking at the impact of poetry for PwMS and their carers as a tool to encourage empathy and understanding.

The chapter then explored the poem sharing experiences in detail and considered how reader participants found different ways into the poems as suited their relationship dynamics and previous experience or confidence with poetry. These access routes included: recognition of place and prior knowledge of the poet; identification of similar experience and empathy; professional knowledge; and asking for elucidation.

Overall, several findings emerged in this arm of the PaMS study. Some participants and I identified how the poems represented safe, bounded opportunities to engage with MS and one another on an emotional level. For Matilda, the poems acted as a “*bridge*” into what might otherwise be an uncomfortable conversation, whereas for Claudia they were a way of “*sort of removing yourself*” from a difficult interaction while still communicating her experiences and gaining understanding.

I went on to argue that the literary aspects or “*beauty*” of the poems had several impacts. The “*wonderful*” writing evidently sparked strong emotional responses in reader participants. Consequently, I find myself returning to 7.4.3 where I discussed the difficulties core participants and I encounter, or fear, if we attempt to disrupt existing family dynamics in order to make space for our MS needs or experiences. These discrete poem sharing experiences obviously do not alter the broader structural and cultural issues in which these relational patterns are embedded. However, on reflection, I would suggest that the poems were perhaps analogous to pressure valves by allowing the necessary release of pent-up emotion in a controlled and safe way. Thus the poems may have both generated and eased the reader participants’ emotional responses, which would correspond with Wassiliwizky et al’s (2017) findings that poetry stimulates strong emotional responses in pleasurable ways.

Additionally and importantly, I would suggest that the craft element of the poetry writing afforded opportunities for these core participants, all four of whom were substantially impacted by MS, to do something for their relatives and carer. In 6.5, I reflected on how participants had derived positive outcomes from taking part in the workshops and sharing their poems with each other. I would suggest that, by sharing the poems with close contacts, they derived a sense of purpose and further validation, and that this could be seen as particularly important for Tilly, Claudia, Memphis and Saskia, all of whom had given up work early as a result of MS. In return, those reader participants who felt useless in the face of MS were variously able to offer emotional support, understanding and literary appreciation when responding to the poems that they were given.

### 8.5.3 Postscript

Although her mother had refused to read the poems when approached and did not want to discuss them, Saskia offered me a tantalising piece of information in her follow up interview: *“I printed off [the ocean poem]...while [her mother] was here and it had the picture of the beach at the bottom as well, and she, she kind of read it and then she just said, ‘Can I keep this?’”*. We cannot know why Saskia’s mother asked to keep this poem. Maybe she just liked the beach photograph. Or maybe Saskia’s mother knew her rejection of the poems was hurtful. If so, keeping this poem may have been a tacit acknowledgement of that hurt and an attempt to minimise it without engaging directly. Or maybe the poem had resonated with Saskia’s mother on some level and she wanted to return to it again in private. I find it particularly interesting that her mother asked to keep the ocean poem because it focuses on beauty and acceptance and does not confront the reader with the harsh difficulties of MS. Maybe, for Saskia’s mother, this was an emotionally easier read than a poem like *“Did I Boil the Kettle”*, which presents a specific problem in need of a solution. As discussed in 7.4.1, on occasion Saskia’s mother offered practical support, such as washing up gloves to prevent Saskia burning her numb hands. However, she may not have had any suggestions for minimising Saskia’s difficulties with sequential action and prospective memory. Perhaps like Matilda and Timmy, in 8.2.2, Saskia’s mother was comfortable with acts of situation modification to ease Saskia’s situational suffering and felt inadequacy or distress when faced with the emotional dimension of MS and dementia. Regardless of why her mother kept this poem, Saskia interpreted the act positively; *“So maybe there is a step forward there (laughing).”*

## Chapter Nine

### poeMS: Reflections, conclusions and implications

*'One's destination is never a place, but rather a new way of looking at things.'*

(Miller, 1957, 25)

#### 9.1 Introduction

This thesis has explored the ways in which poetry written by PwMS may influence expressions of, and communication about, the illness. By writing poems, participants articulated a range of embodied and social experiences. They also derived positive outcomes from sharing these poems with each other and with a small number of their family, friends or carers. In this concluding chapter, I will provide a summary discussion of the theoretical and methodological issues raised by the PaMS study and the limitations which arose with the sample and my researcher positioning. Then, I will summarise key data findings, discussed thematically in Chapters Five, Six and Seven, before addressing conclusions which extend beyond the identified chapter themes.<sup>13</sup>

Poetry is both methodology and data in this research; I attempt to disentangle these different aspects as far as possible by discussing workshopping and authorship within 'Methodological reflections' (9.2) and exploring poems as data within the 'Discussion of findings' (9.4). Finally, I will consider the study's implications for organisations serving PwMS and suggest potential avenues of research for poetry in health in social science.

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<sup>13</sup> Findings and methodological reflections for the reader participant poem sharing strand of the research were discussed discretely in Chapter Eight and will not be repeated here as they are specific to that arm of the study.

## 9.2 Summary of significant contributions

Below, I briefly summarize the key significant contributions of this research to methodology and knowledge in the fields of health and medical humanities, before going on to discuss these in greater detail later in the chapter. These contributions may also be relevant to those working in the sociology of health and illness.

### 9.2.1 Method

Facilitating poem writing by participants in order to create data about their experience of MS is a novel research method, which proved to have several benefits. Writing poetry increased participants' control over the form and presentation of their data. It also afforded participants more time than they would generally have in a spoken interview format to consider their specific word choices. The methods employed in this study had ethical advantages. They challenged academic assumptions about authorship and ownership of research data, and I worked to ensure that participants held copyright in their poems beyond their licenced use in this research. Furthermore, the use of group poetry workshops in this research led to a number of wellbeing outcomes for participants: creative occupation; validation of their experiences; and additionally they promoted empathy and positive relationship building. Participants found writing and discussing poetry to be a safe and "*boundaried*" way to approach difficult or emotive themes around MS, and this led to sustained engagement and deep, rich data.

### 9.2.2 Knowledge

This research has significantly contributed to the knowledge of MS lived experience in the UK workplace and also in a post-work landscape. This thesis demonstrates the ways in which participants were alert to the role of work as a determiner of status in UK society and revealed their awareness of the ways in which MS disrupted the dynamics of work interactions and other social relationships. Moreover, study data illuminated the various strategies that participants consciously employed in attempts to counteract these disruptions, variously compliance, silence, performativity and humour.

## 9.3 Methodological reflections

### 9.3.1 Context: COVID-19 pandemic

Before reflecting on key theoretical and methodological issues arising in this research, I will first consider how the context of the COVID-19 pandemic shaped the study in tangible and subtle ways. The emergence of the COVID-19 pandemic in the UK in January 2020 has profoundly shaped this research. As discussed in 4.1, the original PaMS study aimed to explore the impacts of poems written by PwMS and shared with their neurology clinicians. However, it was necessarily halted because of its planned clinical setting, and a new, entirely online study was designed which engaged with PwMS and their non-clinical contacts.

I am confident that the online study was accessible for a large number of potential participants. People who would not have been eligible for the initial Edinburgh-based study participated from both Scotland and England. Also the online setting was much more accessible for participants who experienced more severe levels of disability, such as Tilly, Memphis and Claudia. Conversely, Nina, who was generally in good health, was able to negotiate 90 minutes to join study Zoom meetings when working from home, but may have found it difficult to get more time off if she also had to travel to participate. However, the online setting for the resulting study did present possible barriers to access. It may have discouraged some potential participants who lacked confidence with teleconferencing or general computer skills. For some, the cost of a suitable electronic device and a Wi-Fi package may have been prohibitive.

The pandemic necessitated poem sharing with personal, rather than medical, contacts. On reflection, I think that this increased the possible participant pool; several participants spoke about the difficulties they experienced in their relationships with neurologists or GPs. It is my feeling that these participants may not have joined the study if they thought their poems would be seen by their clinicians, or they may have been more circumspect about what they shared in interviews and workshops.

COVID-19 also impacted on the research more subtly. The PIS anticipated that ‘Some participants may also enjoy the social aspect of the workshops and value the opportunity to spend time with others who have similar illness experiences to their own.’ As discussed in Chapter Four, in the UK, PwMS were initially designated as at increased risk of severe illness or death from COVID-19. At a time when globally people were experiencing high levels of anxiety, this was exacerbated for those of us who had pre-existing health conditions. Many PwMS in the UK were either officially advised to ‘shield’ or to take extra care<sup>14</sup>. It was appropriate of governments and medical institutions to make provision for the possibility of increased health vulnerability, yet some chronically ill people became further isolated from wider society than they had previously been, as confirmed by study participants. As discussed in 4.3.1, the isolation and boredom incurred by the curtailment of normal life may have had a positive impact on recruitment.

Tilly said that the UK government’s treatment of COVID-19 in care homes had given her the “*feeling*” that “[disabled people are] *beyond expendable*”. While not all participants expressed their feelings as explicitly as Tilly, I would suggest that the pandemic caused many PwMS to confront existential issues regarding their place and value in society.

Contemporary media discourse largely focused on the impact of COVID-19 for the healthy majority of the population. I acknowledge that healthy people were adversely affected by the pandemic, however I feel that encouraging clinically vulnerable people to shield from COVID-19 also had the effect of shielding mainstream society from the realities of ill and disabled life. Participation in the research presented opportunities for social engagement with other people who had also been marked out as ‘vulnerable’ because of MS. I suggest that these engagements potentially became deeper and more closely involved than they may otherwise have been because of the specific pandemic circumstances. Perhaps unsurprisingly, much of the social chat that occurred in workshops and interviews was about the pandemic. Analysing the data created about the pandemic is beyond the scope of this thesis, however, I sense the opportunities for participants and me to be vulnerable together during the pandemic may have had greater social wellbeing benefits than originally anticipated.

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<sup>14</sup> I was advised to take extra care as though I were over the age of 70. Four years later and substantially under 70, I still have no idea what that means.

## 9.3.2 Ethics

### 9.3.2.1 Authorship

In Chapter Three, I considered the ontological and epistemological theory underpinning this research and explored the ethical responsibilities and possibilities inherent in my own complex positioning. Bakhtin (1984) holds that no one is the first speaker; each interlocutor or writer builds on, and contributes to, a pre-existing discourse. This was particularly evident in the study workshops where participants and I discussed themes and ideas before drafting poems, and then sharing them with one another. Occasionally participants then changed a poem after sharing before emailing it to me. I suggest that the collegiate atmosphere of workshops, and the discussions that we all had before and after drafting, contributed to the resulting poems in subtle ways. In 2.4.2.2, I discussed Prendergast's (2009) distinction between poems which have been co-created with participants and those which have been solicited from them, the latter arriving to the researcher fully formed. However, through the course of this study, I have come to realise that authorship is not necessarily such an easily defined concept. These poems were not co-created in the traditional sense of multiple authors contributing purposely to the same poem; each poem was conceived of and written by one participant. However they were not created in vacuums. In this way I feel that the study poems are analogous to interview data; they are definitely the contributions of individual participants but were created in a context of social interaction.

I think my background in literary and creative practice may have inclined me to question assumptions that may be made in some qualitative health research about knowledge and authorship belonging to the institution and researcher. Throughout the research, I have held the ethical stance that participants must hold copyright in their study poems but had not realised this would be an unusual provision within an academic setting. Ensuring that participants' copyright was protected, while also guaranteeing researcher access to the poems, was a surprisingly complex process, however, with advice from the UoE Legal Services department, I was able to insert a suitable clause into the Participant Consent Form. Hopefully, this will be a helpful model for future researchers working on creative projects with participants.

### 9.3.2.2 Decentring

In accordance with my feminist and disabled positioning, throughout this research, I have attempted to be alert to the various roles that I have played and how my relationships to the study themes and participants have necessarily shaped the resulting data (Foster, 2016). Following on from this, it has been my intention to decentre my role as researcher and trouble the accepted power dynamic between researcher and participant. As I reflect below, this has been a complex process with varied results.

It was evident in the study that I have professional experience in poetry, especially as I facilitated the poetry workshops, and some participants asked for reading suggestions or advice regarding poetic technique. Yet I intended to minimise perceptions of me as a 'proper poet' whose opinions or writing might therefore have been judged more valuable than those of participants. This was of limited success with some participants, for example Memphis frequently referred to me as "*boss*". However, I attempted to be transparent about my own limitations as a writer and to be explicit about reasonable expectations regarding what anyone, myself included, might achieve in a relatively brief workshop. The workshops developed into 'communities of practice' (Peary and Hunley, 2015, 190) where we all wrote together in ways that supported one another's efforts. Building creative communities has been, for me, a key outcome of the study, offering a type of participation that edges towards more neutral power relations. Additionally, some participants reported that the study offered them more purposeful and enjoyable interaction than MS support groups. Participants spoke of finding fulfilment in writing poetry and also in positive feedback about their poems, reflecting current research into arts engagement and wellbeing (Pesata et al, 2022). Several participants had lost employment as a result of MS; through participation they were finding new forms of creative 'occupation' and subsequent validation.

Other efforts that I made to conduct more power neutral research were less successful. Originally in first interviews, I invited participants to suggest questions which I should ask them, but this was met with blank stares; I was the interviewer, surely I was supposed to choose the questions? On reflection, my clumsy attempt to destabilize my position may

have briefly and inadvertently destabilized participants' sense of their own role, while they were attempting to settle into our initial conversations. As I discovered in this study, 'power cannot simply be "handed over" through the research process'; it is not a commodity which can be given or taken easily (Kothari, 2001, 121 cited by Foster, 2016, 127). Perhaps a more important and successful negotiation of power was the way in which the study facilitated participant experiences and expressions and enabled participants to feel validated and/or part of a community through the research.

I feel that my attention to power dynamics in the research facilitated my awareness of my own and participants' positioning throughout our different study interactions, during analysis and also in this thesis. Again, I go back to Bakhtin (1986); just as no one is the first speaker, no one is the last; discourse is unfinalizable. As a 'researcher [I] cannot set aside [my] own language, life and understandings when I interpret data' (Ramazanoglu and Holland, 2002, 112). Accordingly, I acknowledge that my claims to truth and knowledge in this thesis are tentative and situated. Within this thesis I have attempted to be reflexive and explicit about how I have reached my conclusions, and I acknowledge that others, including the study participants, may interpret the study data differently and draw diverse conclusions (Ramazanoglu and Holland, 2002).

### 9.3.3 Data creation and the role of the poem

The rationale for the study design was discussed in Chapter Four where I set out the multiple methods of data creation in this research; semi-structured interviews, participant-written poems and group interactions during workshops. This was a sustained period of engagement for participants which resulted in large quantities of data for analysis. The number and length of participant interactions were designed to be flexible and support any participant who may have needed to miss one or more workshops because of illness. Accordingly, I suggest that there were a number of benefits to this study structure. Frequently, themes of discussion and writing were emotive or uncomfortable, however repeated study interactions afforded time for participants to return to these subjects when they felt more at ease. The sustained engagement seemed to encourage the building of trust in study relationships both among participants and between participants and myself. I

would argue that these long and deep participations resulted in richer data as conversations and poems developed into and out of each other.

Furthermore, I advance that the use of poetry as a form of data creation afforded participants greater control over the structure of their data than they might have experienced if they only answered verbal interview questions. Similarly, if they had written more traditional autobiographical narratives, they may have perceived an expectation to follow traditional arcs such as the restitution or quest tropes (Frank, 2013). Participants variously wrote narrative poems and lyric poems which formed phenomenological reflections or philosophical questions. Several poems were built around imagined conversations between the participant and someone with whom they had a difficult relationship.<sup>15</sup> Some poems incorporated multiple elements; for example, *“This is me”* by Ellen, discussed in 5.5.2, combines an imagined conversation with phenomenological observations. The decision about which form of poetry to use seems to have been largely instinctual on the part of the participant; when (re)presenting events people tended to use a wholly or partially narrative form, sometimes combining multiple events in order to reflect on a theme. I would tentatively suggest that the use of poetry as methodology in this research begins to trouble the notion of what PwMS are expected, and therefore implicitly allowed, to say about their health experiences. Also, I think that this has wider implications for people living with other chronic health conditions: how might they ‘tell’ their experiences differently if stepping outside of traditional narrative methods?

Some core participants identified poetry as a safe, distanced way of engaging with emotionally difficult themes, given that the poems, once written, were separate from the poet. They were perceived by some core and reader participants as more comfortable, *“bordered”* ways of discussing MS. Claudia, who avoided talking about MS, said in her follow up interview, *“We didn’t really talk about the MS..., did we? We talked about how it made us feel in the poetry but we didn’t really focus on that in the talking.”* While I would gently disagree – we did talk about our MS experiences in the workshops – I recognise that,

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<sup>15</sup> Narrative poems included *“Such a lovely time!”* and Tilly’s iPad drawing poem. Phenomenological poems included *“My Legs”* and *“Machine”*. Philosophical inquiry was present in *“Dreams can come true”* and imagined conversations included *“This is me”* and *“Rude Man”*.

for Claudia, because the purpose of these conversations was to inspire poems, it was different and more comfortable than other discussions of MS that she may have encountered.

#### 9.3.4 Analytic methods

My analytic methods, discussed in Chapter Four, were developed using key ideas from Bakhtin (1981, 1984, 1986) and Gee (2014). Bakhtin provides the overarching principle of the pre-existing, ongoing and unfinalizable nature of discourse in a way that also supports analysis of both literary and spoken data. The concept of utterances was also central to the handling of data as it suggested how I might divide the interviews and workshop transcripts into manageable units of analysis while preserving a more holistic understanding of data. Gee's (2014) notion of figured worlds and framework of detailed questions to interrogate data facilitated my consideration of the social framing of every utterance. Thus, I was able to pay close attention to the bones of the spoken and written data, including the individual word choices and grammatical constructions used by participants. As a poet and literary editor, I attend to the technical features of poetry such as rhyme, metre and lineation, and felt confident to include consideration of these in my poem analyses.

I analysed each interview, workshop and poem chronologically, following participants from one group through their participation journey before moving onto the next group. This facilitated comparisons between participants' interview and poem data and highlighted the elucidations or contradictions in a participant's data. This helped me to build a more complex, holistic understanding of participants' experiences and self-constructions. I decided not to employ CAQDAS as an analytic tool because I was wary that it might not permit sufficient attention to the nuances of participants' language (Coffey and Atkinson, 1996), although this made data analysis very time consuming. Nonetheless, my methods provided opportunities to reflect closely on all aspects of the data before establishing themes through which to present data in this thesis.

There was no provision in the study design for formal member checking because interviews, workshops and poem sharing already necessitated substantial participant time and

commitment. However, the format of multiple interactions over several months naturally provided opportunities for elucidation and clarification. Additionally, sharing poems within workshops meant that participants and I could untangle any confusions I had about their poems, as discussed in 5.3.2.

## 9.4 Limitations

I discuss the limitations and benefits of the sample and my own research positioning below.

### 9.4.1 The Sample

Data sufficiency is hard to anticipate in creative qualitative research and I found it difficult to know what sample size was most appropriate for this research. It is increasingly acknowledged that sample size should be determined according to the 'specifics of the particular project' (Vasileiou et al, 2018, 16). The methodological novelty of this study presented additional challenges in terms of determining sample size. I decided to aim for the maximum number of participants I felt I could manage without overloading my, or their, limited energy. I was also aware that there was potential for substantial attrition because of study fatigue caused by the length and depth of the interaction, however this did not happen. There was only one case of attrition; Eleanor attended her initial interview, all workshops and the group Zoom to discuss sharing, but she did not respond to requests for a follow up interview. Consequently, a large quantity of data was created in the study, and I am confident that I would have found it difficult to incorporate more data from additional participants, both in terms of analysis and presentation. Furthermore, I may have found managing additional study relationships and data emotionally overwhelming.

There would have been benefits in having a sample which showed greater diversity. There is a substantially higher rate of MS among white populations in the UK, although MS does also occur in Black and Asian populations. (See statistics quoted in 1.2.1.) All of the PaMS participants were white which may have been a reflection of both the small sample size and the statistically low levels of participation in health research by ethnic minority groups

(Routen et al, 2022). This lack of diversity may also have resulted from the increased burden that COVID-19 has placed on ethnic minority communities in the UK (Patel et al, 2020). At the time of recruitment, PwMS from Black or South Asian communities may not have felt that they had capacity for the relatively large commitment of participation in this research.

As discussed in 4.2.2, men are reluctant to participate in MS research, and I had anticipated that the added element of poetry and personal interviews may discourage them further. Therefore I was pleased that Memphis participated in the study but acknowledge that it would be beneficial to have more male voices represented in the sample. The sample showed some heterogeneity in terms of age (35–60), and people with RRMS, PPMS and SPMS were all represented, leading to diversity in terms of MS experience. Seven of nine participants were educated to university level and three had post-graduate degrees; this is not uncommon in research participation generally. However, one participant was school educated and another had a vocational college education. While none of the participants reported being economically deprived, there was clearly a range of incomes and socio-economic statuses within the sample.

#### 9.4.2 Researcher positioning and wellbeing

My position within the research is unique or at least highly unusual. As discussed in 3.3, I occupy numerous roles as poet, researcher and PwMS. I maintain that my close location to the study subject has largely benefited the research; my having MS encouraged participants to trust me and share information which they may not have done otherwise. Broadly speaking, they expected greater levels of understanding than they experienced from people who did not have MS. This was an element of the study which required concerted attention and reflexivity from me; I had to be constantly alert to whether participants or I were making assumptions because of our shared MS status. I think that overall this was something we negotiated carefully and successfully in interviews and workshops. However, my positioning in the study presented particular challenges. With my supervisors, I made provision in the study protocol to manage my wellbeing. Prior to data creation, I had predicted that I may find it difficult to be confronted with severe MS disability if I felt that it potentially foreshadowed my own future. However, sometimes the reverse was the case.

Reflecting in her follow up interview, Tilly spoke about the different stages and types of MS represented in workshop Group One: *“I just felt completely like we’re all in this together. It’s the same boat. We might be sitting in different parts of the boat.”* Seeing how other people have grieved for their losses and made adaptations, often with great insight and humour, has struck me deeply. An unexpected outcome of this research is that I feel participants have gifted me a nautical chart by which I might navigate a range of possible futures should I end up in a different part of the boat to my current cabin.

That said, the emotional and psychological impact of this research has been greater for me than I anticipated as it has evoked some difficult memories and situations from my own experience (Samson, Bloor and Fincham, 2008). Transcribing portions of some interviews was very challenging, particularly when difficult family attitudes towards MS, inadequate medical care or workplace discrimination were discussed. (These are issues to which I can relate on a personal level.) On reflection, I wonder if this distress may have been exacerbated because of COVID-19 restrictions and my decision to shield as a clinically vulnerable person. Transcription happened during a time of isolation, and activities such as socialising with friends or family, which may otherwise have offered welcome distraction from the emotional challenges of work, were not available to me. Furthermore, I had the increased awareness of vulnerability that many chronically ill people felt during the pandemic and this, compounded by my experience of participants’ vulnerability, impacted on my wellbeing. As per the study protocol, I had access to four free counselling sessions with the UoE Counselling Service which I took up in the third year of the research. I found this to be of limited use but did find much greater benefit from discussing my situation with my supervisors. Also the support of my partner has been invaluable throughout the research. In later stages, it has been helpful to be connected with resources from the Emotionally Demanding Research Network.

## 9.5 Discussion of findings

This thesis has explored the experience of living with MS through the spoken utterances and written poems of research participants. In the study I have considered participants' expressions of living in, or as, MS bodies in several ways: the individual somatic experiences of MS bodies; being an MS patient; being, or no longer being, a worker with MS; social and familial impacts of MS. In this section I will summarise key findings on these themes as presented in Chapters Five, Six and Seven. Then in 9.4.4 and 9.4.5, I will discuss three threads which weave throughout those chapters: how PwMS understand their place in structures of power; silence and compliance as strategies for (non-)engagement; and the performativity and humour employed by PwMS, and people without MS, in order to manage their interactions.

### 9.5.1 The MS Lieb and Körper

Participants' poems and interview data about living in, or as, MS bodies articulated the frustrations, pain and loss they experienced. A detailed analysis of these data illustrated deeply phenomenological awareness of embodiment in participants who were wrestling with contrary experiences of their pre-MS and current bodies. In line with Young (2005) and Leder (2016), a key theme which emerged for some participants was grief at their loss of abilities which in some cases impacted their construction of a stable identity, and caused some to wrangle with the concept of mind–body dualism (Leder, 1990, 2016; Carel, 2016). For some participants, this dissonance was increased by the ways in which they felt their doctors perceived their animated, lived bodies as exterior objects of disease. Several participants explored through poems their frustration at not being understood as holistic selves. In some cases, these poems partially or completely rejected the medicalised view of their bodies. I contend that the act of writing poems about these somatic experiences gave participants opportunities to engage with difficult existential themes more deeply than they usually felt able to do in conversations with family, friends or medical teams.

### 9.5.2 Workplace and occupation

Work emerged as a key strand of the data even though it was not a study workshop theme. Participants considered employment to be an important component of their status and validity in society; it was and remains 'crucially definitional of social membership' (Abberley, 1997, 39) even, or perhaps especially, for some participants who had retired early from work because of MS. Working participants spoke about the attitudes and actions they adopted to facilitate their professional roles. Nina talked and wrote about "*masking*" in order to reinforce her capable and confident workplace persona. Eleanor and I considered together the wider socio-political framing of work as morally and socially essential and how this has fed into our personal work ethics in ways which can frustrate attempts to take care of ourselves, physically and mentally, while maintaining employment.

Participants' post-work experiences were also revealed to be complex and saturated with various types of loss: purpose and identity (Saskia and Philippa); financial security (Memphis); the ability to care actively for others (Philippa and Saskia). Participants also spoke of positive post-work experiences and a cheerful outlook for their future, however, Saskia and Memphis's determined optimism occasionally felt vague and jarred a little with their other utterances. (See discussion in 6.3.2.) I suggest that this possibly speaks to both uncertainty around their declining health and a dearth of middle-aged role models in society who have severe health impairments. Claudia and Tilly's data illuminated their traumatic experiences when made to retire because of MS. From their interviews, it was evident that they felt their former employers had used the administrative frameworks that should protect employees as tools against them.

In analysis it became clear that those participants who spoke and wrote about work did so in ways that were much less embodied than when they explored medical or social interactions. I contend that this is indicative of the suppressed role of the body in the workplace (Marx, 1990; Frayne, 2015), but more specifically it suggests that PwMS may feel compelled to conceal their somatic experience in order to function as 'healthy' or 'normate' (Garland-Thomson, 1997, 8) in the workplace.

### 9.5.3 MS and social interactions

Viewed through Leder's (1990) work on social dys-appearance and Tyler's (2020) thinking on stigmatisation, the data has shown that, to varying degrees, most participants found that their public, social and/or family lives were hindered by MS. I have argued that the level of suspicion and objectification they experienced from others was partially rooted in political attempts to stigmatise disabled people as unproductive, fraudulent, and therefore less worthy members of society (Tyler, 2020). Participants described the ways that strangers reacted to their visible disabilities with disbelief and hostility (Memphis), intrusive curiosity (Ellen and Saskia) and evasion (Claudia).

I explored how participant utterances about friends' behaviour revealed polite avoidance which, although subtler than the behaviour of strangers, created obstacles in their relationships. Some participants also explored the family challenges they experienced because of figured world views of familial roles and responsibilities. Memphis and Claudia spoke of avoiding or downplaying the impact of MS when talking to family. Saskia and Ellen wrote about and discussed their pain and frustration at their mothers' non-engagement with important elements of their MS experiences.

### 9.5.4 Power

The theme of power emerged throughout the data. Participants were aware of the power structures within which their relationships existed and the ways in which MS had altered the dynamics of those relationships. Speaking about their clinical interactions, some participants discussed the ways in which they felt that their experiential knowledge of their lived bodies was ignored whereas their objective medicalised bodies were prioritised (Leder, 2016). As Ellen described it, her "*whole*" self was unseen and unacknowledged. Memphis showed a lack of confidence with medical terminology which, I would argue, is indicative of the lack of status that PwMS may experience in the doctor–patient relationships. It is after all much harder to express yourself articulately if you are not familiar with the language that your doctor is using with bilingual fluency during your conversations.

In medical consultations, participants were very conscious of the different ways that doctors (unconsciously) exerted power over them. They spoke of the constraints of short appointments and were aware that they were one patient among many on a doctor's roster. Eleanor described how she was used as a teaching tool by her neurologist when he told her she had MS in front of a group of medical students, thus compounding her sense of being objectified. Although Eleanor did not suggest that teaching during appointments was necessarily negative, being given an MS diagnosis so publicly caused her to reflect that the experience which should have felt "*so human, was not*". Tilly and Claudia both spoke of a lack of communication from their neurologists regarding their diagnoses. These were likely accidental oversights by their medical teams, however, because their medical records were updated, but Tilly and Claudia were not informed, it is possible to infer that, in these cases, the medical teams prioritised their interactions with one another over interactions with their patients.

Some participant data revealed ways MS had contributed to a reduction in their status as employees. Generally participants were aware that, both with RRMS and progressive forms of MS, their status in the workplace was provisional and subject to change with a relapse or symptom progression. This was especially evident for Claudia and Tilly who were "*made to leave*" their jobs. Tilly said that accommodations to facilitate her remaining longer in the workforce made her "*too expensive*". She spoke of how she felt that in order to retain her pension she had to engage in a combative process where she made sure that her employers "*kick[ed her] out*", thus having to collude in a process which would ultimately 'prove' that she was no longer employable. The sense of being devalued was exacerbated for Tilly when her employer and medical team excluded her from their communications.

This sense of becoming disposable or redundant was experienced in wider society as well; some participants spoke of being ignored, challenged or abused when going about their daily lives. Claudia was distressed and isolated by the 'ocular evasion' (Garland-Thomson, 2009, 84) of strangers and acquaintances who acted as if they literally did not see her in a wheelchair. I would suggest that these attempts to exclude wheelchair users from the non-disabled social reality are powerful and harmful indicators of society's inability to find easeful relationships with visible illness and, by extension, death (Carel, 2016). Ellen, Saskia

and Memphis all expressed upset or frustration at being stigmatised and treated as less valid than those who were not visibly disabled. Memphis and Ellen were very aware that non-disabled strangers assumed power in their interactions and felt entitled to ask intrusive questions, often impolitely. I conclude that participants were frustrated by a discourse which was unfolding around them, about them, but predominantly without them. When they were 'invited' to contribute by strangers in car parks or swimming pools, they were expected to be compliant and answer questions posed by non-disabled people who assumed their own normality and controlled the exchange.

In light of these power imbalances, next I will reflect on several strategies participants used to construct their social selves in attempts to influence or 'control the terms of the encounter' with others (Garland-Thomson, 2005, 35).

#### 9.5.5 Compliance and silence

Overall, participant data showed that they constructed themselves as compliant when interacting with others. This was particularly evident when interacting with doctors. Participants overtly or implicitly described presenting themselves as 'good patients' (Sointu, 2016, n.p). They were very conscious of managing the limited time available with their doctors, and, both in poems and spoken data, they described strategies they used to derive maximum benefit from their appointments. It was evident that Ellen, Saskia and Nina made definite efforts to be informed about MS and ways that they could try to manage their health, although it could be difficult for them to raise different opinions to the ones given by their doctors.

When relating incidents of verbal abuse or inappropriate curiosity from strangers, participants also generally showed themselves to be compliant or passive. In cases of verbal abuse, Ellen spoke of being scared and not wanting to provoke further anger or physical assault. However, as she demonstrated in "*Rude Man*", and other participants described in spoken utterances, they felt there was a widespread social expectation that disabled people should explain or justify themselves. Compliance was also a feature of some participants' interactions with friends and family; Claudia did not want to challenge her family about

pointing her wheelchair the wrong way or leaving her outside shops. Similarly, Philippa and Tilly accepted being “*pigeonholed*” with elderly guests at parties even though it frustrated them. I would argue that these examples of compliance indicate, if to varying degrees, that PwMS may internalise the idea that chronically ill and disabled people are less valuable in society (Campbell, 2008). The fact that the study was conducted by and with PwMS provided opportunities for people to explore their feelings about this without feeling “*judged*” by others, and Ellen, Philippa and Tilly used their poems as spaces to imagine challenging these attitudes.

While some participants described their compliant selves as socially engaged, writing of being “*dutiful*” and “*grateful*”, what they are *not* saying, as I would suggest, is more illuminating than the “*pleasantries*” they “*get through*”. Many examples of participants’ social compliance involved their withholding information or emotion from others, whether as a way to feel safe (when verbally confronted by strangers), to maintain friendships, or to keep the peace at home. These silences may speak to participants’ perceived lack of status and power, however in some cases, the withholding of information was a way of maintaining or protecting the status that they did hold. For example, Nina did not tell her new employers about having MS until she felt valued and comfortable in the job. Similarly, Tilly’s poem “*Left-side weakness in a left-handed woman with multiple sclerosis*” reflects on what she feels but does not say to her doctors in her efforts to protect certain aspects of her life by keeping them separate from her role as a patient.

Considering participants’ data about silences when (not) discussing MS with family, I questioned Lorde’s (1984, 41) assertion that ‘[y]our silence will not protect you’. I suggested that while not healing the problems between them, silence can be a coping mechanism which allows family relationships to continue on reasonable terms without causing further fractures. Participant data about their silences in response to not being seen authentically or holistically by their mothers raise questions about the unfairness of the expectation for chronically ill people to be the ones who challenge both family dynamics and the broader cultural contexts in which they operate.

### 9.5.6 Performativity and humour

In addition to the compliance and silences discussed above, participants used various strategies to manage their interactions with others. All social interactions happen between consciously, or unconsciously, constructed versions of selves (Riessman, 2008). Across the data it emerged that several participants were very aware of intentionally enacting roles as PwMS. Memphis, Claudia and Nina all presented themselves as “*very positive*” and Claudia spoke and wrote about her efforts to be friendly and “*disarm*” people who might otherwise ignore her. By sharing “*Did I Boil the Kettle*” with her physiotherapist, Saskia was able to present herself as a capable and creative person while also ensuring that she would receive more tailored dementia support.

Participants also presented themselves in ways which were overtly entertaining or humorous. Memphis’s charismatic recounts of medical appointments, Philippa’s impression of a drunk at parties and Ellen’s “*miracle*” of rising from her wheelchair with her son all show participants attempting to minimise harm or humiliation by constructing themselves as entertaining company in potentially uncomfortable settings. These self-presentations gave participants opportunities to be witty and fun, stepping outside of the stereotype of disabled people as objects of pity or aversion (Lockyer, 2015). I would suggest that these strategies enable participants to create or strengthen social bonds with others, while simultaneously making interactions more comfortable for themselves and their contacts.

Similar to Galvin’s (2005) study of disabled identity, interview and workshop conversations were an opportunity for participants and me to share our experiences and reflect on how MS had impacted on our sense of self. Performativity and humour was also used widely within study workshops and interviews and I expect that also evolved as a way for us all to feel at ease in unfamiliar and potentially uncomfortable situations while we began relationship building. It became increasingly apparent that humour functioned to situate and strengthen the study workshops as sites where we could explore and express our identities as PwMS.

## 9.6 Implications and Future Possibilities

Although this research was not practice-directed, my conclusions are such that I can make suggestions for those working with PwMS in clinical and non-clinical settings. I also offer possible ways in which dissemination of aspects of this study may be beneficial for other researchers before suggesting avenues for future research.

### 9.6.1 Implications for those working with PwMS

#### 9.6.1.1 Power and patient involvement

In clinical and health practice, professionals should be attentive to the power dynamics of patient–practitioner relationships. Participant data illustrated that silence or compliance is not always indicative of comfortable agreement but can suggest a lack of confidence or empowerment, especially in their interactions with neurologists. Although MS may have significant psychological effects (Silveira et al, 2019), participants did not always feel that their holistic and emotional selves were acknowledged or welcome in clinical spaces and this added to their dis-ease. Similarly, participants reported feeling that some of their somatic lived experience was ignored or undervalued in consultations. I suggest that poems from this study may be useful tools for educating clinicians about the holistic wellbeing of patients and their experiential knowledge. This type of engagement with poems as training materials may aid clinicians to think more holistically about their patients and interact with them accordingly.

Participants related the ways in which they informed themselves about their illness and the research that they did into various treatments and their side effects. Some, including those with substantial physical or cognitive impairments, described how they wanted to take more active roles in planning their courses of treatment in conjunction with their medical teams. Listening to the priorities and concerns of individual PwMS, including those who wish for greater involvement in treatment decisions, may help to increase patient wellbeing and sense of agency.

### 9.6.1.2 Support groups

Charity support groups working with PwMS may find it worthwhile to add purposeful creative groups or poetry classes to their existing provision of client services. Poetry groups may offer a counterpoint to some of the negative life impacts of MS that charities aim to address, such as isolation and lack of purpose. Participants in this research derived distinct benefits from taking part in the group poetry workshops. Writing poems provided creative occupation, which boosts self-esteem and ‘can contribute to positive emotions’ (Croom, 2015, 24). The social benefits conferred by creative group settings were also significant: practicing poetry encourages emotional recognition between participants and validation of each other’s experiences (Morris, Urbanski, and Fuller, 2005); promoted acceptance (Skudrzyk et al, 2009; Heinonen, Halonen and Krahn, 2018); and encouraged connection and empathy (Furman et al, 2002; Skudrzyk et al, 2009, Croom, 2015). These outcomes were all seen in this research specifically in the context of MS, and the format enabled participants to offer peer support to one another. Furthermore, while MS was the common denominator which brought the participants and researcher together, and it was our main topic of writing, the practice of attending regular workshops together allowed participants to find common ground outwith the shared experience of MS. Interactions in group workshops reinforced our wider identities and acted as a reminder to everyone that, to paraphrase Claudia, we could “*find that bit of [us] that’s still [us] without the MS on top.*”

The purposeful elements of a poetry writing group attracted participants to the research who told me that they chose not to go to ‘coffee and conversation’ MS support groups. Thus, poetry groups could enable charities to support some within the MS population who do not engage with their existing provision. Also, the sharing of poems with friends and family in the study suggested that it may be helpful for some people to share their poems more widely. This could be utilised by charity groups when supporting PwMS and their family members to live well.

I have noted that, in this research, it took time and care to establish suitable safe spaces for these groups and for their deep relationships to develop and sharing to unfold in a meaningful and supported fashion. Accordingly, charities seeking to establish poetry groups or workshops for their clients should be mindful that the outcomes described above were

met through committed, regular small group sessions for a consistent membership<sup>16</sup>, as opposed to a drop-in or one-off format. Another significant feature of the Poetry and Multiple Sclerosis Study has been my own status within the groups as a poet facilitator with MS. Although I am not the only poet with MS, this feature is one which would probably not be reproducible for every charity or support group wishing to establish their own poetry groups. I suggest that charities work with a poet who has experience of facilitating group workshops, ideally for people with compromised health, in order to deliver the poetry aspect of sessions. Also, it would, I think, be important that a member of staff who ideally has MS themselves or has extensive experience of working with those who do is present as a co-facilitator with a specific emphasis on practical or emotional support regarding MS.

### 9.6.1.3 The research community

There is an increasing focus on ‘emotionally demanding research’ (Kumar and Cavallaro, 2018, 648) and its impacts on researchers. My methodological findings and experiences of being closely located in this study may fit usefully within the developing canon of literature that supports researchers who are negotiating their vulnerability and personal involvement with study themes.

It is my firmly held belief that it is not only the responsibility of the early career researcher to prepare for and negotiate potential harms in conducting ‘emotionally demanding research’ (Zschomler et al, 2023, 1). Funders, institutions and senior research staff also have a duty to provide targeted support to their junior research colleagues and thus influence the prevalent research culture. Qualitative training materials rarely include the experiences of early career researchers who are themselves part of the marginalized communities they are researching, even though institutions are attracted to such researchers and their work in their attempts to focus on inequity (Kinitz, 2022). Better understanding of, and professional responses to, researchers who are ‘out’ regarding their personal connection to their themes of study would benefit the whole research community, especially at a post-graduate and early career levels. A number of articles and publications are beginning to do this (Kinitz, 2022; Zschomler et al, 2023) in addition to several academic networks, such as the

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<sup>16</sup> Consistent attendance in this case recognises and accommodates individual absence because of illness or appointments which is practically unavoidable when working with cohorts of PwMS.

Emotionally Demanding Research Network Scotland and the Researcher Wellbeing Group. The experiences around early career conferences discussed within this thesis may fit well within this literature and could be reframed as training materials to enhance awareness of the increased emotional labour of marginalised researchers and to ease peer interactions within the academy.

### 9.6.2 Implications for future research

This study was exploratory in nature and indicates several possible courses for future research in the field of medical humanities. As previously stated, I found that poetry writing and sharing led to an increased empathy for, and understanding of, participants' MS experience both within the workshop groups and with their chosen wider audiences. Plus, for Saskia, this had positive health outcomes when she shared one of her poems with her occupational therapist. Accordingly, this research is relevant to traditional medical humanities with its aim of better healthcare through literary or artistic interventions (Dolan, 2015). However, I would argue that this research can also be situated within the developing field of critical medical humanities and is also relevant to disability studies. Below I briefly summarise my reasons for this positioning of my work before going on to suggest possible avenues for future research.

Although this research explores participants' clinical experiences, it also examines their wider social and work lives. As such this thesis is socio-culturally situated and politically aware in ways that align with the critical medical humanities. As a researcher, I have strived to be alert to the entanglements and intersectionalities that arose during data creation and analysis. One example of this was the deeply phenomenological aspect of some participant poems and speech. Several participants were very aware of the intersections, and dissonances, between their inner and outer experience of MS. Tilly, Ellen, Eleanor and, to some extent, Saskia demonstrated their understandings of their ill/disabled bodies as politicised and how this directly impacted their treatment in clinical settings and more broadly in society. In these conversations and poems, participants showed not just a desire for empathy but also to be understood by others as MS experts by experience. This expertise was complex, rooted in their positioning as embodied beings *and* as sites of MS (treatment).

Participants' wish for acknowledgement of their phenomenological and social expertise by clinicians mirrors arguments in critical disability studies for increased representation and understanding of experiential and embodied impairment (Hughes and Paterson, 1997).

Furthermore this research is partly produced through and about my body and my MS experiences in the understanding that 'our own bodies – as scholars, artists and activists – are [also] sites through which knowledge is produced, political claims are staked, and experimental methodologies can be explored' (Whitehead and Woods, 2016, 16). My experiences of MS lead to occasional cognitive impairment, and the practical and time-sensitive elements of the research have necessitated that sometimes I work during times of mild cognitive impairment. Like Chen (2015, 29), this has caused me to reflect on 'the ways that idealities of scholarship value cognitive elaboration, purity and clear thought' and how these are not always possible for me. Through my positioning as a located researcher, I have purposely troubled the traditional boundaries of researcher–patient, thus aligning this research with critical disability theory in our shared efforts to deconstruct ableist methodologies and assumptions.

Although poetry is used within qualitative and social science research, the majority of that poetry is currently written by researchers or compiled by them from participant data. This study's novel methodology of facilitating poetry writing workshops to create rich participant-written data could be applicable to future qualitative research which seeks to centre participant expression and aims towards more nuanced power structures in research relationships. It is a method that may be used to explore experiences of a number of different illnesses and could be conducted in online or face-to-face settings. My positioning as a poet–researcher has enabled me to explore the possibilities of this type of research and to create suitable environments and activities in which participants could experiment for themselves with writing poems. Researchers who may be interested in using this approach but lack confidence in delivering poetry workshops may wish to work in collaboration with poets. The poets could facilitate participants' poetry writing, allowing the researchers to focus on other aspects of the research.

Scope remains for an iteration of the study that was originally conceived for this research; PwMS writing poems about their MS experiences which would then be shared with their neurology teams in order to explore how it might enhance the understanding of patient experience. The findings of the current research lead me to suggest several changes to the PaMS study as first conceived; I recommend that such research be done with an awareness of the entanglement of the institutional environments, clinical and university, and how this impacts the participant experience and resulting data. This thesis has indicated that PwMS can be acutely aware of the power imbalances between them and their neurologists. I anticipate that, in a study with clinical teams, participants with MS should be supported to ensure they feel comfortable with the sharing component of the research. Because findings in this study indicate that participants may feel more comfortable and less formal in relationship with MS nurses, one possible direction for such a study could include MS nurses as the initial intended audience for participant poems. Also, I have been alert to the ways in which participants responded to my status as a researcher and have tried to be transparent about this in both analysis and this thesis. I anticipate further levels of entanglement if this type of research were to be conducted in a clinical setting. Thus such study may do well to be attentive to the question posed by critical medical humanities scholars: 'how [might] modes of collaborative and cross-disciplinary working...negotiate the challenges to academic and disciplinary expertise that are inevitably entailed?' (Whitehead and Woods, 2016, 26).

Future research could usefully further explore the potential role of poetry in relationships between PwMS and their carers; such studies could provide opportunities for both carers and PwMS to write poems about their perspectives and experiences of caring or being cared for. Ideally this work would, I suggest, be conducted by research teams, or poetry workshop facilitators, who combine experience of having worked as carers and being PwMS. Thus the research might provide beneficial in-group experiences for both the PwMS and the carers, many of whom are regularly lone workers without opportunities to share their working experiences with peers.

I would suggest that on occasion the assertion in social science that the poetic representation of data enhances compassion (Furman, 2007; Macdonald, 2017) is assumed to always be correct. Poetry and compassion would seem to be rooted in complex elements

including a reader's comfort with poetry; any pre-existing relationship with the poet or theme; and the interpretation of individual poems. This could be interrogated in future research by exploring the emotional responses to poetic data in a range of different readers. This research has presented both spoken utterances and participant-written poetry as data. I hope that readers of this thesis will consider how the different forms of participant expression affect them emotionally, aesthetically or cerebrally. Future studies that create multiple forms of data, including poems, could explicitly explore the emotional impacts of the different data types for different readers.

### 9.7 *poeMS: (Un)Final thoughts*

This thesis has explored the possibilities of poetry written by PwMS as a tool for influencing and enhancing communication about the condition. MS is a complex chronic illness which can affect people in multiple ways. Through close, reflexive analysis of the poems and spoken data of participants, I have shown how they used poetry to explore and express a wide range of their health experiences, including the physical, social, and workplace impacts of MS. I have observed that, by writing poems rather than the commonplace forms of illness narrative recognised by Frank (2013), participants have articulated knowledge about their lived experience of MS, which has variously been deeply embodied, phenomenological and socially situated.

This thesis has demonstrated how participants construct their identities in light of their experiences and perceptions, with particular focus on strategies that they use in medical, professional and personal interactions with others. Additionally, this research investigated how sharing their poems may affect conversations about MS between participants and significant people in their lives (family, friends, carers). Analysis of this data indicated that for both the PwMS and their chosen readers, poetry offered a safe or "*boundaried*" way of approaching the uncomfortable subject of MS. The use of group poetry workshops in this research as a method of data creation is novel and has highlighted particular benefits for participants, who were able to interact socially with other PwMS and derived personal affirmation from the recognition of shared or similar health experiences. In addition to the creative validation that participants gained from poem writing, this research has shown that

poetry may offer a novel route for PwMS to contribute to the discourse on health and disability on their own terms. To return to the quote at the beginning of this chapter: 'One's destination is never a place, but rather a new way of looking at things'(Miller, 1957, 25); this thesis has shown that poetry can provide new ways of looking at MS for people with the illness, their contacts and future researchers.

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# Appendix A – Core Participant Consent form



## The Poetry and MS (PaMS) Study: Consent Form

Researcher: Georgi Gill

Please type your initials in each box

1. I confirm that I have read and understood the information sheet (version 1 dated 13/5/2020) for the above study. I have had the opportunity to ask members of the research team any questions and these have been answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
3. I understand that I will be asked about my illness experience. If I become distressed by this, I can take breaks and/or discuss avenues of support with the researcher.
4. I agree to my interviews being audio-recorded.
5. I agree to the workshops being audio-recorded.
6. I understand that relevant sections of data collected during the study may be looked at by individuals from the Sponsor (the University of Edinburgh), where it is relevant to my taking part in this research.
7. I confirm my understanding that the copyright to the poems written by me as part of the study will be owned by me and I will be free to publish these and deal with them as I see fit. I confirm that I have granted a licence to the researcher/ Georgi Gill and/or the University to use these poems for the purposes of the Study including in her thesis and any other reports or publications relating to the Study.
8. I agree to the use of my anonymised data in future studies.
9. I agree to take part in the above study.

## The Poetry and MS (PaMS) Study: Consent Form

Researcher: Georgi Gill

**Please complete the boxes below**

Name of person giving consent:	
Date:	

*Thank you for completing this form.*

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**For completion by the research team:**

Name of person taking consent:	
Date:	

*1 x email copy to participant, signed email copy retained in the Study Master File*

## Appendix B – Core Participant Information Sheet



THE UNIVERSITY  
of EDINBURGH

### The Poetry and Multiple Sclerosis Study

Poetry as a method for exploring individuals' relationship with multiple sclerosis (MS) and communicating their experience to others

### Participant Information Sheet

The Poetry and Multiple Sclerosis Study (PaMS) is a research study for people with multiple sclerosis which involves attending poetry writing workshops and interviews about your experiences. This information sheet gives further details about what is involved.

#### 1) The PaMS Study Team – an introduction

Georgi Gill at the University of Edinburgh is leading PaMS; a study to explore the effects that poetry writing may have on the way people with MS (PwMS) relate to their own bodies and the way PwMS communicate their health experiences to others. Georgi Gill is a PhD researcher, professional poet and has multiple sclerosis.

#### 2) Invitation to Participate

We would like to invite you to participate in this study but, before you decide, please take enough time to be sure that you fully understand the study and are happy to participate. What is involved, together with the uses of your data are described in this information sheet; but if anything isn't clear please ask us what we mean. Our contact details are at the end of this information sheet.

#### 3) The aims of the PaMS study

People with MS can find it difficult to communicate their individual symptoms and experiences successfully to friends, family and others. This study aims to explore how writing poetry may help PwMS to develop new ways of sharing their illness experiences.

#### 4) Why have I been invited to take part?

You have been approached because you have had a diagnosis of multiple sclerosis for a minimum of one year and are aged 18 or older.

#### 5) Do I have to take part?

**No, it is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason.** Deciding not to take part or withdrawing from the study will not affect your legal rights. Your data collected up to the point of withdrawal will be retained and included in the study.

#### 6) What does the study involve?

Taking part in the study will involve: a) up to two one-to-one Skype or Teams interviews with Georgi, the researcher, b) a series of four online group poetry workshops with other people who live with MS. You will also be given opportunity to share your poems with somebody of your choice (e.g. family member, friend, colleague). No prior experience of writing poetry is required to participate in this study.

#### What will the interview involve?

The first interview will explore your experiences of living with MS, with a focus on how you talk about those experiences with others. The interview will last around an hour, but can be longer or shorter to suit. Interviews will be held via Skype or Teams so you can choose a place where you are comfortable and can speak confidentially.

Georgi will ask:

- how MS has affected your physical, mental and emotional health and lifestyle
- how you talk about MS with others
- about your previous experience of poetry.

At the interview, Georgi will also ask about any accessibility requirements or support that you might need to participate fully in the project. This will help her to make sure that everything required is in place for the workshops. If you would like to discuss your requirements with Georgi before deciding whether to participate in PaMS, you can contact her via the phone number and/or email address given on page 4 of this Participant Information Sheet.

After your interview, if you think of anything that you forgot to tell us or there is something you would like to clarify or tell us more about then you can tell Georgi via email.

#### **What will the workshops involve?**

You will take part in a series of up to 4 online group poetry workshops, led by Georgi and lasting up to 90 minutes each. Workshops will be held weekly, and will involve working with Georgi and up to 2 other participants to explore and try out writing poems about MS. We ask that you attend as many of these workshops as possible. Workshops will be flexible and relaxed, so you can take breaks as needed. Workshops will be held on the secure online learning platform, Collaborate. Georgi will explain how to use Collaborate and can give you a 'guided tour' of the platform prior to the workshops so that you are comfortable with using it.

At the workshops:

- Poems on the theme of illness will be provided for the group to read and discuss. These will then be used as prompts for you to write your own poems exploring your experiences of life with MS. You can write your poems with pen and paper or on your device.
- Georgi will support you if you require help or assistance to complete your writing, or if it is helpful for you, you may ask a suitable person in your household to record your writing on your behalf or you may make an audio-recording.
- You will have the opportunity to share your writing with other members of the group, but this is voluntary and you do not have to share your work with the group if you do not wish to do so.
- There will be a break in the middle of the workshops in addition to any other breaks that you may need to take.
- If you are unwell or have to miss a workshop for any reason, that is fine. Try to attend the next workshop if you can. Each workshop will have its own topic so you won't need to worry about catching up on anything you have missed.

With your consent, both the one-to-one interviews and the group workshops will be audio-recorded.

#### **What does poem sharing involve?**

At the final workshop, Georgi will discuss poem sharing with you. You will be encouraged to think about which, if any, of your poems you may want to share and with whom (e.g. friend, family member or colleague). There will also be opportunities to discuss any concerns you might have about sharing your work. You do not have to share your poems if you do not wish to do so.

The method of sharing is likely to vary according to where you and your chosen reader are located. For example, if you choose to share your poems with somebody living in the same household, you could do this face-to-face. Or you may choose to share your poems via email or Skype with somebody from another household. The researcher will not be present during the poem sharing.

The purpose of poem sharing is for you and your chosen readers to experience and reflect together on your use of this alternative form of communication. After poem sharing, Georgi will ask if you would be happy for us to contact your chosen reader to find out what it was like for them to read/hear your poem(s). You do not have to consent to this contact if you do not want to. If you do not consent, you can still be a part of the study.

It is possible that you may choose to share your poems informally with close contacts while the workshopping process is ongoing. This is absolutely fine: participants may share their poems with whomever they wish and whenever they wish to do so.

**What does the follow-up interview involve?**

A final one-to-one interview will be offered at the end of the study, to explore your experiences of participating. This interview will ask about:

- Your experiences in the poetry workshops
- How the workshops have affected your relationship with your body
- How the workshops have affected the ways in which you talk about MS.

**7) Consent to participate in the study**

If you agree to be contacted by Georgi Gill, the researcher for this study, she will contact you by email or telephone, according to your stated preference. When she contacts you, Georgi will answer any questions that you might have about the study. If you then decide to participate, Georgi will email you the consent form and, when it is returned, signed, via email, she will arrange an interview for a time that suits you. At the beginning of the interview, she will ask you to confirm verbally that you still consent as per your signed form.

In the unlikely event that you lose the capacity to consent during the course of the study, your data collected up to that point will be retained and included in the study but no further data will be collected.

**8) How will we use information about you?**

We will need to use information from you for this research project.

This information will include:

- your name
- your email address
- your telephone number (if you wish us to contact you via telephone)
- your postal address (if you wish us to send you the study findings by post)
- information from interviews and poetry workshops
- poems

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. We will pseudonymise all of your data by giving you a pseudonym (fake name) and changing any potentially identifiable details. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Your personally identifiable information including contact details and audio-recordings from interviews and workshops will be securely destroyed six months after the completion of the study. Other pseudonymised information in the study (interview transcripts and poems) will be securely stored for five years.

Participants are responsible for the storage of the original copies of their poems. You may want to store your poems in a notebook or in a file on your computer.

**What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information by contacting Georgi or any of the other people named at the end of this sheet.

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

You may find the experience of writing poems enjoyable and you may find it helpful to share the poems with people you know. Some participants may also enjoy the social aspect of the workshops and value the opportunity to spend time with others who have similar illness experiences to their own. Possible benefits to the wider MS community are the development of new methods of communication that have potential to enhance PwMS's modes of self-expression in a range of settings. There may, however, be no benefit to you in taking part in the study.

**11) Are there any risks or disadvantages of taking part?**

PaMS will ask about your illness experience. The process of reflecting on your experience might prompt emotions that you were not expecting. If this happens and you need to take a break or have a chat with the researcher, then she will encourage you to do so. She will also be able to suggest additional avenues of support for you if appropriate, such as: contacting your GP; the MS Society telephone helpline on 0808 800 8000; or the MS-UK telephone helpline on 0800 783 0518.

You may be worried about a negative outcome from sharing your poems with others. Georgi will guide you through the process of choosing which poems you may wish to share and with whom. She will talk with you about the potential implications of sharing those poems.

**12) What happens to the findings of the study?**

The findings will be presented at academic meetings, and published in a doctoral thesis and academic medical/scientific journals. Participants will own the copyright in their poems and are thus free to publish these and use them as they see fit. Participants also grant a licence to the researcher/Georgi Gill and/or the University to reproduce these poems in her thesis and any other reports or publications she may make in connection with the study.

At the end of the study, we will send you a brief report of the findings to either your consented postal or email address.

**13) Who is organising the research?**

The study is organised by Georgi Gill at the University of Edinburgh as part of her PhD research project.

**14) Who has reviewed the study?**

The CAHSS Research Ethics Committee, which has responsibility for scrutinising all proposals for research within the College of Arts Humanities and Social Sciences, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research be made available for scrutiny by monitors from the University of Edinburgh, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

**15) Contacts for the study**

If you have any further questions about the study please contact the study's principal researcher:

Georgi Gill, Principal Researcher

Telephone 07541 854085 email: [g.e.gill@sms.ed.ac.uk](mailto:g.e.gill@sms.ed.ac.uk)

School of Health in Social Science, Doorway 6, Teviot Place, Edinburgh, EH8 9AG.

Rosie Stenhouse PhD FHEA RMN, Project Supervisor

telephone: 0131 651 5160 email [Rosie.Stenhouse@ed.ac.uk](mailto:Rosie.Stenhouse@ed.ac.uk)

School of Health in Social Science, Doorway 6, Teviot Place, Edinburgh, EH8 9AG.

If you would like to discuss this study with someone independent of the study team please contact: Dr Marion Smith email: [marion.smith@ed.ac.uk](mailto:marion.smith@ed.ac.uk)

If you wish to make a complaint about the study please contact the University of Edinburgh research governance team:

email: [cahss.res.ethics@ed.ac.uk](mailto:cahss.res.ethics@ed.ac.uk)

# Appendix C – Website and Social Media Screenshots

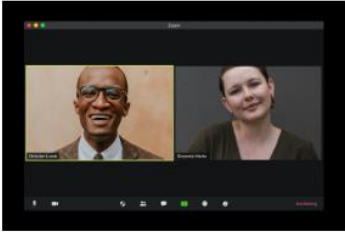
From Poetry and MS website<sup>17</sup>

‘Taking Part in P.a.M.S.’<sup>18</sup>

## Taking Part in P.a.M.S.

At the present time, we have recruited enough participants for the final workshop groups and are not recruiting more participants. Thank you to everybody who has expressed an interest in P.a.M.S. and to everybody who has helped to spread the word.

If you're interested in participating in the Poetry and Multiple Sclerosis Study here are the three steps you can take to find out more and get in touch.




**1. Find out if you are eligible.**

In order to take part in the P.a.M.S. study, you must meet the following criteria:

- have had a diagnosis of multiple sclerosis for a minimum of one year.
- be aged 18 or older.
- be resident in the U.K.


You do not need to have any experience of writing poetry, just a willingness to have a go.



**2. Read the information sheet.**

If you meet the eligibility criteria, read our [Participant Information Sheet](#). It has everything you need to know about the study including what happens in each stage and how we will use participants' data.

It's more detailed than the other information here so we recommend you make yourself a cup of tea and find a comfortable seat before reading.



**3. Get in touch with us.**

If you meet the eligibility criteria, have read the Patient Information Sheet and would like to take part, get in touch with us.

Maybe you are considering participating but want to talk it over first or ask us some questions?

Email Georgi at [g.e.gill@sms.ed.ac.uk](mailto:g.e.gill@sms.ed.ac.uk) or telephone on 07541 854085.

<sup>17</sup> The subscription for this website expired in June 2023 so it is no longer available online. These screenshots were taken before the site expired.

<sup>18</sup> Alternative text: Screenshot of webpage ‘Taking Part in P.a.M.S.’. Page divided into three columns: 1. Find out if you are eligible. Column headed by image of two people in video conference, one black man in suit and glasses and a white woman in a green top. Both are smiling. The accompanying text lists the eligibility criteria for participation. Column 2 shows image of an open laptop on a table, next to a teacup and a plant. The accompanying text directs the viewer to read the PIS. Column 3 shows image of a woman in glasses and jacket who is sitting in a wheelchair at a desk on the phone. Accompanying text invites the viewer to contact the researcher.

'The P.a.M.S. Study'<sup>19</sup>

## The P.a.M.S. Study

For thousands of years, people have written poetry as a way to explore complex experiences and feelings. People with M.S. can find it difficult to describe their symptoms and illness experiences successfully to friends, family, colleagues or doctors. The Poetry and Multiple Sclerosis study (P.a.M.S.) aims to explore how writing poetry may help people with M.S. to develop new ways of sharing their illness experiences. Watch our short film to find out about the study. There is also more information below.



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<sup>19</sup> Alternative text: Screenshot of webpage 'The P.a.M.S. Study'. Text introduces aim of study 'to explore how writing poetry may help people with M.S. to develop new ways of sharing their illness experiences' and invites the viewer to watch the short introductory film. Thumbnail of film shows woman with blue hair, wearing a black top and smiling to camera. Behind her is a window, some houseplants, a bookcase and a cupboard.

'Frequently Asked Questions'<sup>20</sup>

## Frequently Asked Questions

### Who can take part in P.a.M.S.?

People who have had a diagnosis of multiple sclerosis for a minimum of one year, are aged 18 or over, and live in the U.K. may be eligible to take part in P.a.M.S.

### I've never written poetry before. Can I still participate?

Yes. No prior experience of writing poetry is required to participate in this study. All you need is the willingness to give it a go. Some participants may have written poetry before and that is also fine.

### Where will the interviews take place?

The interviews will happen via Skype or, if a participant doesn't wish to use Skype, the interview can happen via Teams, a different online video conferencing facility.

### What will you ask me in the interview?

The interview will explore your experiences of living with MS, with a focus on how you talk about those experiences with others.

### How long is the interview?

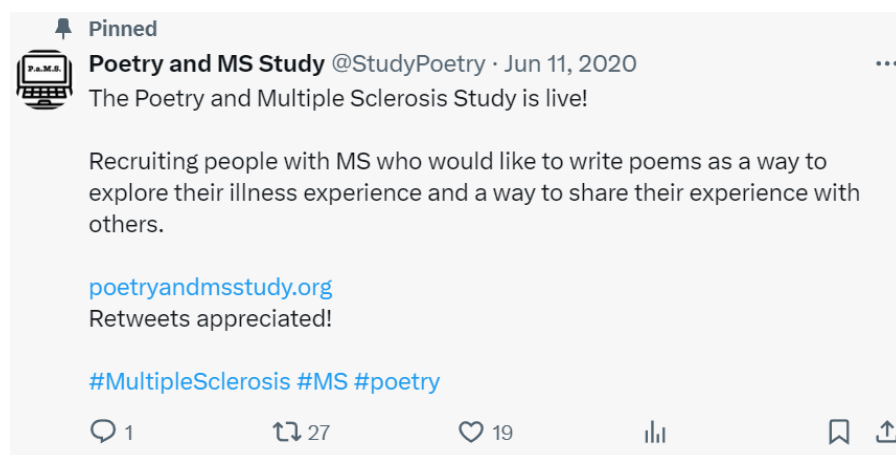
The interview will last around an hour, but can be longer or shorter to suit.

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<sup>20</sup> Alternative text: screenshot excerpt of 'Frequently Asked Questions'. Text clarifies eligibility criteria and explains that interviews will take place online and explore experiences of living with and talking about MS. Interviews will last around an hour.

## From Poetry and MS Study (@poetrystudy) Twitter

### Poetry and MS Study (11 June 2020)<sup>21</sup>



### Poetry and MS Study (14 October 2020)<sup>22</sup>



<sup>21</sup> Alternative text: tweet from @StudyPoetry account, 11 June 2020, 'The Poetry and Multiple Sclerosis Study is live! Recruiting people with MS who would like to write poems as a way to explore their illness experience and a way to share their experience with others.' Link to [poetryandmsstudy.org](https://poetryandmsstudy.org) 'Retweets appreciated [#MultipleSclerosis](#) [#MS](#) [#poetry](#)'.

<sup>22</sup> Alternative text: tweet from @StudyPoetry account, 14 October 2020. 'The first two groups of participants in the PaMS Study have completed their workshops and written lots of great [#MS](#) poems. We're now recruiting people with MS to take part in group 3. Interested? Find our more at: <https://poetryandmsstudy.org>' Image of woman, wearing a light-coloured shirt, sitting at a table, typing on a laptop, next to a notebook and phone. Her head is not visible.

## Poetry and MS Study (19 October 2020)<sup>23</sup>



## From The Poetry and MS Study Facebook

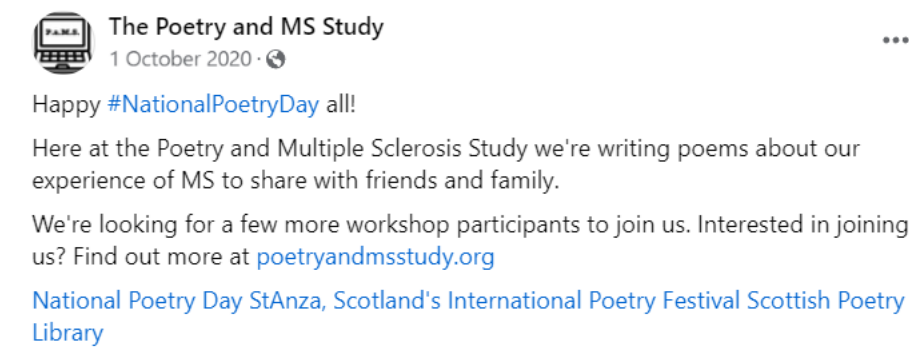
### The Poetry and MS Study (22 June 2020)<sup>24</sup>



<sup>23</sup> Alternative text: tweet from @StudyPoetry account, 19 October 2020, 'How may poetry help us find new ways to talk about Multiple Sclerosis? The Poetry and MS Study is recruiting people with MS who want to write poems exploring their experiences. Find out more: <http://poetryandmsstudy.org> @MSTrust @mssocietyuk @MSUK6'

<sup>24</sup> Alternative text: Facebook The Poetry and MS Study post, 22 June 2020. 'The Poetry and Multiple Sclerosis Study is live! Recruiting people with MS who would like to write poems as a way to explore their illness experience and a way to share their experience with others. [poetryandmsstudy.org](http://poetryandmsstudy.org)'. Image of a woman with glasses and red jacket in wheelchair, typing at laptop at a desk with coffee nearby.

## The Poetry and MS Study (1 October 2020)<sup>25</sup>



**The Poetry and MS Study**  
1 October 2020 · 🌐

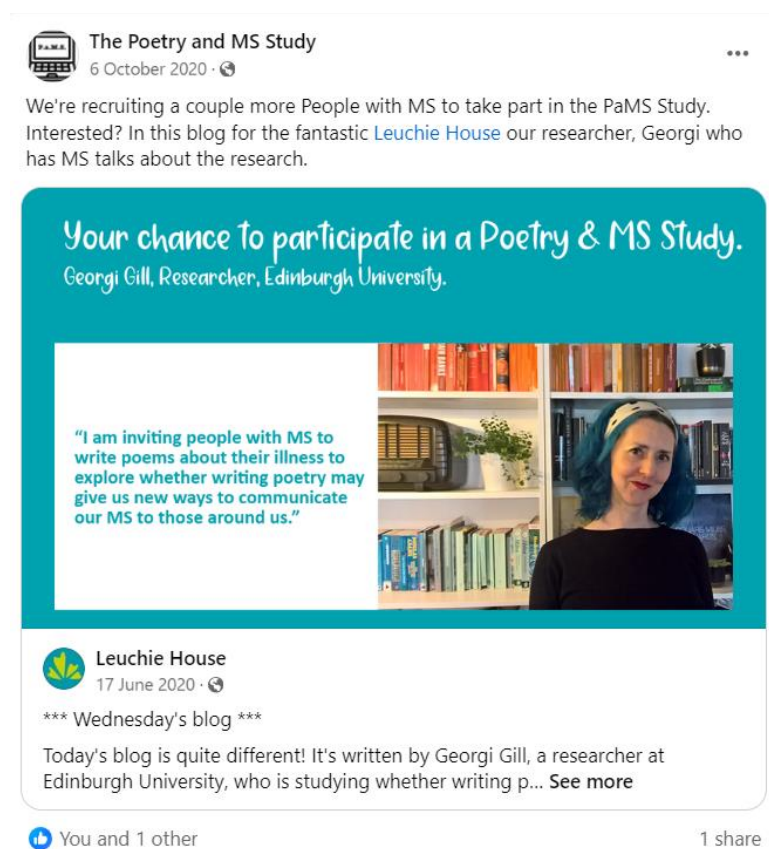
Happy [#NationalPoetryDay](#) all!

Here at the Poetry and Multiple Sclerosis Study we're writing poems about our experience of MS to share with friends and family.

We're looking for a few more workshop participants to join us. Interested in joining us? Find out more at [poetryandmsstudy.org](http://poetryandmsstudy.org)

[National Poetry Day StAnza, Scotland's International Poetry Festival Scottish Poetry Library](#)

## The Poetry and MS Study (6 October 2020)<sup>26</sup>



**The Poetry and MS Study**  
6 October 2020 · 🌐

We're recruiting a couple more People with MS to take part in the PaMS Study. Interested? In this blog for the fantastic [Leuchie House](#) our researcher, Georgi who has MS talks about the research.

*Your chance to participate in a Poetry & MS Study.*  
Georgi Gill, Researcher, Edinburgh University.



"I am inviting people with MS to write poems about their illness to explore whether writing poetry may give us new ways to communicate our MS to those around us."

**Leuchie House**  
17 June 2020 · 🌐

\*\*\* Wednesday's blog \*\*\*

Today's blog is quite different! It's written by Georgi Gill, a researcher at Edinburgh University, who is studying whether writing p... [See more](#)

You and 1 other      1 share

<sup>25</sup> Alternative text: Facebook The Poetry and MS Study post, 1 October 2020. 'Happy [#NationalPoetryDay](#) all! Here at the Poetry and Multiple Sclerosis Study we're writing poems about our experience of MS to share with friends and family. We're looking for a few more workshop participants to join us. Interested in joining us? Find out more at [poetryandmsstudy.org](http://poetryandmsstudy.org) National Poetry Day StAnza, Scotland's International Poetry Festival Scottish Poetry Library'

<sup>26</sup> Alternative text: Facebook The Poetry and MS Study post, 6 October 2020. 'We're recruiting a couple more People with MS to take part in the PaMS Study. Interested? In this blog for the fantastic Leuchie House our researcher, Georgi who has MS talks about the research.' Sharing of post by Leuchie House which links to blog. Thumbnail of blog is titled 'Your chance to participate in a Poetry and MS Study' and has image of woman with blue hair and black top standing in front of bookcase smiling at camera.

## Appendix D – Poetry and MS Study Website Film Transcript

What is the Poetry and Multiple Sclerosis Study? Hello, I'm Georgi Gill. I'm a researcher at the University of Edinburgh where I am running the Poetry and Multiple Sclerosis Study - or PaMS for short. I'm also a poet and I have multiple sclerosis. I'd like to briefly introduce the study here.

For those of us with MS it can be difficult to explain or describe our illness experiences to others. Symptoms can be unpredictable and can impact on our lives in lots of ways. It can be very confusing to live with MS, let alone explain to family, friends and others how the illness affects us.

PaMS is a study inviting people with MS to write poems about their health and exploring whether writing the poems may give us new ways to communicate our MS to those around us. The study also looks at the effects that poetry writing may have on the way people with MS relate to our own bodies.

PaMS is being run online to make sure that people can take part safely at this time when many of us are being asked to stay at home more. People who take part in the study will be invited to an online interview with me where we will explore their experiences of living with MS, particularly how they talk about those experiences with others.

After the interview, participants will be invited to take part in a short series of online poetry workshops. In the workshops they can work with me and up to two other participants to try out writing poems about MS.

After the workshops, participants will be given the option to share one or more of their poems with someone they trust. Maybe a friend, family member or colleague? Nobody is required to share their poems but participants who wish to share can do so privately in a way that feels best for them. Maybe over a cup of tea at home or via email with a friend? Finally, I'll invite participants to a second online interview so we can discuss what taking part in the project has been like. If participants are happy for me to do so, I'll contact some of the

people that were chosen to read their poems and find out what the experience was like for them.

People living in the UK who are 18 or over and have had a diagnosis of MS for a minimum of one year may be eligible to take part in PaMS. No previous experience of writing or reading poetry is required. Just a willingness to give it a go.

If you'd like to find out more about PaMS, including who is eligible to take part and how to get involved, click on the site link to read the Participant Information Sheet. You'll also find information there about how we have made the study accessible for those with support needs. If you have any questions about PaMS, just ask. You'll find contact details on the information sheet.

Thanks for watching.

## Appendix E – Blog

### **Participate in a Poetry and MS Study**

Since my diagnosis with relapse remitting MS in 2003, I have found it difficult to describe my illness experiences and symptoms to family, friends and colleagues. I have become fluent in its medical terminology. My mouth no longer stumbles over the terms *dysesthesia*, *optic neuritis* or *cognitive dysfunction*. Yet these words don't help me to communicate what it feels like to live in this body, with its intermittent numbness, blurred vision, dizziness and slowed thinking. I am not alone in this: it is acknowledged within the MS community, that many of us have difficulty explaining our illness to those around us.

As a poet, words are my stock-in-trade. It's no surprise that I am keen to find potential ways to improve this communication shortfall. This desire has led me to develop the Poetry and Multiple Sclerosis (P.a.M.S.) Study, at the University of Edinburgh. In the study, I am inviting people with MS to write poems about their illness to explore whether writing poetry may give us new ways to communicate our MS to those around us.

Study participation starts with a 1:1 online interview where participants can talk to me about their experiences of living with MS. This will be followed by a series of up to four online poetry workshops, in which up to three participants and I will try writing poems about our MS. These sessions will be flexible and relaxed, so everybody can take breaks or access support as needed. No previous poetry experience is required to take part in the study – just a willingness to give it a go.

After the workshop series is finished, participants will have the opportunity to share one or more of their poems with a contact of their choosing, such as a friend, family member or colleague. Poem sharing is optional and no one has to share their poems if they do not wish to do so.

To round off the study, I'll offer participants a follow up 1:1 online interview to explore their experiences of taking part. With participants' permission, I will also approach some of the people with whom poems were shared and ask about their perspectives of the study.

There is no guarantee that writing and sharing poems *will* help us to develop new ways of communicating our MS. However, people may find the experience of writing poems enjoyable and they may find it helpful to share the poems with people they know. Some participants may also enjoy the social aspect of the workshops and value the opportunity to spend time with others who have similar illness experiences to their own.

To find out more about the P.a.M.S. Study, take a look at the [study website](#). If you have any questions or would like to get in touch, my contact details are on the site.

(Gill, 2020a) Published on Leuchie House blog, 16 June 2020.

# Appendix F – Reader Participant Information Sheet



## The Poetry and Multiple Sclerosis Study

Poetry as a method for exploring individuals' relationship with multiple sclerosis (MS) and communicating their experience to others

### Reader Participant Information Sheet

The Poetry and Multiple Sclerosis Study (PaMS) is a research study for people with multiple sclerosis which involves their attending poetry writing workshops and interviews about their health experiences. This information sheet gives further details about what is involved for participants with MS and also for reader participants who may choose to participate by attending interviews to talk about their perspective of the project's impact.

#### 1) The PaMS Study Team – an introduction

Georgi Gill at the University of Edinburgh is leading PaMS; a study to explore the effects that poetry writing may have on the way people with MS (PwMS) relate to their own bodies and the way they communicate their health experiences to others. Georgi Gill is a poet and has multiple sclerosis.

#### 2) Invitation to participate

We would like to invite you to participate in this study but, before you decide, please take enough time to be sure that you fully understand the study and are happy to participate. What is involved, together with the uses of your data are described in this information sheet, but if anything isn't clear please ask us what we mean. Our contact details are at the end of this information sheet.

#### 3) The aims of the PaMS Study

People with MS can find it difficult to communicate their individual symptoms and experiences successfully to friends, family and others. This study aims to explore how writing poetry may help PwMS to develop new ways of sharing their illness experiences.

#### 4) Why have I been invited to take part?

You have been approached because someone you know has participated in the study and they have shared their poem(s) with you.

#### 5) Do I have to take part?

**No, you do not have to take part.** If you do decide to take part, you are still free to withdraw from the study at any time without providing a reason. If you choose to withdraw from the study or are withdrawn from the study for any reason, we will retain your data up to that point. Deciding not to take part or withdrawing from the study will not affect your legal rights.

#### 6) What does a reader participant's participation in the study involve?

An online Skype or Teams interview with the researcher to explore your perspective of the project's impact. Interviews are anticipated to take around 30 minutes but that depends on how much you have to tell us. If a Skype or Teams meeting with the researcher is not convenient for you, we can complete

the interview by telephone or email. With your permission, the researcher will make an audio-recording of your Skype or telephone interview.

You do not need to have any knowledge about poetry in order to participate in the study.

#### **7) What will the interviews ask?**

The researcher will ask about:

- your experience of reading or hearing the poem(s) written by the person with MS
- ways in which the PaMs Study may have affected how the person with MS talks with you about their illness experience.
- You may also be asked about your experience of using the 'How to read a poem' tip sheet which you may have been given prior to reading the poems.

After your interview, if you think of anything that you forgot to tell us or there is something you would like to clarify or tell us more about then you can tell Georgi via email.

#### **8) How will we use information about you?**

We will need to use information from you for this research project.

This information will include:

- your name
- your email address
- your telephone number if you wish us to contact you via telephone
- your postal address (if you wish us to send you the study findings by post)
- information from your interview

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. We will pseudonymise all of your data by giving you a pseudonym (fake name) and changing any potentially identifiable details.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Your personally identifiable information including contact details and audio-recordings from interviews and workshops will be securely destroyed six months after the completion of the study. Other pseudonymised information in the study (interview transcripts) will be securely stored for five years.

#### **What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

#### **Where can you find out more about how your information is used?**

You can find out more about how we use your information by contacting any of the people named at the end of this sheet.

#### **10) What are the possible benefits of taking part?**

Participation in this study will give you an opportunity to reflect on dialogues and interactions with your family member/friend/colleague in a new way. Possible benefits to the wider MS community are the development of new methods of communication that have potential to enhance PwMS's modes of self-expression in a range of settings.

**11) What are the possible disadvantages of taking part?**

Participation in this study does involve a short time commitment from you as the interview will last around 30 minutes. Talking about your experience of reading or hearing the poem(s) might prompt emotions that you were not expecting. If this happens and you need to take a break, the researcher will encourage you to do so.

**12) Withdrawal from the Study**

**You can withdraw from the study at any time without your legal rights being affected.** This can be done either by calling the research team at 07541 854085, emailing Georgi Gill at [g.e.gill@sms.ed.ac.uk](mailto:g.e.gill@sms.ed.ac.uk) or by writing a letter to Georgi Gill, The University of Edinburgh, School of Health in Social Science, Doorway 6, Old Medical School, Teviot Place, Edinburgh, EH8 9AG. Should you withdraw from the study, any information or data collected up to that point will be maintained.

**13) What happens to the findings of the study?**

The findings will be presented at academic meetings and conferences, and published in a doctoral thesis and academic medical/scientific journals. You will not be identified in any presentation or publication.

At the end of the study, we will send you a brief report of the findings to either your consented postal or email address.

**14) Who is organising the research?**

The study is organised by Georgi Gill at the University of Edinburgh as her doctoral research.

**15) Who has reviewed the study?**

The CAHSS Research Ethics Committee, which has responsibility for scrutinising all proposals for research within the College of Arts Humanities and Social Sciences, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research be made available for scrutiny by monitors from the University of Edinburgh, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

**16) Contacts for the study**

If you have any further questions about the study please contact:

Georgi Gill, Principal Researcher

telephone: 07541 854085 email: [g.e.gill@sms.ed.ac.uk](mailto:g.e.gill@sms.ed.ac.uk)

School of Health in Social Science, Doorway 6, Teviot Place, Edinburgh, EH8 9AG.

Rosie Stenhouse PhD FHEA RMN, Project Supervisor

telephone: 0131 651 5160 email [Rosie.Stenhouse@ed.ac.uk](mailto:Rosie.Stenhouse@ed.ac.uk)

School of Health in Social Science, Doorway 6, Teviot Place, Edinburgh, EH8 9AG.

If you would like to discuss this study with someone independent of the study team please contact: Dr

Marion Smith email: [marion.smith@ed.ac.uk](mailto:marion.smith@ed.ac.uk)

If you wish to make a complaint about the study please contact the University of Edinburgh research governance team:

email: [cahss.res.ethics@ed.ac.uk](mailto:cahss.res.ethics@ed.ac.uk)

# Appendix G – Reader Participant Consent Form



## The Poetry and MS (PaMS) Study: Reader Participant Consent Form

**Researcher:** Georgi Gill

Please type your initials in each box

1. I confirm that I have read and understood the information sheet (version 1 dated 13/5/2020) for the above study. I have had the opportunity to ask members of the research team any questions and these have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I agree to my interview being audio-recorded.

4. I understand that relevant sections of data collected during the study may be looked at by individuals from the Sponsor (the University of Edinburgh) or other authorities, where it is relevant to my taking part in this research.

5. I agree to the use of my anonymised data in future studies.

6. I agree to take part in the above study.

**The Poetry and MS (PaMS) Study: Reader Participant Consent Form**

**Researcher:** Georgi Gill

**Please complete the boxes below**

<b>Name of person giving consent:</b>	
<b>Date:</b>	

*Thank you for completing this form.*

---

**For completion by the research team:**

<b>Name of person taking consent:</b>	
<b>Date:</b>	

*1 x email copy to participant, signed email copy retained in the Study Master File*

## Appendix H – Prompt Poems

### Appendix H.a - Prompt Poem for Workshop 1

*from 'Grief'*

When grief comes to you as a purple gorilla  
you must count yourself lucky.  
You must offer her what's left  
of your dinner, the book you were trying to finish  
you must put aside  
and make her a place to sit at the foot of your bed,  
her eyes moving from the clock  
to the television and back again.  
I am not afraid. She has been here before  
and now I can recognize her gait  
as she approaches the house.  
Some nights, when I know she's coming,  
I unlock the door, lie down on my back,  
and count her steps  
from the street to the porch.  
Tonight she brings a pencil and a ream of paper,  
tells me to write down  
everyone I have ever known,  
and we separate them between the living and the dead  
so she can pick each name at random.  
I play her favorite Willie Nelson album  
because she misses Texas  
but I don't ask why.

By Matthew Dickman (2008, 54)

## Appendix H.b - Prompt Poem for Workshop 2

### Migraine

The first warning: it begins  
with borders thinning. Light  
entering my pores, some substance  
leaving.

I am smudging beyond  
the boundaries of my body,  
encircling it,  
as ectoplasm, halo,  
lipstick slipping  
over the edge of the lip.

Submerged, I hear  
boomily, speak in tongues.  
There are acrid odours, unrecognisable.  
I tell my hands to move. I'm amazed to see  
them hopping, jerking,  
marionettes, wild bunnies.

The walls are water,  
swishing, falling, swaying.  
Lights hover,  
multitudinous spirits thrown from heaven,  
towers sprouting,  
ramparts shimmering,  
the looming battlements of god.

Then the pain,  
considerably less interesting.  
It is bashing, insistent.  
It swallows everything.  
Afterwards I am like a newborn.  
I forget words for days.  
I hold my breath, my head,  
fearfully, stationary,  
a balloon tugging its string,  
a saucer brimming.

By Kitty Coles (2017, 204-5)

## Appendix H.c - Prompt Poems for Workshop 3

'What Can You See?'

The question could be practical,  
well-intentioned, but it pins  
me down completely.

My answer confuses her:  
'What can you see?'

'Er, normal, I guess...'  
I shrug: 'Yeah, me too.'

By Holly Magill (2017, 48)

Prompt Poem 2 for Workshop 3 (used with Groups 1 and 4):

*from 'Homage to Clotho: A Hospital Suite'*

Why must the young male nurse who preps the plain  
Of my knife-thrower's-target abdomen  
With his conversant razor, talking snicks  
Of scything into my sedated ears,  
Talk also in his flat and friendly voice,  
So far from showdowns, on a blasé note  
Of reassurance, learnt by classroom rote?  
It is that he must make his living, too.

By L.E. Sissman (2009, 128)

(Efforts have been made to obtain permission from Houghton Mifflin to reproduce this poem extract within this thesis. No response has been received but I reproduce the extract here as I understand that it falls within non-commercial, fair use)

## Appendix H.d - Prompt Poem for Workshop 4

In close

In a dream  
I saw a ticket booth  
at a bus stop where  
birds' feathers were sold instead of tickets  
and the seller was...  
an old man  
with the early spring sun in his eyes

and for you young lady...  
he said slowly  
and took from somewhere next to the door  
where there might have been  
a bin and a broom  
one more feather  
a white plume  
light and as tall  
as himself

I paid and went  
in dream's muddy buses  
no notion of waking  
no fear of inspection

By Kristiina Ehin (2013, 61)

## Appendix J – Participant Poems

### Group One Poems

#### **Nina's poems**

##### Nina Workshop 1 Poem

###### Waves

They rolled in gently, at first, lapping against her feet,  
Cold, calm, shimmering and bubbling on top of the abyss  
Crashing higher and becoming intense, the waves rock her from side to side.  
The ice cold water rises up,  
And falls, leaving her tingling and burning  
Like fire and ice against her legs  
Before the tide slowly glides back into the sea  
This is MS, and this is me.

##### Nina Workshop 2 Poem

###### Electric

A shiver that seems unending,  
It crawls and creeps across the skin.  
Like the bass at a concert when it rattles through the floor and up into the feet.  
Electricity sparks nerves into life, a reminder it's still there.  
I feel everything and nothing at all.

### Nina Workshop 3 Poem

Her mask glitters gold in the sunshine,  
She wears it all of the time.  
But not always the same one.  
She tips her mask to acknowledge  
Its presence, but does not remove it.  
Her mask, whichever one she chooses, is her protector, her strength.  
Just like her shoes she has one for each occasion.  
Sometimes, just sometimes, the mask slips.  
But that's okay too.

### Nina Workshop 4 Poem

I hold her in my arms telling her not to worry.  
We will be there soon.  
The train station is bustling with people  
A boat has just berthed at platform nine.  
I hold on to her tight as the crowds of people push past - "Haven't you heard of social distancing?!"  
I scream. My grip loosens on her.  
My face mask begins to melt as the sun beats through the glass panels.  
BOOM.  
She's gone.  
Running confused and scared into the crowds I look on helplessly as she swerves from the hustle.  
Bereft. Face mask fully melted, I drift back to home.  
There.  
She waits for me. A miracle A nightmare turned good.  
Who said cats weren't loyal?!

## Philippa's poems

### Philippa Workshop 1 Poem

#### A Plate In The Washing Machine.

It's not where one would usually find a plate  
It was a shock – unexpected  
Knocking around in the washing machine  
The wrong machine – how did that happen?  
Scooped up by accident with the bedclothes  
Battered bruised – looking old now and used.

A pretty little side plate, fine china – Granny's side  
Little scrolls around the edges  
Little chips now too.

It's a miracle it didn't break  
It must have come quite close  
I can relate  
To the plate  
Still useful but not to be given to guests  
Who wants cake from a chipped old plate?

It's ruined the whole set now!

## Philippa Workshop 2 Poem

### Out With It Then!

My body won't let my tongue be free  
It's twisted in knots behind enamel guards  
Poking a way out to be heard  
Making up words by dicing and splicing  
Like when it "steezes"  
And I'm jolted.  
Midflow.  
Discom .....em.....no it's gone!

My mouth feels stuffed full with letters  
Such as you might find on an old-fashioned typewriter  
All the little arms desperate to win the race to the paper  
Jammed and crammed together – so tightly none can move  
Tipitty tap, pittery splat, writing crap Kerching!  
I've said it now.

Conversation is exhausting .....

Part of me is dealing with two squibbling toddlers  
Brian and Thomas – usually so in tune  
While a I'm also fending off a third child  
Freaya who is clingy and needy  
Whining in my 'hear'  
Clutching at my 'loot '  
Why can't I just have a simple 'chalk' for once?

Attention! Attention!!! Yes – bloody remembers that word!

Like a sleep deprived parent I cave  
I lose my thread  
    And the needle  
        And the thumble thingy.

### Philippa Workshop 3 Poem

Such a lovely time!

I wear my role as party guest  
I put it on as I put on my dress  
Over my head.  
I steel myself – warm, friendly smile  
I've got lots of make up on so I wait for the first,  
"But you're looking so well!"  
*Yup, £70 worth of Touche Eclat will do that!*  
*If I wash my face right now you'd call an ambulance.*  
But I'm too polite to say that  
I say, "Thank you"

I am pigeon-holed - most kindly done –  
With the elderly – seated in the chair near the fire  
Assisted – waited on – fussed over lovingly  
Everyone takes turns at keeping me company  
I'm always polite – I smile  
I am brought a plate from the buffet  
"A little bit of everything?" *questioning head tilt*  
I'm too polite to leave anything on my plate  
So often I eat food I do not like but  
I say, "Thank you"

In my head The Grandma turns into the Toddler!  
I WANT to roam the room  
I WANT to help with the dishes  
Gossip in the kitchen and pour my own wine  
I DO NOT want to leave early – before I get tired!!  
Foot stamp – pout!!!  
"I'll fetch the car to the door"  
Have you got your bag? Stick? Scarf?  
Politely I say, "Thank you"  
And, "Goodnight"

Philippa Workshop 4 Poem

Dream

I'm running now on a grassy path  
Through knee high bracken  
By the side of a burn  
Criss crossing it – jumping from rock to stone  
Sure footed as a goat.

I dream the remembered feeling of invincibility  
The joyful energy of the little girl I once was  
Pedalling my bike furiously  
Jumping off it before I've even stopped  
Running up the garden path to the house....

And then I wake.

Wistfully, tantalisingly the brief spell of my dream lingers.

Until the heart crushing truth floods back  
Catching in my throat  
Only truly whole in my dreams now  
Cruel but wonderful

## Tilly's poems

### Tilly Workshop 1 Poem

#### This Pebble

You hand me a pebble  
Set it in my hand wordlessly  
Fold my fingers round it  
Like a fond auntie giving me a sweetie  
Or a fiver

I hate you and your pebble  
Don't want it  
Can't give it back  
If I dropped it on the carpet of your immaculately hoovered home  
You'd notice

So I sit and stare  
Unclench my fist  
Unfurl my fingers  
Consider this pebble  
Wonder how it's supposed to fit  
How I'm supposed to fit in  
a basketful of pebbles,  
a truck load of chuckies  
an avalanche of boulders  
make sense  
speak a language I can hear

a single, solitary pebble  
smooth, soft almost  
cool at first,  
now warm, sweaty  
heavy in my palm  
isn't going to cut it

I'm filled with a sudden longing  
To touch it with my tongue  
taste the sharp salt-tang  
Of its sea-home  
To stand ankle deep in salt-water  
Toes sinking into sand as the waves suck me under

## Tilly Workshop 2 Poem

Left-side weakness in a left-handed woman with multiple sclerosis: A case study

I don't tell my neurologist

    I am not your subject

    My life is not your case to study

I dutifully present my symptoms, in carefully curated sound-bites

Digestible by medical professional and family-member alike

Trim off the excess heartbreak of losing my ability to

    write shopping lists

    sign my own name

    draw doodles

    sketch faces

    knit ugly christmas jumpers

    spend just one day without pain

The physio is hopeful I'll walk again

I am appropriately upbeat about my chances

Leave out mentioning the aching void left by

    Schiehallion

    Bennachie

    Balmedie beach

    Lochnagar

    Arthur's seat

Stolen from my landscape,

filled instead with wheelchairs,

walking frames

two-minute daily standing practice

### Tilly Workshop 3 Poem

Weak tired  
Lockdown mired  
Count the cost  
Left-hand lost  
Paints, pens  
All dried-out  
Heart, tears  
All cried-out  
(Paints dried-out  
I'm all cried-out)  
Neighbours caring  
Me despairing  
Nothing doing  
Just angry stewing  
No more knitting  
Just Vacant sitting

100 days  
100 days  
Right hand works  
Right hand plays  
Makes a mark  
Has a lark  
Draws a face  
A cat, a hand  
Beavers, bears,  
Dragons, hares  
Hurdler, sprinter  
Owls, fish  
Old photographs  
Elephant, flowers  
Cubes, cones  
Spheres, domes  
A fox, a mouse  
Newts, bees  
My best pal's dog  
Fanciful fish  
A pig, a goose  
A mallard duck  
Magpie, snails

Post on instagram  
I've got it back  
Like a gift  
A sudden shift  
(I can draw again)

## Tilly Workshop 4 Poem

In a dream

In Vienna

no St. Petersburg

He looked like James Mason

I took his hand and led him through the streets

War torn

Bombed out skyline

My knees scabby

My shorts worn and dusty

Blue serge

(My favourite pair)

Right pocket: superball - black, penknife - girl guide standard issue, big hankie

Left pocket: pack of cards, pack of chuddle, string, conker, sixpence, thrupence, a single penny

(deerskin money bag)

His suit a thick black tweed

Its damp smell lingers and mingles with a coppery tang

The blood pooled in the hand he held to his crisp white shirt

I found him shelter

Afraid he'd die

I went in search of food

A stolen biscuit

From the (biscuit) tin in our larder

Yesterday's sandwich

Hidden in the secret place in my bookcase

Between its ornate top and the first shelf

## Ellen's poems

### Ellen Workshop 1 Poem

#### Hoops

I don't understand you I never will.

My very own Olympic Hoops  
Yes just for you MS  
I devote these interchangeable circles  
I try to keep you at an arms length  
Although I feel you, I see you.  
You are so very sneaky.  
Ove night you can grow,  
If I'm lucky you may shrink  
Just in a blink.  
Without warning you can put a bleak cloak around me  
And I know you wont leave.  
You will stay a while.

Yes you, cognition hoop, so very grey  
A monster lifting its webbed feet,  
Through my mind of sludge  
Turning my thoughts to dust  
You, I resent, more than all the other hoops  
I cannot have a stick to aid  
The slowness that comes on through the day  
You are the biggest thief,  
The one I cannot explain,  
You sent my aspirations rushing down a drain  
You smother my love and turn it grey.

## Ellen Workshop 2 Poem

This is me  
I am not you  
I stand in my shoes  
be it wobbly  
be it stubborn  
I am free  
I am not chained by my disease  
be off with your drudge  
I can decide, not you  
They offer me poison  
It may dampen the devil  
but it does not discriminate  
and treat me in parts  
I am fond of my liver  
I think it's fond of me  
I'll treat it with kindness  
I'm careful with the gym these days  
Hey, another loss with this disease  
So why is it OK for you to say,  
I'm only interested in your disease  
Well, I'm interested in me  
all the parts of me from my webbed toes  
to my tender head  
I will decide how I will nurture me  
I am not you  
I am not a statistic  
I am a partner a mother a lover  
I am passionate about this world  
I love the beauty of the world  
I see it through my eyes  
not the glazed drugged eyes  
ones that I get prescribed  
I am whole  
Please see me this way.

Ellen Workshop 3 Poem 1

Rude Man

Please don't stare  
I am not your property  
Im like you  
I belong to know body

I might be in a chair, but how very dare'  
I rise!!  
I can walk! take a look,  
Integrate me with your eyes'  
You will not find out  
What is my curse ?  
It is not for you to know.  
I do not wish to share  
I'd like to say " piss off"  
And you'd think, how does she dare.

## Ellen Workshop 3 Poem 2

Ostrich

Dear Ostrich

It does not help me to pretend that all is well  
Help you it may, shield you from the pain  
That I seem to be not me

Look closer, I am me

See through your pain to see mine  
It is a lonely place when the ones who say they love, refuse to see your pain

I am not my illness, but it's part of me  
I am not the person down the road with MS  
I am not the neighbour's nephew  
We share the shared diagnosis  
We are each unique  
As are you

Hear me, hear me, hear me

Do not change the subject when I tell you I may drown.  
In sorrow, in loss, in pain and lonlieness  
By denying my illness you deny me  
Accept and set yourself free.

It is not about you

It really is about me  
Set me free

Ellen Workshop 4 Poem

Disappointment

A distant memory  
a feeling of lightness  
Weights lifted  
Such brightness  
a vivid blue sky  
Am I flying?  
Faces looking skywards.....  
quizzical  
I felt this too

Running bouncing leaping  
Faster and faster  
Higher and higher  
The tallness of green trees  
swaying  
There was no fear of falling  
No vertigo from height  
Just confusion  
How could this be?  
I looked down  
it was me  
Running  
on and on  
Bright white trainers  
the shiniest coiled springs inserted  
The faces will never catch me  
I will stay here  
Here I am free  
And light

A cloud came over  
Heavy and Grey  
Confusion.....  
I stumbled out of bed.

## Saskia's poems

### Saskia Workshop 1 Poem

Her life was as perfect as a rosebud  
Ready to blossom and reveal her intricate layers  
Surely, in time, she became colourful and bold  
And her life was magical.  
Gradually her petals began to age and she knew change was coming  
But she did not expect it to change as quickly  
And so painfully.  
Everything she knew her life to be was changing.  
As the first petal floated to the ground, a part of her was lost too.  
But she was still the amazing, magical bloom as she started as.  
As each petal dropped and the rose changed  
So did she.  
She could see her life changing before her,  
Tearing away possibilities and replacing them with challenges  
Unlike any she had anticipated.  
But she is strong and while her rose will wilt over time  
She is determined to maintain her magic.

## Saskia Workshop 2 Poem

### My Pain Not Yours

It's not like a headache or a sprain, tension or cramp  
It's the constant feeling of lightning bolts rushing through my veins  
It renders my arms and legs almost worthless

Nothing helps  
No massage nor acupuncture procure relief  
Instead I ingest chemicals to control it  
But still it controls me

I may look or appear 'normal' to you  
But to be unable to take the weight of my newborn granddaughter in my arms  
For long is heart breaking

You sympathise and you compare your backache  
Or your sore shoulder to my pain  
I scream at you inside my head

But it is perception and who am I to belittle you experience  
I watch as you lift and cradle my granddaughter  
I don't cry  
I don't complain  
I sit and feel the extra pain within my heart  
And I know  
It is my pain, not yours  
But mine is the cruellest of all

## Saskia Workshop 3 Poem

### I Say Nothing

She's 80 and spritely  
She's 80 and quick minded

She looks at me and sighs impatiently  
"You must know where you are going by now" she says.  
I don't. I need help with navigating these days, as she knows.  
I say nothing.

"What's taking you so long?" sounding irritated.  
I can't do things as fast as I used to, as she knows.  
So I say nothing.

"Are you stupid?" she asks  
I want to cry now because I'm not  
But to others I may seem to be.  
I say nothing.

She's my Mum and she's 80  
I know she loves me unconditionally  
So I say nothing.

## Saskia Workshop 4 Poem

### Dreams

The walk is enchanting  
Sun glows through the branches of the trees  
Fluorescent greens flutter above me  
Squirrels run across the leafy ground  
Warmth envelops me

As I walk  
I come across a choice  
Do I go right or left  
Along this journey of mine

I am tempted left....

I am cold  
There are no colours  
Only shades of grey  
My legs are weak  
I am tired  
But I can't go back

I wake....

My journey through this life  
Has taken a direction I do not care for  
I must look for my inner strength  
I will look for colours  
For the sound of birdsong  
For the furry tails of squirrels  
To be enveloped with love

This my journey now  
And I will walk through it  
I will achieve my own dreams

## Saskia Supplementary Poem 1

### Did I Boil The Kettle?

It's Monday today.  
It's probably not but hey who cares.  
It's a new day which of course starts with a pot of tea.  
I fill the kettle.  
What now? Not sure.  
Maybe I should wash the few bits in the sink.  
All done. Did I boil the kettle?  
It feels hot but I will boil it again.  
While I am waiting I will clean the hob.  
It doesn't need much cleaning as I do it most days -  
After washing the few bits in the sink.  
It's nice and shiny now. Hang on,  
Did I boil the kettle?  
It feels hot but I will boil it again.  
I rinse the teapot and add the tea.  
I am getting there now. I think.  
Did I boil the kettle? I'm sure I did but I will boil it again.  
I need milk. The fridge is behind me.  
I gaze inside the fridge wondering why I have opened it.  
I guess I need to prepare lunch and dinner for today.  
I need to check my meal planner on the computer for that.  
It's not far, in fact it is on my desk next to the fridge.  
As the screen opens I spot I have 3 emails.  
I note on my daily planner to read the electric meter.  
Planner says today is actually Wednesday –  
Today I am scheduled to do the washing.  
As I turn back to the kitchen counter, I spot the teapot.  
You can't miss it, its bright yellow. Now did I boil the kettle?  
I must have but I will boil it again.

Saskia Supplementary Poem 2

Untitled

Layers of sapphire, turquoise, teal, aqua  
To crystal clear, owned her vision  
Her love of the ocean was intrinsic

She inhaled deeply  
Feeling the tension in her damaged body  
Become absorbed by each flurry of salty breeze.

The ocean possessed powers that could  
Embrace, heal, destruct, create change  
She looked on with respect

Her tears tumbled down  
Adding a tiny part of herself  
To the expanse in front of her  
She asked the Ocean, why?

With each sound of gentle rush of Ocean  
Reminders invaded her mind that  
Life like the Ocean could not be controlled  
Life too demanded acceptance of change

As she waited for the next gentle rush of warm Ocean  
Wash over her damaged, unsteady feet  
She was grateful for the magical feeling of sand between her toes  
She thanked the Ocean for the reminder to live

## Claudia's poems

### Claudia Workshop 1 Poem

#### Little Prick

you ask me what MS is like.  
well to be honest Its  
like a bramble thorn in the garden strangling and infringing on every thing and everyone  
It wraps around your legs dragging on you  
ripping and tearing.  
You want to move forward but frustrating it trips you  
You drag up the roots pleased to have it only  
for it to resurface in a new arrangement.  
It's relentless in its advance  
It encircles and stumbles  
it, is unsettling and familiar  
you want to say it's ok  
but it invades and smothers  
all that's normal and steady  
thriving in derelict wind blown wasteland  
like some sad western  
and yet it produces warm and comforting BlackBerry crumble  
go and figure out the irony.

## Claudia Workshop 2 Poem

### My Legs

encased in my head the feelings rise from the deep  
black exploding firework colours  
emanating from cringing frustration

my brain is firing orders to the seargent major who barks instuctions to deaf recruits  
trapped by bad wiring

my legs are a massive dissappointment  
it is profoundly sad  
my mind races ahead soaring on warm thermal currents  
quietly gliding above the patchwork squares

I am dragged back with violence to earth  
struggling with the energy sapping heaviness

I'm scared of my legs  
fighting a memorable battle to stop me slipping  
into the quicksand I clear my head and

breathe.

## Claudia Workshop 3 Poem

### The invisible

I'm the invisible person  
I sit here in my chair  
on a different eye line to others

confined in wheels  
dependent on others good will  
I turn to talk and am facing the opposite way

left outside, foxed by mountainous steps  
I face a mindfield of clothes and dummies

my race track around confectionery and body wash  
bored

all well meaning and earnest  
I am a question mark  
people don't know how to answer

so I disarm with a smile and openness  
honesty and lack of embarrassment  
I have a reason for being here

#### Claudia Workshop 4 Poem 1

soaring towering heights  
are my dreams  
not ones confined to my nights  
but ones that speak of hopes and  
desires  
that speak of yearnings of  
a life past and apprehension for a  
future unknown

I dream of possibilities that flow with  
light that roll relentlessly in and  
out as predictable as breathe

dreams keep me hopeful they are not obscure  
with hidden meanings  
they live with me colouring my life constantly  
bright shimmering flashes that light the way

#### Claudia Workshop 4 Poem 2

my dream does not make sense which  
annoys me  
I have spent the whole day believing it was  
real  
I don't want a world of fantasy  
of white feathers and rainbow endings  
I want to live in reality  
but maybe I do crave the dreams  
when I slept the sleep of a younger girl  
where life was less complicated  
when I didn't wake staring onto the midnight sky  
trying to find my way back to the  
land of feathers and rainbow endings

### Claudia Supplementary Poem 1

I can't tell you why

I can't tell you why I fell  
In my mind I perfected the perfect pirouette  
I turned beautifully on one side  
The other side did not follow  
I can't tell you why I fall

### Claudia Supplementary Poem 2

Autocorrect

I love autocorrect  
it throws out words that surprise and amuse  
words that offer a new image  
one I haven't thought of  
one that offers a new direction  
I meant wheels not squirrels

## Memphis's poems

### Memphis Workshop 1 Poem

#### Banana skin

The Banana skin of MS made me feel like my life was slip sliding away, give up walking, toil with talking, retire from work and feel like you shirk, from freedom to captivity in on step, try to keep positive you can't lose your pep.

Frustration abound well that's how I feel, I think in my own mind. I am keeping it real. MS my captor an ever present in life, if a cure could be found it would ease this strife, slipping and sliding in my daily routine the banana skin of MS is dangerous even when not seen.

An icon of danger the innocent stranger in its own way, a double-edged sword that is innocent yet deadly as time goes by, keeps me focused on surviving, we all have to try, some days I feel lucky to be alive, others it's a struggle just to survive.

## Memphis Workshop 2 Poem

### Leg Tremors

Is this really happening to me,  
Control although easy to imagine has become impossible to me,  
As the lightness or loss of weight sensation, an out of body experience transcends my  
imagination.

I detest that feeling of loss of control, although strangely the rhythmical discourse that my  
legs are experiencing does make me smile?  
Waves lapping onto a sandy beach,  
Sheets blowing in the Autumn wind, creating a rhythm to write music to.

A cascade of energy from my waste to my toes, that somehow overtakes me and leaves me  
in its wake,  
A comfortable feeling, even enjoyable to a fashion,  
Which feels like it isn't really happening to me.

Pain does not enter nor leave my body,  
but is there transfixed in the back of my mind almost as an afterthought,  
can this really be happening to me.

## Memphis Workshop 3 Poem

### Perceptions of me

What do you see when you look at me, some will say you, others you've never changed, are they telling me what I want to hear? Being nice or being honest, a mixture of both?

I feel a bit different, others can see, a shell of the person I used to be, My bodies the same but things have changed many not visual or even that bad, but I do miss the things that I always had.

You think I'm the same and things haven't changed, but deep inside I occasionally look for someone to blame.

Peoples perceptions mean the world to me, but when you look at me tell me what do you see?

## Memphis Workshop 4 Poem

Dreams can come true

Is ambition a dream

do your wants and needs have an arrival or expiry date?

Where am I going and where have I been, recalling memories of things that I have seen

there was a time when all of that was a dream

when and how did it happen? Was the plan achieved?

Can I, will I, did I, are all questions that I've asked

in a dream to take me to the future and deliver me from the past

Dreaming of retiring early, of being financially secure

dreams from my youth that were innocent and pure.

An aspirational dream, that was well on it's way, until that fateful day

I was diagnosed with MS what more can you say, but life for me is not over

I have plenty things still to do and wish you health, wealth and happiness in everything that your dreams bring to you.

## Alex's poems

### Alex Workshop 1 Poem

#### The Window:

I stare out, the street framed by elegant dimensions.

Familiar

Unchanging

Dull

I am bored of being by myself, the monotony of being inside

Endless.

I could go outside

It is technically possible

But thinking back to when I last tried it,

The difficulty, the fall, the embarrassment.

It is easier to stay here, to look out and observe

The old familiar life, stuck behind the glass.

Preserved in memory.

## Alex Workshop 2 Poem

### Machine

Old machinery whirring  
The guarantee expired or lost.  
Cogs stick and rub, movements jerk and stop.  
Toes curl into tight balls unable to separate.  
The engine coughs and splutters.  
Limbs dead weight, blood collects in stagnant pools. Sensations lost.

## Alex Workshop 3 Poem

### The List

Filling up the page,  
Preparing your approach,  
Tactics  
Tactics

Get through the initial small talk,  
The pleasantries.  
Hit them with the questions that matter.

Too soon you're waiting at the bus stop,  
Watching as it comes round the corner.  
You stare out the window,  
Listless  
Deflated

The door did not unlock  
Nothing was found.

## Alex Workshop 4 Poem

### Journeys

My eyes flit between the different displays  
Up and down the lists,  
Understanding the names but then instantly forgetting their significance.

Waiting for realisation to blossom and pop.  
Nothing comes.

I must have taken a decision at some point  
But that memory is lost.  
I stare out at the passing landscape, unsure of what I'm seeing.

The journey carries on  
Hanging by a thread,  
Twisting and turning in the breeze.

## **Eleanor's poems**

### Eleanor Workshop 1 Poem

#### More than listening to music

Listening to the music is much more than that  
Loud and soft, beautiful and ugly,  
A mysterious and difficult thing.  
Sitting in the dark I am lost.  
With the players, with the audience but alone and immersed in the music.  
Distanced from the others  
Confused and trapped by what I don't understand.

## Eleanor Workshop 2 Poem

When I can't walk as far as I did before

When I can't walk as far  
or as well as I did before,  
it feels like dusk  
when the light is failing  
and the colours have gone.  
It appears silently. Unstoppable.  
I crave a place to rest,  
to recover,  
But I can't stop the change.  
I have to remind myself  
to appreciate what it is about to go

## Eleanor Workshop 3 Poem

### How Strange

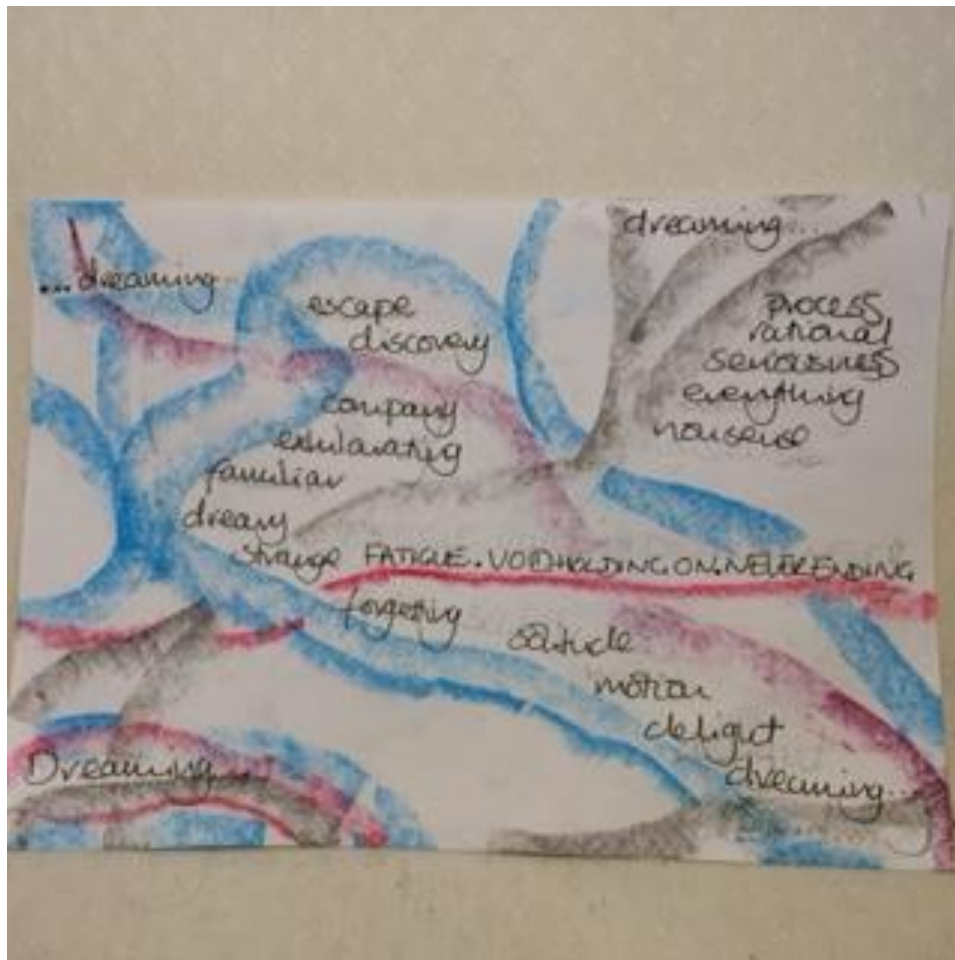
It's probably just mild MS, he said.  
Friendly, smooth and smiling.

Months later, in the underground room,  
where two others were having eye tests  
He sat opposite me and said  
It was definitely MS.  
The other patients heard.  
The line of medical students  
behind him heard.  
Through the open door,  
The people in the corridor waiting room heard.

How strange, I thought,  
that something so human was not.

Eleanor Workshop 4 Poem

[Eleanor created a visual poem and sent the following image of it.]



## Appendix K – Georgi Two Study Poems

ERA URE

I

y pto , *n.*

**Pronunciation:** /' ɪ ptə /

**1. Pathology.** A (bodily or mental) phenomenon, circumstance, or change of condition arising from and accompanying a disease or affection, and constituting an indication or evidence of it; a characteristic sign of a particular disease. *E p.*, in modern use, a subjective indication, perceptible to the patient, as opposed to an objective one or sign ( *sign n.* 9c).

**2. a. gen.** A phenomenon or circumstance accompanying a condition, process, feeling, etc., and serving as evidence of it (orig. and properly of something evil); a sign or indication of something.

**b.** With negative expressed or implied: A slight, or the least, sign of something; a trace, vestige.

**'y pto** *v. rare*<sup>-1</sup> (*transitive*) to indicate a by a y pto ; *looly*, to ybolize.

[I wrote this poem in an attempt to create a sense of cognitive fog in the reader by removing the letter 'm' and 's' throughout the dictionary definition of the word 'symptom'.]

(struggles to find words)

I will forget the questions and

I will ramble and

nah, it's gone again

I am so sorry

it will come back

I may forget words on occasion

I'll stop and

then I'll go

no, it's gone

my bandwidth is just flat out

MS brain going off on a trail

it's who I am

[I made this poem from remarks I made during study interviews and workshops relating to my own MS cognitive fatigue.]