

ME and its Discontents:
Life Stories and Photo Elicited Diaries of
A Severe Chronic Illness

(ME) Myalgic Encephalomyelitis

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In Fulfillment of the Requirements for the Degree of
Doctor of Philosophy

June 2016

Abstract

Myalgic Encephalomyelitis (ME) remains a controversial disease, shrouded in medical and social uncertainty. This thesis examines connections between language, space and representations of becoming diagnosed and living with the often severe effects of this chronic illness. Dominant medical and political institutions, often successful in funding, hold the power to drive the medical debates surrounding aetiology and treatment. As these institutions govern and wrangle over the ‘making’ of a definable truth, people are living with the ‘reality’ of illness. In order to address the issues of living with this chronic illness, this thesis examines 9 life stories and 8 subsequent Photo-Elicited Diaries of 2 males and 7 females diagnosed with ME (also known as Chronic Fatigue Syndrome).

This thesis adopts a transdisciplinary approach and employs critical discourse and narrative analyses to both the bio-political and socio-cultural contexts. A kaleidoscopic view was applied to examine the discursive, material and relational aspects of living with a particular chronic illness. This method identified issues of ‘doing’ illness whilst ‘being’ chronically ill. Taking such an approach exposed the power relations, social practices and subjective experiences of becoming and mastering illness, often within the enclosed spaces of homes/hospitals and house/bedbound. The findings reflected on the severe effects as a causal agent for displacing personal and social truths, for continually plugging in and out of social worlds and the conditions of possibilities for resisting and surviving chronic illness. By combining narrative and visual accounts the rich complexities of living with a severe chronic illness could be better explored.

This study advocates the benefits of combining spoken and visual experiences of illness for future studies and has the potential to impact approaches employed within the therapeutic setting. As the house/bedbound tend to remain the missing voices within medical and social research, this study joins an urgent call for research to focus not merely on disability issues, but impairments and the associated effects - relapsing, recovering and surviving chronic illness.

Key words: *ME, CFS, chronic illness, severe, impairments, narrative, photo-elicited-diaries, language, space, representation, discursive, material, relational*

Declaration

I certify that the work submitted herewith is my own and that I have duly acknowledged any quotation from the published or unpublished work of other persons.

Signature of Candidate:.....

Date Submitted:.....

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Abbreviations

AfME Action for ME
AIDS Acquired Immune Deficiency Syndrome
ATA Advanced Textual Analysis
AYME Association of Young People with ME
BACME British Association for Chronic Fatigue Syndrome/ME
BoC Birth of the Clinic
BRAME Blue Ribbon for the Awareness of ME
BNIM Biographic Narrative Interpretative Method
BwO Body without Organs
CBT Cognitive Behaviour Therapy
CDA Critical Discourse Analysis
CDC Centre for Disease Control
CEBV Chronic Epstein Barr Virus
CF Chronic Fatigue
CFS Chronic Fatigue Syndrome
CFIDS Chronic Fatigue Immune Dysfunction Syndrome
CHROME Case History Research on Myalgic Encephalomyelitis
CNR Centre for Narrative Research
CT Cognitive Therapy
DD Disability Definitions
DoH Department of Health
ECHO Enteric Cytopathic Human Orphan Virus
GET Gradual Exercise Therapy
GP General Practitioner
HIV Human Immunodeficiency Virus
ICC International Consensus Criteria
ICD International Classification of Diseases
IPA Interpretive Phenomenological Analysis
ME Myalgic Encephalomyelitis
MUI Medically Unexplained Illnesses
MUS Medically Unexplained Symptoms
NA Narrative Analysis
NHS National Health Service
NICE National Institute for Health and Care Excellence
NMEC National ME Centre
NOG Northern Officer Group
OT Occupational Therapy
PACE Pacing, graded Activity and Cognitive behaviour therapy: a randomised Evaluation
PVFS Post-Viral Fatigue Syndrome
PCP Primary Care Plus
PCT Primary Care Trust
PED Photo Elicited Diary
PT Physical Therapy
SEID Systemic Exertion Intolerance Disease
TB Tuberculosis
UEL University of East London
UPIAS Union of the Physically Impaired Against Segregation
WHO World Health Organisation

Acknowledgements

So many have made my PhD journey possible; none more so than the participants who agreed to share their stories and photo-diaries. I am grateful to have met you all. To Professor Leslie Findley who encouraged and supported the project I extend my sincerest gratitude. My journey was supported in so many ways, from Professor Corinne Squire who gave invaluable help and fondly tried to protect me from the physical rigours of writing a PhD. To Dr Mark Davis who was enthusiastic and helpful in the early stages. From my Director of Studies Professor Maria Tamboukou's insightful philosophy seminars and her encouragement to find my author's voice was immeasurable. I am also indebted to my supervisors; to Dr Darren Ellis for his ever-friendly, practical advice and Dr Angie Voela for a place to form my early ideas and be bold. To those who supported me practically and emotionally through the process of writing, Danni Almond, Dr Angela Gosling, Helen Starr, Dr Helen Taylor, Maria Williams et al. and to Dr Mary Lodato to 'own' my disability, Rose Gallagher and Geraldine Webb care. To friendships formed within the CNR and Medical Sociology conferences.

My love and appreciation to Andy my partner in life, who never fails to believe, inspire and care for *me*. Whilst having limited energy and remaining house/bedbound, my sons Darren and Harry have always understood and step children Lauren and Tom, all selflessly encouraged me to complete my project. To my mother Jean Castle for support in life and especially throughout my illness, I am honoured to be your daughter – your honest, fun-loving approach lives on through my words and actions.

DEDICATION

Finally, I dedicate my PhD to my father John Castle, who was kind of heart, a passionate political activist and a deep thoughtful thinker. As a stevedore at the Royal Albert Dock's where you loaded and unloaded cargo, I complete my PhD at the same spot and realise – places may change but spaces remain for us to continue our journeys in the circle of life...

Preface: Researcher's motivation

Since my early childhood and often during my adolescent years, I experienced numerous viral infections often treated via antibiotic medications. Whilst working in the US during the early 1980s, I became ill with a non-definable fever and swollen glands. I subsequently returned to the UK and over time experienced health issues, as with *Quinces* (bacterial infection of the throat), and a few years later *Glandular Fever* (viral infection of the lymph glands). By the late 1980s, I began to experience long term symptoms; severe painful visibly swollen veins/headaches, spending weeks/months in the dark. My lymph glands in my neck, underarms and upper thighs often felt bruised and ached constantly. Along with relentless weakness and sore muscles/bones, the slightest movement or touch became excruciating. I felt as though I was in a personal prison. My doctor was unable to help. I was sent to a 'specialist' who checked whether I was suffering from depression and confusingly proceeded to prescribe antibiotic medication. Within a short time, I became bedridden; my general practitioner (GP) was puzzled, frustrated, he sent a rheumatologist to my home who swiftly declared "you do not have rheumatism". However, in 1989, after completing a succession of tests and scans, a neurologist diagnosed Myalgic Encephalomyelitis (ME). During my hospitalisation I was shocked, not only by the severity of my symptoms, but that of others. I have since been hospitalised numerous times on neurological wards and witnessed many ME sufferers with very severe symptoms, unable to physically speak and owing to food intolerances, intravenously fed. Importantly, during and after my experiences in hospital, I became aware of the mismatch between these highly debilitating symptoms and that of the media which described the illness as '*yuppie flu*' and used derogatory terms such as *Malingers disease* which began a precedent for the illness being associated with tiredness and an '*all in the mind*' approach. This has continued to perpetuate social skepticism about the 'reality' of this illness which continues to cause frustration for those who care for and suffer with the effects of ME.

Specific to this project, whilst initiating and facilitating a mentoring group for disabled students at the UEL (2006), I became aware of how sharing stories relieved feelings of alienation and stigma and how those with severe illnesses were often unable to attend. My present project therefore takes the maxim 'the personal is political' (Hanisch 1969) as I join and bear witness to the everyday challenges of surviving what is deemed a 'contested' and can often be experienced as a 'severe' chronic illness.

Introduction

On the 25th November 2005 Sophia Mirza died from Myalgic Encephalomyelitis (ME) after battling severe symptoms for six years. When Sophia refused to go into an ME clinic, doctors and psychiatrists threatened a number of times to section her, finally carrying out their threat in July 2003. Her health subsequently deteriorated and she died at the age of 32. The private post mortem report recorded her death as acute renal failure owing to ME¹. What is startling about her story is not only the lack of awareness of how this illness can lead to fatality, but also the lack of control she was allowed to exercise over her illness, sadly her case is not unique². Suggestions have been made that a diagnosis or misdiagnosis, along with harmful symptom management and advice, has caused many to develop severe ME and become housebound and/or bedridden.³ At the time of completing this thesis, no positive interventions are available for the severely affected in the UK.

This thesis considers the issues raised by living with a ‘contested’ and often ‘severe’ chronic illness and builds on previous work within disability studies and medical social research into contested illnesses. The motivation for the research was the lack of medical, social, political and cultural understanding of what it means to experience severe ME. The data which informs this study was gathered via nine life stories and eight Photo-Elicited Diaries (PEDs) of people living with severe ME. This thesis will employ the term ME and will alter to reflect the preferences of different disciplines and individuals PVFS, CFS, ME/CFS and CFS/ME.

The first problem encountered when studying ME is the naming of the illness. Medical literature revealed a plethora of bio-medical and psychological studies producing various definitions and aetiologies. Initially, I made tentative steps into the quagmire of medical literature, naively expecting to find a clear point of origin to produce a ‘reality’ a ‘category’ to name the condition. I moved from positivist medical literature to interdisciplinary approaches, such as social psychology which often focused on the interface between patient and doctor on the journey to name and frame the illness. The

¹ <http://www.sophiaandme.org.uk>

² <http://www.meassociation.org.uk/wp-content/uploads/Web-seminar-28-interview-with-dr.-Speight.pdf> paediatrician Nigel Speight (2014) recorded that at least 30 children with ME symptoms have been forcibly removed from their family homes in the UK

³ <http://www.meassociation.org.uk/2015/12/its-time-for-doctors-to-apologise-to-their-me-patients-dr-charles-shepherd-in-the-daily-telegraph-7-december-2015/>

different approaches revealed numerous contentious and contradictory debates. Consequently, I narrowed my focus into outlining a medical context for the emergence of an illness termed ME.

Chapter one therefore offers an abridged yet comprehensive review of the major debates within the fields of medical and social health into the uncertainties associated with the emergence of chronic illness and the journey to the categorisation of this illness. I critically account for the tensions between medical reductive and social constructive approaches to the body and illness including those within medical sociology and disability studies. Literary works and feminists' own experiences of living with chronic illness are also considered. I conclude by considering the critical issues raised by discourses of uncertainty and the lack of literature and general understanding of severe symptoms of ME.

The primary research question is: How is a 'contested' and 'severe' illness constructed within rigid medical and social regimes? Followed by the subsequent emerging research questions: How do social practices and cultural discourses intersect with the process of *doing* and *being* ill? How is a contested chronic illness reconfigured by those affected with severe illness from childhood through to adulthood? How is it possible to illustrate the everyday experiences of surviving ME? What are the possible dilemmas, contradictions and conflicts that constitute a way to manage a life with chronic illness? These questions underpinned the broader question: What does it mean to experience a contested and often severe chronic illness?

A kaleidoscopic lens is employed in Chapter two to disentangle the power relations that underpin the productions of a diagnosis and to understand the material conditions of living with a severe chronic illness. Like a kaleidoscope, which can be turned different ways, the views reveal the connections between the productions of discourse and the patterns that emerge through the power relations and social practices, that constitute ways for 'doing' illness whilst 'being' ill. This trans-disciplinary approach adopts a particular reading of the epistemological relations between power and knowledge suggested by Michel Foucault (1926-1984) and the ontological connections between power and desire proposed by Gilles Deleuze (1925-1995) & Pierre-Felix Guattari (1930-1992). Mikhail Bakhtin's (1895-1975) literary works were then read in order to understand how it is possible to produce a self through narration. This process offers a means to examine how the act of discourse can function to marginalise the unhealthy

body. I then worked to expose particular social practices that constitute life and the subjective forces that are constantly at play in nature and narrative. This brings together arguments on the binary oppositional categories of what it means to be productive/operative, part/subject, self/identity, disabled/impaired. This chapter sets the theoretical groundwork to attend to and refine the research questions.

- What it means to have a ‘contested’ and often ‘severe’ chronic illness.
 - How does the process of gaining a ‘contested’ diagnosis affect the practices of doing ‘severe’ illness?
 - How do these practices intersect with the process of being ill? How may life experiences help us understand these issues?
 - How is it possible to give depth of meaning to the everyday experiences of surviving with ME?
 - What dilemmas, contradictions, conflicts and/or acts of resistance work to constitute surviving chronic illness?

Chapter three discusses the practice and procedural methods for collecting and organising the life stories and PEDs. A rationale for employing life story and the PEDs is offered, along with the benefits of critical discourse and narrative analyses. Ethical considerations are explained and a reflexive account discusses my position as researcher and a person living with the illness I am investigating.

Chapters four and five provide a reading of the life stories in relation to the themes of language and space. Chapter six examines the representation of a life with illness through photo-narrations. Chapters, seven through to ten each focus on an individual participant’s life story and PED. Interpretations were then based on themes that emerged which were significant to the participants, literature in the field and the theoretical framework.

The final chapter is an overall discussion of the seven data chapters, exploring the diversities and similarities within them. The conclusion considers the implications of the thesis, specifically the impairing consequences of living a life affected by severe ME, and joins a call for research to focus on this under represented group. In this way, the final chapter seeks to address the title of this thesis; ‘ME and its Discontents: Life Stories and Photo-Elicited Diaries of a Severe Chronic Illness’.

Chapter 1: Discoursing Chronic Illness: From ME to Severe Illness

“...People [...] are much freer than they feel, [...] people accept as truth, as evidence, some themes which have been built up at a certain moments during history, and this so-called evidence, can be criticized and destroyed”

(Foucault 1988:10)

1.1 Introduction

This chapter presents a cross disciplinary overview of medical and social research on chronic illness. For the purposes of this study, attention is given to the disease categorised as Myalgic Encephalomyelitis (ME) and its present counterpart term Chronic Fatigue Syndrome (CFS). Considerations are given to how the disease of ME emerged from bio-medical discourses around poliomyelitis and how the later term CFS was promoted by psychiatry, privileging the symptom of fatigue and making tenuous links to neurasthenia. The discursive problems and cultural dilemmas encountered by the emergence of a contested illness are introduced, by focusing on debates within bio-medicine and psychiatry, medical sociology, disability studies, narrative research, literature and feminist accounts of living with and researching ME and/or CFS.

A brief historical assessment critically accounts for the emergence of the layperson and the expert, as well as issues of care and control, contextualising the processes between society and health, patient and physician, self and society. Sociological medical researchers are concerned with how chronic illnesses are experienced and the potential for contested illnesses to disrupt normative patterns of seeking diagnosis and treatment, while recent narrative research has pointed to the issues of living with ME/CFS. Some of these works have addressed the issues of performing contested illness and its implications for fulfilling healthy or unhealthy identities. These binary distinctions are also of interest within disability studies, which focuses on the labelling of bodies as disabled/able and how to manage long term impairments. Meanwhile, feminist sociologists have examined the patterns between the discursive and material aspects of the illness, highlighting how it disrupts binary oppositions in a similar way to gender.

It is worth noting that literary and biographical works can offer insight into severe illness, which is lacking in other studies. Such works, as discussed later in this chapter, draw on the experience of being ill and demonstrate the need for critical inquiry into the subjective world of pain and illness. Social research has gone some way to explore the lived experiences of pain, but has paid limited attention to contested and long-term illness. However, some social geo-feminist researchers have combined research with their own experiences of living with ME/CFS to raise issues of contestation and suffering (Price and Shildrick 1998; Moss and Dyck 2000; 2003; Moss and Teghtsoonian 2008). Their approaches can be used as a springboard for further enquiry into an area that is currently grossly under-researched – namely that of severe illness. This chapter offers a broad and comprehensive review of medical and social research, political policy, literary works and social understanding of ME to highlight the lack of attention given to the severely and chronically ill, thereby framing the research questions for the study.

1.2 Chronic illness

The subjective processes of pain and sickness are experienced within shifting socio-historical and ideological contexts (Lupton 1994). The body is seen as a site that is continually inscribed upon. In the case of illness, symptoms are unraveled through a set of complicated characteristics, devised by discourse, constructed predominantly by ‘man’. The discursive root of the term ‘chronically ill’ is complex and ambiguous, laden with subjective meaning and the very nature of chronic illness is that it is rarely curable or preventable (Lubkin and Larsen 2006:6):

Chronic illness is the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability (Curtin and Lubkin 1995:6-7).

Chronic illnesses are, therefore, persistent and their effects often long lasting. Indeed, prior to the 19th Century, chronic and acute diseases were seen as life threatening. As the field of medicine expanded its disciplinary borders, illnesses mutated and evolved. Meanwhile, industrialisation and globalisation provided the social and environmental factors for the increase in chronic illnesses.

1.2.1 Chronic Illness: A particular socio-historical medical path

This section will explore the triadic tensions between medical, political and social power relations that seek to control and understand chronic illness. The discursive possibilities for the sick body are intimately linked to and constrained by the particular moment of social and cultural history in which the holders of expert knowledge, such as medical professionals, locate a truth of existence that enables a particular illness to be recognised and treated. The history of disease has been created via a nosological reference system, producing a hierarchy of nomenclatures, which has become the basis for naming all diseases. Therefore, it is important to examine how the contested chronic illness of ME emerged.

Chronic diseases such as tuberculosis and cholera have been documented since the 19th Century, being compartmentalised into a variety of so called ‘abnormalities’ to account for particular illness states. One of the challenges faced by the medical professionals was the difficulty of precise diagnosis and treatment. During the 18th Century tuberculosis (TB) was a sub-category of epidemic proportions, which left many survivors with long term chronic illness (Porter 1997). Some of the recorded symptoms are similar to those occurring with ME⁴.

The social experience of TB is only made visible by affluent writers of the 18th and 19th centuries, such as the Bronte sisters, Byron and Shelly, who wrote about this ‘romantic disease’ (Gotera, Dominguez and García-San Miguel. 2005). Tubercular fever, which predominantly affected the chest, was used by writers as a metaphor to serve their own interest in romanticism, establishing a particularly melodramatic view of TB. It is important to note that, as mortality rates climbed, middle class sufferers were able to receive private treatment, which included sanatoriums, rest therapies proclaiming the benefits of hot climates, spas and health resorts to escape the smog of industrialised towns.⁵ Conversely, for the poor, TB resulted in greater devastation, yet their voices remain absent from history. As the disease spread, care for the poor was implemented via disciplinary systems, which instilled work regimes as a far harsher approach to health therapy than the model of the sanatorium (Craddock 2000:173). It would seem that the inability to be productive led to many being blamed for absence from work, as

⁴ Symptoms consisted of ‘a persistent cough, difficulty in breathing and sweating, elevated pulse, loss of weight, pain in joints, followed by severe fatigue where it was often difficult to speak above a whisper’ (ref).

⁵ Please see *The White Death: A History of Tuberculosis* by Thomas Dormandy (2000).

if they had ‘unwittingly, caused their disease and [were] made to feel that they deserved it’ (Sontag 1991:58).

Arguably, industrial factories and labouring bodies *interfaced* with machinery, as the individual was an instrument required to play a receptive melody to satisfy growing capitalist needs. As Friedrich Engels (1820-1895) stated, the workforce prior to industrialisation were like ‘toiling machines’, while industrial changes caused them to become ‘machines pure and simple’ (Engels 1845:09 cited in Hunley 1991:16). As a result, there was limited time for labouring bodies to rest, as the development of the Protestant work ethic bound together social and moral obedience, normalising the worker through acts of piety, obedience and self-mastery (Weber [1958] 2003). The growth of capitalism encouraged satisfaction via hard toil, which was combined with religion to create a moral code that became ‘a sort of tyranny against nature and reason’ (Nietzsche [1886] 1997:57). In effect, the work ethic and the ‘devotion to labour’ remain characteristic of capitalistic culture (Weber [1958] 2003:78).

As the burden of labour increased, so did disease and chronic illness. In 1894, George Beard coined the term *Neurasthenia*, after his study of male patients in private health care tried to account for multiple symptoms associated with exhaustion. He suggested that so-called professionals in what he termed ‘the higher walks of business life’ were ‘deadly earnest in the race for place and power’ (Beard 1894:1293)⁶. Intriguingly, like TB, treatment for Neurasthenia was based on the rest cure – the ‘three gospels – rest, work and change of work’ (Beard 1894:1182). Again, like TB, by the time the condition was identified within the working classes in 1906, treatment shifted from rest to exercise (Wessely, Hotopf et al. 1998:112).

During this period, biomedical researchers and the government were working to regulate and safeguard subjects by using ‘quarantine’ for the ‘eradication’ of so-called social diseases⁷, with vaccinations becoming a protective civil and moral duty. The body was now managed via a matrix of regulative laws and policies, as inoculations and medications became a way of controlling the sick body. This national governance

⁶ Jean-Martin Charcot (1825-1893) (1889) also took a neurological focus on neurasthenia. However, Sigmund Freud’s (1856-1939) development into psychoanalytical approaches to unconscious sexual desires ([1909] 1962) were the motivation for him to suggest that neurasthenia was associated with sexual exhaustion as the effect of a disposition of the nervous system which in turn affects physical health and the ability to work. For the proponents of the time neurasthenia, for the female, was associated with being part of the weaker sex. For Freud, female neurasthenia had the propensity to come via the male which mixed neuroses causing hysteria in the female (Freud [1893] 2001:180-181).

⁷ The Vaccination Act 1853 was enforced in England. By 1871, monetary penalty could be issued to parents who refused the highly invasive smallpox vaccination. Anti-vaccinationism fought against the policing of the law and, in 1892, commissioners agreed that those detained in prisons were not to be deemed ‘criminals’ (Durbach 2000:45-63).

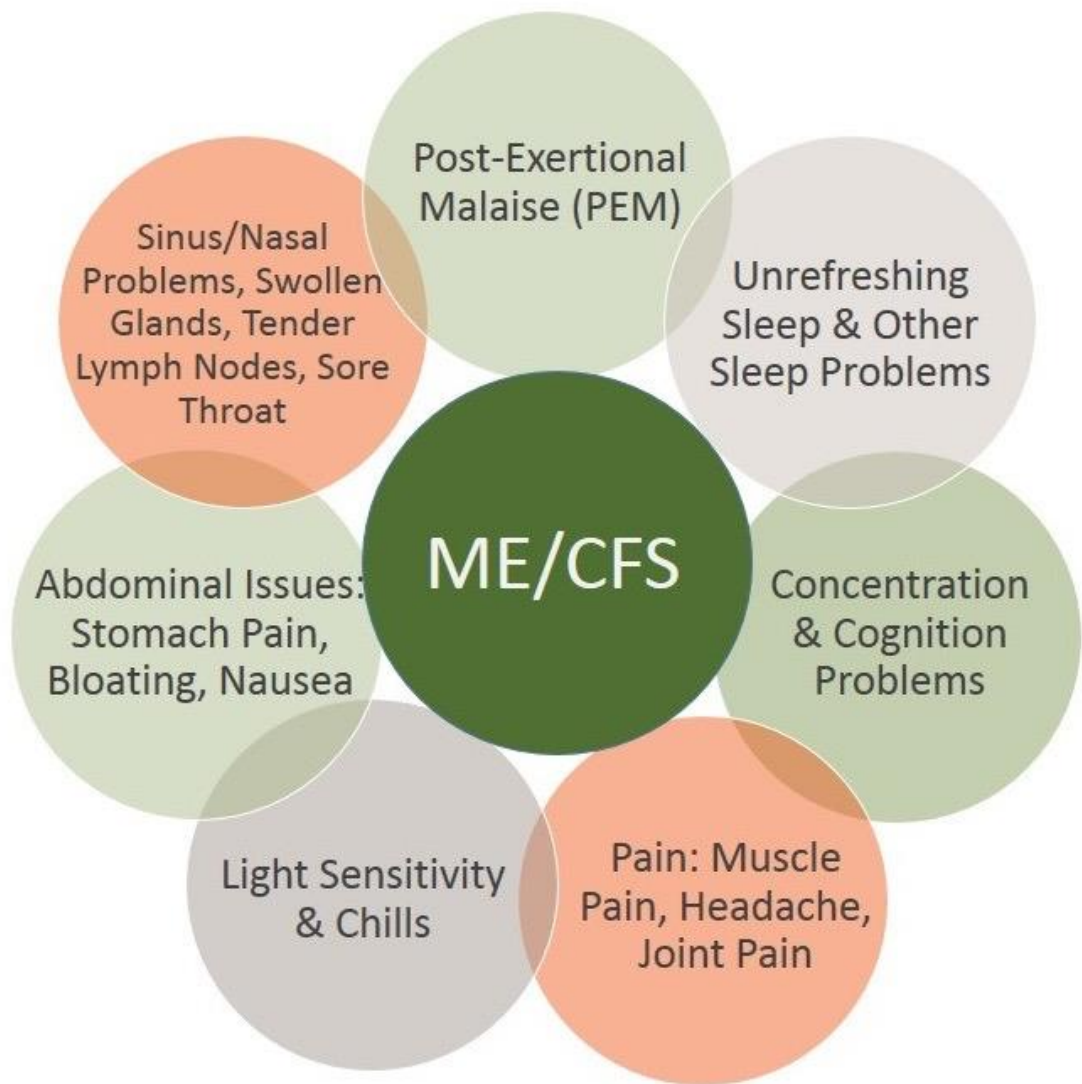
supported the strategies of control established by the World Health Organisation (WHO) (1948), which sought to promote health and eradicate disease worldwide. The WHO normalised preventative treatment of diseases, establishing the rights to research and treat populations, while the naming of diseases was given credence by the International Classification of Diseases (ICD). Although it has been stated that to ‘completely eradicate disease unintentionally contributes to the medicalization of society’ (Huber, Green et al. 2011), this strategy does go some way towards sustaining a functioning workforce. During the early 1900s, the *Poliomyelitis* pandemic outbreak (1910-55) led the newly formed WHO to implement their model of eradication (Isea, Bai Er et al. 2011). It has been argued that the resultant mandatory inoculations may have caused other viruses to mutate into emergent illnesses, such as ‘post-polio era’ type conditions like ME (Macintyre 1992; Colby 1996:21).

1.3 ME – Disease of a 1,000 names

This section traces the emergence of ME, arguing that it followed similar paths to the epidemic and pandemic diseases of influenza, TB and poliomyelitis.⁸ These conditions changed how illness was experienced and perceived, as chronic illnesses that were moderately or severely debilitating were not necessarily fatal, often leaving sufferers with life-long chronic conditions. An all-encompassing definition of chronic illness is difficult (Lubkin and Larsen 2006). A chronic illness such as Myalgic Encephalomyelitis (Leading Article 1956; Ramsey 1988), also described as Chronic Fatigue Syndrome (Holmes 1988), is variously defined as both a disease and/or a syndrome, with complex debilitating symptoms.

⁸ For a detailed and fuller account of ME and its associated nomenclatures, please see Appendix III

A diagram showing the main symptoms of ME/CFS (2016)



(Retrieved from Solve ME/CFS initiative, 2016)

1.3.1 Tracing the bio-medical category of ME

The categorisation of ME appeared in the 1950s as clinicians conducted research into the epidemic and endemic proportions of poliomyelitis in Western societies. As advancements were made in epidemiological studies, epidemic outbreaks were reported. In Los Angeles, US, an *atypical poliomyelitis* was associated with *neuromyasthenia* (Gilliam 1938). This had ‘non-paralytic’ symptoms of poliomyelitis and required a new classification, *abortive poliomyelitis* (Sigurdsson, Sigurjonsson et al. 1950; White and Burtch 1954). By 1951, Melvin Ramsey concluded that a particular epidemic of *non-paralytic poliomyelitis*, (1949), should be replaced with the term *myalgic encephalomyelitis*, as the symptoms were similar to poliomyelitis (Pellew and Miles 1955).

By 1955, there was a reported epidemic of ME in Cumberland, UK (Wallis 1955). In 1956, an article in the *Lancet* reported on a ‘new clinical entity’ called ‘*benign myalgic encephalomyelitis*’ (Sigurdsson and Gudmundsson 1956) – benign referring to unrecorded mortality rates – which appeared to cause serious disability. This new label combined the Latin terms *myalgic* for muscle pain, *encephalo* for brain, *mye* for spinal cord and *litis* for inflammation (Hyde 2006). The aetiology remained unidentified, but it differed from poliomyelitis due to severity and symptoms, with ME displaying damage to the nervous system and notable effects on the lymph glands (The *Lancet* 1956:789-790). Connections with worldwide epidemics were also made⁹. Between 1960 and 1970, a number of different UK outbreaks were reported. An epidemic including staff and patients at the Royal Free Hospital (1964-6), which exhibited symptoms of a contagious, viral and/or possibly neurotropic illness, was defined as ME. The hospital was highly involved with the treatment of polio and it was argued that this may have led to the development of a lesser strain of ME (Acheson 1954; McEvedy and Beard 1970; Hyde 2006:6). Although reports of outbreaks continued¹⁰ the condition was considered non-epidemiological, with aetiological links to an echovirus, one of a family of viruses affecting the gastrointestinal tract (ECHO 9) (Lyle 1959; Landsman and Bell 1962).

In 1969, WHO classified ME as a disorder of the central nervous system (WHO 2016), whereas McEvedy and Beard believed the epidemics were connected to mass hysteria

⁹ The *Akuryri Disease* also known as *Iceland Disease* in Sierra Leone 1957, Durban 1959 and Athens 1961 (Acheson, 1959; Ramsey et al, 1997).

¹⁰ For example, in London in 1972, at Great Ormond Street Hospital the pathogenesis of the disease continued to be aligned with epidemics.

and championed a new term, ‘myalgia nervosa’ (McEvedy and Beard 1970:11). Ramsey dismissed this ‘damning indictment’, saying their evidence made no account of the number of people still unable to work after six months, with some remaining disabled after three years (Hill et. al. 1959 cited in Ramsay 1988:38). During this period, Ivan Illich made connections between clinical and social iatrogenic conditions, arguing that treatments developed to eliminate diseases had in turn produced counter diseases, in what he described as the medicalisation of life (Illich [1976] 2002:39).

1.3.2 Tracing the bio-medical term CFS

In 1988, with growing interest into viral causes of illness, the US Centers for Disease Control and Prevention (CDC) looked for a new description for the condition. Believing that the ‘chronic Epstein-Barr virus syndrome’ was related to ‘chronic mononucleosis or chronic mononucleosis-like syndrome’, lead author Gary Holmes put his name to a list of criteria attached to the label *Chronic Fatigue Syndrome*, as guidelines for ‘evaluating patients who have chronic fatigue of undetermined cause’ (1988:387). However, as the illness was characterised by immunological and neurological abnormalities as well as fatigue, another term put forward in the US at that time was *Chronic Fatigue Immune Dysfunction Syndrome* (CFIDS) (Swartz 1988).

1.3.3 The psychological components of Chronic Fatigue

By the 1990s, the view that CFS could be linked to psychiatric and somatic symptoms was increasingly popular, with claims that it displayed a ‘striking resemblance’ to the 19th-century fatigue-based illness neurasthenia (Beard 1869; Beard 1894; Abbey and Garfinkel 1991:1638). Many within psychiatry began to lobby for a change of name from Myalgic Encephalomyelitis to Chronic Fatigue Syndrome (Wessely, Hotopf et al. 1998). Wessely, Hotopf and Sharpe’s study into *Chronic Fatigue and its Syndromes* took an epidemiological stance to define a socio-historical and neurological basis for dysautonomia – the effects of the autonomic nervous system – which linked past illnesses such as neurasthenia and hysteria to modern fatigue states (Wessely, Hotopf et al. 1998:96). This neurological approach meant that unexplained illnesses, such as ME, could be investigated via a more integrated approach, taking into consideration both the physical and psychological.

By 2001, articles in psychiatry proliferated, with a number of proponents discussing the issue title, ‘Does ME exist?’ focusing on the symptoms of chronic fatigue (The Lancet 2001). Although CFS originally emerged from studies into viral based infection, proponents ignored these links, often making the historical leap back to neurasthenia

(Abbey and Garfinkel 1991). Lian and Bondevik (2015) conducted a historical study comparing the periods 1860-1930 and 1970-2013. Examining literature associated with neurasthenia, encephalomyelitis and long term exhaustion, they revealed how medical opinions moved from somatic ailments, to individual accountability through a ‘self-inflicted psychiatric ailment’ (Lian and Bondevik 2015:920).

1.3.4 The complexities of labelling, defining and researching ME/CFS

At present, Carruthers et al. (2003), provide the main basis for the diagnosis of ME/CFS in the UK; a criteria led definition which promotes the organic and often epidemic nature of ME (Appendix 1). This replaces the definition put forth by Fukuda et al. (1994) which focused on chronic fatigue (CF) as the main component and included other illnesses associated with CF, such as neurasthenia, yet excluded ME (Fukuda, Straus et al. 1994:956). Previous definitions of the illness are seen by many as controversial. The ‘Oxford criteria’, outlined by Sharpe et al. (1991:118-121) as a guideline for research into Chronic Fatigue Syndrome, was predominantly developed by psychiatrists and psychologists, with few non-psychiatric specialists involved. Even though ME was associated with immune system disorders, no endocrinologist was present (Hyde 2006:15-16). In contrast, the 2003 Canadian criteria developed by Carruthers et al. excludes psychiatric disorders, suggesting that current diagnostic and research guidelines are at odds with those used in treatment programmes.

These inconsistencies are reflected by the WHO, which classifies CFS and ME as two distinct illnesses; ME is indexed as a neurological disorder, whereas CFS is cross referenced with a number of other illnesses with similar symptoms (WHO 2015). The lack of specificity has led to accusations that the recent term of CFS has become a ‘diagnostic dustbin’ (Spence 2005). The confusion continues, with the Institute of Medicine (IOM) in the US publishing a recent report entitled ‘What’s in a name?’, advocating a name change to *Systemic Exertion Intolerance Disease* (SEID) (Wright Clayton 2015).

Work within the biomedical fields of endocrinology, immunology and neurology continues to focus on immune systems and entreoviral factors as possible causations (Abbot 2002; Lombardi, Ruscetti et al. 2009). Meanwhile, psychiatry-based research concurs that there are predisposing psychological *and* physiological factors (Afari and Buchwald 2003). Some suggest that ME/CFS may be a variant of an autoimmune disease (Fluge, Risa et al. 2015), while the most recent medical information has caused

the governments of Canada, Australia, the US and the UK to recommend that people diagnosed with ME or CFS should not donate blood (Milton 2010; National Health Service (NHS) 2010). Presently, an exploratory study (in its second trial phase) has begun to identify the effectiveness of anti-lymphoma drug Rituximab to treat the illness as an immunological condition¹¹ (Fluge, Risa et al. 2015). However, many medical and patient groups¹² continue to stress the biological components of this illness.

These changing definitions are governed by the disciplines of those conducting research, the funding providers and the government. The debates circulate between, but not exclusively within, bio-medicine and psychology, as battles over physiological and/or psychological/psychiatric causes and/or effects persist. The contentions and inconsistencies impact diagnosis and treatment of the illness (Abbot 2002; Shepherd 2006:1182) and have implications for researchers and activist groups, who wrangle for funding and ownership.

The UK government estimates that CFS/ME affects up to 250,000 people (National Institute for Health and Care Excellence (NICE). 2007) with 25% severely affected – which makes studies that omit the severely affected less relevant. The UK government are interested in pursuing research into those severely affected (National Institute for Health and Care Excellence (NICE) 2007:39). A research summary based on McDermott et. al. (2014) states that

Whilst significant progress has been made in researching and treating CFS/ME in mild to moderately affected individuals, housebound patients are generally too ill to travel to out-patient appointments for treatment or research. There are currently few in-patient beds in the UK for this patient group (McDermott and Richards 2016).

Such research could greatly improve understanding of the most severe manifestations of the condition.

1.3.5 Treatment for ME and/or CFS

The predominant treatment for ME/CFS funded and endorsed by the UK government was established through the Pacing, Graded Activity and Cognitive behaviour therapy (PACE) trial that began in 1998 lasting five years (White, Goldsmith et al. 2011), which

¹¹ The project began 01.02.15; project completion date 06.30.17)

¹² Such as the ME Association and National ME Centre (NMEC, closed in 2007), British Association for Chronic Fatigue Syndrome/ME (BACME), Association of Young People with ME (AYME), the 25% ME Group (which supports those severely affected), Action for ME, Blue Ribbon for the Awareness of ME (BRAME), CFS Support Forum and Foggy Friends. Groups which advocate for more biomedical research include: Invest in ME (IIME) and ME Research UK.

promoted the therapeutic use of CBT and GET (NICE 2007). It is worth noting the similarities with early treatments for TB and poliomyelitis. The trials were based on the disputed Oxford definition of CFS, which identifies fatigue as a main symptom, and validates the use of CBT and GET for mild or moderate CFS/ME and the severely affected (Chalder, Goldsmith et al. 2015:26). This treatment follows the Expert Patient Programme (2007), which advocates self-management and is arguably a catch-all self-help treatment programme to alleviate the economic burden of chronic illness within the UK. Such programmes also potentially exclude those who are severely ill.

Interestingly, the opposition of patients to the PACE trial, was based on the lack of focus on the biomedical aspects of the illness. Lesley Cooper described the tensions that arose between doctors and patients, whereby patients were met with 'miscommunication, dismissal and disbelief' (1997:186). This is supported by McQueen (2002:1214) who states that 'patients are, however, not equals, and their beliefs do not have the ontological status of medical knowledge', while White calls for doctors to enter into an alliance with those who have personal knowledge of the illness (White 2002:1214). When an illness is contested, the lack of conclusive medical evidence offers greater potential for the patient and physician to work together to 'manage the complexities' associated with contested illness (Swoboda 2008:453). Therefore, the potential obstacle of the scientific Cartesian approach has in some way become overtaken, as the patient's voice has become necessary for the production of knowledge (Hooper 2007). Moreover, as the medical debates continue on whether CFS/ME is a syndrome or disease, the search for legitimacy has encouraged the layperson to become the expert in their illness (Clarke 2000). White suggests that the 'ME-CFS debate may be remembered in future more as one of the tipping point for the rejection of Cartesian dualism than for diseases that lie within' (White 2008:1).

It would seem that the failure of doctors to agree on aetiology and pathogenesis of ME has produced an 'illegitimate illness experience', causing a devalued and stigmatised social identity for those unable to overcome the illness (Millen and Walker 2000; Raine 2004). Anthony Pinching & Louis Freedman identify similarities between discourses surrounding AIDs and CFS/ME (2003) stating that both have generated uncertainty and fear, compounded by social stigma, blame and neglect. This has resulted in derogatory language, such as 'gay disease' for AIDS and 'yuppie flu' for ME in the 1980s, which suggested the illness 'was all in the mind' (Hodgkinson 17 July 1988). However,

although such headlines cause frustration, they also galvanised the need for activist groups which offer valuable information and champion research funding.

Equally problematic is that most studies omit the severely affected, as this group are often housebound and/or bedridden. However, a longitudinal study started in 1994, Case History Research on ME (CHROME), which collated information from those who were severely affected, suggested that complete recovery was unusual, that many remained severely incapacitated and some had deteriorated (Pheby, Sneddon et al. 2010). At present, there are no inpatient facilities within the NHS or privately in the UK for this group of patients. Importantly, the NICE (2007) recommendations for severe ME, as reported in the above research, are not being upheld. Furthermore, the government's guidelines for treating the severely ill, which propose offering telephone consultations, seem highly inadequate for the degree of suffering experienced.

Clearly, these medical discourses demonstrate major problems, as the theoretical rationale used to espouse CFS/ME as a disease or syndrome and establish a particular truth of existence, is in contention. Methodologies lack scientific rigour and yield flawed results (Hooper 2010:4), while definitions are designed by consensus, which varies between different fields of inquiry. The research participant selection process, which often excludes the severely ill, raises questions about the applicability of findings to the whole CFS/ME community. The growth of chronic illnesses within western societies has caused medical practices to shift the clinical gaze to include self-help programmes. This has created new ideological approaches to body maintenance and shifted the responsibility of care from the clinic to the self, arguably moving the body from surveillance to self-surveillance.

1.4 Social Sciences: chronic to a contested illness of ME/CFS

Within the social sciences, medical and feminist scholars have focused on the power hierarchies that dominate the constructions of illness and gender. As noted in the previous sections, the discursive dilemmas of the medical, political and social contexts frame illness within a particular set of definitions and meanings. This section then looks at sociological and literary works through which a 'contested' and often 'severe' illness, can be understood.

1.4.1 Social constructions of chronic illnesses

Social constructionist approaches in the 1960s argued that what is deemed to be reality is based on a matrix between processes and practices, in how ‘man constructs his own nature, or more simply man produces himself’ (Berger and Luckmann 1966:67; Goffman [1959] 1969). In terms of illness, the patients’ perspective takes in not only the constituted patient role, but also social factors which shape the illness experience (Conrad and Barker 2010):

First, some illnesses are particularly embedded with cultural meaning – which is not directly derived from the nature of the conditions – that shapes how society responds to those afflicted and influences the experience of that illness. Second, all illnesses are socially constructed at the experiential level, based on how individuals come to understand and live with their illness. Third, medical knowledge about illness and disease is not necessarily given by nature but is constructed, and developed by claim-makers and interested parties (Conrad and Barker 2010:S67).

Although medical knowledge informs how particular truths of existence emerge in relation to labels such as ME and/or CFS, the power to retain or erase factors becomes contingent on the social, cultural and historical context (Nettleton 2013:15). Social constructionist interest in health and illness is, therefore, specifically focused on the epistemological privileges that sanction diseases. The critical approaches to sociology of diagnosis are of considerable interest as there is a growing need to investigate the ways in which medical truths influence social and personal understanding of illness. In particular, the concept of medicalisation offers a means to critically examine the processes and practices of diagnosis, in which medical authority constitutes a means of social control (Zola 1972; Nettleton 2013:17).

The labelling of illness legitimates a deviation from the role of healthy citizen. Parson’s sick role concept was based on the passive alienative category of dependency and conformity, a temporary deviant position (Parsons 1951:285). Freidson (1970), building on this concept, focuses on American medical procedures and suggests that gaining a sick role offered conditional and temporary legitimacy, but ‘where illness is thought incurable or chronic, its legitimacy can no longer be conditional’. This produces a deviation, an unconditional position that stigmatises illness and makes it ‘illegitimate’ (Freidson 1988:238; Nettleton 2013:67). In turn, chronic illnesses can only be diagnosed by medical schemas that organise and classify an illness via biological clusters. This process is governed by three general signifiers: is the illness progressive,

constant or relapsing/episodic (Rolland 1987:204)? This, arguably, puts the chronically ill in a state of personal and political ‘perpetual becoming’ (Armstrong 1995:402).

As noted, within Western societies, there is a personal and moral duty to find a medical cause of illness to fulfil the first stage of the sick role (Parsons 1951). Conrad (2007) cites Broom & Woodward’s 1996 study of CFS, agreeing that the medicalisation process may be used as way to gain coherence for legitimating and granting permission for a ‘range of human troubles’ (Conrad 2007:11). He suggests that illnesses such as ‘chronic fatigue syndrome, fibromyalgia *syndrome* [my italics], irritable bowel syndrome and multiple chemical sensitivities are medically suspect because they are not associated with any known physical abnormality’ (Conrad and Barker 2010:67-69). However, as noted earlier, valid medical connections have been established between CFS and the Epsom Barr Virus. As different medical disciplines sought to situate ME, the illness became entangled within a discursive framework, where aetiology was superseded by the need to shape and identify a diagnosis via symptom criteria. As a labyrinth of hegemonic networks divided and traced the nosological trails for the emergence of ME and/or CFS, the factors became disjointed, causing medical contention and social scepticism due to the lack of a clear defined historical path and medical evidence.

This forces a collaboration between physicians and patients for diagnosis, rather than solely relying on medical ‘professional dominance’ (Broom and Woodward cited by Conrad 2007:12). Specifically in the case of ME, this detracts from the discursive practices that have constituted a biological reality since the Enlightenment (Foucault [1963] 2003). David Armstrong, using Foucault’s investigative approach, stated ‘the importance is not how something which is so obvious today had remained hidden for so long, but how the body had become so evident in the first place’ (Armstrong 1983:xi).

The discrete methods by which illness is interpreted, constructed and treated are based on that which is already known. Terms are created in relation to a set of medical confounders that give illness credible meaning and, in turn, provide personal and cultural understanding. Prior to the increase in chronic illnesses, these labels divided the sick into those who could be cured and those who could not (Illich [1976] 2002:91). Since the 1970s, the sociological lens began to scrutinise how ‘medicine [was] becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law’ (Zola 1972:487). This, as Illich argued, was ‘at a rate of miscarriage that no court system could tolerate’ (Illich [1976] 2002:93).

By critically reviewing the processes of defining illness, fact becomes fiction, a narrative that changes as it sweeps through the discursive corridors of medicine. This then requires a particular lens to account for how medical knowledge can be challenged. Medical sociologists address the medicalisation of society, where all human conditions are made into treatable disorders, where there is no place for an illness that cannot be treated, where there is strategic interaction that controls those who are sick through health professionals, pharmaceutical companies and healthcare policies (Conrad, 2007). This system becomes active once a patient is able to enter the medical arena with a *diagnosis*. The label activates a chain of medical events that will sanction the ‘truth’ of the illness experience. As this emphasis on truth combines the power of diagnosis and medical knowledge, there is a need for a sociology of diagnosis to examine ‘the social basis of diagnostic categories and diseases, the process of diagnosing and the consequence for both the practitioners and patients’ of applying a diagnosis (Jutel and Nettleton 2011, cited in Nettleton 2013:27).

1.4.2 Contested illnesses

The crucial issue raised by contested illness is the inability to fulfil and/or remain within a nosological category. In a study of neurology outpatients with medically unexplained symptoms, Nettleton referred to their *chaos narratives* which revealed ‘confusion and uncertainty’ [...] in emotive accounts of ‘hope and despair’ (Nettleton 2013:77). The inability of illnesses of this nature to become or remain framed, means that treatment is also uncertain, with a cacophony of both medical and social opinions on diet, rest and lifestyle changes. Chronically ill subjects are always expected to be working towards a state of ‘good’ health (Nettleton 2013), which emphasises the cultural responsibilities of performing illness (Goffman [1959] 1969). The powerlessness to fulfil the binary opposites of healthy and unhealthy call to mind Judith Butler’s theory in relation to the ‘doing’ of gender (Butler 2006). Like gender, contested illnesses are mediated by cultural meaning, as specific diseases fail to be acknowledged widely by medical discourses, which causes suspicion (Conrad and Barker 2010:S69). These refusals or uncertainties in achieving a particular diagnosis not only cause personal suffering and social doubt, but also build a discourse around the illness being ‘not real’ (Ware 1992:347). This in turn affects government policies on healthcare management, social benefits and financial support from employers (Brown, Evans et al. 2013). How then can a person living with long term and often severe symptoms provide accounts that will gain social understanding?

1.4.3 Disability studies and chronic illnesses

The interdisciplinary approach of disability studies evolved in Western society throughout the 1970s, along with other social rights movements, and has since led to collaborations between academics and activists, as with Union of the Physically Impaired Against Segregation (UPIAS) (1976). This gave disabled people the opportunity to become more active in their own affairs (Albrecht, Seelman et al. 2003:1) and contributed to the development of the 1995 Disability Act (Barnes and Mercer 1996:2). The focus was on the meaning of disability in society, which influenced the emergence of the social model of disability, confronted issues of inclusion (Ferguson and Nusbaum 2012:70) and helped build better understanding of the complex issues associated with being disabled (Barnes and Mercer 2004:45). The reform of disability rights as a social entity has been theoretically and empirically explained by accounting for the oppressive nature of disability (Thomas 2004).

The social model of disability has moved attention from the ‘body’ to the ‘social’, yet it is not simply the issue of inclusion that needs addressing, but also the subjective experience of suffering and pain and the social barriers arising from living with long term impairments. The debate about whether a diagnosis is ‘real’ highlights the social constructions of illness, but can sideline long term, often severe, symptoms.

One of the major contributions to disability studies has been to establish a dialogue into the disparities between disability and impairment. In *Disability Rights and Wrongs* (2006), Tom Shakespeare argues that the focus should include the issues of impairments, the embodied state and physical effects which affect identity. As Carol Thomas confirms, the International Classification of Functioning Disability and Health (ICF) makes a distinction between two constituent elements of impairment: body functions and body structures (Thomas 2007:14).

Body Functions are physiological functions of body systems (including psychological function)

Body Structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss

(WHO 2002:10)

There is a need to critically examine the dichotomies between medical and social, impairment and disability, disabled and non-disabled (Shakespeare 2006). This is especially important for illnesses like ME, with no stable definition and/or symptoms and ‘changeable and episodic’ impairments (Shakespeare 2013:218). It is also important

to note that a range of subject positions, such as ethnicity, sexuality, class and marital status, may also impact the experience of illness (Shakespeare 2013:221). What is then required is a biological and social model for disability, whereby those living with ‘severe’ illnesses can be empowered. However, continuing welfare cuts in this area are attacking people with disabilities and further marginalising those with severe long term illness.

1.4.4 Embodied experiences of chronic illness

The disciplinary technologies of medicine, which schematically structure disease within a Cartesian dualist approach, have been effective in helping to eradicate major diseases such as polio and smallpox within Western society. Yet they have also potentially increased the burden of chronic illnesses. Social theorists, interested in the ways in which body, biography and self-interact with society, used grounded theory to investigate how people live with the effects of chronic illness and their findings suggest a fundamental loss of self (Charmaz 1983; 1999; Williams 1984). Bendelow and Williams suggest that pain is a subjective, emotive experience which is dependent on cultural perceptions and beliefs and is, therefore, always contestable as it ‘lies at the intersection between biology and culture’ (Bendelow and Williams 1995:140; Bendelow 2000). Clearly a person’s subjective experience of illness is not just made up of biological components, but also relates to time and space, shaping how illness is understood and what it means to be ill. Therefore, in the case of ME/CFS, what it means to live with a contested illness is politically, socially and culturally mediated.

1.5 Subjective accounts of long term illness

This section focuses on autobiographical writings of illness and feminist accounts of the personal/political nature of the embodied experience of chronic ill health, to capture alternative ways to illustrate a world affected by pain and suffering. While the above section was concerned with the social constructions of ‘doing illness’, this section is informed by what Virginia Woolf terms, the state of ‘being ill’ ([1930], 2008).

1.5.1 Literary works: Being ill

Prior to works by writers such as Charlotte Perkins Gilman (1860-1935), Marcel Proust (1871-1922) and Virginia Woolf (1882-1941), the experience of living with illness was under-represented in literature. In *The Collected Essays – ‘On Being Ill’* ([1930] 2008) Virginia Woolf offers a means not to subvert suffering, but to reveal the space of

seclusion experienced through illness. As Lorraine Sim states, ‘Woolf discusses the internal and external topographies that, she writes, offers a means to enter the bedridden world of the invalid’ (Sim 2003:88). Sims further suggests that ‘Woolf presents the sick body as a vehicle for knowledge and suggests that common illness poses a challenge to many of our everyday assumptions about self and the world’ (Sim 2003:88). Indeed, Woolf amplifies how illness affects us all, but is socially under-represented, as being ill takes us into the ‘doings of the mind’ (Woolf [1930] 2008:99). The subjective quality of pain is mainly experienced alone, while the depth of pain has the capacity to actively destroy ‘language, deconstructing it into the pre-language of cries and groans’ (Scarry 1985:172; Sim 2003:88). As Woolf notes, experiencing pain opens up our senses and imagination as it,

sets us to wait, hour after hour, with pricked ears for the creaking of a stair, and wreathes the face of the absent (plain enough in health, Heaven knows) with a new significance, while the mind concocts a thousand legends and romances about them for which it has neither time nor taste in health ([1930] 2008:102).

The imagination Woolf alludes to was influenced by her knowledge of Marcel Proust’s (1871-1922) *In Search of Lost Time: Volume One – Swann’s Way* [1913], in which he describes in rich prose the experience of going to sleep, listening, watching, lying in bed. Proust constructs a colourful, cultural tapestry of a middle-class gentleman of his time, almost able to enjoy the space of the bed. The gratification of rest and imagining provide him with a way to enter other worlds and may have little connection to what it means to suffer when bedridden.

I had only the most rudimentary sense of existence, such as may lurk and flicker in the depths of an animal’s consciousness; I was more destitute of human qualities than the cave dweller; but then the memory, not yet of the place in which I was, but of various other places where I had lived, and might now possibly be, would come down like a rope let down from heaven to draw me up out of the abyss of not-being, from which I could never have escaped by myself (Proust [1913] 2014:8).

As with Woolf, we have a glimpse of time, space and the imaginary world, which is devoid of social constraints. Proust often presents the bedroom as a refuge, a tranquil space in which to battle the demons of his illness, as he reveals his attempts to recapture his social life through his memories and imagination. Although these literary works describe living with illness, they lack the experience of severe pain and suffering over many years. However, while these writers demonstrate to some extent a whimsical

account of the adversity of illness, they do offer a way to understand how those bedridden may gain power, escaping the physical confinement of illness by imagining other worlds. Bamberg (2011) suggests that autobiographical narratives of this nature display three identity processes – ‘sameness’ by making connections with the past and present, ‘uniqueness’ to differentiate themselves from others and ‘agency’ as their experiences suggest accountability. This accountability is revealed in a moving account of the struggles of living with the everyday challenges of disability by Irving Zola (1982). He refers to caring for the self and the resistance to, as well as the working with, being dis-abled, through his understanding of what it means to be ‘normal’ (1982:74). What is readily apparent is how, for those with severe disabilities, ‘a major expenditure of time and energy’ (1982:75) is taken up with the everyday tasks of being.

1.5.2 In dialogue: conflating the binary dilemmas for gender and ME/CFS

Of all academic disciplines, feminist approaches have best interrogated the dangers of dividing body/subject and disabled/non-disabled identities. Specifically relevant to this project is how these approaches have often combined personal and political understandings of living with this type of chronic illness. Susan Wendell, who was diagnosed with ME/CFS in 1985, reflects on her personal and political struggles with illness in her book *The Rejected Body: Feminist Philosophical Reflections on Disability* (1996). Wendell draws on the psychosocial and ethical dilemmas of living with illness and the demands of being classified as a disabled subject. Applying feminist ethics to the issue of embodiment, Wendell describes the conflicts between medical authority and the issues of impairment (Wendell 1996:3). Indeed, she identifies the boundaries between being healthy disabled and unhealthy disabled which, in effect, make self-identification uncertain (Wendell 2001:17). This philosophical reflection on disability outlines the social barriers within particular cultural and political ideologies and uniquely frames her own interpersonal experiences of living with ME/CFS.

Equally, Janet Price and Margret Shildrick in a chapter titled ‘Uncertain Thoughts on the Dis/abled Body’ (1998), provide an interesting dialogue on the problems of classifying disability and impairment. Price, who has also lived with CFS since the 1990s, eloquently discusses with Shildrick their experiences of classification and labels that validate what it means to be disabled and non-disabled. They follow Michael Oliver’s (1996) plea not to ignore the social model of disability, but ‘advocate its use, yet, at the same time demand an unsettling of its certainties, of the fixed identities [with] which it is bound up’ (Price and Shildrick 1998:243).

These feminist approaches critically examine the dichotomy of binary oppositions, confronting and transcending the embodied controls that are placed on the body. Price states that her experience of living with CFS

is characterised by, above all things, material instability. I do not/cannot 'know' my body, this body that has been so marked by illness. I cannot keep pace with its/my twists and turns, my sudden surges or dips of energy, my fevers and rashes and pain (Price and Shildrick 1998:243).

In *Women, Body and Illness* (2003), Pamela Moss and Isabel Dyck discuss their findings from 49 in-depth interviews with Canadian women with chronic illness. Whilst working on the project, Moss was herself diagnosed with CFS. The study highlights the struggles that take place between dualistic borders – healthy/unhealthy, normal/deviant – as their framework produces a radical politics, which exposes the discursive material, spatial and political formations for experiencing chronic illness (Moss and Dyck 2003:9). Interestingly, in the book they employ a fictional character, Patience, to explore how the body is inscribed with an 'ill identity', which limits the 'movement through spaces' and requires continuous work in reconstituting a 'sense of self' (Moss and Dyck 2003). The character of Patience offers a means to disclose the intimate, personal accounts of women living with chronic illness. The authors' explorations into the social and physical environments in which to situate the body are derived from images, texts and actions. This approach contextualised 'being ill' and endeavoured to 're-embodiment women with chronic illness – spatially, materially, discursively, politically as ill bodies [living] in a healthy society' (Moss and Dyck 2003:10). Although Moss and Dyck describe the capacity for labour in terms of leisure, economic need and physical restrictions (Moss and Dyck 2003:372), they pay limited attention to how women living with long term effects of chronic illness could be supported. These feminist approaches have begun to explore the discursive and material conditions which the chronically ill subject lives by. However, there are no accounts of those who live with severe symptoms of ME and/or CFS.

This review of the literature has by no means identified all the bio-medical and psychiatric studies of the illness, but rather has set out how ME is viewed and experienced as a contested illness. It would seem that ME has a nomadic status, travelling between disciplines, across nations and political agendas, moving through and transgressing the barriers of medical and psychological discursive disciplines, so that those who suffer find it difficult to anchor their illness within any particular medical

landscape. Definitions are highly political and are loaded with social and cultural meaning, for those who live with illness and those who investigate, treat and care for those who suffer.

1.6 Research questions

This account of the categorisation of ME demonstrates how the condition has caused discontent within traditional medical disciplines. Many medical sociologists and feminists are interested in the social and political effects of illnesses that are categorised as contested. The inability to define ME within a stable medical discourse constitutes it as a phenomenon open for constant medical debate and social suspicion. Medical evidence has identified ME variously as epidemic and endemic, affecting both genders and being experienced from childhood through to adulthood. Disciplines within bio-medicine tend to focus their research on the cause, such as immunology. Whereas, those within social psychology and psychiatry tend to link ME/CFS to the precipitating factor of chronic fatigue, concentrating efforts on psychosocial approaches to managing the illness. These medical accounts have focused widely on discursively narrowing the illness within disease and/or syndrome definitions and ignore those who are severely affected. Consequently, the social practices that impinge on living with long term illness are under researched.

Medical sociologists interested in contested illnesses often focus on the issue of medicalisation; the need for making all human conditions treatable. Yet, these accounts also pay limited attention to those who are severely ill. Disability studies have focused on the social model of disability and addressed what it means to be dis-abled, but once again, there is a lack of attention paid to what it means to live with constant impairments, pain and suffering – in what can be described as ‘doing illness’. Literary works help to substantiate some of the issues of being ill, while feminist explorations of living with a contested illness open up the collision between power and ideology, the complex and often ambivalent experience of being female with a chronic illness. These studies describe how women reflected on chronic illness and in particular ME/CFS. They revealed rich material on how chronic illnesses blur the boundaries between social identities, such as what it means to be healthy/unhealthy, normal/deviant and the issue of reconstituting a sense of self whilst mastering a body with illness.

Importantly, and central to the focus of this thesis, questions that arise from this review of available literature are as follows: How is a ‘contested’ and ‘severe’ illness constructed within rigid medical and social regimes? How do social practices and cultural discourses intersect with the process of *doing* and *being* ill? How is a contested chronic illness reconfigured by those affected with severe illness from childhood through to adulthood? How is it possible to illustrate the everyday experiences of surviving ME? What are the possible dilemmas, contradictions and conflicts that constitute a way to manage a life with chronic illness? These questions frame a particular theoretical approach to the broad question that will be explored in this thesis: What does it mean to experience a contested and often severe illness?

Chapter 2: Inscribing Selves: Discursive, Material and Dialogic Turns for ME

2.1 Introduction

This chapter introduces key concepts which underpin the method and practice of investigating chronic illness. It takes a transdisciplinary approach to the question: How can we understand ME/CFS as a *disease of 1,000 names*, which espouses culturally derogatory responses such as, '*it's all in the mind*', '*yuppie flu*' and a '*malingers disease*'?¹³ If ME/CFS defies medical theories of containment, how is it possible to gain a conceptual understanding of both the issues of contestation associated with a diagnosis and the subjective experiences of living with severe illness symptoms? Rather than simply theorising how a contested chronic illness is both medically unstable and debatable, this chapter argues for an understanding of how such factors that impact on the 'doing' of illness and being ill.

The chapter draws on Michel Foucault's body of work to explore how power determines a particular truth through language. Foucault's genealogical perspective offers a means to understand the historical and discursive impasses and iterations which perpetuate the uncertainties associated with contested illnesses to understand the material processes by which we may understand illness. My reading of Deleuze and Guattari's approach offers a means to critically account for the intensities of pain and suffering which alters life trajectories and acts of becoming. This may be particularly relevant to those living with a capricious illness like severe ME which, as noted, is associated with, but is not essentially an unexplained illness. ME has been described in medical research as a multi-system disease which affects organ and bodily systems producing a myriad of symptoms (Crowhurst, 2015:46). These symptoms are varied,

¹³ References: *Chronic Fatigue Immune Disease [CFID] A Disease of a 1,000 names* (Pollard, 1988) and media coverage most recently condemning and countering the term past media phrase of 'all in the mind' in the article by Jenny Hope [accessed 10/11/2015] for the Daily Mail *ME Patients are told: it's all not all in the mind*'. Finally Tucker (2015) *Chronic Fatigue Syndrome, Wrong name, real illness* [Medscape Rheumatology 8/01/2015] [Accessed 10/11/2015]

changeable and unstable profoundly affecting an individual's life. Specifically, for the severely affected taking for granted everyday acts are potentially impossible as they become isolated from the world (Crowhurst, 2015:35) which exacerbates the continuous work in the making and remaking of self. I also turn to Bakhtin to discuss how narrating is in effect a relational act that is useful when discussing the fragility of life in terms of chronic illness. These approaches are employed to conceptualise the issues of contestation, subjective and material conditions by which a severe chronic illness of this nature may be explored.

I developed a particular 'kaleidoscopic view'¹⁴ to account for the discursive, material and relational aspects of living with chronic illness. The kaleidoscope has been employed previously as a conceptual metaphor to analyse gender (Spade and Valentine 2007), and to demonstrate the multiplicities of life within biographical methods (Stanley 1987). My employment of this metaphorical device is to demonstrate how each part holds multiple reflections that are working together and can be read differently, depending on the viewer, subject and intention. This chapter is not set out in order to offer an in depth theoretical reading, but aims to elicit an active conceptualisation for understanding 'doing' and 'being' chronically ill. As a person who lives with the illness under investigation, 'the theoretical fact [is] that only those directly concerned can speak in a practical way on their own behalf' (Deleuze cited in Bouchard 1977:209).

Medical sociology has explored the process by which medical discourses produce knowledge and how the diagnosis is a political and cultural necessity to access treatment and financial support (Conrad and Barker 2010). Contested illnesses assume a debatable existence which amplifies uncertainty for those diagnosed, such as with Medically Unexplained Symptoms (MUS) (Nettleton 2013). Conditions such as MUS and ME reveal the dilemmas when an illness is unable to be named or remain named. Major works within medical sociology and disability studies focus on struggles with identity/self and the body in pain (Bendelow and Williams 1995), as well as material and psychosocial factors which underpin notions of stigma and vulnerability (Wendell 2001:17). The continuous need to clarify differences between 'healthy' and 'unhealthy' disabilities and the lack of understanding for the often accompanying impairments associated with chronic illness (Shakespeare 2013:214). Social psychologists adopting a discursive view have explored the effects stigma as a contributing factor to feelings of

¹⁴ I have created 3 individual and 1 main diagram to demonstrate the kaleidoscopic approach to analysis.

hurt, searching for legitimacy (Dickson, Knussen et al. 2007; Swoboda 2008). Challenges to the ontological aspects of illness have gained momentum since post-structural works, such as Fox and Ward on health identities (2008) and Shildrick and Price on ME (1998). Fox has opened up the dilemmas and the tension between fulfilling healthy/unhealthy identities whilst living with the subjective experience of illness, while Shildrick and Price encourage a need to take into account of the discursive practices, material conditions and relation aspects of negotiating a life with illness.

2.2 Philosophical reflections on discursive subjects

This section explores how the power to inscribe subjects not only constitutes a reality, but also becomes the means by which we accept our material existence. I also discuss how a genealogical perspective allows us to explore the emergence of particular notions of truth in relation to knowledge and power, which helps us understand present conditions. This sets out the ways in which it is possible to conceptualise performance, space and the means by which to comprehend medical discourse, as well as offering a means to understand the social constructions of multiple identities which are governed by performance and representation. For those who are diagnosed with a contested illness and often experience severe symptoms, the act of illness disrupts and limits the process of diagnosis and the practice of illness.

2.2.1 Critically mapping discourse

Like Foucault, Norman Fairclough (1941-present) is interested in the power of discourse, critically engaging with the order of discourse within social practices to examine the interdiscursive linguistic elements of language (Fairclough 2010). His exploration of the ways in which particular groups become marginalised through language, parallels Foucault's assessment of how categorisations within language work to confine the subject. Critical Discourse Analysis (CDA) offers a means to account for the relationship between the production and understandings of the social relations that constitute discourse. Fairclough suggests that,

the terms discourse and practice have what we might call 'felicitous ambiguity': both can refer to either what people are doing on a particular occasion, or what people habitually do given a certain sort of occasion (Fairclough 1989:28).

This accounts for the social preconditions that govern the actions and the social conventions of language, which are constrained within various types of social practices.

Fairclough's approach offers a means to map the social practices and power relations by which differences and inequalities may emerge (Fairclough 1989; 2010). In order to critically engage with language and discourse, he developed a framework comprised of three separate forms of analysis: to read language as text; examine the social structures and discursive actions that produce the text; and identify the events that constitute socio-cultural practices (Fairclough 2003). This offers a way to understand the social and ideological effects of text and consider the power relations, struggles, identities and social agents that emerge within socio-political networks and define social roles.

The use of Fairclough's CDA produces a reading that not only critically accounts for the social structures that categorise an individual, but also addresses the implicit interconnectedness of what it means to culturally understand our social identities. Sociolinguistic and social theorists have engaged with how language positions social categories such as gender (Weiss and Wodak 2003) and ethnicity (van Dijk 1984). As a consequence, subjects who are unable to fulfil categorised positions within society – such as those with a contested illness – slip outside of normative practices and are forced into positions of social deviancy. By critically engaging with discourse as a practice, the various social and political judgements that underpin categorising subjects are made accountable. This establishes the social nature of categorising subjects as relational, involving both institutional and cultural configurations, as these aspects are interchangeable and impact on subject positions.

For Fairclough (1989), text is analysed through an inter-discursive approach that combines communicative *genres* (social actions) and *styles* (social roles) of discourses to integrate the dialogic presuppositions of language. Fairclough¹⁵ draws on Kristeva's concept of intertextuality to map the explicit and implicit assumptive, hidden, unsaid elements of text that are attributed to, and have the potential to include, voices of others (Fairclough 2010). For Kristeva, text is *a priori* based on shared codes in which the text is made from and via other texts (Kristeva 1980). Although Fairclough's interests lie predominantly within political and public identities, his framework ultimately examines the order of discourse. He used the term 'synthetic personalisation' to account for the 'power behind the discourse', when a social actor, such as a doctor, may ask 'how are you feeling?' (Fairclough 1989:62). This provides a means to observe the totality of

¹⁵ The term intertextuality coined by Kristeva, 1986 was taken from Bakhtin, 1981 works – Fairclough uses the term to describe 'direct speech' that implies a statement of intent as opposed to 'indirect speech' which alludes to and may presuppose particular realities (Fairclough 2003:39 and 223).

discursive and social practices and the subtle ways in which institutional languages constitute particular ‘ways of being’ in language (Fairclough 2003:223). The macro and micro productions of power and knowledge thereby produce particular understandings of self and other that cause social inequalities, as language interfaces with meaning, and define what it means to be categorised within an institutional, ideological context.

2.2.2 A genealogical perspective: the emergence of particular truths

Fairclough’s approach is ostensibly underpinned by Foucault’s seminal works on the studies of structures¹⁶. Foucault’s critical theories and concepts were based on the premise that systems of thought were deployed and governed by power, which produced knowledge and activated particular discourses that constitute a truth of existence. Foucault’s work described how asylums, clinics and schools became exemplary sites of discipline that controlled and maintained the subject, such as the madman, patient and pupil. In *Madness and Civilization* (Foucault [1961] 2001) Foucault used an archaeological approach to excavate the notion of madness. Although he had not at this time explicitly developed his genealogical approach, in retrospect it was the implicit application of genealogy that allowed him to trace the emergence of a particular truth, namely the category of madness. By analysing the contingencies and events that were put in place to govern and regulate ‘madness’, Foucault was able to argue that medical discourses and institutional practices, such as psychiatry, used scientific neutrality to sanction a truth of existence (Foucault [1961] 2001:136). He argued that this process produced the ‘birth of the asylum’ and led to a plethora of social, political and ethical controls upon the body of the insane, which still exist in psychiatry (Foucault [1961] 2001).

Therefore, the genealogical approach offered Foucault a tool to trace discursive formations and filter historical epochs, to cut through the disruptions and discontinuities of knowledge that lie behind social and political change. Foucault was able to go beyond the existence of a category, such as ‘madness’ (Foucault [1966] 2002), and analyse discursive formulations that govern ‘practices which are apparently organised around something that is supposed to be madness’ (Foucault [1978-79] 2008:3). He thereby traced the discursive structures of psychiatry by unearthing and unpicking the silences, the languages which create knowledge and the power to control, identifying the category of ‘madness’ as political governance and cultural practice which ‘both

¹⁶ Michel Foucault’s early works: *Madness and Civilization* (1961), *The Birth of the Clinic* (1963), *The Order of Things* (1966) and *The Archaeology of Knowledge* (1969).

establishes and impugns it' and mapping particular moments to describe how discursive and social practices executed the social and physical exclusion of madness (Foucault [1961] 2001:xiv). Foucault's genealogy provides a set of strategies to consider how the power of language disciplines the body through classification and regulation, while his study on madness can be employed as a means to understand the emergence of the sick body.

In the *Birth of the Clinic: An Archaeology of Medical Perception (BoC)* (Foucault [1963] 2003), Foucault examined the rise of socio-political interventions to counter the process of normalisation that occurs within institutions such as medicine. Principally, the work was 'about space, about language, and about death; it is about the act of seeing, the gaze' (Foucault [1963] 2003:ix). Foucault traced the history of medical discourses to examine the dimensions of disease in order to 'disentangle the conditions of its history from the density of discourse' (Foucault [1963] 2003:xxii) which allowed him to 'locate within the fine meshes [a] web of power' (Foucault 1980:116). He critically explored how this power produced epistemic shifts in the organisation and management of the sick body. By exploring how the medical institution developed, he contextualised the ways in which disciplinary systems of the body emerged. His theory of the clinic offers a way to understand how the patient/subject is constructed and constituted, through a discursive corporeality by which language constitutes the body. This approach describes how it is possible to question the reality of a disease that is constructed via past knowledges, an observable, constantly shifting organism embodied and embedded within a medico-political and socio-cultural context.

In *BoC*, Foucault charts the emergence of medical discourse via the anatomical observations of the autopsy, whereby investigations began to invade the body and, following Cartesian dualism, divide the mind and body. He argued that a medical system is derived from the practical processes of observation combined with medical discourse where '*diseases*' constitute a nosology, a particular set of languages – such as the use of Latin names – that are maintained by wardens of control or medical experts. Foucault developed the term 'the clinical gaze' to describe the power of observation and language used to govern sick bodies and validate an illness experience, as symptoms are observed and analysed within a medicalised 'speaking eye' to legislate illness and sanction the truth of existence via a medico-politicised system (Osborne 1994:35).

This closed system of medical knowledge has thereby reached a further stage of biopolitics (Rose 2007), whereby the subject of illness is removed and technologies that determine illness are based on a set of observable medical truths. Foucault's approach offers a means to observe how institutional power emerges not in a linear evolution but, by a complex system of disciplinary regimes (Foucault [1963] 2003). Foucault was able to deconstruct the particularities of madness and disease, to identify the transitions that led to present day psychiatric and pathologic realities. His approach is, therefore, helpful in revealing the events and contingencies which brought about the emergence of present understandings of current social categories, such as that of a contested illness.

Foucault offers a way to expose the processes which constitute pathological realities and reveal the bio-political gaze that normalises material bodies. In this way, he presents an opportunity to disrupt the ideas, discourses and images of the body, and to ethically and reflectively question the modes of power and truth that procure knowledge of self and other. Inherently, genealogy¹⁷ sets out to map the exercises and effects of power in relation to context and the specifics, as with socio-historical and institutional settings. With the concept of governmentality, bio-power establishes stable fixed categorises for subject-positions, not only via technologies of domination, but also through discursive systems of control that govern families, school and the workplace. Foucault's conceptualisations of the often ambiguous and messy processes that constitute social norms, highlights not only acts of conformity, but also how subjugated voices may display resistance. It is important, therefore, that we question regimes of truth and the mechanisms of control that produce discourses within a particular time and space, such as those surrounding contested illness.

Foucault uses the term *dispositif* to describe an apparatus, which is 'the system of relations' between a 'heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions'. He identifies an 'interplay of shifts of position and modifications of function' between these elements and sees the apparatus as 'responding to an *urgent need*' at a 'given historical moment', such as the need to control madness, sexual illness and neurosis at a time of a mercantilist economy (Foucault 1980:195). This offers a way to examine the surveillance and policing of the sick body within an ethico-political context (Dreyfus

¹⁷ Please note when discussing genealogy this is in terms of Foucault's take on Nietzsche's 'Genealogy of Morals' ([1913] 2003).

and Rabinow 1982:121). The sick subject is managed via systems, such as the UK's expert patient programme which relies on self-surveillance (Rose 2007; Nettleton 2013). The dispositif, therefore, provides an analytical tool for mapping out the various epistemic power systems. Arguably, for Foucault, the epistemological foundations inscribe the subject into society, through language and discourse as a residue of power relations. Resistance occurs in breaking through the linguistic walls of language by finding the voices that are missing. This is not to suggest that Foucault had no ontological recognition of the human condition, but rather that his interests lay with the structures of power and the 'doing' of subjectivity woven within the threads of knowledge and discourse.

2.2.3 Conceptualising other spaces

As Foucault states in *BoC* his aim was to find out 'how the medical gaze was institutionalised and effectively inscribed as a social space, so that the norm of the hospital was both the effect and the support of a new type of gaze' (Foucault 1980:146). These specialist spaces, such as hospital clinics, were governed by doctors and the political imperatives that sought to administer them and were in essence managed through surveillance of space and time (Foucault 1980). For Foucault, spaces are not real but relational, made up by the disciplines that contain them. The systems of spaces that have been institutionalised, from the home to those of leisure and work, contain cultural, social and moral codes of conduct and behaviour (Foucault [1984] 1998:177). Although these spaces are culturally communicated, it is the concept of production and the act of producing spaces through the context of time that is of interest for long term illness (Lefebvre [1974] 1991:15). Foucault argued these social spaces became sites of control, but he also recognised that spaces were affected and effected sites, as well as being contested places for those who need to resist the normative practices of institutional sites. Foucault's genealogical approach offers a means to focus on the relationship between space and time, as well as relations of proximity within private and public spaces, between the family space, cultural space and useful space, between spaces of leisure activities and the space of work. Foucault states that 'these are controlled by an unspoken sacralisation' and normalised (Foucault [1984] 1998).

Cultural expectations of how spaces should function are woven into the fabric of our social identities and are systematically part of our subjective processes. However, those who become severely ill may be unable to fulfil the social imperatives that dictate how places should be used, so that the physical geo-politics of the fixed states of family

living and its power relations can become unsettled. Spaces may become unworkable when severely ill bodies disrupt the ‘network of relations’ by which the ‘semi-closed sites of rest – the house, the bedroom, the bed etcetera’ (Foucault [1967] 1984:46) oppose the social practices by which these sites are maintained. Spaces that are opposed or alternative to what can be said to be ‘real places’ can be read through Foucault’s notion of the heterotopia, which is ‘fundamentally and essentially unreal’ (Foucault [1967] 1984:46). Foucault used many examples to explain the concept of heterotopia, the most common being the analogy of the mirror. He states that ‘due to the mirror I discover myself absent from the place where I am since I see myself over there’ (Foucault [1984] 1998:179). It has been argued that the concept of the heterotopia can be vague and lacks consistency (Genochio 1995:37; Soja 1995:162; Johnson 2012), I agree with Johnson that, rather than a detailed examination of spaces, the idea helps to account for how ‘spaces do not exist, except in relation to other spaces’ (Johnson 2012).

For Foucault, heterotopias are based on the tensions between ‘myth and the contestation of the real’ (Foucault [1967] 1984:48). These spaces determine how it is possible to invent places for particular types of people and behaviour. He sees *crisis heterotopias* as forbidden places, putting certain people, such as menstruating women and adolescents, in isolation (Foucault [1967] 1984:47). In her genealogical examination of the historical autobiographies of women teachers (2003a), Maria Tamboukou opened up the spatial dynamics of the private and public spaces occupied by the female educator. Talking about a set of *technologies of space*, she developed Foucault’s notion of crisis heterotopias, referring to ‘spaces of transition and tension, emplacements that gave rise to women in crisis’ (Tamboukou 2003a:80).

Foucault outlines how *crisis heterotopias* were replaced by *heterotopias of deviation*, spaces for people whose behaviour deviates from required norms, such as psychiatric hospitals and old people’s homes (Foucault [1984] 1998:180). This is relevant to those who become severely ill and bedridden, disrupting the institutional setting of the home and the bedroom by using the bed, not as a place of rest, but as a place to live and survive. The concept of heterotopia offers a way to understand how heterogeneous spaces are governed by social and systematic proprieties, by time and context. For those who become bedridden due to serious illness, the site of the bed/bedroom may, therefore, cause a need to transcend both real and metaphorical places.

2.2.4 Deploying a particular genealogical perspective

In terms of this research project, my take on genealogy enables me to critically analyse discourse associated with past illnesses, ‘which transmits and produces power: it reinforces...but also undermines and exposes’ (Foucault [1976] 1990:101). Charting the genesis of ME draws out ‘the details and accidents that accompany every beginning’ (Foucault 1984:80) which constitutes the contestation of ME in the present (Horton-Salway 2004). My study explores the medical language trapped within the scientific lens, which ignores its own methodological flaws that constitute contested illnesses. CDA may offer a means to view the biomedical modes of truth involved in the categorisation of disease and thereby ‘expose a body totally imprinted by history and the process of history’s destruction of the body’ (Foucault 1984:83). In *BoC* Foucault’s interrogation of French medicine argued that the principles of language confined the sick subject, which may be rhetorically challenging when converting the approach to British medicine (Atkinson 1995:41). However, others continue to use Foucauldian frameworks to generalise the employment of medical power and knowledge and historicise the separation of the body from the mind (Lupton 1994; Armstrong 1997; Nettleton 2013).

I deploy Foucault’s genealogical axis of truth in relation to the categorisation of ME not only to deconstruct the historical formulations of disease, but also to locate and reveal its origins within a particular truth. I will frame the discontinuities and ruptures within medical knowledge and investigate the historical emergence of ME and/or CFS through storied and visual narrative accounts. This will offer a way to understand how medical and political institutions discursively manage and control the categorisation and diagnosis of ME/CFS, to contextualise the uncertainty that exists for those who live with a contested illness and to address the gap in the literature relating to the severely ill.

2.2.5 Performative perspectives on the sick body

Foucault’s genealogical approach was employed by Judith Butler in *Gender Trouble* (1990) and *Bodies that Matter* (1993) to interrogate the reified category of the female, as a unified identity that stands outside of other classifications, such as class and ethnicity. Butler’s theory of performativity and the ‘doing’ of gender also used Lacanian ideas to challenge the morphological and constitutive ideologies that constrain and maintain the body of the female within social, political and cultural systems that function to label being female as ‘biological, linguistic and/or cultural difference’

(Butler 1990:9). This notion of inscribing bodies was taken up by Elizabeth Grosz in *Volatile Bodies* (1994) to account for corporeal space and to conceptualise the repressive site of the female body. As with Foucault, this not only contests discourses of power but also dislodges epistemological weapons that seek to constrain the body within particular political and ideological truths. The regulative and normative practices that recognise and govern the body of the female as *other* can be applied to the sick body. The dualistic medical approach to the body continually outlines the need for sick bodies to either return to healthy subject positions or fulfil the sick role. The presentation of the self is not only about performing an appropriate role, but also avoiding the stigma associated with an undiagnosed and/or untreatable condition (Goffman 1963; [1959] 1969). Those who are diagnosed with a contested illness and/or a Medically Unexplained Illness (MUI) are continually made to feel responsible, as their condition falls outside accepted medical truths and socio-political governance that grant legitimacy (Nettleton 2006:1167).

Butler's argument for dispelling political and social forces, which reinforce the myth of gender, can be used to investigate the myth of the healthy subject. Like Foucault, Butler emphasises the biopolitical regimes surrounding the body, whereby ethics of control categorise, regulate and maintain economic and social order. Similarly, the institutional domains that categorise identity – and thereby the sick body – are formulated by patriarchal powers. Therefore, Butler's theory offers a way to understand how social powers operate to produce categorisations that often work to marginalise those living with contested illnesses. This marginalisation has been identified by feminist writers interested in disability studies. Margit Shildrick, inspired by Foucault's genealogy, sought to ontologically map the web of power, which entrapped the disabled body. Her theorisations, inspired by her work with illnesses such as ME, explored the historical and political processes by which disability became a social entity. A number of feminist writers call for an ethics of vulnerability to illuminate the processes and practices of contested illnesses (Price and Shildrick 1998; Moss and Dyck 2003; Gilson 2013). As Shildrick and Price (1996) argue, the 'broken body' of illnesses like ME/CFS, is an opportunity for us to explore the fantasies that constrain our identities, where contested illnesses make it possible to observe the vulnerability of being outside the binary boundaries that define the experience of illness via the power of medical discourses.

2.2.6 Power of medical discourses

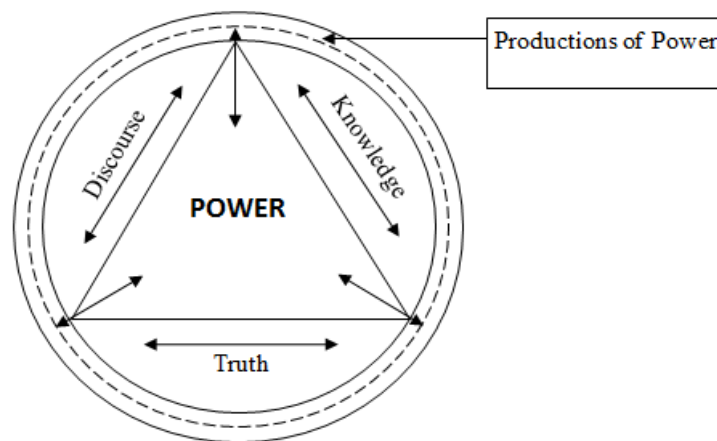
Social medical theories investigate the structures of discourse which form clinical and political institutions and thus inform society and culture about the meaning of illness (Mishler 1984). Paul Atkinson (1995) argues that medical discourses are based on a language of recognition which produces, challenges and redefines knowledge(s) to construct an accepted narrative. Medical research thus exists by validating evidence-based research methods. These methods of inquiry are the primary means by which illnesses such as ME/CFS are defined, labelled and become a psychological and/or pathophysiological truism. Poststructuralist feminists such as Debra Lupton specifically challenge how medical discourses create knowledge(s) and truths, arguing that the subject may not be separated from the practices which position them, as the subject's biography becomes entwined within medical discourses (Lupton 1994:160). In effect, the patient is in a paradox, as they experience a dependency on medicine to define the cause of illness and disillusionment when their illness remains contested.

Following Foucault, David Armstrong (1995) employed a genealogical lens on the discursive powers which manage the sick and his approach on TB was able to document the rise of surveillance medicine which has created a normative structure of what is meant by health and illness. Docile bodies are moved from 'compliance' to 'concordance' as medical logic embraces the expert patient, which leads to the question what happens to bodies who cannot be coerced into good health, namely the long-term severely ill. Bryan Turner states that human beings 'have bodies and they are bodies' (1996:37). This reflects the emergence of social theories which discuss the effects of a somatic society, where the body is both an object of enquiry and a symbol of political and social control. For Turner the body is a site of corporeal uncertainty, where issues of ontology are mapped between the complex relationships of discursive management and the social role of the citizen. Turner suggests that, with the decline of morbidity rates within western society, we have seen an ageing of the nation and a prevalence of chronic illnesses, which conflicts with society's demands for the body to remain healthy (Turner 1996).

Medical sociologists interested in contested illnesses have challenged the medical and political systems that discursively constitute particular illness behaviours as a social deviancy (Conrad 1992). This arguably, situates the disabled, or what may be described as a disordered body, as passive and malleable. Post-structural theorists concerned with chronic illness suggest that contested illnesses offer a view of what could be described

as the ‘leaky body’, trapped within the discursive practices and the material experience of illness (Shildrick 1997). The vicissitudes associated with ME/CFS allow us to ponder the fact that all our bodies are unstable and ultimately ‘unknowable’. In relation to her own experiences of living with ME, Price’s desire to know and read the body as a feminist, in order to take control back from others, demanded that the instability of the body be silenced – a fantasy that cannot be sustained when illness has taken up residence (Price and Shildrick 1998:243). Equally, Moss and Dyck (2003) focused on the issues of the material and discursive practices of what they term ‘radical body politics’. Their approach takes into account Foucault’s approach, which decentralises the subject and centralises the notion of power and knowledge. These accounts of living with a chronic illness such as ME are useful in acknowledging the discursive disciplines that actuate how specific bodies are controlled and managed by a play of dominations which, through processes and practices, situate self, subjectivity and identity (Grosz 1994). As Price and Shildrick state, in their moving accounts of being disabled (living with ME) and non-disabled, ‘it becomes clear that vulnerability is not the special case of disabled people, but the condition of all of us’ (1998:246).

Diagram 1 – Discursive Turn



This section has identified a discursive view that demonstrates how power is reflected through discourse, knowledge and truth. This calls to mind Foucault’s dispositif that accounts for the social structures which produce an epistemological foundation for governing and constituting the subject through language.

2.3 Philosophical reflections on materiality

This section of the chapter moves from Foucault's epistemological approach to ontologically conceptualise the act of being ill. The nature of a severe chronic illness means that it affects the sensory modalities of human existence and can, through the reality of suffering, subordinate the discursive model of language. The physical pain displaces that which is known, the intensities of pain and suffering causing language to maybe become momentarily lost. How is it then possible to explain long term suffering? How is it possible to confront, live and survive with an impaired body? While Foucault employed a genealogical lens to understand the mechanisms of power, Deleuze and Guattari (Deleuze and Guattari [1980] 2004) utilised the rhizome as a conceptual tool through which to amalgamate the multiplicities of desire that constitute life. For them, existence moves in and out of discourse, with no walls or divides, a flowing system. These two approaches can be used in a complementary way to explore both the rigidity and the fluidity of power that is governed by forces of desire, in which an illness can be constituted as contested at the same time as being severely and physically experienced.

2.3.1 Critically mapping subjective experiences

In *Difference and Repetition* (2012 [1968]), Gilles Deleuze (1925-1995) builds on mathematical concepts to map out multiple capacities for the continuous process of 'becoming', rather than the journey to the destination of 'being'. For those who live with a chronic illness, change is constant through physical suffering. While for ME in particular, the capricious nature of the illness means the process of becoming is more problematic, as the stability of the diagnostic label and symptomology are both difficult to stabilise. Deleuze extends his work on becoming in his two volumes with Felix Guattari (1930-1992) on 'Capitalism and Schizophrenia' comprising *Anti-Oedipus* (Deleuze and Guattari [1972] 2004) and *A Thousand Plateaus* ([1980] 2004). Guattari, a trained psychiatrist and radical activist, explored mental illness and worked with Deleuze to counter psychoanalytical myths. The dense and often difficult concepts they developed offer ways to understand the productions of desire, to make materialist connections between identities/entities and selves/bodies, and may be employed in the ontological abyss where actions and words are intimately related (DeLanda 2002).

2.3.2 Conceptualising desire

My reading of Deleuze's philosophy of immanence sees thought as part of a force, as a flow or movement where reality comes via an active process of becoming. Deleuze questioned Kantian views on pure reason and argued for going beyond the

epistemological basis of rational thought. Foucault identified the historical constructions of categories and processes through which power exists in the present. Deleuze and Guattari's work, however, explores the relational practices by which the processes of logic produce particular realities. As with Foucault's genealogy that mapped the constructions of a particular phenomenon, Deleuze worked from the premise that all matter creates difference, which leads to repetition. He applied a machinic assemblage to the flows of energy and exposed not a passive but an active process in the continuous unfolding of life.

While Foucault's genealogical approach is useful for tracing the emergence of a contested illness such as ME, Deleuze and Guattari use the concept of the rhizome as an anti-genealogical approach as '*a map and not a tracing*' process (Deleuze and Guattari [1980] 2004:13). The act of mapping refers to productions rather than reproductions; it can constitute the continuity of reality and the unconscious. Importantly for those with severe illnesses it could be argued that the nature of suffering is in a constant state of flux, giving rise to different strata of multiplicities, so that rhizomes may produce different ways of surviving embodied pain. These multiple dimensions produce codes of survival, through a process of becoming detached, reversed, modified, torn, reworked or mounted on, by an individual or social formation (Deleuze and Guattari [1980] 2004:13). The uncertainties of diagnosis and suffering which typify the disruptive nature of ME constitute multiplicities, which are not only associated with the contestation and confinement associated with ME and severe illness, but also the paradox of accepting the physical confines of pain and escaping through the sensory world of the imagination.

Deleuze developed the notion of multiplicities in his early works on the *Logic of Sense* (1969), as energies that are non-linear, not necessarily sequential, always workable and hold an active capacity for lines of development to produce affects as with the management/living with a chronic illness. Deleuze suggests that this notion of multiplicity has been used in Foucault's work, such as *Archaeology of Knowledge*, whereby the 'discursive order of places and the position occupied by the subject' correlates and connects to 'the statement and the subject', which he sees as a possible multiplicity in action (Deleuze [1986] 2006:10). Equally, those with a contested illness such as ME, may continually be forced to search for the discursive stability of a label/diagnosis that offers the subject a positioned identity. He further states that the *Order of Things*, the processes through which scientific structures produce the episteme

enabling knowledge to constitute the conditions of possibility, ‘represents the most decisive step yet taken in the theoretical-practice of multiplicities’ (Deleuze [1986] 2006:13). It then follows that any situation, event, movement is as an assemblage of multiplicities. Foucault’s use of a *dispositif* [apparatus] is similar to that of Deleuze’s notion of assemblages [arrangements] as both comprise diverse strata. Deleuze employed his concept as a means of reference for the dynamics of desire to include the expressive material response of life:

On the one hand it is a *machinic assemblage* of bodies, actions and passions, an intermingling of bodies reacting to one another; on the other hand it is a *collective assemblage of enunciation*, of acts and statements, of incorporeal transformations attributed to bodies. Then on a vertical axis, the assemblage has both *territorial sides*, or reterritorialized sides, which stabilize it, and *cutting edges of deterritorialization*, which carry it away (Deleuze and Guattari [1980] 2004:97-98).

In relation to severe illness, the bedroom, the bed and the bedridden can be seen as an assemblage necessary for survival. However, these do not represent the totality of a life of severe illness; these are parts, not determinants, as the capacities are always relational (DeLanda 2002:67). In other words, the capacities are always transient and in process. Deleuze’s idea of singularity identifies the possible decisive points where change occurs. In relation to those with severe illness, these singularities may be seen as the active responses to the subjective experience of pain and fatigue. The combined singularities constitute the multiplicities of a moment, an episode of suffering, where the sufferer is not passive but takes an active response to becoming bedridden. This may not be directly connected to, but is affected by, the multiplicities of the social world beyond the doors or windows of the bedroom. Actions are, therefore, relational, affected by the perceptions, beliefs and actions of self and others. This reflects the affects and effects of objects and subjects. So, it could be argued that, although not engaging with the social world whilst bedridden inside a bedroom, one is nonetheless affected by the social multiplicities beyond the space of the bed. This then describes how movement is part of actual and/or virtual multiplicities, while the intensities differ and reflect the flows and flux of energy, constituting a particular materiality by which a life can be lived with embodied suffering. DeLanda offers a point at which to develop a new material ontology by synthesising connections between past and present memories, the cyclical return that binds and stabilises both traditional ideas for the subject and the

desire that metamorphoses that which may have no name, such as the symptoms of illness which rupture the previously known self (DeLanda 2002).

2.3.3 Employing a particular reading of the concepts of desire

The schizophrenic approach in *Anti-Oedipus* could be said to craft connections between what Foucault thought of as power and Deleuze and Guattari as desire. Yet, the notion of the desiring machine can be used to understand life with a chronic illness, as it is based on two concepts – desiring-production and social-production. These are used conjointly in systems such as capitalism, which encourages us to be a labouring workforce that continues to produce energy, so that we are valued as machines through financial rewards. This sparks the psychic desire to live outside of the body's confines and adhere to the social norms of the work ethic. Pleasure is based on psychic energy and demonstrates how social productions work to manifest desire, ranging from the individual need to be healthy to work and be part of the institutions of the family, the workplace, the hospital. The rise of TB during the 19th century and Yuppie Flu in the 20th century demonstrates how illness affected the means of production and confounded social norms.

As a desiring machine, a severely ill subject may not always be able to put into language the experience of illness. The psyche and social productions can drive the body to work beyond its capacity, as the supply of energy strives to disrupt and distribute, to work and rework 'the productions of consumptions', to feed the endless demands for interrelated actions and passions within the desiring machine (Deleuze and Guattari [1972] 2004:4). Importantly, these actions distinguish all types of energy forces whether animal, plant or the environment. This approach takes into account the purity of life where all forms are bound by binary laws of flow-producing forces and desiring productions. For the unhealthy ME body, energy input and output becomes disrupted, while the inability to manifest a social self and manage the body under attack causes the sufferer to experience a draining of their life force.

For Deleuze and Guattari, the human body has the capacity to represent all living organisms as it can affect and be affected. Deleuze's early reading of Antonin Artaud's (1948) notion of a 'Body without Organs' (BwO) in *Logic of Sense* (1969) was further developed with Guattari in terms of the production of desire. This is not necessarily connected to an actual body, as BwO offers a means to envisage the state of constant flux within and outside a body. It refers to organisms, an organ which has no

boundaries, which has the capacity for continuous change and the potential to venture into spaces. In its simplest form, it is an essence of different intensities and rests on assemblages that produce different affects within the fields of immanence and the state of continually becoming. The BwO cannot escape the psyche; it is not about the lack, as in psychoanalysis, rather it is tied to processes of production and is the opposite of lack. Shildrick suggests that with a disability, as with sexuality, the focus should not be on parts of bodies, or disabled or able bodies, but rather upon ‘the process of becoming that is often an unmapped circulation of desire’ (Shildrick 2009:135). My reading of Deleuze’s BwO is that the synthesis constitutes a particular mode of production and requires an infinite analysis that is part of and may be included in the body, which is always occupied and populated by intensities. Importantly, the BwO ‘is not space, nor is it in space; it is matter that occupies space to a given degree’ (Deleuze and Guattari [1980] 2004:169). The BwO could be said to personify the desire for the perpetual becomings that is life itself – it is the raw existence of life, the matter that rests on the plane of consistency. Fox (2011) takes up the BwO to account for how ill-health is an assemblage that is attached to various networks that include biological, psychological and sociocultural relations. He argues for biomedical approaches to move the focus from within bodies, to explore embodiment itself, the ontological aspects that shape the ill body, not as a separate entity, but as a living cell without boundaries, a ‘Body without Organs’ that is based on *assemblages*, and consistent *territorialisation* (Fox 2011:359).

Fox’s (2002) notion of refracting health in terms of the body/self - examines the dynamic tensions that exist between cultural practices and embodied subjectivity. He focused on the effects of anorexia, which can be seen as a psychological issue that produces physical effects. Both anorexia and ME may cause particular singularities through which to escape the imaginary or physical confines of pain. The multiplicities of physical limitation, such as being confined to the bed, may mean that outside stimuli will be used to deterritorialize from the incorporeity of pain, of the shame of being bedridden. This may suggest a role for the virtual aspects of the self, in order to excite memories that will offer a way to escape the reality of pain and open up new possibilities for surviving life with a severe chronic illness.

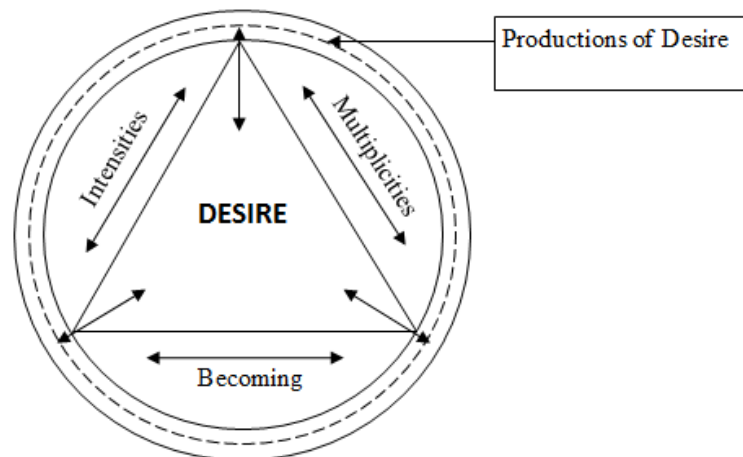
Deleuze’s materialist stance creates an ontology of the relationship between repetition and difference. Repetition of time and structure produces difference via the notion of habit, which leads to assumptions which produce what he terms *larvae selves* (Deleuze

[1968] 2004). In contrast with Foucault's use of the inscribed subject, larvae selves are made up of miniature egos that can be part of material as well as constructed notions of reality. Equally, Freud used these excitations, or energies, in a systematised way (Freud [1912-1938] 1984). For Deleuze, egos fragment the meanings associated between I and self (Deleuze [1968] 2004:320). Like Proust (Proust [1913] 2014), Deleuze demonstrates how the relationship between the past and the present reveals the cyclical nature of time. Repetitions ignite sensory evocations, where actions or memories in the moment can produce a passion linked to the past, while a rupture that breaks through anew produces difference within what is termed empty time (Deleuze [1968] 2004:136). A chronic illness is continually rupturing and moving, at times, in on itself, as the body in pain may be said to exist outside the constructions of time.

Deleuze's notion of the refrain, although often employed within music theory, may also be used in relation to the experience of chronic illness. The concept relates not only to the socio-political imperatives that produce the subject, but also to the ontological and aesthetic methods for producing the beginnings of order out of the forces of chaos. The refrain can mark out a territory such as a home, as well as suggesting lines of flight from that centre into the sphere of the cosmos (Deleuze and Guattari [1980] 2004:343-344). Deleuze's notion of the refrain denotes a relationship between the forces of chaos and the rhythm of life which is helpful in understanding the way in which those who are bedridden plug in and plug out of their social worlds.

Foucault offers a way to understand the dynamics of power that operate to produce the subject. Deleuze, meanwhile, allows us to explore the rhizomatic and interconnected nature of all experiences, people, bodies, events and places. For Deleuze and Guattari, it is not about the substance of matter but the assemblages and multiplicities by which forces unfold. The line of flight could be said to refer to 'the deterritorialization that carries away all of the assemblages but also undergoes all kinds of reterritorializations' (Deleuze and Guattari [1980] 2004:98). For those who are bedridden, the boundaries of the bed represent an imaginary circle within which they negotiate living in an internal space, while the forces of chaos are the continual occurrences of pain and suffering. The battle with illness takes place as those who suffer may search for lines of flight to escape the confines of the body in pain and find a passage out of what may be experienced as a 'black hole' (Deleuze and Guattari [1980] 2004:344).

Diagram 2 – A Turn to New Materialism



For Deleuze and Guattari the model of the rhizome demonstrates how different intensities and multiplicities activate particular acts of becoming. This diagram could be used to demonstrate Deleuze and Guattari's concept of an assemblage, as well as employed to understand the epistemological and ontological dynamics that identify the process of becoming.

2.4 Philosophical reflections on the narrating subject

This section will discuss particular theorisations of narrative that are pertinent to the research project, looking at how narrative is both a functional and communicative social tool. For both Foucault and Bakhtin, a life world produces a text. Meanwhile, language for Foucault and Roland Barthes (1915-1980), is based on a structure, a regulative device that signifies inclusion and exclusion of the author. For Bakhtin and Deleuze, language inscribes the subject through text and the dialogic apparatus of the linguistic and the institutional power relations. This takes into consideration the context in which one inscribes the self. Arguably, Foucault and Bakhtin consider the practice or the 'doing' of language, whereas Deleuze offers a way in which to explore the process of constructing a language of 'being' – which for Deleuze is always about becoming, as existence is in continual process.

2.4.1 A particular reading of Bakhtinian concepts

Bakhtin's concepts are important in informing any theorisation on narrative. His work on the interactions between time and space, the dialectic qualities of speech and

language and how storied selves produce a social, cultural and personal context, are all relevant in the context of this thesis. Their consideration allows for an understanding of what it means to portray acts of suffering and joy in the forms of both the spoken and written word and yet the focus does not disregard the stories that emerge from that which is unspoken. Bakhtin's concept of the chronotope provides a way to understand the relationship between time and space in narration. He recognised the temporal and spatial relations, which in literary novels are governed by particular genres, relating to an event or particular moment in which a story is told. Specific to chronotope is the positionality of the narrator – who speaks and when – such that the narration is always governed by context. For Bakhtin, foremost is the social and cultural context which governs memories, actions, speech and acts of listening and 'characterises the chronotope' (Bakhtin 1981:250).

Bakhtin goes on to suggest that the chronotope produces narrative events that constitute a particular materiality. He offers specific and heterogeneous ways in which to understand places on the journey of life, within time and space. Importantly, the chronotope is historically contextualised as it moves from one moment to another. Bakhtin critiques the figure of the ready-made hero in the majority of novels, suggesting that 'the aspect of man's essential *becoming*' is often ignored as 'events change his destiny... but he himself remains unchanged' (Bakhtin 1986:19-20). Unlike the literary hero, this thesis focuses on how the hero/heroine continually changes in the context of time and space.

Chronotopes have an interactive quality that is governed by the relationship of the reader to the text, or the relationship between the narrator and the listener in the case of spoken narrative. Bakhtin identified the links between language and materiality as a means by which the chronotope is able to facilitate the interactions between real and possible worlds, as well as mediating the relationship between self and other. For Bakhtin, the utterance is shaped by the object of discourse (such as illness) and the listener, displaying their belief systems and how this can be understood (Bakhtin 1986:17). An utterance is made by the subject and is produced in social and personal contexts, in relation to the situatedness of the subject in terms of others, objects and space. The author/narrator needs to convey to their audience the authorship of the utterance. With a contested illness, a storyteller may be aware of both the social stigma associated with their illness and the medical contestation affecting the presentation of their story.

Following Bury's idea of the 'biographical disruption' that is associated with chronic illness (1982), Gomersal and Madill develop the notion of chronotope disruption, which focuses on 'the grounding of biographical disturbance in time and space' (2015:408). They argue that a chronotopic analysis is useful for establishing connections and disconnections between the spatial and temporal situatedness of illness. The fusion that usually occurs in a chronotope is made problematic when one is chronically ill. The chronotope, in its endeavours to include both time and space, also takes into consideration cultural aspects not only in relation to illness but to all the fragmentations of life.

Rather as Foucault's genealogy concentrated on the interaction between history and language, Bakhtin's use of the term heteroglossia relates to the specificity of the relationship between utterance and context. He employs the term to account for the multiplicities of language, dialects and the associated qualities they have with various social groups.

all languages of heteroglossia, whatever the principle underlying them and making each unique, are specific points of view on the world, forms for conceptualizing the world in words, specific world views, each characterized by its own objects, meanings and values. As such they all may be juxtaposed to one another, mutually supplement one another, contradict one another and be interrelated dialogically. (Bakhtin 1981:291-2)

In this way, heteroglossia takes into account how language does not exist in isolation but is a product of and is constituted by context. For Bakhtin, language is always in relation to another, even when that other is the inner voice (Bakhtin 1981:xxi). In terms of heteroglossia, it is the layers of language, the dialogic qualities that reveal how, in the involuntary acts of language such as laughter, the parody of life can seep through. Therefore, stories that include the events that lead to the diagnosis and a life of chronic illness may not simply be conveyed in words, but also through actions.

Bakhtin's theory of language is useful in the context of this thesis as a tool to conceptualise the way in which language can be understood in terms of the historical and contextual disruptive aspects of living with chronic illness. In order to understand how heteroglossia can be used in terms of chronic illnesses, it is useful to make connections with Hyden's notions of illness and narrative as a particular amalgamation between languages and a specific community of speakers. When telling the story of

illness it is often recounted through the tension between a healthy and unhealthy subject.

Hyden states that:

Often the narrator vacillates between these two perspectives in one and the same illness narrative. To speak in the illness voice is to depict the illness 'from the inside', from the vantage point of the suffering person's ongoing situation. To speak in the illness voice is to identify with the illness and accompanying suffering. It is to talk like a person who is, in fact, 'ill'. To speak in the voice of the healthy is to talk about the illness as something extraneous, something that has invaded one's life from the outside; or also it is to talk about something that has been, something that had befallen one earlier in life (Hyden 1997:62).

In this way, Hyden highlights the capacity of narrative to depict the different voices that co-exist when conveying the unsettling experience of illness.

2.4.2 Performance and narrative

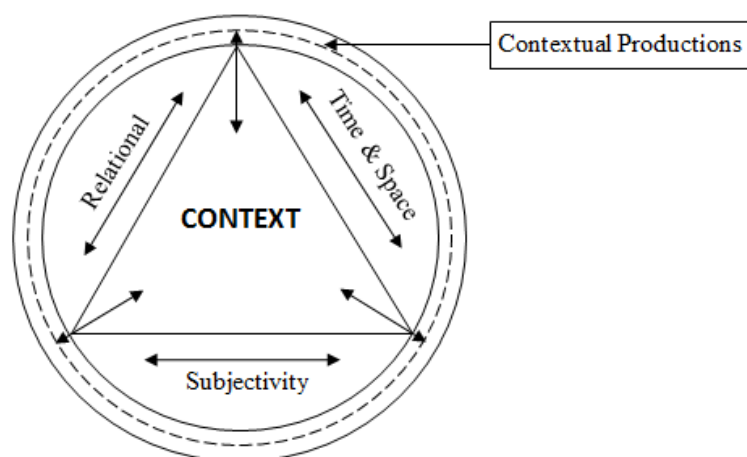
Bakhtin describes the carnival in terms of its historical manifestation as an oppositional display of medieval ecclesiastical and feudal culture, whereby the performer has the opportunity to live a kind of utopian existence for a moment when all things seem possible (Bakhtin 1984:4). Participation offered both the actor and the spectator freedom and release in the form of humour, akin to Bergson's notion of the parodies of laughter (Bergson [1911] 1999). This offered the possibility of living briefly as the other, resisting the boundaries of social and cultural hierarchy and morality and the realities of life. Ironically, severe illness may also allow the individual to step outside normal social roles, by presenting an opportunity to succumb to the desire to abandon the acceptable appearance of the social self. As with Bakhtin's aesthetic materiality of the grotesque, a space for unfinished bodies resides in a non-vernacular world, where a mask may be worn to juxtapose reality and imagery (Bakhtin 1984:40). With severe illness it could be argued that there are long periods of a kind of grotesque realism where it may not be possible to wash, get dressed or eat unaided. Although stories may depict this in a negative light, it could arguably be seen as a kind of carnivalised performance.

For Foucault, the constructions of subjects such as the madman, the prisoner and the patient are regulated by exterior powers and are discursively constituted identities. In a similar way, Butler's notion of the female highlights the difficulties of resistance when

a subject is captured and constrained by discourse and social practice (Butler 1993:15). Just as Butler identifies how we learn to perform normative cultural expressions of gender (Butler 1990:25), it is also possible to identify how we perform the role of the healthy subject. In a study of male illness narratives of living with Multiple Sclerosis, for example, Riessman demonstrates how performances of gender and illness intersect (Riessman 2002:11). The social requirements of performing as a healthy subject may weigh heavily on those with severe illness as they are loaded with moral and social values which dictate ‘civilised’ ways of being. For those who feel obliged to pretend to be well, performance can be seen in acts of monotonous role play.

For those for whom the performance of the healthy subject becomes impossible, the use of a proxy to fulfil this role may occur. Hyden (2008) discusses the problems of having an authorial voice in relation to people who have suffered an illness/accident. He notes the interaction between those who have lost or have no voice and a person who works as their supporting or ‘vicarious voice’, where the production of a self is made possible through another who acts as their storyteller. Hyden outlines how people with broken voices need a cohesive relationship with another person to reconstitute the self into an integral whole, as responsibility is shifted to the teller (Hyden 2008). The problems of giving a voice where one is absent must be acknowledged, but it is also important to consider how stories are never told but shared, through a collaboration of social and cultural knowledge.

Diagram 3 – The Dialogic Turn



The act of storytelling represents a way to connect the discursive material and subjective contexts of life. The above diagram identifies a dialogic approach which focuses on the importance of context and the relationship between time and space. The

dialogic relationship between self and other, between and within things, are brought together in a socio-cultural context that can be achieved through narration.

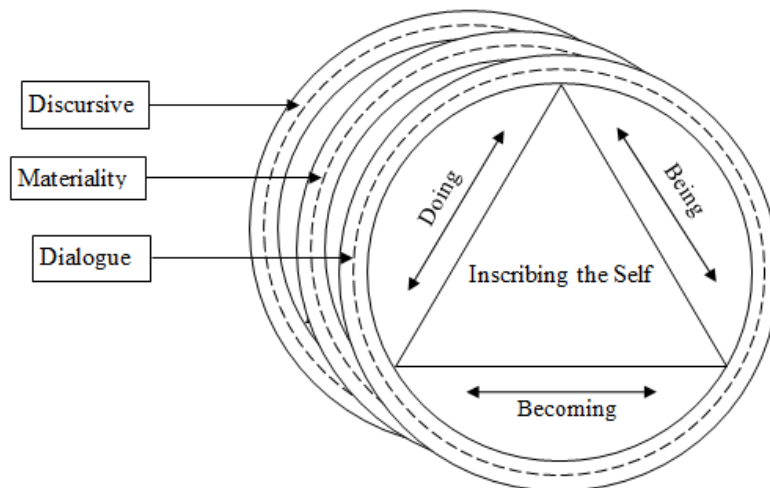
2.5 Conclusion

This chapter has focused on a number of key concepts in order to define and refine the research questions. In so doing, it has outlined the importance of considering a conceptual framework that can be used to investigate the reflective properties of the discursive, material and subjective context of living with a contested and often severe chronic illness. Foucault's *dispositif* reveals how social systems produce layers of discursive relations. Institutional regulative laws and moral codes form the structures of truth within which a contested and severe illness is experienced. The mechanisms that control the body are, therefore, seen to be discursively governed. By situating how language inflects the constructions of the subject, the notion of 'doing illness' can be explored in terms of how it is possible to gain resistance and reconstitute sickness norms. However, when looking at a long term illness that defies medical and social understanding, it is important to not only examine language, but also take into account the corporeal site of a sick body and the material conditions of illness. Deleuze and Guattari's concepts can, therefore, be used to facilitate a new materiality. Equally, theorising narrative offers a means to highlight the contextual and relational aspects of space and time in the storied self, which reveals how the subject is a political, social and cultural artifact made up of different and often internalised voices.

The metaphor of the kaleidoscope demonstrates how one slight turn can offer an alternative viewpoint. As with mechanisms of power which control technologies of the self, the formulation of subjectivity is rarely stationery. The complexities derived from multiple reflections show how control of the object/subject is merely suspended in momentary episodes where technologies of the self are woven within symmetrical socio-cultural patterns. Multiplicities of socio-cultural forms govern within particular political resolutions of power in time and space. Each turn of the kaleidoscope allows macroscopic and microscopic details to emerge, opening up the pathways between knowledge, truth and power. The kaleidoscopic enquiry enables us to examine genealogically the formations, discontinuities and complexities as multiple reflections, providing the opportunity to take a bio-psycho-social perspective, which incorporates the interactions of body, self and society. When taken together, the three turns of the

kaleidoscope explored in this chapter, demonstrate how the intersection of the theories mobilised in this thesis help us to understand the discursive, material and dialogic implications of living with severe ME. These aspects are embedded, embodied and inscribed in the acts of becoming diagnosed with a contested illness and living with the severe symptoms of a chronic illness such as ME.

Diagram 4 – Kaleidoscopic View



My aim has been to develop a framework that will refine the research questions:

- What it means to have a ‘contested’ and often ‘severe’ chronic illness?
 - How does the process of gaining a ‘contested’ diagnosis affect the practices of doing ‘severe’ illness?
 - How do these practices intersect with the process of being ill?
 - How may life experiences help us understand these issues?
 - How is it possible to give depth of meaning to the everyday experiences of surviving with ME?
 - What dilemmas, contradictions, conflicts and/or acts of resistance work to constitute surviving chronic illness?

Chapter 3: Collecting Life Stories: Embodying a Contested Illness

3.1. Introduction

As discussed in chapter one, research in the field of social psychology has used narrative accounts of living with ME/CFS to explore ‘meaning making’ and ‘contestation’ (Horton-Salway 1998; Horton-Salway 2001; Bulow 2003; Tucker 2004), while social medical studies (Cooper 1997; Clarke 2003) have used narrative to employ discursive approaches to illness, health and self-identity, focusing on memory and attitudes to illness, rather than asking how illness is experienced through power and discourse. This study builds on previous social research in four ways: through recruitment, method, analysis and reflexive procedures. First, recruitment was centred on those who had experienced severe symptoms of ME/CFS and had been formally diagnosed with ME and/or CFS or ME/CFS. Second, a biographical approach combined with photo elicitation allows for consideration of the social events and contingencies embedded in how illness is negotiated, and offers an opportunity to represent and reflect on the dilemmas of becoming diagnosed and living with a contested illness. Third, the analytical approach seeks to examine the production of text and the art/act of narration, which opens up the possibility for new epistemological and ontological understandings of the social processes that produce and construct the diagnosed ME/CFS subject. Finally, my reflection on the challenges of being both researcher and participant in the study offers new insight into insider-outsider positions.

This chapter outlines the primary aims of the research and gives an account of the methods and the processes of collecting and analysing the narrative and visual material. I argue that this thesis offers one particular hermeneutical reading that is both activated by and produced within the process of the research. A short account of illness narrative and life story approaches is offered and an explanation for the inclusion of visual methods in social research is provided. I also describe the recruitment and research procedure, including the conducting of interviews. Nine participants were visited three times, once for the life story interview when cameras were also given to participants, a second time to collect cameras and a third time to conduct interviews based on their

photo-elicited diaries, totaling up to 30 hours of interviewing. I present a rationale to substantiate how analysis will be carried out, outlining case selection and the reason for highlighting the four cases in Chapters Five, Six, Seven and Eight. Finally, the ethical issues that arose in relation to the process of interviewing people with chronic illness are discussed.

3.2 Attending to the research questions

The purpose of this research, as discussed in Chapter One, is to investigate how the sick body is produced and how the chronic illness of ME/CFS is constituted. Chapter two refined and narrowed the research questions by considering the discourses and social practices that produce multiple uncertainties and contradictory subject positions for those negotiating a contested illness of this nature. The analysis is focused on the complexities that exist for healthy and unhealthy bodies from childhood to adulthood, exploring the multi-layered connections between the personal and political uncertainties of becoming diagnosed and living with the effects of chronic illness. While previous illness narrative studies provide insight into the experiences of living with a contested illness, they often sideline past events and experiences, focusing instead on illness as the experience. This obliterates the processes of constructing narrative subjects that discursively develop and change over time, producing and constituting subject-positions within the context of power and ideology. The nature of narrative research is that questions are consistently revisited; clarifications are therefore made at the end of data chapters. The stories are individual experiences, personal stories, the researcher's particular interpretations in respond to the research questions are then standalone accounts and where possible similarities and differences are drawn from each of the life stories.

3.3 Oral and Visual narratives

This section defines oral and visual narrative approaches as a method of meaning-making and accounting for practical implementation of these methods. In particular, this section focuses on two particular narrative approaches, illness narratives and the life story approach. It also includes an account of visual approaches as a supplementary tool in narrative research.

3.3.1 Oral narratives as meaning-making

Narratives are universally used to document human experience. We tell stories through visual, written or spoken *re*-presentations in many forms, including painting, fables, news articles and conversation. In the last four decades, due to the inherently interdisciplinary nature of storytelling, a wide narrative research community has been developed, generating various approaches to the accessing and processing of stories. The traditional socio-linguistic perspective of Labov and Waletzky (1967) offered a systematic approach to the analysis of socially mediated acts of language, by proposing a six-part model to understand the classic plot of personal narration, with a beginning, middle and end. Although oral storytelling tends to adopt a sequential and spatial structure, other forms such as conversational storytelling may interrupt the temporal order (Riessman 2008). In narrative studies, the emphasis is on ‘exploring the different and sometimes contradictory layers of meaning, to bring them into useful dialogue with each other and to understand more about the individual and the possibility for social change’ (Andrews, Squire et al. 2008:4).¹⁸ The multi-layered environment provided by storytelling invites a reading of the socio-cultural and institutional practices that constitute the ‘coming-into-being’ and ‘belonging’ to narrative identities (Bamberg and Georgakopoulou 2008:184; Yuval-Davis 2011). Kathy Riessman (2008) addresses how the act of storytelling reconstitutes past experiences through discourses and social practices, makes truth claims and operates emotive and imaginative modes to engage and entice the audience to listen/read. Stories are by nature co-constructed, interactive and fluid. In particular, the social interactions involved in storytelling offer an opportunity for communities and individuals to seek social change (Riessman 2008).

Narratives are defined by signs, symbols, and a semiotic milieu recognisable within particular social, cultural and historical contexts (Squire 2012). Critics of narrative research tend to argue that imposing a functional framework for narrative onto the closed act of storytelling which may diminish the messy complexities of life experiences (Frosh 2002; Craib 2004; Cowen 2009; Squire 2012). However, stories offer a medium through which ‘moments of exceptionality can often be recognised in even the most conventional narratives’ (Squire 2012:7). Squire (2012) counters with others these that a growing body of narrative research has sought to highlight ‘the incoherence, the intrinsic multiplicity and contradictions of stories’ (Hyvarinen, Hyden et al. 2010). By

¹⁸ Narrative research seeks to identify the multiple meanings and interactive co-constructive nature of storytelling (Elliot, 2006, Mishler, 1995, Polkinghorn, 1988, Riessman, 1993, Squire, 2008), within psychology (see Sarbin, 1986, Crossley, 2000), Psychoanalysis (Freeman, 1993), health care and clinical practice (Greenhalgh & Hurwitz, 1998, Hyden & Brockmeier, 2008, Mattingly & Garro, 2000).

applying a multi-layered approach to analysis, including an intertextual reading, narrative research offers the possibility for an open-ended and interpretive reading to the productions of text, in relation to how and to what extent contexts are made meaningful in relation to the purpose of a particular study. The function of language is dialogical, with discourse being shaped by linguistic structures consisting of both internal and external voices, the limits of meaning and interpretations, bound by context and relativist interpretations (Bakhtin 1981). The construction of narrative is, therefore, a production of semiotic realities that identify Self and Other. This inductive approach exemplifies language as the means to constitute the self and understand the social world and possible futures, as opposed to the deductive methods that quantifies phenomena and becomes representative of a populace (Flick 2006).

Within the narrative genre, subtle differences have been offered between event-centred and experience-centred approaches to personal narratives (Andrews, Squire et al. 2008). The latter offers a broader means of understanding the intertextual processes that produce fluidity, multiplicity and uncertainties and thereby constitute multiple realities rather than one particular truth in the act of storytelling. In the realm of illness narratives, Mike Bury's (1982) concept of 'biographic disruption' has become an important way to account for how the cognitive and materiality of suffering and pain is affected by the socio-cultural and political contexts.¹⁹ Gareth Williams' (1984; 1993) builds on Bury's work on employing narratives as a means to expose the disruptive nature of chronic illness. Williams then goes further to discuss the re-negotiations of being ill which disrupt the telos of what it means to be human (Williams 1984). Williams focused on how biographical disruption is made meaningful, revealing the intersections between body, self and society that is fragmented and reconstituted with the experience of chronic illness. Illness narratives are therefore a useful method to explore the interrelations between medical practices and the patient's ever changing embodied experience of illness (Mishler 1984; Charon 1986; Kleinmann 1988; Frank 1997; Mattingly 2002). Arguably, the medical practitioner's reductionist approach pathologises the body, causing the voice of suffering to be made silent. In this way, the illness narrative approach may offer an opportunity for people living with severe illness to speak about the '*unspeakable*' (Squire 2007:193).

¹⁹ Mike Bury (1982) study on people experiencing Rheumatoid Arthritis, a chronic illness to account for the fluctuating symptoms and uncertain outcomes associated with negotiating chronic illness were made meaningful within different contexts as cognitive and material experiences associated with pain and suffering were negotiated.

Narrative researchers have employed multiple approaches to investigate the issues that shape subjective understandings of self and other, such as the Biographic Narrative Interpretative Method (BNIM), which adopts a semi-structured approach, not limited to the researcher's own interpretations of the data but discussed within a panel (Wengraf 2001). Content-based approaches to narrative, such as Interpretive Phenomenological Analysis (IPA), take a relativist approach to the storied self (Eatough and Smith 2008), while and social constructionist approaches tend to use rigorous inductive procedures to substantiate particular social phenomenon, such as chronic illness (Charmaz 1993; 1999). Narrative approaches can also work alongside different perspectives as with Maria Tamboukou's (Tamboukou 2003a) Foucauldian genealogical perspective which brings together the epistemological and ethnological aspects of life writings (Tamboukou and Ball 2003; Tamboukou 2003b). In Molly Andrews's (1991) life history research on political activists, events and experiences are seen to coexist in the making of biographies. These latter approaches bring in notions of 'life history' and 'life story' methods (Atkinson 1998), which have subtle differences. A life history may be said to locate life experiences within an historical perspective and tend to include extensive interview periods (Sandino 2007). Ethically, this approach would not be appropriate for those who suffer from long-term chronic illness. What is arguably retained within the life story method is a framework of biography, history and society (Harrison 1996). Jerome Bruner (1986) sees narratives as structured and organised by memories which account for events and experiences that help us understand ourselves, communities and cultures we live in. In this way, the life story has become a fundamental tool within various disciplinary settings, from sociology to anthropology and from medical to psychoanalytical studies (Atkinson 1998). The life story provides multiple propositions to describe life events, moments where the productions of meanings may be drawn and provide a socio-historical context to understand life experience (Hatch and Wisniewski 1995:7). The main principle behind life story method is that these oral histories encompass the social and political implications of the shifting boundaries between the self and the other, past and present (Stanley 1994).

The importance of autobiographical and biographical approaches for social research is, therefore, important in terms of the complex ethical issues involved when addressing the somatic conditions which marginalise and hail the sick body as disabled (Couser 2009). The pathological nature of illness and/or disability may be the impetus for life writing which confronts the boundaries of disability (Zola 1982), and the female

disabled/body (Mintz 2007; Carel 2008). In this way, ‘lives can be understood, revealed and transformed *in stories* and by the very *act of storytelling*’ (Sandelowski 1991:163).

3.3.2 Visual narrations: An additional layer of meaning-making

Photographs bear witness to life and play a valid social role (Harper 2002; Holliday 2004). As Bourdieu (1990) suggests, photographs are reflections of our ontological needs, capturing who we think we are and how we want to show ourselves to others, as in family albums. Photographs prove our existence and, although they may easily be manipulated and altered, the power of photography to detail and record events is valued in contemporary society, as modern conditions reify and represent social life through the spectacle (Debord [1967] 2004). Arguably, photographs may be detached from temporal existence, yet embody a life and/or event that has been lived.

Within the social sciences, no definitive method has emerged for the analysis of photographs. As with social research in general, the main focus for using photographs is to offer a view of ‘everyday life’, to account for social practices and actions that frame knowledge and understanding about self and other (Harrison 2002:97). As such, although the practice of using cameras has been prolific within western societies, social research has tended to privilege the spoken/written word, using visual material as supportive and/or supplementary to the textual (Rose 2007). Yet visual material goes beyond the spoken and written to convey what is valued and provides a useful and reflective way to reveal the ambiguousness of life. Illness is experienced subjectively and is not always verbalised, therefore images may elicit further information (Harrison 2009). Images operate within power structures and what we see are visual ‘functions of representation’ (Dreyfus and Rabinow 1982:24).

As with narratives, the photograph is either part or the whole of a temporally ordered story. Barbara Harrison (1996) has investigated the symbolic meaning within domestic family shots, analysing the production of the images and the intertextuality of the visual and the spoken word, in capturing the moment within practised, organised and socially regulated systems (Harrison 1996). For Barthes (1977), images remain imitations, as they can never produce the actual. The image is constructed through notions and thoughts – language is the framework of reference and provides the ‘rhetoric of the image’ (Barthes 1977). Meanwhile, Berger suggests that, as with artists, the photographer ‘plays upon the spectator’s sense of acquiring the real thing’ (Berger 1972:14). However, Susan Sontag asserts that images bring ‘material realities in their

own right' (Sontag 1973:178). Visual material can be understood as just one way of understanding life experiences, the key questions being: what is the content and meaning and how do images work in showing us how they live their lives?

Jo Spence's autobiography (1986) works with photographs as a means to narrate her life experiences. She uses a photo-diary to document becoming diagnosed and living with cancer, exposing the body not as an act of bravery, but as an 'absolute necessity' (Spence 1986:215). Indeed, Susan Bell's article on Spence (2002) suggests that the visual narrative has the ability to go beyond oral and textual accounts to enlarge and enrich experience (2002:5). Putting herself in the frame she was able to contest western science's expectations of the passivity involved in being a patient, attempting to break codes of representation and unmask the everyday normalised institutionalised practices associated with the representations of gender, family and the female body (Bell 2002). The images are a witness to her illness. Breaking codes of beauty and disease forces us to think how visual codes are used to make us fit for public consumption (Dykstra 1995).

Photo-elicitation originated in the mid-1950s (Collier 1957). Harper suggests (2002) that photo-elicitation reveals the 'polysemic quality' of images and is capable of 'decentering ...the authority of the author' (Harper 2002:15). He identifies one of the key preoccupations of photo-elicitation as identity, with illness an important aspect of this. He concludes that photographs have the ability to penetrate more deeply than 'words-alone interviews' as 'remembering is enlarged by photographs', while the photos themselves 'appear to capture the impossible' and 'retrieve something that has disappeared' (Harper 2002:23). However, it was Alan Radley and Diane Taylor's (2003a; 2003b) study using photo-elicited diaries as reflections upon a stay in hospital that informed my approach. Radley and Taylor asked patients during their stay in hospital, to take photographs of their environment. The resulting images were used as aids to trigger participant's memories and make sense of their stay in hospital, as they explained why they recorded a particular image and its relevance to them. This method has also been used to gain understanding of the challenges of living with illness where both the text and the visual make the invisible, visible (Radley 2009; Lorenz 2010; 2011). By including visual material the act of storytelling is able to incorporate the later reflections and productions of feelings associated with experiencing and/or recovering from illness (Radley and Taylor 2003a; 2003b; Frith and Harcourt 2007). This approach requires reflexivity from both researcher and participant, to account for what Paula

Reavey and Katherine Johnson (2008:312), following Latour (2005), call the multiple assemblages of ‘spaces, objects symbols and signs’. The abstract nature of visual imagery allows us to go beyond intellectual and social boundaries, to reach into the world of emotion, which is especially useful in relation to the embodied experiences associated with serious illness (Radley 2009).

3.4 Pilot Study

I conducted a preliminary study before my main research, to test areas of the research design, contextualise my conceptual framework and identify any practical issues for the target group. This pilot study compared two narrative approaches, namely illness narrative and life story methods. My only recruitment criterion was that the participant should have been formally diagnosed with ME (Fukuda, Straus et al. 1994). A purposive case sample of one male of 53 years, who I knew informally, offered to take part in the pilot and main study. The participant (pseudonym ‘Robert’) defined his disability rate as ‘moderate’ (Cox and Findley 1998) (Appendix IV). I conducted three interviews with Robert, one was based on the illness narrative design where I partially employed a Biographical-Narrative Interpretive Method (BNIM) (Wengraf 2001), second was a life story interview (Atkinson 1998), and the third was based on a photo-elicited diary (PED) as supplementary and supportive material for the life story (Radley & Taylor 2003a; 2003b).

The following excerpts are merely used to exemplify how different methods of interviewing may illicit different responses. Illness narratives are limited to the one specific viewpoint which tends to constrain the embedded nature of meaning-making, whereas a life story approach demonstrates the multi-layered aspects of life experiences that constitute how illness comes to be experienced and negotiated in the present. The final extract demonstrates how the visual material produced supportive data for the life story²⁰.

Extract Illness Narrative

Er I think erm obviously, obviously my biggest fear for the future at the moment is is losing my job, cos [...] I am fairly lucky that my, that my company have been have been fairly good with me about this. But, obviously if I lose my job there’s going to be

²⁰ The pilot study was based on an earlier interview with Robert.

problems financial paying the bills yeah I think everyone knows erm what the cost of living is like these days and it it and it's obviously rising all the time so yeah there is going to be is going to be a fear a financial fear and erm [PS1.10]²¹

Extract Life Story

Erm (-) I used to I I used to I I used to like work at that stage it was i-it was I used to enjoy g-going in to work cos erm we was involved with um stocks and shares and we ended up having a few shares ourselves so there was always er there was always there was always an added incentive going into work to see see if you see if you was making money or losing money and it was erm it was all quite buzzy (.) especially in the early stock broker days erm there wasn't the there wasn't the strict erm rules and regulations as-as-as there probably are now in the city after the af-after the the Nick Leeson affairs an-an-an-and things like that you know it was all it was all fairly um tut it was all fairly cas-casual we worked hard and when needed to work long hours but it was enjoyable and and you used to get rewarded um w-w-w-with the bonus schemes [T1.20]²²

(2) Um s-so you know so at present time I-I'm I'm actually I-I'm actually off o-on the um on the sick because um tut er the work place had been very good about it but but they th-they needed someone there all the time cos um obviously in my periods of um of sickness they had to get temps in and they'd train them up I'd come back they'd get rid of the temp and then two months later they'd be in the same boat again [T1.52]

Extract - Visual narrative (PED) of walking his dogs and household chores

Really that is a lot of what my day consists of unfortunately without going to work it's half hour to hour then resting you know CBT OT have pointed me the direction of this sort of life style it does seem to have helped a bit [T2.23-24]

The Biographic Narrative Interpretative Method offered an opportunity to build my conceptual framework and narrow down my key question for the overall study, while the life story and PED interviews stimulated renewed meanings on the negotiation of everyday life with chronic illness. The pilot study was an invaluable way to test the most appropriate method of interviewing a sensitive participant. First, I was able to discover that focusing solely on illness is reductive, ignores the complexities of personal experience and prohibits other stories of self from emerging. Second, the illness

²¹ PS abbreviation for Pilot Study

²² T abbreviation for Transcript; first number represents interview 1 or 2; latter number reflects the section number as seen in transcript.

narrative approach limited the flow of the vast psychological and physical aspects of dealing with a long-term illness. As illness is part a life story, life experiences influence how the illness comes to be experienced. The pilot study demonstrated, therefore, that the life story offers an opportunity to explore the range of human experiences, social practices and actions that impact on how illness may be experienced. The PED, meanwhile, proved to be a useful ethnographic tool, providing supporting and supplementary data to convey what is valued and assist people's reflective accounts of everyday life (Rose 2007:238; Harrison 2009). Until now, there have been no other studies which combine life stories and visual representations by people living with chronic illness and/or ME/CFS.

3.5 Generating narrative data

This section provides an account of the recruitment strategies and general characteristics of participation, including the issues of consent, selection criteria and sampling design. I explain the collection of interviews as a means to produce data not yet constrained by the research questions, as well as how material becomes data from collection to analysis. Finally ethical concerns are discussed in relation to the research process.

3.5.1 Ethical decision-making in the process of recruitment

Ethical considerations in the process of decision-making were sensitively adhered to in participant recruitment procedures. The target group were those under-investigated namely, those who are 'severely affected by ME and/or CFS. My initial plan was to interview participants in their own homes to provide an understanding of the everyday challenges of living with severe ME/CFS. At the start of the project I approached a leading consultant on ME, he was a principle administrator for the only dedicated ME clinic in the UK, at the Queens Hospital, London. UK²³. Due to his own experiences of diagnosing and treating ME/CFS patients, he was keen for severe accounts to be recognised (Cox and Findley 2000). It was agreed that, due to the ethical implications, no participant who was experiencing severe symptoms of ME/CFS would be interviewed. I then re-evaluated the sampling procedure to include those who had been diagnosed at some point with 'severe' ME and or CFS and were either in remission or recovering from long-term episodes of their illness. My recruitment strategy was driven

²³ This clinic had a six bed facility known as the ME ward, which was the only national unit treating the condition until 2011. Patients were often admitted as very severe cases and stayed for long periods. Their disability rates were defined by the unit and medical treatment, financial guidance and occupational therapy administered. The ward closed in 2011 and, by 2012, the clinic had closed and Professor Findley retired. At present the only replacement has been through the medical psychological department in Kings Hospital London which uses CBT therapies, not suitable for those who are 'severely' ill.

by the benefit of having an experienced Medical Advisor (MA) as a gatekeeper. Once these recruitment details were clarified, I applied for and was given ethical clearance by the ethics committee at UEL.

The next stage was for the MA to send email contact details of five of his patients that he felt would not have any adverse implications during the interviewing process. Although the MA offered access to participant sample and some guidance on selection procedures during the early stages of sample selection, the MA had no connection to the actual data collection process and final research outcomes. Throughout the design and planning stages of this study consideration of participant's general well-being and sensitivity to their needs was of paramount importance. In this way I felt that potential ethical problems were avoided.

Nine participants, two males and seven females were recruited; this ratio proportionately reflects the gender imbalance for people diagnosed ME/CFS within UK, USA, Canada and Australia (Carruthers, Kain et al. 2003). Five participants were recruited via the MA, three via snowballing and a self-interview was included. Participants were not selected based on their gender, age or socio-economic status. The only criterion was that they should have been formally diagnosed with ME/CFS and fulfilled the disability rates of either mild/moderate or severe (Cox and Findley 1998) (Appendix IV). Interviews took place between 2009 and 2012.

Predominantly, recruitment was from two different geographical locations; from what may be described as a working class region of outer London and a largely middle class county on England's south coast. Participants' ages ranged between 23 and 55 years. Occupations were either within the financial or educational services, referred to as the 'service class', with one participant unable to take part in paid work for the majority of her life. At the time of the interview, two male and four female participants were unemployed due to the severity of their illness; while three worked part-time, one within the financial sector and two within the educational sector. Six participants had partners (three of whom were married), two were single and one remained undisclosed. Any other details relating to participants' income, housing circumstances and educational qualifications were left to individuals to disclose as part of their stories. In some interviews, these issues were not raised at all. The selection of participants could be seen as a 'convenience sample', based on accessibility (Bryman 2001:97). However,

other sampling methods such as ‘probability’ or ‘random’ sampling would not have been ethically viable for interviewing such sensitive cases.

My sample is not representative of the heterogeneous ME/CFS population, it offers credible and transferable accounts that may be defined as dependable sources of information as to how individuals come to be diagnosed and negotiate a chronic illness of this nature.

3.5.2 Logistical decisions for interviewing

Participants were briefed about the aim of the project prior to the interview and, at the start of the interview, given an information sheet and consent form (Appendix V), outlining the collection of research material for publication and guaranteeing anonymity²⁴. I used pseudonyms to protect participant identities, but the name of the clinic referred to by many of the participants has been retained. I ensured that ethical principles were followed in regard to the ways in which the life stories and photo-elicited diaries were gathered. I have previous experience of conducting qualitative empirical work at the University of East London and am, therefore, aware of the ethical implications of doing research involved with human subjects. My justification for employing participants in the study was to improve knowledge and understanding on the everyday life experiences of people living with ME/CFS. As participants were not being recruited via public clinics or hospitals no medical ethical approval was required from these institutions.

The pilot study offered an opportunity to test not only my narrative approach and logistical procedures, but also the ethical issues of interviewing people with a chronic illness. As a researcher, this early experience allowed me to prepare for the possible intrusive effects of researching participants with health limitations. Participants were reminded that there was no obligation to speak and that if they felt the process was becoming too intrusive the interview could be stopped at any time. Information regarding private details has been stored in a secure location until the completion of the research.

My pilot study gave me the opportunity to test the most appropriate interview setting. As part of being sensitive to individual needs, each participant was offered the

²⁴ These were approved by the Ethics Committee in the school of Law and Social Sciences at the University of East London.

opportunity to choose the location of the interview. Six interviews were conducted in the participant's home the rest were at a private setting of my choice. To record the interviews a digital voice recorder was placed where the participant felt most comfortable. In most cases, I would set up the participant in a reclined position, where cushions were placed behind their back and under knee joints to hold their body for support. I sat adjacent to them, often mirrored in the same position to put them at ease. Participants had control of the recording time and at any stage the participant could stop the recording.

The nine participants were interviewed for nearly 30 hours in total and all but one of the participants was interviewed twice. The shortest life story interview lasted 51 minutes and the longest took one hour and 50 minutes. The last participant interviewed was following a strict therapeutic regime and was only able to speak for 10 to 15 minutes at a time, with breaks of up to 20 minutes. In retrospect, this style of interviewing might have been more appropriate for all participants, as the physical demands for some were apparent once the interview had been completed. The majority of participants preferred semi-structured questions, as many referred to cognition issues. The gap between the life story and PED interviews ranged from two months and a year (due to the participant having a baby).

I recorded my self-interview during a severe relapse in 2009, as I believed that completing my life story whilst experiencing the severe symptoms of ME would help to shed light on how past social practices/events were inherently linked to how I coped with the struggles of living with severe illness in the present. Additionally, during this bad episode, not concerned about my own anonymity, I took photographs of myself and my assistant (who completed a consent form) (see Chapter Four). At the end of each interview a debriefing session was completed in order to assess how the participant felt about the interview and if there were any issues that needed to be further discussed.

[3.5.2.1 Interviewing approaches](#)

Life story procedure

Narrative interviews offer the storyteller the opportunity to set the scene, outline the plot and social relations, to draw the listener into their particular view-point and thus produce a narrative performance which can lead to multiple readings (Riessman 2008). Although, the point must be raised that the nature of narrative interviewing is to observe multiple voices, not 'to give voice' but to 'hear a voice' in the act of research (Riessman

2008). The storyteller may have a particular agenda and use the interview as an opportunity to air views on medical interventions and their personal acceptance of illness. I adopted a life story interview approach which used chronological mapping, incorporating childhood, teenage and adulthood years, and questions were based on life history interviewing guidelines (Appendix VI) (Atkinson 1998). However, all participants were encouraged to elaborate and expand on points that were raised. This meant there was often a digression from the chronological progression and in many cases participants would refer to more current experiences. My opening question was: ‘what are your earliest memories as a child?’ These early memories produce emotional and relational accounts, connected to the negotiation of home and educational spaces. Such memories may seem distant from the research question, but open a world of meanings and justify the life story approach. By framing the phenomenological question ‘how did that make you feel?’ the challenges of the sick role and inhabiting illness identities were further interrogated. At the end of the interview, many of the participants would sit or lie and rest. During this time we often continued to speak about their illness experiences. If they wished to add further information I included these additions, as these unrehearsed repertoires allowed the participants agency, as they reengaged with their story often leading to insightful commentary. These *additional reflections* were included in the analytic procedure.

I also recognise that the process of telling is selective, based on imaginative recall and recounting, with no right way to recount a story (Bruner 2004). It became apparent at the end of one of my interviews that the digital recorder had become disconnected. When the participant gladly agreed to repeat the interview, we both realised this story was very different to the one she had told previously. She declared, ‘I think my first interview was much better, I think I have forgotten things’ (taken from field notes).

Photo-Elicited Diaries

At the end of the first interview a disposable camera or similar device (as with mobile phones) was left to enable the participant to keep a photo diary of anything that wanted to photograph, excluding human subjects. I also asked them to keep short descriptive notes on the images. Eight participants completed the PEDs, most supplying hard copies of their photographs and one sending images via email. The number of images submitted ranged from seven to 16. One male participant, who had recently left hospital and was following a strict therapeutic programme, had consented to complete a PED. However, after attempts to contact him failed, I concluded that he did not want to

participate in the second part of the study and I felt that it would have been unethical to continue trying to make contact. Once the PEDs were completed, a second interview was scheduled. This process allowed additional questions to be discussed on themes which had been either missed in the first interviews or needed clarification.

During the PED interview, all participants chose to discuss the photographs in the order in which they were taken. The photographs were held and described and, although participants initially referred to descriptive notes, for most the images seemed to open up new meanings and ignite past memories. Although a dialogical storytelling approach was adopted, a number of questions were posed at the end of interview. These included asking participants if they could give the images an overall theme and how they thought the images would have differed if they had been given a camera before their illness. Finally, they were asked: 'How do the images make you feel?' The last question was, in essence, to discover the impact of taking photographs on those with chronic illness. All participants seemed moved when viewing the images, but all declared that 'doing' and 'reflecting' on the PEDs was an insightful experience. The PED interview also provided an opportunity to expand on the previous interview. One participant provided a typed letter to supplement information about the illness that she thought was missing from her life story.

3.5.3 Processing the interview material

Research materials employed for the analysis consisted of 30 hours of interviews with nine participants, including the pilot study, field notes, research journals and secondary material, photographs and transcripts. In Chapter Four, I provide an overview of each life story and include a collection of images from the PEDs.

3.5.3.1 Interview Processes

The nine interviews and eight PEDs were collected over a period of four years, so were processed and transcribed at different times, giving me time to reflect on the data collected. A trajectory can be identified from the initial to the final interviews. One of the main aims of this research is to understand the development of discourses around illness, thus the extended period of fieldwork allowed for reflections on the discursive changes associated with naming and categorising ME/CFS and changes in treatment, such as the closure of the ME clinic in 2011. As an 'emancipatory researcher' – a researcher living with the illness that is the subject of the research (Oliver 1997) – I was concerned with how the discourses around this illness are fast-developing and

constantly shaping the understanding of living with chronic illness. I wanted to record the fluidity associated with such changes in relation to myself and others.

3.5.3.2 Transcription process

I am interested not only in the production of discourse but also the interactive qualities of discursive and social practices in the constitution of a self living with chronic illness. Producing transcripts of the interviews required decisions about the level and scope of detail required for the study. I have therefore adapted Gee's (1999) style of transcribing that includes paralinguistic and prosodic characteristics associated with intonations and pauses, along with other non-verbal features, such as laughter, stutters and silences, in the attempt to transfer talk into text. As Gee's (1991) early work centred on patient's stories, the transcription technique developed was sensitive to and made links with semantics. Gee offers an opportunity to capture the rhythmic flow so that the production of text reveals how the subtleties of language constitute meaning-making. I am also aware that the transcription process is always embedded and responsive to social and cultural biases (Ochs 1979:44). Over the course of writing the thesis, I used three different people to transcribe the interviews and this may have caused differences in the production of material. Although they were provided with the transcribing key, I recognise that people bring their own preferences into the seemingly 'mechanical' process of transcribing (Elliott 2005:51).

I modified Gee's method of dividing the transcript into three columns for interviewer, interviewee and research notes, with numbered turn taking demarcating the segments of talk. The transcription key (Appendix VII) was devised to reflect my theoretical and methodological framework, to make meaningful connections to the talk and not overcomplicate the nature of speaking (Davidson 2009:32). It used italics for *whispers* and capitals for LOUD tones, while pauses were denoted within brackets, as recognition that silences often hold meaning (Riessman 1993). Non-verbal utterances such as 'mms' and 'ahhs' were noted, while field notes recorded any relevant expressions and gestures not present in the audio recording. The transcription was not seen as a standalone document and constant reference was made to the recorded voice for clarification and direction of talk. In addition, field notes contained information on the events surrounding the interview, including my own reflections and thoughts and logistical demands. Research journals covered academic and personal considerations for the project and offered a means to contextualise the interview material at the time of the interviews and as a reflective summary during analysis.

3.5.3.3 Participants selected for analysis

All interviews, including my own self-interview, provided extensive data for analysis. Previous illness narrative research on CFS has provided data on the experience of illness. My life story approach purposively set out to include not only the experience of illness but also the biographical, socio-cultural and socio-historical contexts, discourses and practices which constitute how an illness is understood. These ‘case sensitive’ accounts produced a multifaceted perspective on how a life comes to be affected by a chronic illness such as ME/CFS. When selecting material for discussion of the whole cohort (Chapter Four) I did not want to synthesise and deconstruct stories into familiar themes, as this would fracture the rich individual biographies and context of storytelling. It was important not to privilege one story over another, but to offer a range of views on what it means to live with the uncertainties and challenges of a diagnosis of ME/CFS. This process led to the choice of four cases for in-depth discourse analysis, which reflected a diversity of experiences.²⁵

The four cases selected for in-depth analysis reflected the gender ratio of the overall cohort. I also decided to select from two distinct periods of fieldwork, to follow the maturation of my research process and reflect the changes in the socio-political positioning of ME/CFS. Robert, who was included in the pilot study (Chapter Seven) and Vivien (Chapter Eight) were both interviewed during 2009-10. Robert and Vivien were of similar ages and were born and lived in the same area of London. Unknown to me before their interviews, both participants had also worked within the financial sector at the same time in the 1980s, when the term ‘yuppie flu’ was produced as a derogatory name for ME (see Chapter One). They both described their Disability Definitions (DD) as ‘moderate’ (Appendix IV), yet due to illness were unable to work full-time. The commonalities in their life stories offered an opportunity to examine historical consistency and possible gendered inconsistencies associated with living with long term chronic illness.

The other two cases selected were two female participants interviewed in 2011-12, this time with distinct socio-historical and biographical differences. Jean (Chapter Nine) was in her 50s and described her DD in the past as ‘very severe’; she had been bedridden for more than four years. At the time of the interview her DD was recorded as ‘moderate’. Helen (Chapter Ten) was in her early 20s and had experienced severe symptoms, but at

²⁵ I made the decision to excluded my own interview for individual case-study selection.

the time of the interview categorised her DD as ‘moderate’. At the interview Helen was experiencing chronic pain and fatigue, but chose to continue with the life story process. Both Jean and Helen had been involved in the educational sector, Jean as a teaching assistant at a primary school and Helen as an assistant art teacher and professional artist.

3.5.3.4 Selection of material

In the early stages of the research process I worked on a Foucauldian Genealogical Analysis (FGA), in an attempt to break from the discursive impasses which tend to surround the present uncertainties associated with ME/CFS. Additionally, I wanted to extend the optical metaphor of ‘the gaze’ as employed by Foucault to reflect epistemological structures of clinical surveillance (Foucault [1963] 2003). I set about developing a ‘kaleidoscopic view’ of the art of governmentality in relation to the life stories of people living with a diagnosis of ME/CFS. Although this conceptual metaphor has been employed to analyse gender (Spade and Valentine 2007), and in relation to the multiplicity of life in biographical methods (Stanley 1987), I used the kaleidoscope to approach the fluidity of the life history narrations. I worked to produce a coherent and systematised approach, which allows multiple types of discourses to fall within specific thematic categories and offer a clear organised analysis (Mishler 1991:88-89). This allowed me to observe how ‘knowledge’, ‘power’ and ‘subjectivity’ can be seen as three-dimensional mirrors reflecting meaning, which I continually reflected on throughout the process of my first reading of the transcripts.

In the second instance, I looked for particular life patterns by coding configurations of discourses and practices, such as those associated with illness, bio-political and social practices, psycho-cultural, identity and selfhood. This helped me to organise the discursive and material prisms which reflect spectrums of knowledge and truth. The third reading was undertaken to establish a grid for the context of experience, the biographical events amassed within the modes of production. Here I was able to chart the institutional spaces of the family, education, workplace and the hospital. Further, this strategy provided the means by which I could analyse disciplinary sites which produce and reproduce mechanisms of control and the regimes that constitute subjectivity crystallised by the reflective force of power and knowledge.

In my fourth reading, I grouped together sets of discourses and practices which held similar themes. I then plotted the flux and flow between the different assemblages to consider the interplay between the various themes. This allowed me to magnify the

colourful interchange of life experiences within the life history and examine the conditions of possibility for counter narratives for the ‘unruly body’ to emerge. Finally, I organised and summarised the extracts into appropriate categories in order to analyse and discuss the discursive powers which produce technologies of the self and constitute reality. I colour-coded the transcripts to highlight the themes associated with political discourses and socio-cultural practices. In this initial phase of analysis, I was attempting to theoretically link the data with my early readings on bio political and social cultural literature.

However, on reflection I realised my theoretical approach to the analysis was attempting to suppress my own subjective experiences of living with ME, and thereby diminish the importance of the life stories. I had taken a deductive approach so that my themes were driven by my theoretical interests, omitting the sequential development and narrative progression of telling a life story affected by illness. I was, therefore, missing the possible transformations and resistances that develop over a life-span (Andrews, Squire et al. 2008:50). My deductive approach restricted, controlled and governed how the stories would be read. Although my theoretical framework was developed concurrently with the research material, I realised that my ontological and epistemological approaches to theorising the sick body should be used to enhance discussions rather than lead my analysis. I remain grateful for this experience, as I have found Foucauldian and Deleuzian concepts relevant to understanding an illness that remains an ‘untreatable *dis-order*’ and still draw on these philosophical ideas in the final stages of my analysis.

3.5.4 Analytical interpretive procedures for narrative performances

The narratives have been analysed as dialogical performances where the interpretative practice is guided by the context and the form of storytelling (Riessman 2008). This approach recognises that a dialogue between a deductive bottom-up and inductive top-down perspective emerges within the research process. The storied format offers a way in which to analyse the sequential and progressive elements that constitute and reconstitute self-understandings, associated with but not confined to illness experiences. The narrative analytical procedure is not set within a hierarchical analytical system, rather each stage of my analysis offers different dimensions to reading and interpreting the data. My analysis therefore recognises the importance of the social practices and discourses that intersect with political knowledge and cultural understandings in the act of performing the storied self.

It has been argued that no readings of the data come from the position of nowhere (Haraway 1991:189; Yuval-Davis 2011:4). Acknowledging my own intersectionality, I am aware that decisions made during the analysis were influenced by my position as female/disabled/researcher, as well as being informed by the literature in the field of inquiry, the maturation of my philosophical perspectives and my own experiences of ME/CFS. This inductive process offered an opportunity to characterise and develop new insights into ‘what’ ways particular people describe a life affected by chronic illness. In this way, I was able to develop a narrative analysis (NA), which unlike thematic analysis, privileges the sequence and progression of the stories (Andrews, Squire et al. 2008). The chronological approach of the life story method details the processes and practices of becoming diagnosed and experiencing the long term effects of this chronic illness. Themes were sensitive to the temporal development of the storied self and changes in context, such as the school and the workplace, in power relations with parents and employers, the medical and political productions of truth and the discourses that relate to what it means to have a ‘real’ illness experience. I endeavoured to map the personal narratives within a socio-historical context and, in doing so, connections were made between the social and political structures and power relations within the interview material (Riessman 2008:76).

I was interested to observe how the story developed and how a person recounted their histories. How persuasive was the line of the story? What emphasis did they place on the past, present and future? Equally, how were past experiences linked to how they cope with their present and future (Ochs and Capps 1996)? What was their stance in relation to themselves as the teller or their audience (Rosenwald and Ochberg 1992)? I was also interested in ‘small stories’, events that seem removed from their illness experience but may hold connections and an understanding of how they live with a chronic illness of this nature (Bamberg 2006). It is acknowledged that stories are based on social practices and actions inscribed to cultural scripts, where storytelling is seen as a normative experience (Andrews and Bamberg 2004:1). However, we are also at liberty to change the meaning of our experiences and actions in storied form: we are able to reinvent ourselves. My narrative analysis makes connections with specific historical terms and meanings, acknowledging that stories are governed by historical conventions relating to time and space.

The narrative analysis was followed by a Critical Discourse Analysis (CDA) of the data (Fairclough 1989), to critically examine discourse as a means by which language is seen

as constituted by social practices produced by social and political forces (Fairclough 2003). Fairclough's (2003) application of Foucauldian concepts provides useful analytical tools to examine the production of life histories and the embedded knowledge of experience through which illness is understood. I used software to thematically code sections of all interview transcripts for discourse analysis. For the four in-depth case studies I utilised 'Advanced Textual Analysis' (ATA) online software, to diminish computerised import of coding themes prior to close linguistic readings that include alternative semiotic representations such as non-verbal expressions (for example, sighs and intakes of breathe). This re-reading offered an opportunity to examine the portrayal and order of discourse and define particular genres (Fairclough 2007; 2010). One of my research goals was to understand 'how' knowledges associated with the categorisation of ME/CFS produce and interact with discursive practices and socio-cultural understandings of how to live with a diagnosis of ME/CFS. My narrative-thematic analysis focused on '*what*', to detail patterns of life experiences, CDA focused on '*how*' the production of text constitutes '*who*' speaks and '*why*' the narration may have been performed in this specific way (Riessman 2008).

Returning to the metaphor of the kaleidoscope, I suggest that the combination of these analytical procedures highlights how social, political and personal forces are reflected within oral and visual forms of narration. My strategies of analysis blur the boundaries between different analytical procedures and, in some instances, I move back and forth between the narrative and critical discourse analysis. This develops insights into the complexities of living with chronic illness, where biographical disruptions are pathologically embodied (Bury 1982).

My interpretations take into account inductive (life and visual narrations) and deductive (theoretical) perspectives. Specifically, my analytical process evolved during the fieldwork and writing stages of the thesis. I was committed to retaining the authenticity of the participants' stories, and asked myself if I had fully acknowledged the participants' stories, while I developed my theoretical approach to the sick body and conceptual understandings of how an illness such as ME/CFS is experienced. In addition, I reflected on my objective and subjective experiences associated ME/CFS, which also underpinned my analytical approach. At times, as a listener I was fully engrossed in the challenges and struggles of living with illness that reflected my own experiences of illness. I also shared socio-historical similarities and cultural and social meanings with participants, which occasionally caused me to enthusiastically agree

through gestures (emphatic nods of the head) and facial expressions. However, recognising this as a potential issue and when emerging themes arose during the analysis, I would often discuss themes with my scribe, who had no theoretical and/or personal interests in ME/CFS, so that I could attempt to stand back and observe from the position of someone outside of the research process.

3.6 Ethical considerations

Although ethical procedures outline regulations to protect participants, codes of practice may not reflect the on-going social and moral commitments of a researcher (Plummer 2001). One example is the consent form, which is signed prior to the collection of research material. However, the nature of life stories means that neither the participant nor the researcher has complete control over how a story will unfold. We cannot know how the research may be developed, as the story is a living entity and unexpected details may emerge. Stories are active, temporal moments; events implicitly mapped within the art of narration (Bruner 2004).

An interviewee's meanings may become distorted as the complexities of language and culture may conceal their original point of view (Ricoeur 1985). Possible misrepresentations of stories could, therefore, occur in my analysis, which seemingly detracts from the original purpose of telling a story. Although, the purpose of the research project was explained, a full awareness of the interpretive and analytical procedures would not have been evident at the beginning of the study (Josselson 2004). Equally, I was often concerned about the level of anonymity that can be maintained during storytelling and am aware of the ethical issues raised when the participant recognises themselves as their stories unfold (Josselson 2004). To partially address these issues, I altered geographic locations and, in some instances, the age and the gender of children to protect participants' identity. However, it is also worth noting that in some instances life stories are seen as a form of activism and hence the issue of 'recognition' is part of a counter-narrative (Andrews 2007). Returning the data to the participant for reflective commentary has been suggested as a way to expand on points raised in the interview (Ballardie 2010). However, participant reflexivity would have put my participants under undue physical pressure, by asking them to read and work through their transcripts. However, I have remained in contact with the participants in the study and they are free to withdraw their participation at any time up to publication. I recognise my responsibility in confronting issues of authority and protecting the act of storytelling (Rosenwald 1996).

Stories that portray ongoing challenges of living with illness may require greater levels of protection. A challenge that often confronted me as a researcher listening to stories of living with illness was the high level of intimate disclosures. I had prepared myself for the ethical issues involved in interviewing someone experiencing chronic illness, but I had not fully understood the issues that would arise in relation to the participant disclosing personal memories. The risks involved in listening to stories are different to those involved in reading transcripts for analysis and interpretation. The interview setting encourages the interviewee to feel safe and secure, which mirrors the setting for therapeutic interventions such as psychotherapy. As I offered my participants to adopt a reclining position, I may have indirectly encouraged personal details to be aired. Therefore, the researcher should be cognisant of power relations within the interview setting.

The pilot study offered an opportunity to reflectively engage with my role as researcher researching the illness I live with. I acknowledged the possibility that this may lead to a certain bias and preconceptions associated with my illness experience. The benefits of interviewing within one's own culture offered an opportunity for rapport and flow, which seemed to enhance feelings of trust, and interviews took on an emancipatory quality (Barnes and Mercer 1997). The research topic was directly related to my position as a disabled woman 'inside' the culture I am researching. As with feminist research, I argue that objectivity does not guarantee an ethical position for seeing the world (Oakley 2007), rather the process of building knowledge through research may be less exploitative and protect individuals and communities from undue harm (Plummer 2001). Indeed, such protection was required with the visual material as I stipulated that the PEDs should not contain images of human subjects to protect their anonymity. Some images did show parts of the body and recognisable neighbourhoods. However, as the participants had no reservations in these images being seen, all photographs submitted were included in the study.

3.6.1 Reflexivity: my positioned identities

As a disabled researcher investigating the illness I live with, I am aware that I hold a privileged position of being both inside and outside the culture I am observing. My responsibility was to remain vigilant to my positioned identity (Riessman 2002). As I engaged with the research process, I could not separate my experiences of living with severe illness from the process of decision-making. Ethical considerations were always adhered to, but my long term experiences of living with severe ME have been woven

throughout this project. Indeed the length of time taken to complete the project occurred as a result of relapses during the research and writing process. This informed how I engaged with the literature in the field and sought to critically conceptualise a life with severe illness, while the methods employed encapsulated the never-ending process of living with chronic illness.

As researcher, I kept fieldwork diaries and reflexively noted the context, actions and events within the research and the limitations and advantages of researching within one's own community. My professional distance was challenged when intimate disclosures often mirrored my own experiences of illness and were greeted by me with passionate nods of agreement when our stories were dramatically similar. Disabled people are often alienated from both the process and product of social research (Oliver 1997). The WHO is seeking to encourage interactive research on disability, yet there remain few studies conducted by disabled researchers. Although, for ethical reasons, I was not able to interview participants whilst they were experiencing severe symptoms, I was able to undertake my own life history and PED during a relapse in 2010. Irving Zola reflects upon his personal and academic experiences to consider the silence of disability (Zola 1991:1), suggesting that the importance is to speak about personal bodily experiences and articulate this particular silence and recognises that 'if listening is hard, telling is worse' (Zola 1982:198).

3.7 Conclusion

The process of my investigation followed two paths. Firstly, I critically explored previous research into ME/CFS and identified those who were most disadvantaged within the research community, namely those who had experienced 'severe' ME/CFS. I followed this with a pilot study which identified the need for pluralistic methodology to investigate the diverse experiences of living with this illness. I also identified logistical issues, which informed how I would gauge my own particular problems of being a disabled researcher. Secondly, my theoretical framework was developed alongside my empirical data. I found the genealogical strategies employed in Chapter Two offered a way to explore the categorisation of ME/CFS, while the exploration into the socio-historical context of naming the illness offered insight into how ME/CFS has become a contested illness in the present. Initially, the aim of the investigation was to listen to peoples' stories of living with ME/CFS, but it quickly became evident that this was not

going to be an easy task. The difficulties were twofold: naming the condition and then reaching those whose stories were most urgent. The voices of those severely affected have inadvertently been made silent within research, due to the constraints of severe symptoms.

The combination of narrative and visual accounts offer a way to understand how ME/CFS is negotiated and reveals how an individual comes to experience and live with illness. Employing a life-story approach provided a way to explore the changing contingencies and events involved in the production of the sick body and the constitution of the sick role. By including visual accounts of chronic illness, the study offered a means for the ambiguous everyday aspects of living with illness to be illuminated. The analytical process has taken a close reading of the production of text and the act of narration, alongside a consideration of the broader themes previous narrative research in the field has offered. The analytical framework takes into account the power of language to constitute meaning through discourse and social practices. This engages with epistemological connections to the socio-cultural context in which the process of self and, in particular, the sick self may be constituted and reconstituted.

Chapter 4: Life Stories of ME/CFS: Language, Power and Uncertainty

4.1 Introduction

This chapter uses narrative and critical discourse analysis to explore the role of language and power relations in the constructions of becoming diagnosed and living with a diagnosis of ME/CFS. The analysis interrogates themes identified within both social and medical research, together with media and scholarly works, and situates them within the field of relations between language, power and notions of truth telling. In Chapter One, the discursive explorations within narrative studies on CFS, identified recurring themes associated with accountability, social belief and the difficulties of living with chronic illness symptoms. These accounts were connected to major themes associated with the disparity between physical experiences and social understanding which produced disruptive identities. The studies drew on the power relations between the medical profession, friends and family.

The life story narratives collected for this study reflect the ways in which medical debates, social judgements and cultural assumptions impact upon each individual's experiences of living with illness, providing an exemplar of what it means to become diagnosed with a chronic illness of this nature. The narratives reveal how the social and political context of the emergence of expert knowledge over the sick body affects individuals, as the struggles and negotiations of power, knowledge and identity are explored. The majority of participants within the study made links between childhood and adulthood in how they understand their present illness experience, while the transformation of their social roles determines how they challenge and resist the social uncertainties associated with ME/CFS.

Inspired by Foucault's use of a genealogical lens, I see a subject as fundamentally an effect of the interrelation of discursive and non-discursive practices that continually, through different epochs, amass a multiplicity of disruptive ideas to contextualise our material existence (Foucault [1984] 1992). I thereby excavate the power relations that, over time, shape our language and social understandings of how it is possible to live

with this contested illness, presently known as ME/CFS. I identify competing cultural discourses, embedded within particular historical moments, and attempt to reveal the discourses and social practices that dominate how we understand what it means to be a healthy/unhealthy subject. Moreover, I explore the sensory nature of illness and the subjective qualities of pain, which operate an inner dialogue, where physical suffering is first experienced outside linguistic boundaries.

This chapter explores four themes within the overall notion of the rhythm of language. First, I look at the impact of labelling the illness, in terms of bio-political discourses and cultural ideologies, on those who have been diagnosed. Secondly, I explore the inadequacy of language in describing the subjective experience of the illness for self and other, as well as the failings of language to generate cultural understanding of the illness. Thirdly, I investigate the dissonance of language, unpacking the use of verbal fillers and laughter to reveal and conceal some of the inexpressible aspects of the illness. Finally, I examine what happens to language when being bedridden causes an individual to be absent from their social world. The themes address the power relations between the production of language, knowledge and truth as individuals plug in and out of their social world. In this chapter, the narrators who took part in this study will be introduced and extracts from their life stories explored.

4.2 Labelling the illness

The majority of narrators described a laborious journey to find a medical expert to name and validate their illness experience. The labels of ME and CFS exist within an historical and biological context, where the order of discourse exchanges multiple meanings for both doctor and patient (Cooper 1997; Horton-Salway 2002). As noted in Chapter Two, at particular moments in medical history, power shifts in the dominant fields of inquiry move the discourse from what Ramsey terms ME and Holmes subsequently named CFS (Holmes 1988; Ramsey 1988). In effect, medical and social codes situate this contested illness using a medical vocabulary which distinguishes between a 'disease' and a 'syndrome'. The profusion of medical terms and phrases, specific to the competing medical disciplines, produce discourses which feed into cultural perceptions of what this contested illness represents (Guise, McVittie et al. 2010). In this way, medical labels become loaded with meaning, as a sense of medical truth is transmitted and transformed through time and space.

As discussed in Chapter Two, Latin terms such as *Benign Myalgic Encephalomyelitis* (Sigurdsson and Gudmundsson 1956) esoterically abstract and objectify a particular ‘disease’. Meanwhile, the CFS symptom-led criteria are based on subjective indicators which lack the traditional meanings conveyed by the use of the Latin counterpart of ME. Arguably, the most recent umbrella term of ME/CFS attempts to gather multiple and diverse pathological bodies within one definition.

The importance of finding a label for the illness, for those who experience symptoms, can be seen in Vivienne’s narrative. Vivienne²⁶ is 50 years of age and describes herself as fatalistic. Her storytelling is lively with emphatic details set within a series of interconnected stories about her marriage, divorce, family and friends, surviving cancer and caring for sick parents who eventually died. In the following extract, Vivienne demonstrates the power of a certified medical validation to legitimate her illness:

Extract 1

it is something you have on paper that you can say to people (smacks hand) it’s real (1)
it exists (1) [T1.77]²⁷

Vivienne’s comment followed my question: ‘What does the diagnosis give you?’. Her response is a propositional phrase. The finite verbs substantiate value through documentation and her indirect phrase ‘you can say to people’ is a declaration that gaining credentials to authenticate ontological proof gives her cultural recognition. The indexical gesture of smacking hands offers a rhythmic signal of approval (Repp 1987). This short applause ideologically symbolises and embodies pleasure at legitimating her illness. Vivienne’s order of discourse contextualises the production of knowledge and reveals the hegemonic trials of medical and political institutions, where both juridical and medical truths produce a reality within which her illness can exist. Vivienne’s expressive narrations were often peppered with gestures and rich intonations; her heteroglossia of language immersed in colourful tropes (Bakhtin 1981). Her storytelling engaged me as her audience, my eagerness to listen and enjoy her enthusiastic narrations ignited my own experiences of validating and naming the illness. Consequently, as our dialogic conversation continued, I delved further into her social

²⁶ Please see Chapter 8 for an account of Vivienne’s life story and PEDs.

²⁷ Please see appendix vii: Transcription Key for the key to all extracts.

practices for naming her illness. I asked, ‘what about the label and the recent inclusion of the two labels - ME/CFS?’:

Extract 2

I find that confusing (1) to be honest and I know chronic fatigue syndrome’s easier for people to understand but Myalgic Encephalomyelitis [mispronounces] Actually sounds like an illness to people [T1.148-9]

The multifunctional elements of Vivienne’s rhetoric elaborate on the social and political context within which a particular illness label comes to exist (Fairclough 2010). Vivienne’s discourse begins by situating her uncertainty with the term/s, while her predilection for one term over another may be a result of her original diagnosis with ME. Vivienne’s extract also reflects the importance placed on the ability of nosological terms to furnish the body with a medical truth. It would appear that the robust path laid by medical discourse (as documented in Chapter One) has discursively produced an ontological and material reality which allows her illness to exist. This has, in turn, imparted a particular truth for Vivienne. Her reception of the term ME appropriates the essence of not only medical but also political language that comes to dominate prevailing ideologies to categorise and maintain her sick body (Fairclough 2010; Foucault [1963] 2003). For Vivienne, the articulation of a Latin name seats ME within an historical and political context where the institutional processes and discursive constellations produce a plethora of terminologies that are epistemologically laboured upon, thereby, substantiating the principles of a medical truth (Osborne 1994:33-36).

For Vivienne, the timbre, phonetics and shape of linguistic signs evoke and transmit different levels of social reality for this illness. The shared usage of medical language is questioned, ME then becomes a real illness, but Vivienne concedes that CFS is easier to understand. Paradoxically, these extracts describe the problems of naming the illness, the bio-political administrative issues that normalise sick roles through naming and treating. The illness works to resist disciplinary powers, as the unstable terms that define the illness reflect the uncertain pathological pathway for this body to exist in language.

Robert²⁸ is the same age as Vivienne and like her worked in the financial sector in the City of London. In his narrative, Robert used a reportage style of speech and referred to

²⁸ Please see Chapter 7 for an account of Robert’s life story and PEDs.

the practical and physical aspects of life in general, rather than his emotional response. Interestingly, when he discussed the trajectory of his illness, he used personal documentation to prompt him, as his thoughts were disjointed. For Robert, the physical act of producing discourse is affected by his verbal stutter, which interrupts vocal flow. This linguistic dis-function may mask his emotional response to the social practices that adjudicate how he thinks about his illness (Chouliaraki and Fairclough 1999).

The pragmatics of Robert's syntactical sequences reveal the cultural transformations that have taken place in the acknowledgement of his illness:

Extract 3

So I think I think there has been a a sort of change in in in the in people's thinking i-i-it has become more of an accepted illness you know rather than just a (1) what people deem it before as a posh name for flu or whatever [T1.98]

The extract begins with an independent clause as Robert attaches a non-finite verb to himself as subject – 'I think I think' – as he offers his own perception of how people have changed their attitudes to the illness. The subordinate clause employs the same verb – 'in people's thinking' – to demonstrate an assumption of socially shared cognition and belief systems, anchored in temporality. After referring to the derogatory belief that ME had previously been seen as a 'posh name for flu', Robert trails off with the pronoun 'whatever' which may allude to his frustrations with the discursive landscape within which the naming of this illness continually takes place and those with the illness are judged. Robert may be implying that society's judgements have become wearisome.

Unlike Vivienne and Robert, Paul's chronotope centres on self discovery and the adoption of a regime of recovery. His illness began with glandular fever at a time when he had a stressful lifestyle connected to his work as a mental health support worker. At 23, he developed numerous viral illnesses and was diagnosed with CFS/ME²⁹. During the interview, Paul took deep breaths and long pauses while he verbalised his experience. As far as naming the illness was concerned Paul, like Robert, assumed that recent changes in the name of the condition demonstrated an increase in medical knowledge and understanding, referring to his own diagnosis:

²⁹ Please see Appendix 8 for a short biography of Paul.

Extract 4

it was more recent than you [myself the researcher] did so they knew a lot more about it then I think so they called it CFS/ME [T1.183]

Paul demonstrates his awareness of the historical trajectory of medical knowledge since my diagnosis of ME in 1987. He also uses an inclusive rhetoric to connect with my own medical history. I often instinctively and avidly nodded agreement during the process of co-constructing these stories, as part of a shared dialogic community which alludes to no final authorial voice (Riessman 2000:107; Riessman 2008). In this way, the participants were always aware of my position as someone living with ME. As a fellow survivor I recognised some of their experiences; as a researcher I acknowledged the need to make these stories accessible to the wider community.

Paul seemed less preoccupied with clarifying the name of his illness and was almost disinterested in the semantic relations between the various illness terms. His use of the term ‘they’, the indefinite subject, assumes that the agent within the sentence who ‘knew’ and ‘called’ the illness by a name has power within a variety of contexts and timeframes. It would seem that Paul’s use of the term ‘I think’ reveals the ways in which he is actively making connections, but also demonstrates a certain amount of uncertainty.

Paul’s use of the catch-all label ‘CFS/ME’ reflects the current preference in medical research for CFS over ME³⁰. Paul expresses this discursive predilection, as it has become the means by which he can name his illness. Arguably, such preferences are always loaded, so that it becomes ‘increasingly more difficult in describing chronic illness and disability innocently’ (Williams 1996:194). A survey of research around the illness demonstrates that the preference for either CFS/ME or ME/CFS has subtle power differences, which reflect the highly politicised arena within which this illness is researched, treated and understood. For example, physiotherapists tend to favour the use of the term CFS over ME, as arguably their approach is based on rehabilitation and management of the subjective effects of pain and fatigue (Cox and Pemberton 2014). Meanwhile, those focusing on the bio-medical implications and physical causes of the illness, as well as the majority who live with the illness, tend to use ME alone or place ME first, as in ME/CFS (Horton-Salway 2004; Hooper 2007). The naming may be

³⁰ As noted in Chapter 1 CFS/ME has been devised for research purposes (CMRC 2013).

strategic, as embracing both names could increase the potential for funding and support, from both government and ME charities, for psychological and/or medical studies reaching different patient cohorts. The merger of the two names seems to break through reductive methods and forego cause and effect, to fulfil an economic necessity that produces ‘data, data everywhere’ (Spence and Stewart 2004:69). However, the outcome of this may be that those with disparate symptoms are lumped together, while severe cases are ignored. Therefore, the social practices established for the research of this illness have developed a genre, within which the discursive act of using the term CFS/ME represents the adoption of a style, which constitutes a way to investigate a large cohort of chronically ill patients. However, for those who live with the illness, the umbrella term constitutes ambiguity rather than clarity.

Angela, who is 30, became ill at the age of 12 and was bedridden for five years from the age of 14. She was open and happy to tell her story, but laughed nervously throughout, especially when tackling difficult topics. For Angela, her explanation about illness is affected by the social and relational context:

Extract 5

Depends who I’m speaking to [laughs] errr... depends on who I’m talking to, I I don’t, I try to avoid talking about it to be honest Outside of people who know me even then I don’t really talk about it erm (6) [T1.245-6]

When I asked her about the labelling of her illness, she struggled to verbalise this and instead talked about the contexts within which she felt called upon to give the illness a name. The repetitions of the verb ‘depends’ demonstrates how Angela controls her speech in different situations. The substitution of the word ‘talking’ for ‘speaking’ highlights the fragile process of deciding how to name her illness. The use of the verb ‘speaking’ suggests that Angela assesses *what* the context is before performing a linguistic act, whereas ‘talking’ is reliant on *how* to proceed and *if* she can adhere to dialogic conventions which require an audience. It would seem that Angela often finds it easier to remain silent.

Angela displays contradictions in the way she sees her audience. Omitted from cultural practices whilst she was bedridden, it is possible that Angela finds social settings difficult. After assessing the context, Angela continues to evaluate her voice as she decides whether to articulate or withhold speech. In this way she withdraws, not merely

from naming the illness, but also from the obligation to embark on the long narrative that often surrounds the illness.

4.3 The inadequacies of language

Just as the naming of the illness has proved to be contentious and problematic for those living with the illness, it is also the case that language is inadequate when describing the symptoms of the condition. For example, the term ‘fatigue’ that now appears as part of the official name of the illness, in no way describes how the narrators subjectively experience ‘tiredness’. The term CFS implies that fatigue is the major symptom of the illness, whereas those within the study clarify that it is one symptom among many.

Not only does Angela struggle to name the illness in certain social contexts, she also finds it easier to remain silent rather than describe her symptoms, as she explains:

Extract 6

a lot of people have said, it’s been said to me in the past, that erm, oh you’re just tired then, ‘well, we’re all tired’, that kind of attitude, and it’s not helpful. So it’s easier just to keep quiet and Erm, I think the majority of people hear that its (.) they just associate it with tiredness [T1.122-23]

Angela highlights generalisations about the illness and, in her use of the noun ‘lot’, she describes how a ‘majority’ make derogatory assumptions about what it means to be ‘tired’, causing her to become silent. She infers that mainstream society can only relate to what being tired means for them, which falls outside of her experience. Angela reveals the struggle over social understanding and seems unable to resist the ways others view her illness. Therefore, it would seem that expectations of others beliefs about this illness impinge upon how it is possible to speak about this illness.

Helen³¹ is an artist, student and part-time special needs teacher. She began suffering from headaches and viral infections from the age of seven and was diagnosed in her early teens. Here, Helen attempts to define what it means to experience tiredness in the context of the illness, as she describes the all-encompassing nature of her on-going and present symptoms:

³¹ Please see Chapter 10 for an account of Helen’s life story and PEDs.

Extract 7

Consistent tiredness and exhaustion of doing stupid things erm I suffer a lot of the time with joint pain, mainly in my fingers, wrists, elbows, knees and ankles and erm I get like really achy legs and it feels like when I use to do cross country then next day but now I haven't actually done anything I just wake up and its like it erm to the point I can't walk down the stairs so I have to go down them on my bum if I really need to erm and that's quite a lot of the time it was like owh no I'll wake up and my fingers will hurt which means I'll know by the end of the day it will spread to somewhere else some days I wake up and its just aching everywhere already and also at the moment well actually for the last few years actually consistently my digestion is really bad so erm its really having an impact on my day because whether or not I'm sick or I can eat or I can't eat then if I don't eat then I get really tired and faint erm if I do eat then I will probably be sick so I can't really win [T1.94]

This extract reveals the continuous nature of not only what it means to be tired, but also the pain which seems implicit in this kind of 'fatigue', and affects mobility and digestion. Elaine Scarry describes the impossibility of verbalising pain as a state with no object, so that 'the absence of referential content almost prevents it from being rendered in language' (Scarry 1985:162). Similarly, Arthur Frank (2002) suggests that we try to mythologize the experience of pain and suffering, turning it into the pronoun 'it', as if it is a kind of god or enemy to be battled against. Helen talks about the pain as if it exists as its own entity with its own course, a tide which comes and goes. She uses the pronoun 'it' to express this, saying 'it will spread to somewhere else'. The extract reveals the all-encompassing nature of the pain, the physical effects and the subjective experience of suffering. The extract demonstrates an accumulation of physical manifestations of pain, with very limited language to fully convey what this means. Helen uses the words 'tiredness', 'exhaustion', 'aching', 'hurt', 'pain' and 'sick', all of which are words with cultural significance, but which also suggest an impoverishment of meaning, as they could be used in many different contexts to convey many levels of pain, from joint pain after exercise, to severe pain during chronic illness.

Importantly, the failings of language to generate cultural understanding for this illness are further fuelled by the media's use of derogatory labels. As noted in Chapter One, the term *Yuppie Flu* (1987) was first coined by the media to reflect a large group of London City workers in the 1980s who were affected with flu like symptoms and exhaustion. A frontline report from the New York Times claims '*Chronic Fatigue No Longer Seen as*

Yuppie Flu' (Tuller 17 July 2007). Meanwhile, an article in The Daily Telegraph has the headline: '*Proof that ME isn't all in the mind?*' – *Belgian doctor solves the mystery of 'yuppie flu'* (Hunt 2 June 2009)³². This cross-cultural statement offers a particular understanding that paradoxically reinforces and amplifies an assumption that doctors are able to demystify illnesses named by the media. However, the seemingly pervasive nature of these popular discourses impact not only on the wider societal understanding of the illness, but also on how those living with ME/CFS reflect upon their own experience. For example, Angela refers to the reluctance of some to embrace psychological treatment because of the common perception that the illness is not physical:

Extract 8

I think they're scared that if you were to say that erm maybe if you was to see a psychologist it might help you at this point that they you're almost saying that its psychological or it's in their mind or they can control it and it's not the same thing at all [T1.251]

Angela contrasts her own position with what she sees as the majority who battle against psychological treatments because they fear confirming the prejudicial belief that 'it's in their mind'. The indefinite subject 'they' works to distance herself from the emotional despair that this may mean for others.

Maria, who is 30 years of age³³, describes herself as sporty, she experienced glandular fever and numerous viral illnesses whilst completing her degree at university. Interestingly, her knowledge of ME came via her mother's severe manifestation of the same illness. Maria talks about her attempts to remain active in sport and her subsequent severe illness and diagnosis of CFS in 2004. She demonstrates her awareness of prevailing opinions about the illness, but believes that new knowledge on the illness has produced more positive cultural responses:

Extract 9

I heard of Yuppy Flu that they're all a Bit (0.5) I think people I think I think they were used more in the past weren't they? I haven't heard of them as in people have used them

³² Similarly, press reports that the illness is 'not all in the mind' occurs consistently in press reports (see for example Hunt as above and Hope 30/7/2011 The Daily Mail)

³³ Please see appendix 8 for a short biography of Maria.

recently ermm and I think they were used when there wasn't so much known about the illness but I think More Recently people are understanding and becoming a bit more aware of actually what a horrid illness it is ermm so I think for me I've been lucky because I haven't really had to deal with that concept of people just thinking oh it's all in your head or whatever [T1.128]

It would seem that the socio-historical context, within which knowledge is built, is not only based on the community of medical scientists but also on the struggles between voices in medicine and the lifeworld (Mishler 1984:83). For Angela and Maria, cultural understanding imposes certain meanings that act to normalise the illness experience. The complexity of Maria's logical conclusion is based on the referent proposition that her illness is 'horrid', so that the intertextual relation of historical perspectives and social concepts causes her to feel lucky. Both Angela and Maria are aware that terms such as 'all in the head' or 'all in the mind' work to diminish the physical aspects of the illness and separate mind from body. The meaning of the proposition determined through the pronoun 'all' and the propositional adverb 'in' is an inflection to bind 'all' and 'your head/ mind', as it situates the symptoms within the noun 'head' and denounces the physical experiences. In this way, words produce meanings which derive a logical dimension so that, through the thread of discourse, incorporeal meanings can then be fastened with a verb (Foucault [1966] 2002:101-106). These divisive tools work to exacerbate cultural misrepresentations of this particular illness.

For those with the illness, the unreliability of language necessitates the aid of linguistic devices, which offer explicit and implicit visual representations. Paul's narrative extract reinforces the use of this rhetorical device to compare and contrast the importance to measure and self-manage his illness:

Extract 10

(2) Life with ME, as you know, can just be 'peaks and troughs' so you do too much when you feel good and you don't do enough when you feel bad so you're up and down, up and down, all the time, I've learnt what they've taught me is how to be go in a straight line [T1.171]

As Paul amplifies the oppositional metaphor of 'peaks and troughs', he sets a pattern of good and bad, up and down – the implication being that he has shaped his understanding of balance through a medical regime. Technologies centre on the need for Paul to govern the self and actively work on his equilibrium, a pedagogical system

where ‘docile bodies’ adhere to discursive and cultural shifts that persuade subjects to restore liveliness (Foucault [1975] 1991). Maria goes on to explain the importance of not compromising self-regulation, as doing so can cause the subject to become sick as a result of deviating from the treatment regime. She explains that the treatment:

Extract 11

teaches you more techniques (0.5) [...]if I Do too much I’m going to make myself worse because I’ve Done that in the past too many times (IB) erm and so what that training taught me it taught me a lot about the brain [...] you know different things are learnt [...] it shows you techniques of how to sort of break those negative thought patterns and [...] habits [T1.83]

The linguistic visualisation of the body as machine imports a strategy that renders the subject accountable for their own health. In her accounts of cancer, Susan Sontag (1991) argues that cultural metaphors are based on social anxieties associated with disease and dying, which encourage us to battle disease and fight illness (1991). This language is mirrored in the media, as with a report in UK newspaper *The Guardian* which stated: *The ‘Battle Fatigue’ between the conflicting ‘warring parties’ of the medical profession are trying to find some common ground* (Burne 30 March 2002)³⁴. The discursive conditions through which the sick subject is supervised are not only produced by the disciplinary systems of medicine to treat illness, but also by the administrative controls of government that evaluate and demarcate funding and representation within medical research and the media.

Maria’s language exemplifies this position when she refers to her own personal struggles to gain funding for her treatment within her Primary Care Trust (PCT):

Extract 12

the National Health didn’t do anything to help me first time round they didn’t know what to do and even the second time round [my local council] YEAH They helped me loads by giving me the funding that was a massive fight to get [...] that’s the problem the Government don’t put enough funding into ME and even Now all local authorities are trying to cut Back on patients [T1.131-2]

³⁴ Although the development of a popular discourse around this contested illness is a fascinating area of investigation, it is beyond the scope of this PhD. However, it is important to bear in mind that the general lack of belief that still persists about the illness is perpetuated by the media and impacts upon the individual dealing with the illness on a daily basis.

Her narration unpacks the bio-political interventions that govern the management of the ME/CFS body. Maria's semantics denote the extent of her attempts to gain financial support, which is defined within a political and social context. Her lexis opens up a further dimension to the medical battlefield and syntactically shapes her understanding of national and local governance, bringing together her problems in terms of structure and agency. The semantic level is not wholly negative but, as Fairclough shows in his example of cultural conflicts, the 'meronymy' of the word 'fight' brings together the relationship between the two parts of power (Fairclough 2003:23) which can be aligned with the paradox of healthy and unhealthy practices.

As with Foucault's *dispositif*, Maria's narrative extract is framed to draw out the social and political context within which the 'productions of discourse is at once controlled, selected, organised and redistributed' (Foucault [1970] 1990:52). The intertextual links between semantic hyponyms such as 'war' and 'fight' offer comparative layers of cultural meaning for those who live with and treat this illness. The dialogic limits of language are influenced by the multiple voices that Bakhtin terms *heteroglossia* (Bakhtin, 1981). So that these morphological repetitions relate to the employment of both discourse and social practices. For the narrators in this study, the subjective experience of illness is difficult to verbalise and this difficulty is amplified by cultural images that are reused by those who treat the illness or represent it in the media. Government bodies are also involved in the propagation of particular meanings which influence the naming of the illness, thereby determining research funding priorities and subsequent treatment plans, which those with the illness are obliged to adhere to.

4.4 Dissonance of language

As referred to earlier, the limited capacity of language to describe ME/CFS can be frustrating. One of the ways in which this manifests itself in the narratives is in the profusion of verbal fillers. Jean³⁵ is in her 50s and is the mother of Maria, who also features in this study. She was diagnosed with ME in her late 40s and was bedridden for six years. She was also hospitalised for a year and received private health care treatment funded by her local council. On several occasions, Jean described her interactions within the clinic using repetitive statements and verbal fillers:

³⁵ Please see Chapter 9 for an account of Jean's life story and PEDs.

Extract 13

So I went to the doctor to talk to the doctor about it and I didn't see my regular GP but I hadn't been with that GP then but I saw a different GP and I said is there any chance that a coil could be related to how I had a particular illness afterwards, before and that and an immune problem could it **blah blah blah** she said I don't know I'll get advice. So she got onto the family planning head sort of person that was more is there a chance of a coil **blah blah blah blah** no, nothing to do with it right [T1AR.29]

This rhetorical device could be to hide her frustration at attempts to deduce a possible cause for her illness. Jean's lexical choices suggest that her words are drowned in a sea of powerlessness, as her own repertoire of medical knowledge appears to be meaningless to those that control her body. As Jean recounts how she suspected that birth control may have been a partial cause of her illness, she seems resigned to the layers of control which wash over her, so that she exhibits a kind of banal conclusion. The use of substitutive language conveys her ambivalence to the systems which control her material self.

Robert also used similar verbal strategies when he talked of his interaction with the institution of the workplace:

Extract 14

people at work don't don't know what you're going through and um they think cos you turn up at work you're not really that bad and **etcetera etcetera** and um so you push yourself...[T2AR.2]

But um unfortunately yet again on the NHS you had there os their um their struggling to get appointments short staff **etcetera etcetera** and at this stage I'm still waiting for the um for those appointments [T1.41]

These lexical features, which were used many times throughout his storytelling, act as a substitute for the continuous nature of discourse that surrounds his social world. The devices used by Jean and Robert not only indicate the assumed value of social judgements on their illness, but also demonstrate the similarities in their discursive systems, as they both have difficulty verbally completing their explanations of their own experiences. Their use of verbal fillers may display their weariness at the inadequacies of medical and social institutions to provide sufficient understanding for them to voice the challenges of living with the illness. The hierarchical structures of these statements

are bound by social contexts and hold complex meanings. Therefore, a hermeneutic reading takes these extracts as mere passages into the sound waves of speech and the individual acts of storytelling (Polkinghorn 1988:7). It could be said that both Robert and Jean demonstrate the ways in which they modify and culturally appropriate their discourse in relation to the knowledges of self and other. When Jean describes herself talking, she recognises that she is not heard. Meanwhile, Robert offers his view of a situation that he feels is continually ignored or he has no control over. Both use syntactical features which may hide their vulnerable positions within the social context of the clinic and the workplace.

Mishler (1995) suggests that we speak our identities, which are performed and inferred through gestures and intonations. Storytelling is active and reactive, making the self heard not merely by language, but also through the body (Hyden and Mishler 1999:19; Riessman 2002). Very often, as the narrators spoke, they would laugh at inopportune moments, especially when explaining some of the darkest moments of living with illness. Angela laughs when she describes pain, saying: ‘erm my neck my neck was really bad under my arms ohh it was really [laugh] painful [laughing]’ [T1.41-2]. Laughter, tuts, intakes and outtakes of breath, hide the absurdity and perhaps embarrassment of what it means to live with this illness. These responses also seem to act as a defence mechanism, to hold back emotions as narrators deal with the parody of life, so that these non-verbalised disclosures work as counter-narratives. As these intermittent acts of communication cut and slice in and out of the narrations, they became bare examples of the unspoken aspects of living with illness. Laughter crashes through the stories like thunder, but it is also a social act. As I shared the narrators’ stories of pain and suffering, I often joined in the act of laughter as it washed over the absurd intrusion of illness and revealed a cultural recognition of a desire to hide the body in pain (Bergson [1911] 1999). Narrators who disclosed their experiences of suffering in the interviews, subverted the possibility of performing their healthy subject positions. In that moment of disclosure, laughter masked the fragility of the suffering self.

4.5 In search of words

For some of those in the study, the inability to find words to explain their illness came about as a result of symptoms that affected their cognitive processes. Those who experienced severe forms of the illness and were bedridden for long periods, not only missed out on the social interactions of speaking, but also became absent from their

socio-cultural environment, as others had to perform the act of speaking for them. Angela, having been absent from society throughout her teenage years, found that when she re-emerged she could not identify with her social world:

Extract 15

everything's just changed beyond recognition 'cause when I got ill I was a child and I liked the eighties, I enjoyed the eighties, cause I was growing up in the eighties and when I went sort of back out again in my early twenties I didn't recognise anything [...] by the time I was back outside in it was 2001 [T1.452/457]

As a child, Angela was unplugged from her entire social world. Unlike those who were bedridden as adults, Angela was entirely absent from the 'outside' environments of secondary school and the workplace, thereby missing out on social interactions between self and other.. The spatial and temporal elements of her discourse represent a kind of visual style, demonstrating the breadth of meaning, as 'everything had changed beyond recognition'. I was immediately able to picture her absence from the daily conditions of existence and the social practices necessary to take part in the social world. Angela's extract exemplifies how illness disrupted her life in terms of both language and cultural landscape and reveals how severe illness can either destroy the formations of past social identities or prevent the development of new social identities. The extract also alludes to the sheer time-span of her confinement and its associated deprivation, as well as the nostalgic reflections that her illness causes. Her ill health disentangled her from the threads that are woven together to make the material self. Angela is fundamentally absent from the social practices that offer a way to control and select behaviour over time, so that she is unable to physically connect to the 'outside' which has become an unknown land.

Angela further describes her alienation in the following extracts, as she describes her first journey 'outside':

Extract 16

it's a bit like being in a country where you don't speak the language you sort of have a little phrase book and you get by, but, you can't speak it. That's exactly how it feels [...] I just sort of adapt to it but I don't feel like I fit in anywhere at all which is strange [laughs] [...] I got into Tesco [supermarket] there was barcodes and I'm thinking what's all this bleeping and I didn't know because when I'd been in there it was buttons [T1.450/454]

Extract 17

was totally different going to WH Smiths [book store] and my mum said to me um 'what was it you actually wanted to look at' and I said I don't know and then it hadn't occurred to me until that point that obviously I wouldn't be interested in kids books but I didn't have any idea what I wanted to look at and it was I dunno it was really confusing [T1.464]

Angela has limited knowledge about the social cues in her cultural environment. In her absence, the world has changed and she seems bewildered as she searches for a language that will enable her to cross the barriers of communication, to find a 'fit' between her intentions and the words of others (Bakhtin 1981:424). In effect, due to her absence from the social practices from which language is produced, Angela is unable to articulate and convey meaning. Although these feelings of being outside social systems are evident in the majority of the stories and appear to be a feature of severe manifestations of the illness, Angela's extracts poignantly amplify the depth of vulnerability she feels on re-entering her social world. She presents an account of her conflicting emotions on leaving the restricted space of her bedroom and home, as she reveals how the nuances, laws and norms that govern space and body are outside of her reach.

For Angela, the social environment has dramatically changed. However, what is more startling is the suggestion that she does not seem to know herself. Her illness has, in many ways, left her adrift and her confusion at coming back may be likened to descriptions of those who have been in a coma. Angela's judgements, awareness and even her excessive bursts of laughter seem to be detached from the emotional states of self and other. Importantly for Angela, because she was affected by severe illness in her early life, she is unable to restore former versions of self-identity. Angela's proposition that she doesn't 'speak the language' is followed by her expression of need for a 'phrase book' that will explain to her the correct words, as she struggles to learn how to be (Deleuze [1986] 2006:12). Angela's extract reveals how the ontological conditions by which one comes to know one's self is missing. Angela is unable to work from perceptions associated with imagery, memory and illusion. More specifically, she is unable to establish a repetition for difference to emerge, as she feels confused and searches for a way forward so that she can interact and decipher her world (Deleuze [1968] 2004). As Angela grapples with both the ontological and epistemological concepts of language and knowing, she seeks to find the social and cultural assemblages

by which she can function in her social world. Subjectivity, knowing a social self, will then emerge through the moving dynamics of the different assemblages (DeLanda 2002:67).

Deleuze's notion of the force of chaos produces the moments in which change occurs. For Angela chaos resided within the territorial spaces of her 'outside/inside' bed/room and her 'inside/outside' body. As she recovers and searches for a repetition of these territories and their implicit multiplicities, entering the social world causes a force of chaos. Angela is unable to move from repetition to difference and 'fit' back in to the social environment (Deleuze and Guattari 2012 [1980]:314). The territorial force of Angela's shopping events brings forth the problem of finding a way to perform. The 'line of flight' is about finding the flow and movement where she can learn the codes of her surroundings. In effect, Angela's search for 'the phrase book' will enable her to capture an apparatus for actions and perceptions to exist. It is poignant to observe in Angela's extracts that she is at a loss to find the social vibrations of space and time. It could be said that Angela has slipped out of the territorial forces, that constitute periodic repetitions for becoming other (Coleman and Ringrose 2013:11). The extracts reveal that, through the chaotic return, she has to appropriate components that make up discourse and social practices in order for her to understand this new social world. Intriguingly, as a result of her illness, Angela could be seen to be not only outside the productions of language and identity but also, through her absence, in a position to imagine new possibilities of becoming.

This particular life story supports a Foucauldian perspective on the power of language to discursively construct subject positions. Furthermore, it is possible to see that by being outside the linguistic systems related to ideology, you plug out of the source of power that governs self-identity. Angela had plugged out to the point where she was unable to recognise or function in her surroundings. These extracts illustrate the importance of analysing the production, consumption and presentation of discourse. They demonstrate how this contested illness, due to socio-political uncertainties surrounding its existence, coupled with the severe symptoms experienced by those living with the illness, leads those in this study to describe the fragility of finding a self that one can recognise, work on or become.

4.6 Discussion

The life stories in this study offer a way to take each life in its entirety and discover themes that are not necessarily governed by illness, but by social practices and everyday life experiences. The contextual, situational and referential elements have been interrogated in this chapter, as implicit connections between language and social practises and the wider political and cultural contexts have been made (Fairclough 1989). A narrative identity sets out to produce a particular reality, oscillating between 'public' outside and 'private' inside perceptions of self and other, entwined within abstract forms of place and time (Sarup 1996:14). The nature of chronic illness continually disrupts both subjective and objective states that foster biographical uncertainty (Bury 1982; Williams 2000). This chapter has explored not only the loss of self and social isolation that is caused through the social and physiological experiences of chronic illness (Charmaz 1983), but also the accusatory stance cultural responses produce in response to this illness, which causes feelings of vulnerability and accountability (Horton-Salway 2001). What is unique to this study is that it reveals the unpredictability of the illness and the impact of severe symptoms, which force some to disconnect with the outside world. This level of isolation has rarely been researched so that there is little understanding of the extent to which those affected have to unplug from their social environment. It becomes important, therefore, to examine the 'conditions of possibility' that this illness offers to potentially re-constitute different selves in 'becoming', 'being' and 'surviving' 'severe' ME/CFS.

The stories in this study portrayed different understandings of the naming of the illness, which for some centred on producing a truth. The narrations reflect a discursive path between power and knowledge in the medical constructions of ME/CFS and substantiate the links between socio-historical events and personal experiences in the production of labels which, for many, constitute 'unstable meanings' (Riessman 1993:66). The material manifestations of these texts transmit, through lexical and grammatical structures, how the macro structures of medical discourses are born of power and ideology. So the operational structures that produce these medical terms encode and constitute how people understand their illness in terms of the political and social context, while the narrators describe the connective relational and experiential values of these labels (Fairclough 1989).

The narrators elaborate on the effects of objectifying their body through the various labels of ME, CFS and CFS/ME which were given to them during diagnosis. The

normative action of discourse establishes the relationship between the macro and micro management of bodies, between medical knowing and social thinking. So the nosological systems of medical language signify disease and constitute authoritative judgements, even without the specific signs of disease being present. As is the case with Poliomyelitis, a disease without a medical ‘cause’ can be made visible, but a disease ‘effect’ without a name may not exist. The dualist Cartesian approach is disrupted by this illness, as medical power shifts in and out of control. The clinical gaze (Foucault 2006 [1963]) strives to restore the regime of truth to keep this illness within the medical production of knowledge. The neo-libertarian attitudes of judicial powers and medical institutional measures can retain reproduction and production of the population, by including a term that will include all illnesses that feature ‘chronic fatigue’. So the play of dominations between political and social context embodies how this illness may be experienced.

Margret Shildrick and Janet Price, feminist scholars who offer a post-constructive approach to autobiographical experiences of being disabled/non-disabled, claim that the social model for disability is a way to confront the political and social conditions ‘to see every form of embodiment not as a fixed category, but as a fluid, shifting set of conditions, which frees us from the grasp of pre-given stable identity categories that slot all too easily into oppositional binaries’ (Price and Shildrick 1998:246). This contested illness, in particular, offers an opportunity to observe how the logical formations of medical discourses situate a dis-ordered body and how the uncertainty of labelling the illness reveals the problematics for those who come to live with the illness, to resist and question the distinctions that are made upon their contested bodies.

4.7 Conclusion

By exploring the production of language this chapter has attended to the overarching research question and the subsequent questions on the process and practices of living with a contested and severe illness. I have examined how discourse as a social practice is immersed within dominant ideologies, while shared cultural understandings are embroiled within a particular time and space. The inter-discursive landscape signifies and influences how subjects are produced and reproduced in relation to socio-historical events and experiences (Fairclough 2003). In this study, the stories highlight not only the function of discourse, but also how internal and external conditions affect the

narrators' abilities and limitations to access language, due in part to their illness symptoms and life experiences. As a result, the narrators in this study reveal through language how social practices and power relations affect the negotiation of living with ME/CFS.

The themes explored in this chapter defined the act and practice of resilience in negotiating the material restrictions that this illness produces. In particular, it focused on the power inherent in language, governed by the functions of knowledge, and the linguistic systems that constitute dialogical speech and grammatical moods used to express social beliefs and personal desires (Fairclough 2003:108). Specifically, these narratives establish the instability of the ME body, which breaks through the cultural tipping points for being a dis/abled subject. This then constitutes fragile, yet resilient selves, where new values and insights are gained as a consequence of experiencing 'severe' ME/CFS. The narratives also have the potential to disrupt and challenge societal understandings of illness and disability as fixed or becoming progressively worse, whereas the rapidly changing nature of ME/CFS requires dis/abled identities to be constantly adaptive. Physically oscillating between being bedbound, using a wheelchair and a walking cane can lead to disbelief from others, while the unpredictable nature of the symptoms produces a capricious self.

The stories in this chapter also go some way to respond to the research question on surviving chronic illness which brings to light the 'particularities' of suffering. As this study has not focused on the search for a rationalised approach to policy driven change, it is able to make available stories that are usually inaccessible. These are the tales of people with severe forms of the illness, who are often hidden as they find ways of living with and surviving this illness.

Chapter 5: Corporeality of Severe ME/CFS – Negotiating Space and Time

5.1 Introduction

This chapter focuses on the corporeality of severe illness and the repercussions for the social subject in terms of space and time. It will explore the effects of living with a condition that can cause the individual to lose the physical, cognitive and sensory capacity to ‘plug out’ of their social world. The chapter focuses on the extreme manifestation of this illness for those who are bedridden for prolonged periods. Although the narrators in this study had similar experiences, the heterogeneity of their life stories is revealed, not least in regards to the age at which they became ill. Attention is given to narrative processes which map the disruption and decentralisation of identity and time during periods of severe illness. Consideration is also made of how being confined to a bed causes a negotiation of the limitations of physical movement and provides an opportunity to mobilise inner thoughts, dreams and memories, to live outside of the restrictions of the body, gaining movement in imaginative worlds. Furthermore, the narrators describe the regimes of treatment to combat symptoms and detail the new pedagogical scheme of CBT and GET, which teaches self-surveillance techniques for managing the use of time and energy.

In Chapter Four, the life stories offered a means to explore the productions of language and the implications of constructing medical and cultural discourses around a diagnosis of ‘severe’ ME/CFS. The relationship between institutional spaces and the intimate spaces of confinement occupied by those who become bedridden emerged as an area of interest. This adds to current national and international research into the barriers to diagnosis and management of CFS/ME, along with the experience of living with an illness of this nature (Bayliss, Goodall et al. 2014). This chapter also builds on recent philosophical research on chronic illness, in relation to the epistemic injustices that produce marginalised voices (Carel and Kidd 2014). The life stories once again offer a glimpse into the struggles and tensions inherent in negotiating and communicating the

'lifeworld', through voices outside of the rational/technical representations of illness (Mishler 1984). These narrative accounts bring to light the 'consciousness of illness' and offer the potential to understand the deep implications of suffering, which cause a dislocation from the body in pain (Frank 1997:35). By critically engaging with the narrative texts, the chapter explores the often rigid cultural dichotomies between healthy and unhealthy subject positions, demonstrating some of the dilemmas and difficulties faced by the sick body. The study challenges the marginalisation of the illness experience as 'other', and instead works to question the normative concept of the body as healthy, energetic and pain free (Wendell 1996:91). The extracts taken from the individual life stories explore events and reflective accounts of specific embedded moments in participants' struggles to make meaning. The chapter analyses narrative extracts in relation to five themes, firstly looking at what it means to embody severe illness. Secondly, connections and comparisons are drawn between personal accounts of institutional spaces and the power relations between medical, professional, family and work commitments. Thirdly, it looks at how 'uncontrollable' bedridden bodies negotiate physical, sensory and cultural struggles. Fourthly, the possibility of a further layer of meaning associated with 'being' bedridden is explored, whereby the experience momentarily offers a point at which to be absent from the social responsibility of time and escape into imaginative worlds. Finally, in order to return and plug back into the social world, time has to be measured, so that the subject becomes vigilant in restricting cognitive desires and physical exertions in their effort to improve their health.

In the final section of this chapter, I undertake a theoretical discussion of power in relation to the process of 'becoming' an unhealthy subject. Foucault's concept of *heterotopia* offers a means to understand how the demarcation and illusion of the bed is both a crisis of space and deviation of place for those who become bedridden. To build on collective and individual understandings of space and time, I employ my take on Deleuze's notions of the body as a desiring machine, and the refrain, to explore the demarcations of a world within a bed. I take a cyclical view of time, synthesising both the repetition and the return of what it means to produce a self to live by while experiencing severe illness. The rupture in space and time caused by severe illness and being bedridden requires a reformation of the repetition, as the limits of movement offer narrators a point to creatively remember past lives and imagine new worlds. In this way, the narrators have been given an opportunity to unplug from the social responsibilities of life and a chance to reflect.

All the narrators in this study at some point experienced severe symptoms, which caused either long periods being bedridden and/or extensive periods of restrictive movement. These stories describe the biographical disruption of ME/CFS and the narrative reconstructions of a social self to live by (Bury 1982; Williams 1984; Holstein and Gubrium 1999). CDA examines how language produces meaningful discourse within the socio-cultural and socio-political contexts of the home and hospital. These two analytical tools link how narrative and the productions of discourse work to constitute particular realities for thinking, speaking, living with a chronic illness of this nature.

5.2 The Corporeality of illness

Chronic illness is an inherently unstable state; the nature of the symptoms causes those who suffer to question how they can regain their taken-for-granted material self to physically and socially interact, to walk, cook and simply plan events (Moss and Dyck 2003:105). The narrators describe the challenges that the illness places upon the physical body, as they reveal the often hidden world of pain and demonstrate how severe illness can cause dislocation from the socio-cultural space outside and inside the home.

In my own story, after experiencing prolonged severe symptoms and numerous out-patient investigations, I was admitted to hospital. As a single mother I had to leave my son with my parents. I experienced physical incapacities and personal isolation:

Extract 1

I was in hospital for a long long time, I think it was about six weeks. I wasn't allowed to see my son for very long, I wasn't allowed to speak for very long talk very long. Everything had kind of broken down. My energies to be able to lift my arms I REMEMBER that when I first had got there I had 3 weeks where I could not lift my head ermm the constant headache was unbelievable I couldn't bear the light, I couldn't bear anything and it seems you know now on reflection seeing myself back there that yeah you know the headaches always put me to bed eventually because I could fight the pains in my body with painkillers or you know I very much but once you get them in your head there's nothing you can do. There really is Nothing you can do, you can't try and read and you can't speak to a Friend you can't (2) you are there in that world of pain and it's the most frightening place to be it is horrendous and you can't speak it. [T1.42]

This extract demonstrates the all-encompassing nature of the illness. Removed from the social world, I was unable to speak to friends, while time with my son was severely limited. I was in a ‘world of pain’ which was a ‘frightening place’, as my body completely unplugged from the world outside and became like a ‘broken down’ machine. It was almost as if I had lost control and the sick body itself was in control, so ‘I could not lift my head’ and the headaches – which I personified with the phrase ‘once you get *them*’ – ‘put me to bed’.

There are two oppositional accounts of time, so that the stay in hospital seems to be ‘long long’, whereas I ‘wasn’t allowed’ to see my son and communicate for ‘very long’. The situational context describes the experiences associated with the power relations between the medical institution and the patient on the one hand, and the patient and their family and friends on the other. The social order has changed so that I am no longer a parent in charge of my child, but rather the hospital is in charge of me as a patient and tells me what I am ‘allowed’ to do. Interestingly it would seem that both the performative aspect of speaking and the communicative act of talking were in the control of the hospital. Although my narrative is a retrospective reflection on the situation I was in at the time, the language used demonstrates the underlying ideologies and power relations at play when I was hospitalised (Fairclough 1989:151).

Although the narrators in this study demonstrate that it is possible to live with severe illness, have a career and family life, there are still moments when symptoms re-emerge and you are taken back to the place of pain. I relapsed during this study following a bout of flu and was reminded of previous pain:

Extract 2

I can feel it today and it’s like someone’s whacked me with a great big bat round the arms, they feel bruised really is no better way to describe the feelings there, and the glands under my arms at this moment and my thighs are throbbing and because I’m talking quite a bit my neck’s hurting [...] I’ve got the cold compress on my head at the moment and you know it’s taking me back to my bedroom at my mum’s [T1.48]

This extract demonstrates that life with severe ME may be experienced as a continuing saga of how pain is embodied and all consuming. The power of pain over the body is visually represented with the simile ‘whacked me with a great bat’. The words ‘bruised’, ‘throbbing’, ‘hurting’ are used, ‘yet they do not describe the experience of pain’ (Frank 2002:29). The subjective qualities of ‘my’ pain are incoherent; there is no

place where it begins or will end. In order to relieve pain, a strategy has been adopted. Pain is always in the moment, the act of using a 'cold compress' not only restores a coherent moment, but also offers an opportunity to remember one of my earliest experiences of pain. The power of pain is seen in the ability 'it' has to transport me back in time.

Maria also described the difficulty in executing everyday tasks during a bad episode of ME/CFS. For Maria, this involved the disconnection from social communication and the physical exertion involved in simple movements:

Extract 3

my glands were really swollen I had bad headaches I didn't have the concentration to listen for very long I didn't have the energy to talk even just looking at texts on my mobile phones was an effort erm speaking to anybody was just exhausting [...] I started trying to build things up and just try and get out of bed and just sitting up in a chair I yeah my vision would just start to go and (tut) I just it was just exhausting I could just feel it being really tiring and not enjoyable just trying to sit up in a chair erm so yeah I knew I was pretty bad [...] I had to then just (1) have washes and every (1) now and then mum would like give me the quickest shower ever but it would be a seated shower so I would be on a seat and yeah and they would just do my hair but no and I mean I had to go, at one point, I went, I think it was a month without having a shower, and my hair was so greasy, and I absolutely hated it but didn't have the energy to do it [T1.49-51]

This extract demonstrates the immense personal negotiations of private space. It reveals how pain and lack of energy are not only symptoms of illness, but also catalysts for a change of lifestyle. The lack of power to control the ailing body translates into a challenge in which communicating and maintaining basic social interactions and personal hygiene become valiant acts. Maria's illness forces her to challenge socio-cultural conventions associated with maintaining movement. Indeed, Maria found to 'listen' and 'talk' 'exhausting' and 'hated' not being able to practice physical and emotional acts of living. Her desire to uphold fundamental social practices to present the self and maintain social identity is disrupted³⁶. In effect, Maria struggles to adhere to moral duties and social obligations while her sick body behaves as if it is beyond control (Frank 2002:58).

³⁶ Shilling (1993) reprint (1999) offers an overview of the 'socially constructed body' and cites Goffman's presentation of self as means to explain how the body is at once individual and social (Goffman, 1983).

5.2.1 Negotiating power and responsibility: age and illness

The life stories also demonstrate how institutions such as the home, school, workplace and hospital exert layers of disciplinary power. During a lifetime these narrators' discourses and social practices are linked to their epistemic communities (Van Dijk 2001:14). Accordingly, what it means to be a child, pupil, employee and patient is contextual, allowing for the identification of specific moments when a life's trajectory is changed by illness. For example, the three female narrators who were over 50 at the time of the study were influenced by political and social power relations that governed the professions they were encouraged to pursue. Heavily influenced by the state and their fathers in the 1970s, two were encouraged to become secretaries instead of following creative career options. The three female narrators between 20-30 years of age, who became ill as children, had their expectations limited by the ideologies of their parents and educational and medical institutions. The two male narrators differed in age and lifestyle, yet both had high expectations and constraint seemed to come from self-governance. The question then arises how the individuals in the study overcame the passivity of past subject positions to become active in the efforts to live with the illness.

The narratives map the movement between institutional spaces and the power relations between parent/child, teacher/pupil, employer/employee and doctor/patient, that constitute subject positions. As Moss and Teghtsoonian (2008) state, when looking at illness we need to take into account 'the material conditions, circumstances and bodily sensations of persons with illness or disability', as well as 'the discursive constructs shaping engagements with health care systems, health care practitioners, medical diagnoses, and social health movements' (2008:19). Since the 1980s, social research has been interested in highlighting the patient's means of understanding and discoursing their world of meaning while living with chronic illness (Bury 1991). The move from simply exploring the sick role, to embracing the relationship between how disease is produced and illness is experienced offers a way to break through the constraints of disease and the isolation of physical illness (Armstrong 1983; Turner 1994).

5.2.2 The power of institutions to silence and offer salvation

I will now explore the actions of institutions upon the lives of those with severe ME/CFS, specifically in regard to the age at which illness began. The power relations between child and parent means that, for those diagnosed as children, parents and doctors tend to speak on their behalf, acting as their 'vicarious voice' (Hyden and Brockmeier 2008:37). Although Hyden uses this term in relation to those who are

physically unable to speak, we can use the same concept to refer to those who act and speak for those who have no power, such as sick children, and are perceived to be unable to voice their opinions. These experiences are context specific; they demonstrate social and discursive orders that relative to particular ideologies and power relations involved in what it means culturally to be a child (Fairclough 1989).

The age at which people start to experience symptoms influences the strategies they employ and the ways in which they engage with institutions. Those who became ill as children and remained symptomatic into adulthood described the lack of power in their dealings with medical institutions. For Angela, the extreme expression of this occurred when she had been severely ill for some time and was unable to eat as a result of nausea (food intolerance is a symptom associated with ME/CFS):

Extract 4

I had an eating disorder because it hurt so much to eat and [...] I went to an appointment with [the doctor] one day with my parents and he weighed me and he said: ‘Oh this is not good because you’ve lost so much weight. I think we should put a tube down and take away the control so you have no choice’ [T1.79]

In this extract, Angela demonstrates how she was unable to voice her opposition to the use of a feeding tube as she was a child. She is then rendered speechless by the physical presence of the tube, thereby becoming doubly powerless to speak. Angela’s doctor seems to see her refusal to eat as an act of defiance, using the words ‘oh this is not good’, rather than a physical manifestation of her illness. Up until that point, Angela was governed by systems of control in the institutions of home and school. Here she comes up against the power systems of the medical institution.

It is interesting to note that Angela adopts the medical term ‘eating disorder’, which implies that her eating habits have deviated from the norm. This is in spite of Angela’s explanation that her inability to eat was due to her pain. We can see the movement of control over the body, which begins with Angela as a social agent demonstrated by the personal pronoun ‘I’ who attends the appointment with ‘my parents’. However, her body is then handed over to the doctor who weighs her and evaluates her weight loss, before using the collective pronoun ‘we’ to justify the action of putting the feeding tube down Angela’s throat. Her loss of control is confirmed by his statement ‘so you have no choice’.

Those who became ill as children have not been immersed in as many layers of social identities. As a result they often find it hard to relate to society, as expressed by Angela when she describes her sense of alienation after returning to society after being bedridden. This is also expressed in relation to her socio-cultural experiences as a teenager and young adult, when she spent a large amount of time in hospital or at home in bed:

Extract 5

I find it really hard to relate to people in general [T1.216] Erm I think maybe it comes from spending so much time at home and so much time around medical professionals but if put me in a hospital no problem put me in what I call like a normal situation and I can't cope with it I just can't understand [T1.217] ... The only thing that I could looking back on it now was that it all felt quite familiar to me erm it I don't know it was just [T1.227] That's exactly it yeah so I was very I was ok as long as I was within that being institutionalised in a way [T1.229] As long as I was within that or if I was at home then it was ok but I used to hate going home I actually hated it so it was a bit of the reverse of everyone else because everyone else was desperate to get back home and then there would be me not really wanting to go back I was more than happy to stay there [T1.230]

Angela's extract reveals how time is negotiated between the two spaces of home and hospital. She welcomes the opportunity to be away from home and has become institutionalised in the true sense of the word. Angela defines the spaces of home and hospital as institutions within which she can function. Implicit in this is are the assumptions she has formed about the overriding power relations and the perceived ideologies of the wider social and cultural context (Fairclough 1989:162).

Angela defines herself as living outside the 'normal' world, saying she 'can't understand' social situations beyond her illness experience, suggesting that she sees herself as occupying a deviant position. However, she says that she is 'happy' in this outsider position and 'hated' going home, positioning herself as the 'reverse of everyone else'. By critically engaging with Angela's discourse it is possible to see the social struggles associated with belonging to different spaces, as well as Angela's ability to adapt and derive comfort from institutional spaces during illness. The fact that she became ill as a child may have prevented Angela from developing normative patterns of social behaviour, to the extent that she views the institutional space of the hospital as an escape from the need to interact in the social world.

However, it is also the case that experiencing ME as a child can produce mistrust of medical institutions. Helen, who had symptoms of headaches and swollen glands from the age of seven, found that when she disclosed her symptoms to the doctor, he asked her to leave the room before telling her mother that he did not believe her. She is now 27 and remains suspicious of institutions. Helen describes how she would like to obliterate her medical history and reinvent herself within another doctor's practice so that her experiences of not being believed could be erased. She also refuses to reveal her illness to her employers for fear they will not allow her to work³⁷. Similarly, Angela has 'no intention of telling [employers] about her illness because she doesn't 'want to be judged on it' [P8:1.299].

While Angela found that she could not operate in normal social settings, for others who became ill as children, the lack of engagement with the institutions of school and work led to different responses. Helen was able to move in and out of institutions. Although her early experiences were of not being believed, which caused her to mistrust medical interventions, she constantly seeks to fit into society by performing as a healthy subject. Paradoxically, for Angela, this may perpetuate a misrepresentation of what it means to live with this contested illness.

5.2.3 Responsibility and Resilience

The narrators who became severely ill as adults were already entrenched in the moral obligations of home, workplace and hospital. They held multiple identities as they performed the social roles of child/parent, employee/employer and patient/caregiver which held layers of societal responsibilities and expectations for self and other, causing them to experience different levels of guilt. Robert found his ascribed roles as partner, father and worker hard to fulfil once he became ill. He was eventually able to work just a fraction of his former working schedule, as was Vivienne. Both also found fulfilling their commitments in personal relationships challenging.

As an adult with severe ME, like Angela I found being hospitalised less problematic as the space removed my parental obligation. It served to legitimate my illness and remove me from my commitments of the home. By the time I was bedridden I was responsible for the care of my son, but was unable to fulfil what I saw as the normative intimate

³⁷ This is expanded upon further in Chapter 8, which focuses on Helen's life story.

roles of motherhood. When my symptoms were extremely severe it was difficult to move, so fulfilling the basic physical parenting acts, such as preparing food and dressing him, were impossible. The following extract shows my attempts to replicate the kinds of physical activities that I could not do with my son, as I attempted to bring the outside into the space of the bedroom:

Extract 6

I would have rather played football with him in a park or swam with him and it used to ohhhhh I used to be broken hearted for him not to know the Sharon that I was the physical Sharon the one that ohhhh we would have had so much fun and I didn't need anyone else I could have just had fun with him you know. And I remember making errr the gladiator's game – I got a hanger and made a loop and leant it outside the top of my wardrobe. I got a balloon and I said to my son, 'you have to run into my room and put it through the hole – we laughed, we would always laugh [...] we made things and we would lie together [T1.45]

The situational context of this extract occurs through my reflection on an instance when I adapted the internal space to mimic an external space, so that the bedroom became an arena. By referring to myself in the third person as 'Sharon' and 'the one that', I am distancing myself from my pre-illness identity, which is associated with a more physical self. Of course, our children never know us as our younger selves, but this suggests that there is a more marked separation between my identity when I became ill and my more physical former healthy self.

Although I was 'broken hearted' to leave my son, I saw my role in hospital as being a patient given the opportunity to return home as a healthy subject. Although I never quite returned as a healthy subject, the fact that I had previously performed the expected role of a mother meant that I could recall social practices and attempt to replicate them. Those diagnosed as adults have accumulated more life experiences before becoming unwell than those who became ill as children. As a result they have been immersed in a variety of social and cultural situations, which may enable them to reproduce previous ways of being.

The extract shows my attempts to conform to the socially constructed role of mother and my disappointment at perceiving myself as unable to fulfil an ideologically acceptable parenting role. It would seem that I presuppose a lack in my parenting due to a loss of my power to perform as the kind of mother I wished to be. As a result, I lament

the fact that we ‘would have had so much fun’ and ‘could have just had fun’ if I had been able to be that mother. Paradoxically, the extract demonstrates that our relationship was filled with fun as ‘we would always laugh’. Although the loss of a previous self has occurred, it is clear that, in order to ride the storm of suffering, I have found ways to hold on to a core sense of self, which is not limited to the performance of social identity and daily routines (Charmaz 1999:367).

5.3 Bedridden bodies and plugging out of the social world

The extreme manifestation of the inability to fulfil social roles and healthy subject positions is seen in the four stories of those who were bedridden for long periods (with six and a half years being the longest). Whilst many illnesses can cause people to become bedridden, these narratives demonstrate how the nature of this illness can cause long term removal from social interactions and spaces outside and inside the home. The illness can lead to a contraction of space, to the extent that the bed becomes the world. The narrators who describe being bedridden offered detailed accounts of how they battled with constant muscular and skeletal pain, including severe headaches, often accompanied by swollen glands in the neck, armpits and upper thighs and hypersensitivity to light, sound and taste. In addition, severe head pain often meant that many of the narrators were in dark bedrooms for long periods and were only able to speak for short periods. These symptoms were often accompanied by food intolerances, causing nausea and stomach pain³⁸.

Angela describes what a good and bad day represented when she was bedridden:

Extract 7

the good when I was 14 would have been humph, I don’t know [laughs], erm, maybe being able to open my eyes and focus on someone for all of five minutes or maybe I could have had that much a small amount to drink that would have been good [T1.313]

Err I, I at the worst I couldn’t move at all I just laid there [T1.318]

Angela uses a verbal filler ‘humph’ before saying ‘I don’t know’ and then laughing, which may seem inappropriate in the context. However, the social convention of

³⁸ For full account of medical symptoms please see Appendix X

laughter, as discussed in the previous chapter, seems to represent both emotional embarrassment at having a failing body and an involuntary response to the search for the appropriate words. The simplicity of the second statement conjures up the bleak reality of her illness at its worst, as the usual understanding of good and bad days takes on new meaning in the context of severe illness. These two extracts reveal the context of time and motion in the physical space of the bed. Angela is able to measure baseline actions on a good day, whereas on a bad day the centrality of the body is evident as life is reduced to lying in wait.

When Paul described being bedridden in his mid thirties for three years, he focussed on the sensory deprivation that often occurs with this type of severe illness:

Extract 8

there (3) ensued that the the [clears throat] probably the most extreme time of my life I was just basically laid [-] down for three years and I was in isolation the light and sound sensitivity was extreme couldn't talk at all couldn't listen to music I didn't read 'cause I couldn't r so I just laid there and got worse and worse and worse but thinking [click fingers] somehow I was gonna sort of snap out of it [slight laugh] [T1.114]

Similar to Angela, it appears that being bedridden causes Paul to become absent from his social and cultural milieu. However, his extract contrasts with Angela's to the extent that he is preoccupied with sensory deprivation.

He talks of his 'isolation' and uses the word 'extreme' twice and 'worse' three times in succession, suggesting a downward spiral that echoes Vivienne's metaphor of Archimedes screw (see Chapter Eight). However, Paul's description of his illness state is abruptly ended with the words 'but thinking' 'I was gonna sort of snap out of it', with a simultaneous click of his fingers. Paul follows the statement with laughter, which audibly breaks the sombre mood of his narrative and amplifies the physical act of finger clicking. The socio-ideological gesture may also reveal his own internal dialogue and frustration at waiting to be well, as if this sudden physical act could put a stop to his current symptoms and to the memory of being bedridden.

The juxtaposition of Paul's severe and isolating experience of the illness with the impulsive snap and laughter is further complicated by the next section of his narrative when he displays a contradictory reading of being bedridden:

Extract 9

I didn't think I was ever going to come out of it and um (6) yeah it was extreme but it was also quite amazing in other ways [...] So that was my life for three years (1) but it was amazing because I I I just went and thought about my whole life and everything everyone I'd ever known because they were all outside in that other world [T1.115-116]

The statements: 'somehow I was going to snap out of it' and 'I didn't think I was ever going to come out of it' both use the pronoun 'it' to objectify the illness. However, the contradictory nature of the statements – one suggesting that he could snap out of the illness, the other that he will never emerge – implicitly show the impact of the uncertainty of the prognosis on those with the illness. He follows this with the surprising statement that 'it was extreme but was also quite amazing', as he exposes the minutiae of daily necessities that have become his whole life, activities such as going to the toilet. In contrast, he finds it 'amazing' to have 'pause' to re-run the film of his life, reflecting on the people he has known, who he is now separated from, as he lies in bed and they are 'outside in that other world'. As Audre Lorde states in her account of cancer, severe illness is often characterised by a preoccupation with daily physical needs such as what to eat, alongside consideration of the 'big' questions such as contemplating one's own mortality and place in the world (Lorde 1980:52).

Paul described his symptoms in detail in some sections of his life story, but at times adopted a reportage repertoire to do so, suggesting that these narratives had been repeated and refined in conversation with professionals and others in the past. At times Paul, like Robert, also seemed to speak in a style reminiscent of a medical case report, offering chronological data through which to describe his illness symptoms (Hurwitz 2004:424). Both men also used mechanisms, such as a prolonged pause or an intake of breath, after revealing their emotional response to suffering. This may be a way of retreating from engagement with the subjective experience of the illness by imposing a hiatus in the narrative.

5.3.1 Suspension of time

For those in the study who were bedridden and had subverted the usual timespan allotted to the space of the bed, time seemed to be suspended. They demonstrated how the stopwatch used to manage their social world ceased to be relevant once they became seriously ill. Life was gauged solely by practical needs, so that those who were bedridden for long periods found it impossible to plan even a few hours ahead. Going to the toilet was, at times, like attempting an assault course and even the thought of it became almost unbearable. Paul described the issues of managing daily exertions,

measuring the limited amount of energy available that had to be spread over a day and only used for essential tasks:

Extract 10

a lot of time I was just I just existed by day and did what I could when I could in fear that my trip to the t y'know it was like my whole life was like toilet and wash (1) and how could I save up enough energy to do those and then not do myself in too much when I done them that I'd recover enough for the next time I had to do that yeah so it was like that the common thread with a with severe m.e. [T1.115]

Paul's extract explains how his existence was defined by the unknown qualities of his illness. In effect, his actions were governed by saving up just 'enough energy' 'for the next time', so that he would only spend time and energy on the unavoidable tasks of going to the toilet and washing. For the healthy subject, these mundane acts usually have no temporal relevance and merely fit in with the more meaningful aspects of the day.

However, although time in the physical world was carefully measured, in Paul's imaginary world, being bedridden allowed his subconscious to exist outside of the functional properties of time:

Extract 11

I I existed by day and I lived in my dreams at night did all the things I existed in my dreams I really lived and I flew and I met people and I chatted I did all the things so my subconscious was just kicking in when I was unconscious and I was having a great time but it was sad y' know at the same time 'cause I I'd wake up crying sometimes d' y' know what I mean [T1.117]

This extract amplifies how Paul views his bedridden 'existence', by contrasting it with the freedom of movement and time in his dreams. Sleep offered him an opportunity to escape his illness, be a social subject and experience pleasure. His description of being able to fly in his dreams, suggests his desire to escape the physical limits of the human body. When I was bedridden, I experienced a similar recurrent dream of flying, which suggested to me at the time both a freedom from the body and from the responsibilities of existence. Arguably the idea of flying has mythological underpinnings, as with the story of Peter Pan, which offers those who are bedridden the chance to transcend the

restrictions of ‘real’ life. In contrast, Paul’s waking was distressing, as he realised that he had to rejoin the physical world of pain and suffering.

Paul describes the two ways of surviving while being bedridden: the focus on the physical restrictions that cause one to be bedridden, and the potential to live in a dream-like imaginative state and escape the body. Paul’s account of the bedroom as a refuge mirrors Proust, as it evokes an opportunity to recapture past memories (Proust [1913] 2014).

5.3.2 The artful management of time

In spite of the severity of the illness, it is interesting to note that there is no pharmacological treatment offered for the condition and no cure has yet been found. The usual path for chronic illness involves the emergence of symptoms, followed by diagnosis, followed by treatment. However, those with a contested illness that has no recognised primary cause may find themselves with limited treatment options. In late 1999, the Department of Health set up a patient expert task-force to address the challenges and effects of chronic illness. The task force produced a paper called ‘The Expert Patient’, which talked about the empowerment of the patient through the development of knowledge about their own condition. The only available medical treatments for ME/CFS are CBT and GET which, as discussed in Chapter One, are based on the management of time. Both treatments are inappropriate for those in the severe stages of the illness, as they may be living outside of time in their endeavours to temporally manage their pain and suffering.

The emphasis moved away from reliance on the NHS, due to economic cost, and talked of not only ‘educating or instructing patients about their condition and then measuring success on the basis of patient compliance’, but also developing patients’ skills so that they can ‘take effective control over life with chronic illness’ (DoH 2001). This approach focused on giving the body back to the patient, moving from a system of compliance, where patients follow orders, to one of concordance, where an agreement is reached between healthcare professionals and patients. While this can be liberating, it also places the responsibility for getting better on the patient, so that those who are unable to manage the illness, may be seen as deviating from the treatment regime for ME and may therefore feel to blame if symptoms become unmanageable.

More than any of the other participants in the study, Paul carefully controlled the time within the interview in order to adhere to the strict time-management regime suggested

by CBT and GET. He would talk for 10 minutes before taking a 15 minute rest and took long pauses in his speech. This time management practice guides every aspect of his life:

Extract 12

what they've taught me is how to be go in a straight line [...] what I know now how to treat and combat and work with even those little I'll get up in the morning (2) put my clothes on (1) maybe (2) yeah I basically do that come in here make myself some breakfast sit down and for 10 minutes I probably won't even eat the breakfast I'll just go into deep relaxation then I'll eat my breakfast and then for another 10 or 15 minutes I'll just rest then I'll do something for 10 minutes 10 or 15 minute rest do something thing for 10 minutes (2) and I can do such a lot in a day if I do that if I don't do that I'll get up I'll have my breakfast make my breakfast I'll sit down and I'll eat my breakfast then I'll do something on the computer and I'll like uuuurgghh It's just hit me and it I hit the wall I get the fuzziness and then I'm like that because I'm not breaking it up sometimes though you don't want to have to flipping break it up because it's just tedious but it's not tedious if you do it because you get the satisfaction out of having accomplished so much in one day rather than just all one end of the day doing too much and then having to rest for the rest of the day [T1.171/176]

Paul's narrative demonstrates that the pedagogical system that he has adopted in order to survive with ME means that he must always live in a state of equilibrium. The extract shows the minutiae of the temporal monitoring of his daily life. He has been taught a particular regime with which to manage his illness, so he sees himself as an 'expert patient' who knows 'how to treat and combat and work with' his condition. The body is seen as a finely tuned machine which will only respond to painstaking attention. In contrast to the precision of his time and body management, if he neglects his regime, he is rendered speechless, as demonstrated by the verbal filler 'uuuurgghh', and instead of control he encounters 'fuzziness' as he hits 'the wall'. It is possible to observe the conflict Paul feels between frustration at the onerous task of managing his day in this way and satisfaction when he achieves the tasks he wants to. This restrictive regime contrasts sharply with Paul's descriptions elsewhere in his life story of his unconventional lifestyle before he became ill.

Maria followed the same regime as Paul, which she learnt during stays at Queen's Hospital and the Marillac care home:

Extract 13

basically I've learnt such a lot about it from being in Queens and being at the Marillac [care home] and ermm I'm trying to cut my rest down so I've 20 minutes rest and a half hour rest now a day ermm but sometimes I don't know yesterday because I was obviously tired I went from a half hour rest and woke up an hour and half LATER (loud laugh) SO I MUST HAVE NEEDED IT (IB) ermm BUT YEAH FOR NOW I'M just trying to build my strength up and then I'm hoping that it I'm not going to be going up and down up and down my whole life I just want to you know I kind of think if I can work at a job that's (IB) more flexible than (OB) than like a permanent teaching job or permanent part-time teaching job then hopefully (0.5) the chronic fatigue will just stay in the background and you know and hopefully it won't you know be too much of a problem [T1.116]

Maria talks about how she 'learnt' to manage her illness with rest periods. In Paul's extract, we see how his cognitive desire for more active time outside of the regime leads to a 'fuzziness'. Whereas Maria's body refuses to be bound by the regime, as she deviates from the time allotted for sleep. Maria complies with the suggestion that the illness has to be managed and the symptoms of chronic fatigue must lie dormant for her to return to her social working role as a teacher. What these extracts reveal is the need for constant vigilance in negotiating and measuring time and energy. Both demonstrate the need to see the body as a machine, which needs to function efficiently so that the individual can plug back into society.

5.4 Discussion

The extracts about childhood experiences of ME/CFS show how the narrators experienced different levels of disbelief from within social and medical institutions, arguably having no voice in the geo-political spaces of the home, school and hospital. These narrators demonstrate how, as children, they were silenced in spaces that were governed, controlled and inscribed through systems of power designed to educate and/or treat them. The silencing of those who have limited power calls to mind Foucault's writing on governmentality which discusses the ways in which the state exercises power over its citizens. Here, those with chronic illness are subject to power controls within the cyclical 'play of dominations', derived from a multiplicity of institutional spaces, as they struggle to find a self they can know and understand (Foucault 1984:83). Just as Foucault's genealogical method offered a way to analyse

how the subject is produced within these mechanisms of power, I have used the life story to unpick the effects of the multiple layers of power in space and time on those with chronic illness. Both moral and normative demands are asserted so that, in order to produce a reality, the narrators must learn to perform axioms of living outside of their illness, to make visible healthy subject-positions. The narrations describe the 'eye of power' that inherently omits the discourses of children, as institutions normalise these 'docile bodies' and give the young patient, like Angela, no voice (Foucault [1975] 1991:135).

Those who become bedridden alter the space of the home, as the bed becomes central, no longer holding an association with restful sleep, but as a space of crisis in which to battle illness. The narrators in this study who were bedridden exist in the borderline between crisis of space and deviation of place, which calls to mind Foucault's concept of heterotopia (Foucault [1984] 1998:180). The home for those who are bedridden is a counter-site, which confounds the conventional use of spaces such as the bed, which was not demarcated for long term use (Foucault [1984] 1998). The inability to transcend what is normally a temporally limited space means that, for some, not adhering to the normative functions of the space causes them to question their identity as they lie and wait to be well in an unproductive state of being. Paul's contradictory statements about his bedridden state, that he would either 'snap out of it' or not 'ever come out of it', reveal a perceived split between the ill self in limbo in the heterotopia of the bed and the potential for a healthy self to exist again.

The illness experience not only problematises the usage of the bed, but also how the body slips between cultural understandings about what it means to be healthy/unhealthy, disabled/non-disabled. Although this can be portrayed as a negative reading of the state of being bedridden and in severe pain, it merely demonstrates the all-encompassing nature of this illness. However, being immersed in the cocoon of being severely ill, we are perhaps offered an opportunity to step outside of the power relations that circulate outside the world of the bed.

From within the forces of chaos, I developed different ways to manage the pain by singing my own refrain, through remedies such as cold compresses for the head, heated pads for the back and painkillers. The bedridden state demonstrates the dynamic nature of becoming, rather than being, as the notion of identity for the chronically ill person is in a state of constant construction. The body is the point of difference, while the

heterogeneous elements that make up the symptoms of this illness are the catalysts to effect change. In this act of suffering, the subject is offered an opportunity to ‘unplug’ from ‘rhizomatic assemblages’ that entwine and entrap them within and outside of the social world (Deleuze and Guattari [1980] 2004). The power to hail and name is lost, as the main imperative is to survive the illness. Paul’s extract demonstrates how he pursued a line of flight through his unconscious, by unplugging his physical body but plugging back into an aesthetic, social and imaginative world where he was free from pain and the territorial forces of the bed.

Foucault has offered a way to contest the power of discourse as a force which utilises truth through institutional regimes and ideological controls, while Deleuzian concepts offer the opportunity to examine the non-textual elements of these life stories. Multiple events in the form of different symptoms impinge on the ability to control the body and fulfil subject-positions, while the power to fight illness depends upon individual life histories. The states of being of severe illness offer a point to privilege the ontological over epistemological conditions for a self to exist, in spaces that are constrained due to physical limitations. Acts of resilience demonstrate the paradox of the ongoing search to escape illness and/or learn to live with the condition.

5.5 Conclusion

The multiple discursive and social practices entwined in the dialogic performance of telling a life story facilitated the emergence of different themes. This chapter again focuses on the primary research question and goes further to embrace questions on doing and being ill by examining the reconfigurations of ‘uncontrollable’ subjects negotiating the labouring boundaries of physical illness, as the narrators discussed the disconnection from and reinvention of space and time. The chapter confronts the research questions on the depth of meaning to the everyday experiences of surviving with ME and the dilemmas, contradictions’, conflicts and/or acts of resistance through the analysis which elaborated on how once healthy subjects come to embody unhealthy states of being, as well as exposing the difficulty of relating the depth of the severe illness experience. The sheer difficulty of physical movement during severe bouts of illness is detailed by Maria, as the seemingly automatic everyday activities of sitting or using the toilet were seen as flights of triumph in a daily battle to survival weakness and pain. However, the resilience necessary during long periods of being bedridden was also

revealed, as the restricted social space of the bed had to be re-organised, challenging normative cultural practices. The bed became a social and physical space to negotiate illness, a place for good days and bad days, where hours and minutes had an unknown quantity and quality, where the temporal flow was governed by sick bodies. The narrators also revealed the paradoxical existence that takes place within the context of the bed, as connections with the social world were limited, at the same time as space was provided to imagine and explore new ways of being in the darkest moments of illness.

This chapter continues to focus on the research questions pertaining to the contradictions of doing and being by examining the institutional space of the hospital which was also seen to be paradoxical, initially representing double powerlessness and voicelessness for Angela. Yet the hospital also offered a sanctuary, where Angela as a child and I as a mother could disengage from social roles and begin repairing our bodies. Complex power relations governed these processes, arising from visible or invisible support from the institutions of family and hospital. The hospital and home became spaces to practice the return of the healthy subject, as well as offering a place of safety and physical spaces to manifest sensory reprieve from the embodied aspects of illness and pain. From home to hospital and back, the narrators tell the tale of learning to understand their illness trajectories, as they are taught in many instances how to embody healthy selves by managing time. Therapies offer a way to keep on, what Paul describes as ‘the straight line’, to retain energies and sustain a healthy equilibrium. As the narrators resiliently negotiate and painstakingly work to build up their energy supplies, time becomes the instrument of control and the mechanism to plug back into the social world. However, as senses are awakened, it may be that illness acts as a means to unplug from the socially shaped illusions of life, so that for a moment we are in limbo and ‘make-believe ceases’ to exist (Woolf [1930] 2008:104).

Chapter 6: Photo-Elicited Diaries: ‘is that what I see every day?’

6.1 Introduction

This chapter employs a narrative analysis to storytelling through visual representations, which bear witness to the suffering and acts of resilience that arise from life with a chronic illness. A small number of researchers have begun to explore the benefits of incorporating visual depictions of health and illness, yet there has been no visual research on a severe and chronic illness of this nature (Radley and Taylor 2003a; 2003b; Oliffe and Bottorff 2007). In this thesis, the use of photography supports the life stories and produces a further layer of narrative meaning, illustrating the complexity and depth of feeling in the narrators’ experience. As discussed in Chapter Three, photo elicitation illustrates the continual, subjective processes of remembering, forgetting and recovering from chronic illness (Radley and Taylor 2003a).

Language alone, or more precisely words, may not adequately signify different individual levels of pain and suffering. Angela’s life story provided an exemplar of how confinement during severe illness produced social deprivation, as during her subsequent recovery she was unable to ‘speak the language’ when she re-entered society [T1.450]. In Chapter Four, the participants’ use of metaphors highlighted how communication is not restricted by ‘what can be said in words’ (Radley 1993:116). The use of images and narrations together has the potential to provide poetic witness to the movement of the illness between restriction and freedom. The photographs in this study demonstrate the embodied aspects of how this illness impinges on everyday life and, thereby, challenge popular views of what it means to live and survive with a long term chronic illness. Although Photo-Elicited-Diaries (PEDs) were supplementary to the life story interviews in this study, they can also be viewed as standalone emancipatory accounts, which communicate ‘*this* is what illness is like for me, that *this* is how it happened, and that *this* is important to tell others’ (Sontag 2003 cited in Radley and Bell 2007:371).

This chapter draws on the eight PEDs and analyses narrative excerpts from the subsequent interviews. The photographs and narrations were selected both for the way they reflected common themes associated with living with a severe chronic illness and for their personal significance for each narrator. Six of the photo-narrations, that constituted both recovery and memories of illness, have been selected to explore the individual themes that arose from their PEDS, which also reflect literature in the field of chronic illness. During analysis, each photograph was framed in terms of visual relevance and contextual significance, taking into consideration *why* the images were taken at the time and *what*, on reflection, these images evoked for the narrators during the subsequent interview. All eight were asked if they could identify a theme that emerged from their collected images, which ranged from how the photos made hidden aspects of their illness visible, as well as displaying their resilience and their progress towards recovery. Two overall themes of restriction and freedom seemed to emerge from their collected interpretations of their images. Three participants who were feeling unwell at the time when they were producing their photos, explained how they had framed the majority of their images around the theme of restriction and the way they had adapted to living with long-term chronic illness. The remaining narrators offered reflective views of the past experiences of illness, as well as presenting the joy of recovery.

The chapter explores how it is possible, firstly, to symbolise the experience of living with a long term chronic illness of this nature and, secondly, to master the temporal and spatial contexts within which the illness is played out. The PEDs, along with their short storied accounts, capture the movement between restriction and freedom in the negotiations of illness. These multifaceted and descriptive productions express the often discreet, difficult aspects of physically experiencing and surviving with severe illness. The PEDs offer a means to visualise and narrativise the process by which an individual with ME has to plug in and out of their social spaces, as well as the subjective chaotic world of pain and the joyful world of good health.

6.2 Symbolism: Living With ME

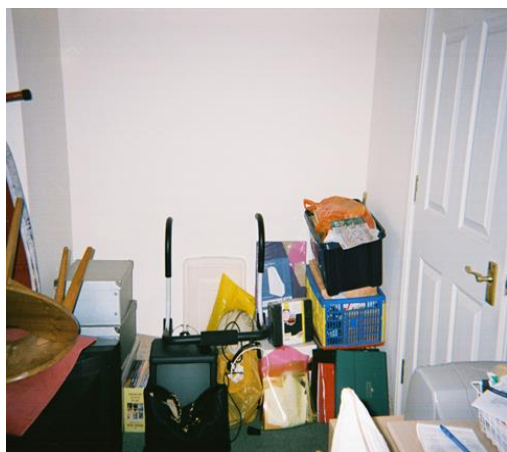
The life stories in the previous chapters offered insight into a life that *comes to* experience the intrusion of illness, the journey for diagnosis and the continual living and surviving with the long term effects of chronic illness. The stories also highlighted the everyday challenges of returning to the land of the healthy. The photographs in this section demonstrate how the PEDs offer a means to demonstrate a deeper level of

symbolic meaning through the use of metaphors and signs. They portray both the home and the outside world as containing iconic signifiers of the effects of living with ME/CFS.

Although Vivienne was able to work occasionally, at the time of the interview she was experiencing more pronounced symptoms of fatigue and painful joints. Like Vivienne, Helen was working part-time and at the time of the interview was experiencing ongoing symptoms, which included feelings of nausea which prevented her from eating or drinking many basic foods. The following two images depict Vivienne's (Figure 1) and Helen's (Figure 2) metaphorical and symbolic representations of their illness.

6.2.1 'My Dorian Gray room'

Figure 1



don't really use – anymore (.) (4) [...] I think it's a place where I'll never go again, I think that's what the point of that is (4) [T2.36]

Extract 1

My spare room or my Dorian Gray room as I call it AND I took the photographs because it sort of akin to how I feel my brain is (-) and my life [...] it's all very jumbled there's nothing straight And number one its having the energy with ME and number two having the enthusiasm (-) But I think more importantly than that I it's like hiding your frailties it's that room you close the door on that nobody ever sees (2) so that's why I took these [...] that's a real private thought (2)' [T2.4-6] 'I did take another one of my cleared out Dorian Gray room but I've managed to get crap in it again I call it Dorian Gray returns' [T2.AR.28-29] 'I think that's a picture of what used to be, that or junk that I

6.2.2 'A good metaphor for how I feel'

Figure 3



doors burst open which had happened here like when I give up its even harder to put that mask

Extract 3

The mess of this cupboard really is bothering me as I hate being unorganised I just don't have the energy [...] it's quite symbolic of myself I like to close the doors and everything look fine but I know still inside that it's not and when the doors burst back open it's even harder to close them again so its kind like a good metaphor for how I feel but it's also really frustrating because I haven't got the energy to sort it out it just explains how felt at the moment [...] so like if I put my make up on I put my clothes on then I look fine but inside things aren't and then erm when the

back up because you feel even worse than you did it's like when you walk past a mirror or when I'm too sick or when my body just gives up and I haven't got any energy and I'm aching and I'm too tired [...] I keep trying to put up a front but I can't so all those types of things that are going on and all the the little things could be different things about ME and that you can normally just shut the doors [...] but sometimes they give in and just burst back open [T2.2]

Vivienne portrays her spare room as metaphor for the 'jumbled' and 'hidden' feelings. She eloquently summarises the novel of Dorian Gray to suggest 'it's that room you close the door on that nobody ever sees'. This discursive style sets the tone of her photo-narrations and echoes the metaphorical expressions that she often used throughout her storytelling. In this way Vivienne makes use of narrative rhetorical devices to convey the continuous movement of her illness, explained in her life story as 'Archimedes screw', saying here her brain and life feels 'all very jumbled there's nothing straight'. Vivienne is able to use the image as a testimony of her feelings about her present world. She has presented a sophisticated description of the complex experience by expressing the contrast between the mess of the room and her inner feelings. As Vivienne looks at the photograph she seems to move away from her notes and become more of a spectator to her world, with a poignant revelation as she wistfully states 'that's a real private thought'. The discarded 'junk' belies a sorrowful realisation that this is 'a place where I'll never go again', which seems to frame her present uncertainty. As she reiterates, her attempts to tidy the room have faltered and Dorian Gray has returned.

Helen uses a similar metaphorical style to Vivienne, by using an object to symbolise herself and represent the chaos that her illness brings. She explained how, as an artist, she found it difficult to take everyday images, as she usually used the camera for aesthetic purposes. Yet it was a challenging yet moving experience. Helen, like Vivienne, wrote at least one paragraph about each image. Her interpretations were grounded in both the content and context of meaning. Helen is able to analyse her motivation for taking the image was its metaphorical meaning, so that 'the mess of this cupboard' is 'symbolic of myself', a 'metaphor' to resemble the lack of 'energy' to present a healthy image. A recurring theme in Helen's PED is the presentation of the self, which is discussed further in Chapter 10. The statement that she has to put on 'make up' and 'clothes' and 'then I look fine' reveals how she has become skilled at hiding her ill self from her social world, but the metaphor of the cupboard doors bursting open shows how sometimes she finds it hard 'to put that mask back'. In essence, Helen's PED emphasises the labour involved for her to perform as a healthy

subject. Her discourse communicates her need to wear feminised armour ‘to put up a front’. The messy cupboard allows her to semantically express her inner feelings of not necessarily surrendering to illness but, like Vivienne, continuing to fight for survival when ‘I’m too sick or when my body just gives up and I haven’t got any energy and I’m aching and I’m too tired [...] I keep trying to put up a front’. Although Helen articulates in intricate detail how her illness affects her desire to perform her role as female, it is worth noting that the powerlessness of illness causes an opportunity to break free from the complex social practices and performative aspects of being a woman. The mechanisms of illness, of ‘aching’ and being ‘too tired’, inhibit and split the constructions of self. Helen reveals how the discursive space to perform the female role is shattered – ‘when I give up its even harder to put that mask back’ – and the body in illness breaks through the constituted practices – ‘when I’m too sick or when my body just gives up’.

These photo-narrations encapsulate what it means to hide the experience of illness, through the objectified space of the spare room and the cupboard, which signify Vivienne’s and Helen’s continued efforts to hide sick bodies and the frustration involved in presenting the healthy self. The coercive power of others to influence subject-positions is therefore not readily obvious from the metaphorical expressions use to describe these images, but what is evident is their need to hide their feelings and representations of illness. These photographs seem to show the desire to conceal illness, not only from others but also from themselves. This also shows the continuous labour involved in the performance of the healthy subject, so that in the same way that objects that cannot be dealt with are hidden away, the manifestations of illness also need to be kept out of sight.

In the following images, Helen (Figure 3) goes on to describe in depth the physical and psychological effects of living with illness. Meanwhile, Angela’s account poignantly details the years of her life the illness has consumed and the slow progress of recovery (Figures 4 & 5).

6.2.3 'Symbolic of that whole process'

Figure 3



down mood where as the rest of the... are a bit like a story [T2.48]

Extract 3

Yeah, I was having a really rough day [...] I saw that cupboard and I didn't have the energy [...] to tidy it up and that bruise on my arm [...] I was feeling really sorry for myself [...] and I was a bit like OWHHH but like a bruise it doesn't hurt it's just so symbolic of that whole process you know it's like I'm sick of keep going to the doctors and nothing coming back and that shows it it's like they have to keep trying to take blood and to see if they can see anything and there's nothing there why do they keep doing it and its like you have to keep fighting that battle so that day it really reflected my

6.2.4 The zone - 'It's the walking tree'

Figure 4



Extract 4

so it's a 30 mile per hour zone and it's got the twenty underneath cross through but every time that sign I see it really winds me up because to me as stupid as it sounds is a constant reminder that I'm now thirty and my twenties are gone [T2.25]

Figure 5



Extract 5

that was another one of a stretch of road which is significant to me because erm I used it as a marker of the distance I used to be able to walk when I moved there erm that was the tree I used to walk to and then walk home but now I can actually walk probably double that distance so every time I see that tree I think ahhh that's how far I used to be able to walk [...] so that tree just reminds me of um yeah how much more I can do now cos that distance really is nothing to me anymore generally so It's the walking tree [T2.37]

In discussing the picture of her bruised arm (Figure 3), Helen makes direct reference to the image and the context. She focuses on the production and origin for framing the meaning and communicative function of the image. From the start of this extract, Helen situates the notion that she was ‘having a really rough day’. She uses the bruise caused by her blood test as a way of showing a physical representation of the clinical gaze, which necessitates a continued search for answers. On first glance it would seem that she is trying to present a visual sign of illness. However, this is not the case, as she states the bruised arm ‘doesn’t hurt it’s just so symbolic of the process’. Helen seems to refer to both the act and treatment of illness. In her life story, Helen explains how she was not heard by the doctors as a child. We get a sense here that the bruise symbolises medical intervention, which appears to be fruitless, as she has to ‘keep going to the doctors and nothing coming back’. For Helen, the image illustrates the literal prodding and probing to see if there is ‘anything and there’s nothing there’, which causes her to thoughtfully exclaim ‘why do they keep doing it?’ For Helen, this image seems to hold particular significance, as she feels that the rest of her photographs work together to tell a story, whereas this solitary image has symbolic meaning for the un-founded and contested aspects of her illness within medicine.

Angela had just begun two days voluntary work at the time of the interview and described herself as experiencing moderate symptoms of ME. As with the others PEDs, she elaborates on the reasoning for taking these two photographs (Figures 4 & 5). Her interpretations of the road sign and the tree give meaning to her missing years while she was bedridden and her steady progress of being able to walk again. Her interpretations display temporality in the form of a ‘sign I see’ that denotes the time spent being ill and is ‘a marker of the distance’ to illustrate progress towards better health. The functional and communicative value of these two images is in their portrayal of the restrictive nature of time and movement. Angela’s figurative trope seems to rest on the measurement of time and change, as the path conveys the lost years of the past and her present resilience, as she marches forward to the future.

The images examined thus far demonstrate the use of metaphors and symbols in describing visually what it means to live with illness. The images and the narrative extracts show the movement between the home and the outside world, from the restrictive nature of the illness to progress made along a ‘literal’ path towards being a healthy subject. Rather than taking a strictly representational approach and simply depicting aspects of their illness, the narrators used the PEDs to convey how the illness

made them feel and the deeper subjective experience of fragility and resilience during their continuous negotiation with the disruption caused to every aspect of their lives.

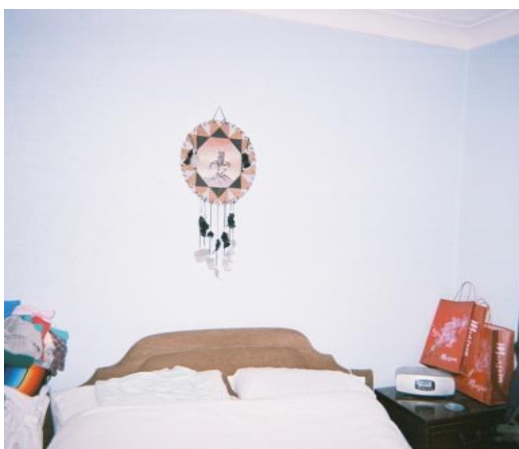
6.3 The Mastery of Illness

This section deals with the spatial and temporal aspects of the illness, moving from the internal space of the bed and the waiting to be well, to the focus on the outside world and eventual re-entry into that world. It was particularly interesting when considering all the images alongside each other how many similar visual depictions were used in order to document life with the illness. This section considers the parallels between these images in order to draw out the recurring themes.

6.3.1 The bed - 'peace' - 'trap' - 'nightmare'

The following three photographs of the bed demonstrate the diverse practice of illness, as they show both the negative aspects of being confined to the space of the bed, as well as the coping strategies and resilience displayed in the ingenuity of the ways in which the bed is used. For Robert (Figure 6) the bed is place of escape, for Helen (Figure 7) a trap and, for me (Figure 8), a holding bay.

Figure 6



Extract 6

the bedroom which is basically what I call the quiet room um if I get to a stage um especially in the evening when everyone's in where um you know th the noise levels might get a bit a bit too loud and I'll I'll take myself off up into the bedroom and um and spend some quiet time [...] -I use that you know if I want peace and quiet then i-I'll take myself off up to the bedroom (1) [T2.6]

Figure 7



Extract 7

my bed with my pyjamas and my controls for the tv [...] I thought I would take this photo as its got mixed messages although it looks all comfy and inviting I actually hate the fact I have to spend so much time in it I have to be there when I'm ill I can't get out of it and it's like a trap because once I give in to it it's like a downward spiral it makes me feel defeated I think that it's an obvious symbol for someone says they've chronic fatigue but its somewhere if I had my own house I would try and avoid because I have to spend a lot of time in there [T2.3]

Figure 8



Extract 8

my bed so that's how I was sleeping because you have the pillows all around, at the sides and under your legs because you're hurting all over, in every joint and in every muscle feels very sore. errrr like last night, the pain in the bottom of my spine, I couldn't cope, it was just unbelievable it was like the worst migraine, along with swollen glands and the symptoms of flu [...] it took me back to when I first had it because I used to rock with the pain and then I remember thinking why was I rocking what was it, because you don't remember, it's so scary, you know, it's your worst nightmare [T2.14]

Robert takes a more normative approach to using the bed, as the bedroom provides a release from social activities in his home. The space of the bedroom becomes a refuge, which he chooses to enter rather than being confined to. It is described in positive terms as a 'quiet room' as he demonstrates his pragmatic and practical approach to the bedroom as somewhere to go to when 'noise levels' are 'too loud'. He uses the room and the bed as a tool for coping, not to relieve pain, but to diminish the effects that noise has for him. This quiet space allows him to tolerate his illness and cope with the social pressures of being part of a busy family. Robert is in control of his own coping techniques and there is a sense that, once levels become unbearable, he will 'take myself off up into the bedroom'.

Helen starts by describing the image as 'my bed with my pyjamas and my controls for the TV'. She then interprets her picture by describing the normative role of the bed as

somewhere that is ‘comfy and inviting’, explaining that paradoxically for her the bed has become a trap. The image, therefore, has ‘mixed messages’ for her. She recognises that the bed is an ‘obvious symbol’ for those with the illness and it seems as though, at this particular time, she ‘feels defeated’. In contrast to my extract, Helen describes the meaning of the bed rather than its use, becoming something she is keen to ‘avoid’. Both mine and Helen’s beds are unmade which may signify how we were continually occupying this space as opposed to the normal sleep practice.

My photographs were taken when I was experiencing a severe relapse and the image highlights the battle to master my body in illness. The photograph is centred on the orchestration of the bed to ease the pain within my body. It shows the practice of illness in dealing with pain in a space usually used for sleep. Pillows are not used simply to lay your head on but as mean to combat painful muscles/joints. The extract uses similes to explain the subjective experience of pain – ‘it’s like the worst migraine, along with swollen glands and the symptoms of flu’. I attempt to make connections with other more commonly known illness experiences in my need for others to understand my suffering. I explain how my performance of illness, as with the ‘rocking’, ignites the embodied memory of pain.

These photo-narrations describe the use of the space of the bed in terms of the tension between its normative function and deviations from that norm as a result of illness. It would seem that the function of the bed changes, so that it becomes a tool to ease suffering for me, at the same time as being ‘a trap’ for Helen and a space of tranquillity for Robert.

6.3.2 The window – ‘outside from the inside’, ‘now a nice view out’, ‘memories’

The following three photographs depict Geraldine’s (Figure 9), Maria’s (Figure 10) and Helen’s (Figure 11) bedroom windows. The first two images were taken from the view they would have had when they were bedridden, the latter image from the position of looking out of the window. All three reflected on the ways in which the window triggered their imagination when they were unwell.

Figure 9



Extract 9

that's a window and it sort of sort of representative of [...] if you're having a bad day and not getting up and you sort of you tend to see the world from a different view to everyone else because you know you sort of see the outside from the inside looking out rather than and er you sort of um watch the world going by but you're not quite part of it um you know and I like that shot because it sort of um not that I have a bleak it makes me sound like I'm awfully bleak um the window is bright and the inside is dark erm and its sort of you know it sort of representative of wishing you could get out there things seem a bit dismal inside [T2.16]

Figure 10



Extract 10

the view out of my bedroom window um because basically I lay and looked out of there for sort of 10 months before finally getting funding from the local PCT to go to a specialist chronic fatigue unit [...] so I thought you know I looked at that view for ages... now well I've changed all of my bedroom around so that actually when I lay in bed I'm not looking at that exact view um because if I did have a bad day I didn't want to be in the same position looking at the same view to stop it taking back and remembering all the bad all the negative um so yeah and now you know it's fine it's just a nice view out the window [T2.3-4]

Figure 11



Extract 11

after a sleepless night I feel too ill to do anything or move I manage to sit up and look outside my window I love this view especially at night when the moon's out because it reminds me of my nan you can't capture it on a camera at night but the moon makes the trees light up and I just find it really calming it reminds me of feelings from my childhood but memories that I can't remember so I like that one [T2.11]

Geraldine is in her thirties, had recently had a baby at the time of the second interview and was still living with symptoms of ME. As Geraldine is a visual artist and uses the camera in her creative work, she chose to take the image at a particular angle, using exposure that seems to amplify the darkness of her room and the light from outside the window. Her statement that the ‘window is bright and the inside is dark’ highlights her reflective emotions. It would seem that Geraldine has taken the photograph from the viewpoint of her bed as ‘representative’ of ‘a bad day’. This sums up her disconnection from the outside world, as if she can watch from a distance but not interact with it, as if she has plugged out of society as she describes how she had to ‘watch the world going by but you’re not quite part of it’. Paradoxically she likes the shot because she is pleased that it represents her feelings, but is troubled by its bleakness.

Maria describes being in recovery. Her view of the window is similar in composition to Geraldine’s, in terms of angle and optical focus. Maria’s use of light, lack of net curtains and feature of the tree outside, gives a brighter view of the inside than Geraldine’s image. Maria occupied her bed for 10 months and attempts to show how ‘I looked at that view for ages’. She explains how her escape route came in the form of PCT-funded treatment. Again she conjures up an image suggestive of a time when she was severely ill, which she remembers but would rather forget. Maria explains how, since her recovery, she has changed the physical position of the bed, to ‘stop it taking [her] back and remembering’ being bedridden.

Meanwhile, Helen continues to use the window as a porthole to the world outside, in order to recall memories. As with Geraldine, it seems that when the body is trapped, the mind can wander. Like Maria, Helen talks about memories, but describes how looking out of the window helps to stimulate fond memories which made it bearable to be unable to move. The composition of the moon lighting up the sky and the trees skirting her ocular view makes her feel calm, as it resonates with memories of her childhood and her grandmother. In contrast to the other two pictures, Helen zooms in to leave out the window frame and thereby immerses herself into the view outside. By focussing on the elements of nature that are ‘calming’, she has removed the physical barrier of the window between herself and the sensory stimuli that engender positivity, which offers an opportunity to override the physical confinement of her illness. This echoes Arthur

Frank's description of seeing a tree outside a window during his own experience of serious illness:

Outside the window I saw a tree and the streetlight just beyond was casting the tree's reflection on the frosted glass. Here suddenly was beauty found in the middle of a night that seemed to be only darkness and pain (Frank 2002:33).

One reading of these photo-narrations is that, for people who are severely ill, the window becomes a means to connect to the world 'outside'. In their darkest moments of suffering this view offers an opportunity to interact with their thoughts and feelings, to cognitively step outside and unplug from their 'situatedness'. The window became different things to these three narrators. Both Geraldine and Maria depicted how they were constrained by the bedroom when they were bedridden and viewed the outside world from behind the window. However, Helen hints at the potential for freedom from the illness, by removing the barrier of the window and focusing on the outside world so she can wander with her memories.

6.3.3 The prone position – 'lying to be well', 'restless legs', 'freezing feet'

These following three images hold poignant messages of coping and waiting for symptoms to improve. They are taken in different spaces within the home, from the bedroom to the sitting room, and all show similar positions. Although participants were told not to photograph human subjects, there was still a desire to represent the physical impact of the illness.

Figure 12



Extract 12

The prone position – What I call lying to be well
(3) It's like you seem to be there for days the picture never changes (.) [T2.15]

Figure 13



Extract 13

Um this is a picture of my legs [laughs] I put after a day of struggling with what I call restless legs I thought that a photograph of me trying to get into position with piles of pillows would reflect this nicely haha although it's not really that funny because they ache so much that I become aware that I'm walking funny and nothing seems to make them better [T2.5]

Figure 14



Extract 14

this is my legs that hurt and socks are always on [...] what I was trying to show there is that's how I always have to sleep with socks on because my extremities are always freezing [T2.17]

Vivienne describes the position she is in as 'prone' and her image and comments suggest the static nature of the process of recovery. She is waiting for something to change, with no timetable for how long recovery will take. Her life story conveyed the impression that she had lived a fast paced life prior to illness, which contrasts with this stillness and her lack of control over time and the arrival of good health. She is in limbo and, as with the window, she is looking out but 'the picture never changes', which may refer to the physical state but also her health. The composition of this image includes the open patio doors and the view beyond, rather than just the body. This implies that she is not focusing on the reason why she is lying there but is depicting the act of waiting.

Helen wants to show the physical adaptations needed while negotiating the symptoms of ME, as certain positions and the use of pillows become tools to cope with the illness. The photograph shows the practice of illness, as she is trying to prop herself up into a particular position where she can reduce the pain from her legs. She laughs, acknowledging the absurdity of photographing her own legs in this way, but chooses the image to demonstrate her preoccupation with pain in her legs at the time she took the photograph. It also shows her resilience in finding remedies for the pain, so that she no longer has to 'walk funny'. Although she is lying down, she is using coping strategies as part of the continual need to monitor and relieve pain and, in this instance, to normalise her gait.

In the often transitional states of severe illness, an imaginative use of the space of the bed is necessary. In Figure 14, I depict myself lying on top of the bed. Although I am focusing on the body, there are books at the end of the bed and my glasses on my lap, as I continue to study and recuperate. The image is an attempt to illustrate how I cope with the subjective experiences of legs that 'hurt' and how my 'extremities are always freezing'. It denotes how I can read my body, as I adapt to its needs and the demands of my social roles, actively engaging with the process of living with long term illness.

These photo-narrations describe the process of waiting to be well, as the sick body causes the subject to plug out. What is interesting about these images is the fact that the subjects are not actually in bed but are in a transitional space and state. On first examination, these pictures could be of healthy people 'relaxing', reminding us of the disbelief directed at people with ME/CFS who do not outwardly appear to be ill. What the photographs actually depict is the lack of energy that occurs as a result of the illness and the frustration felt by those 'waiting to be well'. There is also evidence of active rather than passive behaviour, for example my glasses and books show that I am continuing to work, while Helen talks about her necessary recuperation so that she can walk normally the next day.

6.3.4 To stand - 'be able to walk outside'

These two photographs were taken by Maria (Figure 15) and Jean (Figure 16), mother and daughter, who were both in recovery at the time of the interviews. It is interesting to note that, although they took their images independently, there were many similarities. Their images reflect their recovery as they embrace the outside environment:

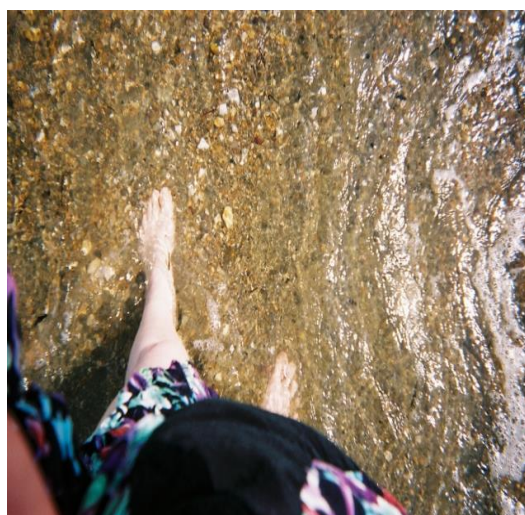
Figure 15



Extract 15

the sun was shining and it was just so nice to be well enough to walk around be outside in the sun rather than sort of stuck in bed you know cause when I sort of for the ten months I didn't get outside many times at all during that time so it was great [...] I just love that you know being outside and I think [...] I appreciate it more from being ill um you know I think it's very easy to take things for granted [...] so you know I've just really appreciated [...] just being able to be out and about and the next couple of photos are just saying how wonderful it is just you know to walk [...]and just be well enough to enjoy it [T2.14-15]

Figure 16



Extract 16

erm (.5) I was in bed for almost seven years erm I was I was out of circulation for eight years or something and so erm it felt like my life had been taken away so it's like I've been given a new life [...] and so everything especially the first couple well the first year but even now at times I'm shocked that some-times I take things for granted was just the fantastic feeling of just being able to walk outside you know but to look at the sea well that was you know get on a beach (.5). Well one of mine when I was in Queens [...] short term goals was to paddle in the sea because I've always loved paddling in the sea so that's my feet paddling in the sea [T2.16-20]

These two images are in stark contrast to the three previous photographs which show feet and legs immobile, in a prone position inside the home. Here, both Maria and Jean are outside and depict their legs and feet in the act of standing, in an active upright position, and both describe the pleasure this brings. In the first image, Maria points the camera downwards encapsulating her dress and focusing in on her feet on the grass. This image is a way for her to describe how she appreciates the simple things such as standing, which was 'taken for granted' before the illness. The majority of her images were about the pleasure felt upon re-engaging with her social world. Maria describes the contrast between being bedridden and the joy of standing as she repeats 'I just love being outside [...] I appreciate it more from being ill'. Using her photograph, she is able

to exemplify the move from the world inside her bedroom to the ‘wonderful’ feeling of being able ‘to walk’.

In the same way, Jean’s image also amplifies the joy of being able to be outside and stand. Her happiness is magnified by her composition which conveys a sense of movement. Like Maria, her image is taken from above looking down on herself, as her feet are positioned as if she is stepping, as she paddles through the water.

6.4 The benefits of using PEDs

In the process of storytelling, the PEDs became an important aid in providing an additional layer of insight, both for the researcher and the narrators themselves. The process of taking the photographs and the later reflections on the images during the interview seemed, at times, revelatory, as so that the narrators often expressed surprise at seeing how they had represented aspects of their daily life. Angela expressed some degree of surprise at the type of photographs she had taken:

I didn’t actually think when I was taking them [laughs] oh dear I didn’t mean it like that [laughing] I just means it made me feel [laughing] I didn’t think I was just taking pictures when I see something like you told me to do I didn’t really... and it’s been so long, I knew I took some of mmmm outside when I went for a walk but I didn’t remember what I had taken [...] It just hits home doesn’t it, it’s not what I didn’t already know, it just hits home. Yeah seeing it I think is that what I am looking at every day, I feel crap, [laugh] it’s not exciting is it [laugh]’ [T2.117-127]

Importantly, the images also became an anchor point in the discussion and a means by which they were able to pause and reflect on life with ME/CFS, as well as appreciate any progress that they had made. As Jean explains:

I think I compare myself to normal people and I think oh you know I’m still taking rests and still I’m not doing you know I can’t do everything that I want to do whereas actually by taking the photos it made me think hang on I’ve got to stop for a minute I have made a lot of progress because you know just by taking them you know and going out for a walk down to the beach and you know driving in the car and it just sort of brought it home to me actually how much progress I have made so I think it helped in that way [T2.33]

Jean also used the photo diary to communicate her active movement from being ill to feeling that she was in a state of recovery:

[It] made me think about where I am and where I've been erm (.5) yeah (1) and some things I'd forgotten and some things it's difficult to look back at erm (.5) and it's nice to sort of think I'm leaving them behind now [T2.126]

The images and the notes taken at the time represented a moment in their lives, a moment in to their past which also works to situate the present. The later reflection on the photographs added another layer of interpretation by each narrator, as they embellished the feelings the pictures aroused or were prompted to explore another aspect of illness. The poignancy of the images seems to cause the narrators to confront their understandings of what they have been through. Their depictions are framed to signify their suffering and resilience in negotiating ME. In all the PED reflections, I observed that the photo-narrations were recounted with a deeper level of passion than the life stories. They looked and pondered, they were astonished and sad, they were spectators of their own world of illness and, for many, this held either uncanny feelings of reliving a difficult moment they were hoping to escape from.

This chapter highlights how the second interview, focused on the photo narrations, offered a further layer of meaning for the ongoing process of living with ME/CFS. It enabled me to access the narrators' reflections on previous experiences and their feelings at the moment of the interview. In some cases, the photographs became a tool to elicit what appeared to be an instinctive emotional response, whilst at other times the photographs revealed hidden aspects of the illness that were not expressed in the first round of interviews.

The photographs provide a tool for securing further narrative data. By asking them to produce everyday images from their lives, the narrators were given a certain amount of freedom, so that to some extent they were taken by surprise by the images they produced. For example, Angela was shocked that she had chosen the images on display, saying 'It's like seeing yourself from another person's point of view' [T2.134]. This disrupts the usual use of the camera for taking family photos, which have a normative value (Harrison 1996). Angela states in relation to her photos 'you wouldn't put them in an album and look back fondly' [T2.150]. Of course, the photographs produced cannot represent unmediated reality. However, what is of interest here is why the narrators selected certain images and how they later interpreted those images (Berger 1972).

The photo narrations provided another opportunity to engage with the linguistic and social conventions of the constructions of self. The meaning-making context in each of

these instances was subtly different. This offered both the narrator and the researcher the opportunity to make further analytical interpretations (Radley 2009:17). Although all life stories vary depending on the spatial and temporal context within which they are told (Hyden 1997:51), in this instance, looking at stories of ME over time exposed the extreme manifestations and continuous variations of living with the illness. The photographs can be unsettling for the narrator in that they provide a snapshot of a moment in time. This tends to break the usual narrative repertoires which require a beginning, middle and end (Bury 2001:263), causing the narrators to disrupt, re-examine and re-evaluate who they are, how they will proceed and, therefore, readjust their narratives of self.

6.5 Discussion

Life stories are always told within a historical and social context, within which various social-political discourses inform the telling of the story and our understanding. The construction and reconstruction of the self is a reality for everyone, but the biographical disruption experienced by those with ME manifests as a constant reconfiguring of life and the social practices therein (Williams 1984). Narratives are always 'situated'. The situated context provides the means for an inter-discursive analysis on the genres of signifying and mastering illness, that come to represent various styles and ways of being (Fairclough 2010:75). By offering narrators an opportunity to reflect upon their own lives through the PEDs, it was possible to see the unfixed nature of identity, such as in the challenges of performing gender and healthy subject positions. Using Riessman's notion of positioned identities, I suggest that the active interpretive position usually adopted by the interviewer, is here given to both narrator and researcher (Riessman 2002:28).

The incorporation of photographs into the study allows the production of a visual language that mirrors and develops the use of metaphor in the narrative interviews. This provides an inter-textual understanding, as the visual image offers an opportunity to interpret and describe life with ME, uncovering the depth of meaning behind words by combining both the visual and the verbal accounts of illness. Interestingly, in some cases, there seemed to be spontaneity in taking the pictures, although it was not an involuntary act. Angela experiences 'a shock just to see [the pictures] looking like [...] nothing' and states that she 'didn't stop to think to take a photo'; as if the act of taking

the images was instinctive. However, her photographs of the 30mph road sign and the tree were both artful and obviously loaded with meaning and Angela recognised a particular truth in the images.

The role of metaphor to describe the stigma of illness is often discussed within chronic illness literature (Radley 1993). The photo narrations are able to communicate a way to legislate and document illness experiences, yet in some cases the symbolism contained within the imagery was not readily apparent without verbal narration. For example, Helen explained the image of the bruised arm as a symbol of the continuous medical interventions that provide no clear answers. Rather than depicting pain, as might be assumed, it represents her frustration with the power and politics involved in examining, re-examining and searching for evidence-based answers to her continual experiences of illness. By incorporating the photo-narrations, there is an opportunity for the narrators to view themselves one step removed, so that they can actively and selectively read and produce their own health messages (Bunton and Petersen 1997:10).

The stories demonstrate the process of material ontology. The event of illness alters our connections to our social world and the need to produce another event to live by (DeLanda 2002), causing a need to plug in and out of the social world. Severe illness makes our worlds smaller, as much as we are seemingly controlled by discursive systems. The different intensities associated with this illness create an opportunity for us to connect to the new emergent processes of what it means to be ill and activate new practices in the 'doing' of illness. In the three photographs depicting resting positions, the implied meaning is one of passivity – but, once again, the active practice of living with ME is evident. In the case of people waiting to be well, we can see the flux and flow of illness and movement towards the goal of getting better.

There are attempts to fix particular behaviours and ways of being to particular spaces which are specified and functional, such as the bed. This situates the strategies of home life within the geo-political and habitual institutions that are designed around how we create spaces of separateness and inclusion (Foucault [1975] 1991:226). For those who have become bedridden, the cultural space of the bedroom becomes disconnected from its socially assigned role. The images of the bed offer a way to view the practical application of this deviated use, the narrators not describing a single way to understand this space, but how it is possible to dwell, survive and study within the bed. Foucault's notion of heterotopias of deviation can be applied to the photo-narrations and to the

photographs themselves (Foucault [1975] 1991:180). In this instance the deviation is not found in behaviours inside an institution, such as a prison or psychiatric hospital, but rather in the disruption of the convention of the bed as a place of rest. Furthermore, the photographs provide a unique way to observe the illusionary qualities of the bed, which, even when empty, bears the marks of a presence and the signs of illness which are often hidden from view. Harrison states that ‘cameras essentially operate to produce a mirror image of how things appear’ (Harrison 1996:88). This recalls Foucault’s description of the heterotopia of the mirror, allowing him to see himself ‘over there where I am not’ (Foucault [1984] 1998:179). The photo-narrators are able to view themselves in the photographs in a place where they are not. In this way, they have made visible, to themselves and others, the discreet space of the bed and the intimate experiences of illness.

In the three photo narrations of the bed, it would seem that the complex systems that organise spaces have been disrupted due to severe illness. Using the notion of assemblages, it is possible to see a machinic way that the body/self links the ‘parts’ of the bed with the experience of illness (Moss and Dyck 2003:46). The assemblage that territorialises the bed as object and instigates the normative codes of use have been broken. In order to survive illness, the body demands a break from the territorialised space of the bed and its coded meanings. The photo-narrations offer a way to witness how the narrators bring together the unification of body/self (Fox 2011). In actively seeking ways to cope, Robert will ‘take myself off’ to the bed/room, as the body determines how he responds to the social world of his family. Fox’s reading of Deleuze’s body-without-organs (*BwO*) is an opportunity to observe ‘the biology and physicality as a (necessary but not privileged) component of the body’ (2011:3).

The extracts associated with the bed show the assemblages that connect the *BwO* to the inanimate object of the bed and to the technologies used to live with the illness (such as my use of pillows). We are able to show how the body is actively engaged in the social context, rather than being merely passive. The struggle to find ways to live with this long-term illness is to break and alter our assemblages of meaning, ‘re-edging the notion of embodiment’ as we are living in illness, moving towards health (Moss and Teghtsoonian 2008:173). For example, while Helen refers to being trapped, she still discusses future possibilities for changing her connections with the space of the bedroom, which would be ‘somewhere if I had my own house I would try and avoid’.

For those unable to socially interact, the window can be their only means of viewing the outside. The bedroom window becomes symbolic of the process of plugging in and out and the disconnections and the reconnections of assemblages. The recurring image of the window demonstrates the potential therapeutic benefits of viewing the outside world, even when being removed from it, as it keeps alive the possibility of – and the desire for – re-engagement with the social world. For Helen, the window helps her to re-assemble and become embodied ‘in the doing of illness’, as she continues to survive in the habitual space of her bedroom. Arguably, illness further disrupts the habitual nature of life. At critical moments, when illness becomes almost intolerable, the mind can recall the possibilities of time gone by and look forward to plugging back in. Helen’s memories are not a snap-shot of actual experience, but are based on intensities, sensory meanings that include others, such as her grandmother.

The narrators describe their deterritorialization from social networks, such as the assemblages of the social institutions of family, school and work. However, they actively interpret ways to re-engage with the forces of cultural ideologies that govern the way we manage our various subject positions. In this way, it is possible to show a self-mastery of illness, to follow Foucault’s statement that where there is power, there is resistance (Foucault [1975] 1991). The deterritorialization brought about by illness has defined these individuals as people with ME. However, resistance can be seen in the movement towards wellness, which is all about the return. I depict my glasses and book as I continue to read, Helen rests her legs so that she can walk again and Vivienne is ‘waiting to be well’. We are all ‘doing’ illness in our own way, as we depict the different ways in which we have constructed our own individual ‘ill-health assemblages’ (Fox 2011:10).

6.6 Conclusion

The photo-narrations attend to the research questions on the aspects of living with a contest and severe chronic illness, but also offer additional depth of meaning to the doing and being of illness, by illustrating and discussing the everyday aspects of surviving with ME. Using Foucault offers an opportunity to observe how the body has intrinsic value, as we work out new knowledge systems that enable us to manage our ME bodies. The photo narrations document this continual need to return to the healthy state, as if the position of ill-health is a deviation from the social norms of society.

Although the latter photo-narrations depict freedom and recovery, others were about the continuous negotiations that occur while listening and waiting for the sick body to improve and allow individuals to return to their social roles. The implication is that there is a ‘doing’ of illness rather than being ill, suggesting that there is a continuous movement in the throes of illness even when being bedridden. Foucault’s genealogical approach establishes a way to situate how power intrinsically maps our epistemological understanding of space and subjectivity.

Deleuze explains that Foucault was describing in his work in ‘geographical elements, territoriality and movements of deterritorialization’ (Deleuze [1990] 1995:150). In these photo-narrations it is possible to observe the flow of connections and linkages where it becomes essential to rethink body/selves. A corporeality where, in the finite world of illness, there is always an essence of becoming. Deleuzian concepts offer a way to move past the disciplines that constrain these bodies, to a deeper understanding of the ‘desiring machine’ that is always in a state of creative flux. In this way, it is possible to deterritorialize and actively engage with illness symptoms and inanimate objects, bringing them together in a cacophony that works within, but is not confined by, an ill-health assemblage.

The final section addresses the research question on the dilemmas of what it means to survive chronic illness in the two photo-narrations which centre on embracing the natural environment that was unavailable during illness. Maria and Jean describe how they are reconnecting particular forces that were entwined in their assemblages of social and cultural relations. Their narratives suggest feelings similar to those that one might feel on leaving prison or coming out of a coma, as if they are plugging back into the outside world. They also demonstrate that the plugging out caused by illness can lead to a new perspective when plugging back in. Although, both go on to say that the joyous moment of re-entry is soon ‘taken for granted’, as seeing trees and walking on the beach become normal again.

While the life stories provided a broad canvas of moments and events, the photographs explored in this chapter offered a glimpse into the internal life of those with ME, producing unexpected reflections. Although none of the images contained people, all were loaded with emotion and displayed sensitive details. The images offered snapshots, moments in time which conveyed the confined space of the unmade bed,

through to representations of freedom in standing and walking, combining both visual and verbal meanings to present stark realities and resilience.

Chapter 7: Battling ME – ‘shot to bits’

7.1 Introduction

The previous three chapters identified the power relations that exist between patient and doctor and constitute the knowledge that determine the nature of a ‘real’ illness. This chapter adopts narrative and critical discourse analyses to explore the discourses and social practices which constitute knowledge of a ‘self’ diagnosed with ME/CFS, focusing in particular on Robert. Previous chapters have identified a discourse centred on legitimating the illness, as well as discursively mapping the social relations between space and time. The subjective accounts of blame, accountability and stigma (Tucker 2004) have been explored, along with deeper feelings of loss of self and agency (Dickson, Knussen et al. 2008). In particular, a strong connection has been made between the illness and the oppositional claims of ‘overworking’ and ‘malingering’ (Horton-Salway 2001).

Robert was born in the 1950s in London, England, and is the eldest of three siblings. He is married with three grown up children. From the 1970s to 1980s, Robert was employed within the financial sector as a stockbroker. In the early 1990s, he twice contracted pneumonia, followed by mumps. From this point onwards, symptoms of ME occurred and Robert was diagnosed with ME in 1998, remaining symptomatic. He attempted to work part-time after his diagnosis, but later became unable to return to work and has since retired.

Robert’s story is inextricably linked to his experiences of school, work and hospital. These ideological spaces determine multifarious identities that became fractured when he experienced symptoms, leading to diagnosis and life with ME. Robert told his story in a logical and practical style. However, his use of metaphors and idioms offer a glimpse into his feelings and beliefs about his illness experience. He adheres to social practice built on the premise that hard work leads to rewards, portraying the struggle of adhering to traditional values whilst configuring and reconfiguring a life affected by illness. His cultural dilemma is negotiating multiple roles and identities whilst living with and becoming diagnosed with ME.

The overarching theme that emerged for Robert was a kind of crisis of identity, as his illness affects the personal and social relations associated with his roles as husband, father and employee. My interpretations necessarily narrowed Robert's life story into different levels of abstraction (Fairclough 2003:68-70), so that I was able to focus on his speech and use of language, interactions and governance of social spaces and time. This chapter focuses on Robert's struggles to maintain a self to live with ME, as he becomes an expert in his battle with his bodily limitations.

7.2 Dissonance of speech and metaphors of meaning

Robert uses figurative language to personify emotional and physical pain, using metaphors of the body at war. He describes his immune system as being:

Extract 1

absolutely shot to bits (.) cos I think um (-) specially having the pneumonia twice I-I-I'd um I'd had a lot of antibiotics pumped into me [T1.50]

Idioms and metaphors continue to be used as allegorical imagery to illustrate the challenges of the physical symptoms of ME. Robert's 'shot' body is seemingly a machine, a war-torn vehicle, continually 'pumped' with anti-bodies, to fight the invading viral army – illness for Robert is a metaphor of war (Sontag 1991).

Robert has experienced defective speech patterns in the form of stutters since the first signs of ME. The following extract demonstrates how his stutter causes him to prolong pronouns and adjectives, especially when asked direct questions. Ultimately, these fissures in Robert's discourse open up conditions of possibility for the unruly 'sick' body to speak, as if it causes a cognitive dissonance within which a counter narrative can emerge.

Extract 2

had good spells but then I'd probably overdo it and and I-I, you know, I'd just go just go downhill again, and it's just like a, just like putting a pin in a balloon like y-you can you can sometimes just feel the energy you know just going from you you know it's a strange feeling [T1.51]

Robert continues to use metaphorical descriptors along with his stutter, as these linguistic devices expose the unfathomable and sensory nature of illness. The challenges of illness become apparent as Robert's language impairment supports the symptom led criteria of ME/CFS (Carruthers and van de Sande 2006:2). Robert describes how his ability to physically interact is radically altered when he experiences symptoms associated with fatigue and pain. As he is confronted with the physical barriers of illness, he finds the experience of losing energy to be uncanny.

Robert's stutter demonstrates how his voice struggles to conform to linguistic structures as it searches the semantic landscape for a discursive signpost, perhaps to hide the non-verbal scream. The constraints of discourse can only reveal 'a strange feeling' which, along with his stutter, may represent the language of pain through a voice that disrupts or cannot describe (Scarry 1985). As with the speech of the madman (Foucault [1961] 2001), Robert's sick body is not listened to, as the uncomfortableness of illness becomes 'a strange feeling'. Robert's extract demonstrates both the physical difficulties of speaking and the problem of describing his illness experience.

This may be seen as a counter narrative, as Robert's illness causes feelings of frustration associated with his body at war. His delayed speech produces a means by which his body *does* communicate. Arguably, these acts of verbal sabotage and dis-rhythmic speech patterns, that split and tear through the folds of language, momentarily ignore the organic sensory modalities that physically interface in the act of language (Morgan 2002; Mooney 2006). His stutter may, therefore, be seen as a mechanism that, in its linguistic delay, allows Robert the conditions of possibility to temporarily resist the order of discourse and reveal the cognitive and emotional effects of his illness.

7.3 Displacing spaces: entering and exiting the social arena

Robert's narration begins with his early recollections of moving between the institutional spaces of home to school, focusing on his emotional non-linguistic response to school life, followed with a 'settle in period' [T1.4]. Robert described how 'a good performance' was rewarded [T1.11] at school. The theme of incentives is carried on into Robert's working life, as financial rewards induce feelings of enjoyment. As he recalls his working life, a cascade of memories flow quickly, triggering not only subjective accounts of excitement, but also the ethical and social demands of working in the City of London as a broker in late 1980s.

Extract 3

I used to enjoy g-going in to work cos, erm, we was involved with um stocks and shares and we ended up having a few shares ourselves so there was always er there was always there was always an added incentive going into work to see se if you see if you was making money or losing money and it was erm it was all quite buzzy (.). . . .we worked hard and when needed to work long hours but it was enjoyable and and you used to get rewarded um w-w-w-with the bonus schemes [T1.20]

Robert's behaviour throughout his working life reflects his childhood experiences of incentives and rewards and links to his unfailing attitude towards hard work and advance. However, it also perhaps caused him to ignore the physical signs of illness.

Extract 4

I spent twenty 23 years er basically at the same firm (name) was taken over a couple of times but erm erm we we ended up with er the the last person to take it over was (name) and that's basically where the work ethic changed out of all recognition tut um [26]. At that stage i-I'd worked my way up to a managerial level and er (name) expected their managers to to do extremely long hours you know i-I was i-I was often int here at seven o'clock in the morning er not getting home till ten o'clock at night er a lot of the time Saturdays as well (1) [27] and I think it was through this sustained period of pre-pressure and long hours of work that I I ended up with erm tut two bouts of pneumonia within six months of each other [28] [T1.26-28]

Since the 18th century, the home, school and hospital have been designated as functional spaces, designed as 'economic and political installations' (Foucault [1975] 1991). These socio-spatial sites employ disciplinary techniques within ideological structures to discursively maintain the subject as child, pupil, employee and patient, via the specialist positions of parent teacher and doctor. From Robert's earliest memories, it is possible to see the transition from family to home to school, as these institutional spaces become sites of power and social practices where Robert acts out the private and public aspects of his life.

Robert's multifarious identities become constituted within a web of discursive practices and become the principles of his subjectivity. Within these social practices, mechanisms of control employ incentives for what Robert described in his life story as 'a good performance'. The social apparatus of rewarding performance, as a mechanism of control, plays on Robert's ego, as he labours to satisfy the production of desire. As a

desiring machine, Robert invests and transfers pure energy from the institution of school to workplace (Deleuze and Guattari [1972] 2004). Arguably, we see the production of desire continually manufacturing docile bodies, through rewarded labour. Robert is enticed by a heady mix of working and profiting. This period in Robert's life coincided with media reports on 'yuppie flu'. 'Yuppie' referred to young, upwardly-mobile professionals like financial traders in 1980s London. Combined with the term 'flu', it suggested that these bodies were particularly vulnerable to viral epidemic. Indeed, we see how Robert allowed little time for the body to speak, as the rewards of the desiring machine compelled him to turn the wheel of financial success and ignore the body's pain. Robert attempts to maintain his subject-position, to 'keep up and er you know the standards of work ethics you you've been used to all over the years' [T2.AR.1]. The body eventually rebels, with bouts of pneumonia and mumps. A rupture in the technologies of self occurs, as the mind of reason which justifies extreme working is broken and the body is unable to maintain a 'good performance'. As the unruly body shows signs of pain and fatigue, the illness is owned by medical institutions and the long term effects of pneumonia and mumps are further translated into medical symptoms. The diagnosis of ME offers Robert a socio-political, temporary sick role (Parsons 1951). Arguably, illness offered Robert a way out of a capitalist system that overtly rewards its subjects through monetary incentives. Yet, as Robert moves away from the disciplinary powers of the financial industry, he still needs to have his illness validated by medical professionals.

7.4 Expert-ism: the journey to know thy self and ME

The following extracts convey Robert's micro-political doctor-patient relationships, which work together to validate and certify Robert's illness and treatment. Medical intervention seems to trigger past experiences of a knee operation, as Robert objectifies and compartmentalises and his body and mimics the words of the consultant:

Extract 5

the consultant did say um when I had my last operation when I was in my forties that if- if I'd a been 10 years younger he-he would have done it then but er but o-on he basis that the joints only last 10 years and you can probably only get away with about three of them in your life time he said you know y-y-you'd be in you'd end up in a wheel chair by the time you were 70 so [22] He-he tried to um you know he's tried to to preserve the

knee as long as possible and um (2) and um tut and and see how we goer [23]' [T1.22-23]

This extract describes Robert's struggle to maintain his body and again resonates with the theme of a machine that is difficult to keep in motion, underpinning his view of his body a warring machine:

Extract 6

I would start struggling again and I would be off work again (2) and erm it wasn't really un-until I-i-I managed to get-get into pro-pro-professor Green's clinic that I've I've I've actually managed to get any any real treatment [31]. Um up until that stage um obviously my-my my company um tut I had I'd regular visits to the company doctors and they-they sent me on to various other people but really n-nobody had any real great idea of what ME was about and an-an-and how you felt [32]' [T1.31-32]

This extract reveals how Robert describes the process of seeking validation and legitimisation for his sick role. As his 'unruly body' slips and slides along the medical professionals' path, he eventually gains a foothold on what he describes as 'real' treatment'. Robert's story highlights his long journey through the regimes of power built into the path of medical knowledge, until he finds a specialist who can certify his condition.

Extract 7

there was always a very long waiting list to see him and um and um I-i-i- you know i-i-it never came to pass(.) um when-when prof when a professor did did get his own um tut his own area in queens then it then it then it actually actually became a lot a lot lot easier to see him and um I started going to his clinic and then I also my my firm paid for er private consultation with the professor and then al-also um the insurance company that pay my wages now also paid for a private consultation with him which was which was both you know very useful and it was it was it made er it made it was a pleasure to actually speak to someone who who really knew the condition and and knew how-how it was effected' [T1.34]

At various junctures, Robert is governed by systems of time, appointments and waiting lists which control his path as a patient. Finding the holy-grail of a medical 'expert' makes Robert feel as if he has finally found someone who can speak about the extent of his illness experience. He shows his relief, as both the Professor and his company insurance accept the impact of the illness.

As Robert's illness is legitimated by the various power structures of the hospital and the workplace, he is then offered treatment. The government-sanctioned treatment, based on therapeutic techniques of occupational therapy (OT), cognitive therapy (CT) and physiotherapy (PT), help Robert cope with his symptoms.

Extract 8

the professor recommended um in CBT [...] I don't think anyone can say these therapies are going to be a complete cure for you (.) They are they do help in-in in their ways you know I don't I don't believe that there is one thing that can cure ME I think y-y-y-you just got to chip away (2) at various piece-pieces and and various thing you do in your life and alter them and hopefully th-that came make it a bit better [T1.37]

These treatments are not 'cures', but inscribe a new belief system to 'chip away at various pieces' of Robert's previous social practices, as he re-evaluates his daily life/time. This mechanism of power produces another method of survival, and anywhere you find knowledge, there also, you will find power (Foucault [1975] 1991:27). The desire to control the growing increase in chronic illnesses, requires a catch-all treatment programme, with CBT and GET being the present government treatment plan for ME/CFS.

These extracts demonstrate how Robert's experience of medical interventions, from his knee injury to his experiences of ME, constitute ways for him to objectify parts of his body, such as 'the knee'. Yet, once the specialist sanctions how he feels, the force of power of the medical profession can determine possible futures for Robert. These micro-political features of power demonstrate how patients become dependent on medical knowledge to gain financial support, via medical certificates that validate a diagnosis and offer 'real treatment'. Conversely, this means that those who have no validation may be deemed undeserving of the sick role. Robert finds the medical knowledge he is searching for as he enters the 'consultation room' and consultant and patient follow the ritualised ceremony of the consultation. Robert is on both a personal and political quest, in which he is a consumer who can theoretically 'shop around' (Wiles and Higgins 1996:434), these private sessions being more personal than those afforded to patients within the NHS (Silverman 1987; Wiles and Higgins 1996).

Although, the discursive power remains within the doctor's grasp, the patient/client may feel able to question this seemingly paternalistic relationship. Following his

consultation, Robert is able to re-negotiate his unstable sick role through a new regime, which does not seek to cure, but helps him cope with illness. The disciplinary system requires Robert to be in concordance with his body, producing procedures and techniques for him to speak about 'ME', as he embraces new knowledge to help him manage his body (Canguilhem 2012:52). Arguably, the desiring machine has once again sought and gained permission to function within a new disciplinary system (Deleuze and Guattari [1972] 2004). Mechanisms of control have once again incorporated Robert within an assemblage of political and social elements, reproducing him as a diagnosed subject.

7.5 Treatment and the temporal stopwatch for ME

The medical mode of production continues to dominate Robert's story as he describes visits to medical experts, which allow him to mechanically observe, dissect and analyse his body. Robert continues to compartmentalise and validate the state of his body in terms of past and present illness conditions, mimicking the clinical gaze, as a list of observable symptoms leads to a 'real' treatment program. Robert works to actively understand the corporeality of his illness, as a means to direct the body through these impasses to a place that will allow him to work within its limitations. In the following extract he explains the difficulties in gaining medical recognition and social acceptance:

Extract 9

in the early stages it was it was very very difficult cos I (1) I don't think a l-lot of people understood it [91] A lot of people especially um GP's um didn't recognise it um i think in our doctor's surgery there was about I think we probably got about 10 doctors down there and there was probably only two that you could you could go down and talk to about it(.) you know there was others down there that just it straight away saying you know I don't believe in it or recognise it or whatever [92] Um as I've said um (tut) um the private medical people have worked up until the last couple of years wouldn't recognise it they'd they'd cover expenses up to the time it was diagnosed and then after that er they wouldn't they wouldn't offer any more cover [93] Er presumably cos there there isn't a miracle cure [94]' [T1.91-94]

Robert continues to explain how cultural perception has shifted from an illness that was initially presented in the media in a derogatory fashion, illustrating his journey along a medically and socially sanctioned route to validate and treat his illness. As he achieves

recognition, he also describes cultural acceptance as he '[doesn't] need doctors' certificates anymore and [101] I don't have to go back to them at all cos um' [T1.98/101-102].

Robert explains in depth the care that is given to him via the 'expert patient programme', a government sanctioned treatment offering coping strategies to those with chronic illness. Although Robert recognised the benefits of these mechanisms, he did describe the difficulties of managing the body's energy reserves in an objectified way. He explains in a very practical manner how the therapists have taught him to recognise his energy in terms of bursts and flows, highs and lows [T1.59-61]. In the following extract, Robert explains how he manages his fluctuating symptoms through regimes taught to him by the occupational therapist (OT):

Extract 10

I think s-s-since I've been to been to the OT's and the CBT it its has real it has helped in that (-) but but I can understand people other people in in different er conditions might not be able to [76] Might not be able to work to um live like that cos um you know if you've got family to bring up or a-an-and other things to do you know it's-it's-it's not always (1) you know its not always easy(.) [77] You know it t-took me it's probably taken me a good six months to to get used to [78]' [T1.76-78]

This offers some insight into the practical implications of managing time, which are the main principle behind OT and CBT. These therapeutic mechanisms are employed to offer a way to manage the physical and cognitive aspects of chronic illnesses such as ME. Yet, as Robert highlights, the body is not an obedient machine. It is unruly and cannot always be mastered. Robert describes how his various roles as a husband and father may have caused him to abandon his regime, as he engaged with the physical aspects of family life.

Robert's life history reveals a kind of temporal stopwatch, driven by discourses and practices, which work to contain him within subject positions. The marginalising discourses surrounding those who live with ME/CFS are produced by a complex institutional system of political and cultural configurations, within which the ME/CFS diagnosed subject has a material existence. The therapeutic techniques require the individual to adhere to a regime that governs the body's energy. By conforming to this particular sick role the reward is hopefully a healthy identity. Under the new treatment programme, Robert shifts to possessive pronouns in relation to his body, with 'my

chest' and 'my knee'. The implication being that the patient has the agency to manage their lifeworld. However, failure to adhere to treatment plans implies that the patient is not fulfilling their role as patient/client, placing them in a deviant position. Robert's adoption of the therapeutic discourse personifies the mechanisms that turn everyday life experiences into timed tasks. The process offers Robert a way to gauge rest and action, as the rhythm of his body is governed by sequential temporality, otherwise he feels he will 'pay the consequences' [T1.61].

Robert is challenged by the new regimes: 'it's not easy it's not a thing you can snap your fingers and say right I'm gonna do – I'm gonna live my life like this now' [T1.80]. However, the therapies enable Robert to 'chip away (2) at various piece-pieces and various thing you do in your life and alter them' [T1.37]. This new mechanism of control does not follow the old patriarchal disciplinary system of rewards, but the contemporary incentives to find a new self to live by, as 'health is something which lies within the control of the individual' (Nettleton 1997:208). The right to welfare state and private health care schemes seduce Robert into becoming an expert patient, as the political economy of market forces encourage him to take on his own illness. The therapeutic element of Robert's treatment returns a ritualised approach to his daily routine (Mattingly 1998). However, Robert senses that, in order to embrace this new regime, he must 'chip away' until he finds a new social routine for an active self. Robert's life history not only reflects the tensions of finding this 'active' self, but also the diagnostic journey in which the label changed from ME to CFS. Robert believed that people's attitudes towards the illness have altered as 'in the early stages it was it was very very difficult cos n I (1) I don't think a l-lot of people understood it' [T1.91], while cultural perceptions have improved since 'yuppie flu' was just 'a posh name for flu' [T1.98].

Robert explained the problems of trying to work whilst experiencing his illness. He repeatedly attempted to re-enter the workplace, but his unpredictable illness became difficult for his employers to manage and he became resigned to a continual state of flux in terms of employment [T1.52-53]. Robert emphasises how his devotion to labour is based on moral and ethical obligations, as he ignores the affects his illness is having on his body.

Extract 11

I've always worked hard and er and (2) you know when you look at some of these people you work with who just go in do the hours they've got to do do the least amount of work they've go to do and then um (1) you know you know especially when you got the ME y-you push yourself to try and keep up and er you know the standards of work ethics you you've been used to all over the years and um you know just doesn't do you any favours at all [1] ...people at work don't don't know what you're going through and um they think cos you turn up at work you're not really that bad and etcetera etcetera and um so you push yourself...[2]...yeah so you know pushing yourself doesn't help (1) but so w-when you've been used to supporting your family and er you know for a long long time it it's had to let go of it [4]' [T1AR.1-2/4]

This extract explains how Robert continually attempts to return to his managerial role, the rationale for attempting to work based on 'the standards of work ethics'.

Robert's use of figurative speech and idioms of meaning convey the effects of illness (Sontag 1991; Couser 2009). The metonymical expression used by Robert manifests in relation to his attempts to fulfil his subject-position of employee, whilst negotiating the symptoms of ME. Robert habitually uses the term to 'push yourself', suggesting another self outside his working identity, pushing him to connect to the social practice of work and the financial machine. The desire to be part of the social system is prominent, as Robert repeats the phrase three times. This figurative language enables Robert to communicate to others an implicit message of a burdensome experience, made up of the struggles he endures to maintain his position as an operative subject. This discursive device enables Robert to communicate experiences of fatigue, such as describing his lack of energy as being like 'putting a pin in a balloon [...] a strange feeling' [T1.51]. These colourful renditions allow others to be made aware of the physical dilemmas the illness brings for him. In addition, as the medical diagnosis and prognosis is uncertain, the device attempts to make sense of his chronic condition (Taussig 1980; Bury 1982).

Robert continues to describe the battling body, however, this time his descriptions of living with illness take on a more ethereal and sensitive quality. As he begins to relate a scene of watching his son working, his discourse seems peppered with emotional longing:

Extract 12

I'd like to able to help him with [5] But I just can't do it you know when I see him and when I see him digging the foundations you know getting [6] stuck in into that sticky

clay and it you know you know he's doing it for hours on end I I know if I started doing that I'd probably last about 15 minutes if I was lucky [7]... I just couldn't do it w-w- I'd love to be able to help [8] [T1AR.5-8]

This piece portrays a dream of how things could be, as Robert is momentarily anchored into the scene, the challenge of living with his illness being confirmed by his son's ability to work. Robert is seemingly positioned as the child, demonstrating his powerlessness, as he is trapped by the physical limitations of his illness.

Indeed, Robert's performative identities of father, husband and employee have been challenged by his illness. His extracts demonstrate the power relations between the socio-political structures and cultural ideologies that constitute the value and beliefs, which determine a constant need to regulate the performance of the body (Shilling 1993:83). The extract shows Robert's struggle for self-identity, focusing on the imitations of his illness experience, as he yearns to return to the position of a healthy person.

7.6 PED

Robert's photographs seemed to offer a way for him to observe himself within the space of illness. His images related to the practical aspects of everyday life, showing the rewards of 'relaxing' inside and 'exercising' outside. The three photo narrations describe Robert's management of space and time. The first is based on Robert's reflection on six images that were predominantly about the interactions between himself, his dogs and the outside spaces of the garden and the local park. These relationships provide a way for him to diminish the feeling of loneliness when the family has left and 'the house is empty' [T2.1]. The second image illustrates what Robert does inside during the day, apart from what he describes as 'the chores'. These images show how Robert frames his inside world. The final photo describes one of the household activities which Robert now undertakes.

7.6.1 'Valuable for companionship and a great source of exercise'

Figure 1

Extract 14



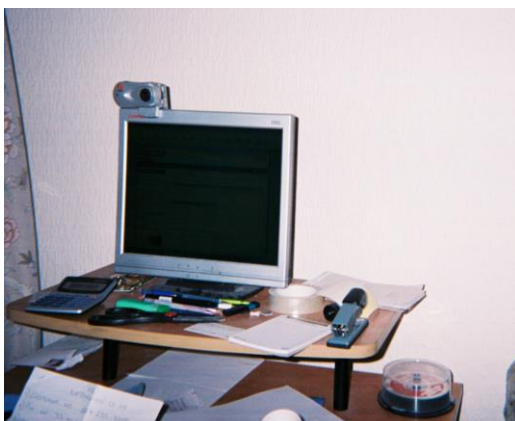
a great source of-of exercise helping you get out of the house for half hour to an hour at a time um our main walks are over the over to the local park where yet again apart from the exercise there's um they're they're social communication over there with with the other dog owners which is which is all very nice and the park is is is quite peaceful and as i say as well as the exercise its its it's a good way of relaxing and and just thinking things through um there's there's other things to watch over the park ie you know when they're playing cricket you know we often stop for for

15 minutes to watch them play cricket (1) and er you know th-th-the whole thing is-is-is-is just a relaxation plus um a bit of gentle exercise [T2.1]

These images are framed around exercise, time, communication and the rewards of relaxation that is activated by Robert's metaphorical stopwatch, whereby each activity is recorded in minutes. However, the style and mood of this extract portrays the inability to plan hours in advance, as Robert is continually taking account of his body. Although he describes activities that give him joy and exercise, these marginalised experiences are continually monitored and controlled. Enjoyment must come after the regime of maintenance over his body, which reflects his maturation in terms of incentives and rewards.

7.6.2 'Relaxation – you just sit down in the chairs'

Figure 2



Extract 15

the television and the computer (-) obviously t-t- the television you know is on quite a while you just sit down in the chairs you know relaxing after after the the exercise um because you know like as the OT has said its best to keep exercise to half hour to an hour especially if its strong exercise and then sit down you know relax have a cup of tea I usually end up watching the telly or or going onto the PC er checking share prices er sports information you know etcetera etcetera(.) [T2.2]

Here Robert describes the learnt behaviour of managing his physical and cognitive output, demonstrating the balance between relaxation and exercise. The extract amplifies the continued negotiation between every movement of the body and mind. This image shows how Robert is mastering his illness in an intensely controlled manner, infiltrating every corner of his world, inside and outside. However, the fastidious monitoring is justified by the incentive that it will enable Robert to cope with the symptoms of ME.

7.6.3 'Household chores', 'jolly ole hoover'

Figure 3



Extract 16

hallway have to be hoovered everyday so yet again its its specially with hoovering and putting the washing on you're talking about 15 40 15 20 minutes um um actual exerc you know exercise there all doing the chores [T2.4]

This image portrays Robert negotiating a different identity outside of the institutional roles of full-time employment. It exemplifies how his role shifted from managing an

office to managing the home. He fulfils the functional needs of the family household, including 'doing all the chores', which would have been negotiated as a form of exercise between Robert and his OT. As Robert adds up the minutes when he hoovers, he acknowledges the exercise regime which limits all activity to half an hour.

The photo narrations demonstrate the practical impact the illness has on Robert's daily life, yet he makes limited connections to the emotional effect of governing his life through the clock. Robert's photo narrations adopt a similar approach to his life history, using a kind of checklist rhetoric. It is difficult to judge how these severe controls over his life made him feel. His ability to operate within the restrictions of CBT and OT could be seen to be based on the principles that he instilled as a manager, which sought a profitable outcome, as his work ethic continues in the management of his illness. Yet these narrations omit out the pain and suffering caused by the symptoms of ME.

7.7 Conclusion

Robert's life story chapter reveals the socio-historical context, which is contingent on a complex series of social practices and discourses, constituting cultural understandings of a self shaped by a series of events/experiences over time (Ricoeur 1985). In this way, this responds to the questions of how Robert's social practices work as a means for the doing of illness. Robert's earliest memories record how he learns to seek rewards for good performance. However, illness disturbs Robert's subject positions as trader/banker, father/husband as he becomes lost in the folds between power and knowledge. The analysis has identified the function of a discourse that allows Robert to visualise and speak about his illness experience. The narrative also shows how Robert learns to become a patient and objectifies his body. However, the use of therapeutic techniques helps Robert return to his body through self-surveillance, as he becomes an 'expert patient'. The research question framed on being ill has been responded to through a world of political and social consequences where Robert's attempts to return to work and live multiple identities, is a battling body which requires knowledge in order to understand the illness.

The chapter alludes to but never fully responds to the research question on being ill, as Robert describes the practical demands of living with a diagnosis of ME, yet his emotional struggles often reveal themselves throughout his narrative in covert gestures which remain part of his unsaid narrative. However, they reveal themselves throughout,

either in the rhythm of his language, or in the silences between his discourses. The narrations emphasise the modes of production which rupture Robert's identity. As Robert dislocates from socio-spatial spaces, discourses and practices immerse Robert within norms and values which impinge on the ways in which he can confront the biographical disruption of chronic illness.

Chapter 8: Sensitising ME – “I call it my ME world”

8.1 Introduction

In the previous chapter, narrative and critical discourse analyses revealed the shifts in Robert’s discursive identities and social roles. In this chapter, Vivienne’s life history reveals dominant constructions between dialectical, relational and authoritative aspects of language and knowledge, power and truth, body and space, identity and subjectivity. Vivienne was born in Essex, England, in the 1950s and is the youngest of three female siblings. She recounts how she was one of the first female traders to work within the stock market in the City of London in the 1980s. Vivienne was married, but is now divorced and lives alone. She maps her illness journey through a series of viral episodes, including reference to inoculations for a trip to Asia and a bout of shingles, leading to her eventual diagnosis of ME in late 1990s. In 2005, at the same time as losing both her parents, Vivienne was also diagnosed and treated for cervical cancer.

The complexities and contradictions of performing femininity are an explicit feature of Vivienne’s early life experiences, as she tries to meet the expectations of her father during the 1950s and her husband in the early 1970s. However, her entry into the male-dominated world of commerce dislocates her previous notion of femininity, as she struggles to reconfigure her gendered position. This chapter identifies how private and public institutions impact upon her socio-economic world, as her subjective experiences are played out through power relations within the family and work environment. Her story begins before the major liberations brought about by feminism in the 1970s and, therefore, portrays the political and social issues faced by many women at the time (Oakley 1972). As she explains, ‘when you met somebody you probably settled down and you did a part time job’ [T1.6].

She begins by describing her early schools years, marriage and employment. Her illness experience seems to emerge as an inconvenience to be managed by a disembodied subject. From family ties to the work ethic, from the medical expert to self knowledge, the rhythm of her story is structured within a rich dialogue, portraying a clear and often

moving account of a life affected by illness. As with Robert, Vivienne recollects her high profile position within the banking sector. An emerging discourse for both offers a glimpse of how the body attempts to speak of experience and, like Robert, Vivienne's life history centres on the complex relationship between temporality, corporeality and subjectivity that makes up her 'ME world'. However, Vivienne's story is structured by relational discourses which provide an interesting contrast to the traditional ideologies of 'being male' that featured heavily in Roberts's story.

8.2 Patriarchy: Expectations and conformity

Vivienne's story amplifies the relational and emotional implications of managing expectations and conforming to socially produced roles. She describes a conflict of interest between paternal demands and social obligations, as her desires were subject to the power relations around her. When she married, the cycles of moral obligation and duty shifted from father to husband, amplifying the dominant male role of provider and protector. As a result, Vivienne erected boundaries which seem to frame and locate her ideological position and can later be seen as possible mechanisms for coping with her illness.

Vivienne's earliest childhood memories of attending school for the first time display similar experiences to Robert.

Extract 1

changed schools for the first time I was on my own that was quite traumatic [I was er a] hated that not having any of them around (.) [T1.4]

Initial coding distinguishes particular linguistic features which include speech acts, conjunctive constructs, grammatical moods and metaphors of meaning (Fairclough 2003). The conjunctive phrase 'I was on my own' [T1:4] appears at particular junctures in her story, in relation to dislocation from institutional spaces which causes relational transitions for Vivienne as daughter, pupil and worker. Finally, illness offers a space of her own, in which she is able to experience a self. Vivienne's lexical formations appear to constitute social events which situate her experiences of life and the events leading to her becoming ill and being diagnosed with ME. Vivienne's prosodic intonations and collocative and colloquial patterns, appear to reflect the relational and emotional elements of her life.

The following extract reveals how the phonetic and structural features of Vivienne's language transmit the intertextual context to provide rich semantic content, coherently captured in the order of discourse (Fairclough 2003).

Extract 2

um (1) I would have liked to have stayed on and done ur A levels and gone to university but my father was 'VIV' who thought should get a good job as a shorthand typist (-) so I left school at sixTEEN (.) [T1.5]

The extract begins with a relative pronoun as Vivienne recalls her own preferences for the future. However, the proposition alters when Vivienne shifts her speech to imitate her father's inflection, as he truncates her name to 'VIV', the act seemingly affixing a moment in her life. As an interlocutor the text predicates, directs and alters Vivienne's reference point. The proposition of her father's cultural beliefs points towards a possessive relative clause, as the act of discourse forces Vivienne to conform to expectations. Vivienne's surface utterance seems to depict the ridged subject positions of father and daughter and conveys an image of the father's instrumental role (Parsons and Bales 1955), rupturing Vivienne's expectations via the disciplinary systems in which her father's own ideological position on education and work are maintained. The textual structure of this short extract is punctuated with the emphasis placed on the second syllable of the word 'sixTEEN'. The overall point of the text coherently symbolises ideological representations of personal and private relations (Fairclough 1989; Fairclough 2010). It is worth noting that her father was speaking in a context where discursive changes of the early 1960s were shifting the labour force from machinery to service industries.

The 'order of discourse' is used to trace the inter-discursive elements between education and economic formations that govern both father and daughter's 'conditions of possibility' (Fairclough 2003; Foucault [1970] 1990). This extract from a heterogeneous account of Vivienne's early experiences may appear separate from her later illness, yet these discursive formations configure the grounding for power relations and dominant ideologies. Vivienne recounts how, over the next 10 years, ambiguous and often complicated economic demands, underpinned by divorce and financial problems, led her to change her role in the workplace.

Vivienne's story reveals how she attempted to transcend traditional gender roles by changing her working role from secretary to financial trader, in order to gain a particular kind of agency which may have been governed by the desire for financial remuneration.

Extract 3

when I did get onto the training desk which in those days in the eighties was erm TOUGH for a woman really tough I mean the the abuse it was like people say about sexism now but you could not imagine what it was like and I decided not to go onto the floor of the exchange purely and simply because I decided I had to become one of them and it wasn't in my nature and I think despite the fact that I had confidence when I was I was in the office on the training desk but I think out there on me own I would have had a real panic [T1.9]

By transcending traditional roles, she entered a world that was not in her 'nature', suggesting a non-subject-position which was outside her gendered practice. Vivienne recounts how she found this role to be 'TOUGH' and, importantly, states 'I had to become one of them', suggesting a disembodied and dislocated sense of self. Vivienne experienced the social divisions of work and home in the early 1980s, when there was a general shift in the position of the female worker and struggles for equal pay and equal rights for women, which contextualised the female experience (Oakley 1972).

During this period Vivienne describes how she was experiencing the lifestyle of a 'high flyer', working and playing hard. Her position involved a series of business trips to the Far East, which required her to be inoculated against tropical diseases, something she 'never gave a thought to' [T1.10]. Vivienne goes on to detail the events which led to her 'completely crashing' [T1.11]. Her story leads to a subject position whereby she can no longer continue with the dislocation between body and self. At this point in her story, Vivienne relates how a friend recognised her symptoms as being similar to those of her husband who:

Extract 4

had been diagnosed with ME (tut) and that my symptoms were very similar so referred me to go and see as he was then er 'doctor' Findley [12] Well that was the 10th of December and even then I finished my project I took everyone down the wine bar bought a box of champagne Came Back Got me Suitcase got in a Cab went off (laugh) to the hospital (tut) March I came out (2) (laugh) (2) [13]' [T1.12-13]

The above propositions seem to represent Vivienne's experience of time juxtaposed with space. The non-lexicon fillers and rhythm of her discourse intercede with the events of finding a diagnosis and maintaining her working role. The coherence of these extracts occurs not only through discourse, but also via the unspoken conventions of language, as Vivienne's socially expressive behaviour communicates a point of dislocation from her ideological position as female and stock exchange trader (Fairclough 2010:37). Vivienne's language is punctuated with structural features and grammatical distinctions, such as the seemingly reactive expression of laughter [R:20]³⁹ and the referent utterance of 'tut' [R:14]. In actuality, the 'tut' sound was made by a slight intake of breathe and click behind the teeth, with a simultaneous upward nod of her head. Along with Vivienne's intonations in the form of *whispers* (denoted by italics) and rushed tones (underscored), the telling of her story was often punctuated with these dramatic expressions.

Vivienne seems to dislocate from her ideological positions and is then forced to search for an alternative power figure in the form of the medical 'specialist'. She describes her urgency in speaking to him [the doctor] and the problems she experiences with those embedded within the medical profession. This highlights the asymmetrical power relations which have developed between her and the medical institution in relation to truth and the 'real' illness experience. Importantly, Vivienne completes the circle of knowledge by using the same medical discourse as her consultant. In the following extract, Vivienne describes the way she confronts the contestation associated with her illness.

Extract 5

It was the hardest thing in the world [73] And when I went to my GP and suggested this – Well he tore me off a strip, told me who was I to think I can come in there and tell him, did (1) did I know it wasn't even a recognised medical phenomenon an and I went to him well maybe but I got private patients and when I went back to see him after I got diagnosed he said oh I have sent three more people to see Findley [medical specialist] – no apology no nothing [74] No and even this time I've got a young doctor and I thought he would be much more perceptive (-) no [75] Well he kept saying it was a virus – and I kept saying yes but I think I'm having, [gap] you know, after 20 years, and he 'well you haven't got it anymore' (1) and you know puts this thing inside you that snapped and

³⁹ 'R' denotes recorded repetitions throughout the transcript

says you know fortunately both times I have had private patients so I have been incredibly luck(.) but even if had taken, second time around all the money I got from mum and dad I would have used it seek help and get it done that was it (3) [76] [...] so I think it is something you have on paper that you can say to people (smacks hand) its real (1) it exists (1) I am a walking case (1) [77]' [T1.73-77]

Vivienne begins this extract by using language to convey the sheer enormity of what diagnosis means, to the point where she leaves the sentence hanging. The narration is unfinished, seemingly revealing the continuous nature of searching for a stable diagnosis. Vivienne demonstrates the movement of power as she describes the way the GP reprimands her for providing her own diagnosis. The narration goes on to demonstrate how Vivienne becomes an expert patient to the extent that the GP gains knowledge of ME through her. Vivienne's private health cover allows her access to the upper echelons of the medical hierarchy and assists her quest for diagnosis and treatment. Importantly, this gave her the opportunity to be believed, creating a pathway for the doctor to send other patients displaying similar symptoms. Although Vivienne is describing how she achieves some sort of validated status, it is interesting to note her inability to actually name her illness: 'And when I went to my GP and suggested this – ' and 'I think I'm having, [gap]'. These breaks in her speech may reveal the unresolved nature of this illness, in the absence of verbalising the term. Vivienne's repertoire incorporates the consultant's observations that she was one of the 'worst walking cases' he had seen, as she uses his words herself at the end of the extract. Although she already possessed an embodied and experiential knowledge of the illness, she adopted confirmative endorsements to offer further validation of her suffering. This reveals the intertextuality between patient and medical professional, as his words become hers.

The rhythm of Vivienne's text reveals the implicit ideological processes governed by the institutional structures of the family home, workplace and hospital. Vivienne's socio-cultural assumptions continually reconstitute her subject-position(s), from affluent city trader to someone living with instability and uncertainty, both in relation to symptomology and the restricted lifestyle the illness causes. Vivienne's private treatment plan resulted in a succession of specialists, including a dietician and an occupational therapist, and treatments including Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET). All of these were available on the NHS, but access was limited by long waiting lists. The ME ward where Vivienne received

treatment, which was the only such ward in England at the time, was closed in 2012 due to inadequate funding.

8.3 The expert patient: Becoming and negotiating illness

This section outlines the progressive processes by which Vivienne begins to acknowledge her illness and find ways to cope with living with its long term effects. I asked her to talk about her symptoms, in order to ascertain an understanding of the direct impact of the illness. This is the point in her life history where she first talks about her body and physical pain. Vivienne associates being healthy and unhealthy with connotations of ‘good’ and ‘bad’. I asked her to elaborate on what she described as ‘a really bad week [where] people don’t realise even just changing the bed is a tail spin in itself’ [T1AR.99]. Vivienne explains that ‘I get really tired legs that’s the best way I can explain it and my extremities get cold (2) really my whole body just feels heavy’ [T1.106/108]. Vivienne goes on to describe the physical and social demands of living with her illness and how ‘you have to be measured in your what you do (1)’ [T1.105], describing a calculated approach to ‘coping mechanisms (1)’ [T1.105]’. Like Robert, Vivienne reveals how her approach to work, which was governed by maintaining structure and organisation, assists in adapting to the CBT training.

Vivienne then describes a trip to Portugal where she contracted hives and eczema. Both are seen as allergic reactions to infections, or a result of exposure to extreme environments or chemicals (Porter 1997). Vivienne also recalls contracting shingles, which caused paralysis, around the time she had inoculations to travel to Asia for work. These illness experiences hold clues to how Vivienne continually adjusts and carries on, until shingles simply stops her moving.

Extract 6

I had shingles (-) I had er shingles that caused paralysis I think there’s a b and c strain I got internal ulcers and everything I didn’t get it the normal way and it paralysed the right side of the face and I had Steroids and they didn’t tell me to decrease the Steroids and I was really ill and I went back to work (sic 42:30) just two weeks later still paralysed (1) [T1.110]

In contrast with Vivienne’s previous descriptions of becoming ill with ME, where she omits the use of the term, she is able to name conditions such as shingles and also her later experience of ‘cervical cancer’ [T1.27]. This may reveal how accepted discourses around these conditions give her the permission to speak of them. These illness

experiences seemed to be treated by Vivienne as a disruption which suspends social practices, whereas the ME is seen as a critical juncture that prevents her from carrying on. Specifically, her social practices reveal how other serious illnesses allowed her to take on the sick role for a period of time, which is not possible with her ongoing experience of ME. In effect, Vivienne searches for answers to the meaning behind her symptoms in order to regain control.

8.4 Naming and Framing ME

In the following extracts, Vivienne describes the problems of naming and framing ME in relation to its history and its contestation. She explains how this affects her understanding of self and cultural perceptions, as well as the importance of clinical investigations, securing a medical name and raising the profile of the illness. Vivienne divulges her historical knowledge of the emergence of a name for her condition in ‘1928 The Royal Free hospital (epidemic)’ [T1.138]. She goes on to account for the cultural representations of ME through the derogatory term of ‘yuppie flu’ [T1.138]. Vivienne then eloquently describes how she believes the naming of her illness is culturally received and infers in the extract below how medical discourses hold a particular cultural meaning.

Extract 7

And I know chronic fatigue syndrome’s easier for people to understand but Myalgic Encephalomyelitis (mispronounces and laughs) Actually sounds like an illness to people [149] IT IS public perception isn’t it [150] Chronic fatigue they go er yeah (sic 51:37) they go oh hang on what’s that [151] YOU KNOW SO ACTUALLY I’m more on the me side the M.E side you know [152] [...] I have this little thing in my head that I always think and I call it ME world you know I think we should have a programme called M.E world, me world [153] [T1.149-153]

The subtle syntactical relation between ‘knowing’ and ‘thinking’ may link to Vivienne’s perceptions of cultural belief patterns, in terms of the representation of the illness. In the collocations ‘knowing’ is placed before so-called accepted medical truths, whereas ‘think’ and ‘understand’ are formed after the reasoned relative belief is proposed, as in the following extract:

Extract 8

But I mean if you did a a a you know one of these bloody shows where you just put er five people up to and said who do you think's got chronic fatigue THEY'D UNDERSTAND the person in the wheelchair [145] They'd understand the person with the er stick [146] But would they understand me standing on the end (.) no (1) and that's where it all [147] I FIND THAT Confusing (1) to be honest [148] [T1.145-8]

Exploring the rhythm of language in Vivienne's life history suggests that, like Robert, she tends to use habitual collocations as syntactical fillers between independent clauses, as with 'you know' [R:93]. Although, the interjection of the subjective pronoun 'you' suggests the interrogative, the overarching implication positions the other, in the form as myself as researcher, as someone with shared understanding. The intransitive verb – 'know' means 'to be or feel certain of the truth'⁴⁰ and functions as a predicative adjective. The order of discourse is to assume shared knowledge. This can be seen as an external discursive practice, whereby Vivienne attempts to pluralise social cognisance, as opposed to 'I know' [R:8] where the pronoun suggests that Vivienne controls knowledge. Whereas, the verb 'think' as a social action means to 'consider, judge, believe'⁴¹, the lexical adverbial clausal conditions of 'I think' [R:35], and 'you think' [R:9] seem to suggest a presumed cultural understanding of self and other. In addition, a further distinction may be drawn in relation to the subjective pronoun 'they think' [R:3]. These social action functions may be seen as a way in which Vivienne moves from shared cultural understandings of ME, to the suggestion of collaborative belief to be shared by Vivienne and myself.

These presumptive phrases adopt specific normative verbs which change the power of the pronouns 'know' and 'think', with the emphasis on who is perceived to have knowledge and/or belief. Indeed these conjunctions highlight the ways in which Vivienne's social expectations of others set the conditions in which she culturally represents a self and other to 'know' and 'think' about the existence of ME/CFS. The syntactical structures thereby reveal Vivienne's social expectations and agency.

⁴⁰ See Collins Dictionary (2002) page 493 for full definition

⁴¹ As above full definition page 963

8.5 Missing voice: metaphors and representing a life with ME

Vivienne's second interview on her photo-elicited diary includes additional reflections where she reads extracts from her private journal, which she was happy to include in her life story. The act of writing seems to have reignited Vivienne's former aspirations. In the extract below, she reads from her journal how she has been able to return to an old passion of creative writing, which was constrained by dominant patriarchal and cultural ideologies regarding female roles during her formative years. The entry is based on relational modalities; as managing daily life is seen to be made possible by closing down emotions, as if the sheer weight of sadness will stop Vivienne moving.

Extract 9

I call it the vault (1) and it's where I store emotions that I Cannot or may not deal with so that they're safely locked away so that I can get on with the practicalities and hopefully work off whatever it is pain, anger, sadness, (1) loneliness, any negative feeling (2) and stick it in there because if you keep on with those they're all thoughts that will stop you moving forward Now my big question here is what I really wanna think about here is er is that a strength or is that a weakness (tut) would people say no you need to deal with that and you think well I have dealt with it (-) I thought about it and I thought well I can't do anything ABOUT it SO (-) I'm gonna move on [T2AR.1]

Extract 10

Got your little vault [5] In you go Filing Cabinet Archive off I'm gone [6] [T2AR.5-6]

Vivienne is not able to simply carry on, as she had with other illnesses, so she appears to have submerged her anxieties into her creative world. The 'thoughts that will stop you moving forward' become something she locks away in a metaphorical vault, an action which enables her to regain a sense of self. Vivienne's linguistic repertoire is peppered with lexical cohesions of social metaphors that illustrate vivid and often theatrical accounts of her life. She repeats the image of shutting away her feelings several times, while the word 'vault' appears [R:3] in both the first and second interview.

In the extract below, Vivienne's description of ME seems to suggest that, although one can sometimes reach the top, this is an unstable and disrupted state which the individual is unable to maintain.

Extract 11

I think for most people it is like an **Archimedes screw** you spiral up to the top you think wooo great [10] But then you spiral back down again so the Archimedes screw goes both ways as opposed to a **helter skelter** [11] Which only goes one way [12] And again I think helter skelter is quite negative way of looking at it [13]' [T2AR.10-13]

These metaphorical expressions are further alluded to in Vivienne's photo elicited diaries, the essence of which again seems to centre on the idea of shutting away emotions that may cause pain and suffering.

This section demonstrates how Vivienne is willing to reveal private and emotional thoughts associated with her illness. Her use of syntax is dramatic and reveals how she feels, in terms of closing off and opening up her emotions. The images seem strangely reminiscent of objects that she has made links with previously – a filing cabinet and the vault, both cold metal containers, compartmentalise her feelings away from the outside. Again, we have a sense of how language draws you in through the creation of a visual metaphor. This invitation by Vivienne to understand her world is in stark contrast with Robert, who refrained from sharing his emotional experiences.

8.6 PED

Vivienne's PED represents the loss of a previous self, as well as the shutting away of pain and what she considers, the sheer mess of life itself. A major theme of control and the compartmentalisation of herself and her emotions, emerges from the images and Vivienne's metaphorical explanation for taking the photographs.

8.6.1 'Dorian Gray Returns'

Figure 1



Extract 12

did take another one of my cleared out Dorian Gray room but I've managed to get crap in it again – I called it Dorian Gray returns – didn't take long to expand that space [T2.28-30]

Vivienne appears to take a retrospective view of her illness when she returns to the metaphor of Dorian Gray (previously discussed in Chapter Six). In this instance, her use of the word 'returns' suggests an inability to maintain control over living space. Her frustration at continually configuring and reconfiguring a life with illness are represented by her efforts to manage the messiness, personified in the picture of her Dorian Gray room.

8.6.2 'My shower tray (.) it's I Hate not having the energy to clean'

Figure 2



Extract 13

it's I Hate not having the energy to clean and I look at it and I think how can I live like this you can't I just want to be able to do normal things like housework (3) [T2.8]

Many of the images from Vivienne's PED were based on the physical demands of domesticity, such as cleaning the shower and ironing. The above is a visual

representation of her exasperation at not being able to complete the seemingly ‘normal’ tasks achieved by her former self. Instead she is forced to adopt the prone position (pictured in Chapter Six), as she is waiting or ‘lying to be well’.

8.6.3 *‘I think that’s a picture of what used to be’*

Figure 3



Extract 14

I’m quite happy for others to take the lead you know I recognise you know my boss now I recognise that she’s got a difficult job to do and I’m not making it any easier but you know that’s the price you pay for being up the greasy pole) – I just think I’m a bit of a square peg in a round hole in the corporate world now [T2.44]

The images taken by Vivienne of her wardrobe appear in two photos, as she portrays the extent of the person she was. She depicts tailored suits and leather coats, a fully equipped working woman’s wardrobe, which could even pass for a man’s wardrobe. It shows the costumes she wore to perform her work identity, which remain hanging, waiting. This could suggest the inability to let go of a former self, which is shut away and seen by nobody, almost as she has experienced a death of a part of herself. However, it seems that Vivienne is now happy to leave the suit of working armour for others to wear and perform in, as she says ‘I’m quite happy for others to take the lead’. She is not letting go completely – as she still has the clothes in her wardrobe –yet there is a suggestion of finality in her language of not returning.

In Extract 14 Vivienne seems to disassociate herself from her emotions, as her narrative displays a strong sense of control. Conversely, in Extract 15, her answer to my question about the PED – ‘How do the images make you feel?’ – reveals her concerns:

Extract 15

...I think what jumps out to me is that (1) I (2) what way do I put, the best way to put this (tut) it's a bit like I suppose it's, is these are my hidden symptoms, these are my hidden worries [T2.51]

Her answer suggests that in the same way as her bodily symptoms are often invisible to the outside world, so too are the worries that she has shut away, which subverts her notion of control over a life with ME. A major theme of Vivienne's story has been one of control, as her emphasis has been on compartmentalising her emotions, as observed in the above verbal and visual metaphors. The extracts and images communicate often abstract levels of semiotics and, although they have been gathered into chronological social events in this context, they define how Vivienne speaks about and illustrates her life experiences. This offers a way to scrutinise the material conditions for the socio-historical links between spoken text and the discursive processes and social practices – the conditions of possibility.

8.7 Conclusion

Like Robert's chapter, in this chapter Vivienne demonstrates, through her linguistic repertoire, how she is constantly driven to perform, but opens up more fully on the issues of being ill which she associates with being bad. It appears that she was able to ignore her illness experiences prior to ME, in order to continue social practices, such as work and family commitments. In so doing, Vivienne is able to temporarily fulfil the sick role before returning to her usual subject position, until her point of entry into what she terms her 'ME world' [T1.149-153]. The question of living with a contested illness is attended to where Vivienne herself works to describe the socio-historical context in which her condition has been disputed and reiterates the problems of naming a condition, which has been given derogatory labels such 'yuppie flu' to devalue the value-laden label of ME. Importantly, it is the power of knowledge and cultural assumptions about the illness that are contested. Although knowledge is available to the majority, access to those who bestow knowledge, such as medical specialists, is confined to those like Vivienne who can pay for private medicine. This two tier system is seen to improve Vivienne's choices and overall healthcare. Both Robert and Vivienne offer similar practical account of doing illness however Vivienne alludes to emotionality of suffering being ill through her similes and metaphors.

As Vivienne's story unfolds, it reveals her shifting identities framed within the hierarchical systems of governance of the school, work and medical institutions. Vivienne's life story responds to the research questions as she produces a dramatic performance of self within a rhythmic and often metaphoric sequence of social practices and discourses. Unlike Robert, Vivienne's subject positions seem to be intrinsically entwined in intersectional relations, related to a play of dominations between father, husband, male colleagues and doctors. These power relations seem to have governed Vivienne's expectations and experiences; they are points on her life compass, mapping power and knowledge, constituting a self for Vivienne to live by as she negotiates symptoms of ME. The analysis revisited the research questions and identified specific elements, namely the action of language, emotional speech acts and metaphors of meaning. Like Robert, Vivienne experiences a dramatic dislocation of space. However, Vivienne's institutional modes of 'being' were juxtaposed with her relational configurations which sought to dispel expectations as she continually conformed to her environment and illness experience.

Vivienne's chapter contributes to the research questions as she describes dilemmas by way of the struggles and challenges of living with and becoming diagnosed with ME. The patriarchal space of the 'private' specialist offered the means to obtain truth, as Vivienne became a 'consumer' of knowledge within a two-tier treatment system. In the fourth section Vivienne describes a self-regulatory technique of living with ME which responds to the research question on the processes and practices of doing illness and being ill. Finally, Vivienne's narration highlights the force and flow of a body unable to fulfil and complete an assemblage of power. A body governed not only by the socio-political context that positions Vivienne within various performative categories, but also by illness which disrupts power. The conditions of possibility for Vivienne is to negotiate the limits of her body and take hold of the illness, open up the hidden aspects of her being able to 'be' on 'her own' to negotiate ME.

Chapter 9: Relating to severe ME – '...just carry on'

9.1 Introduction

This chapter highlights the inter-discursive and intersubjective problems associated with becoming severely ill with ME. In other words, the discursive processes by which an 'expert' produces and constitutes how is it possible to live with an illness of this nature. I will explore how dominant ideologies produce and indeed constitute a sick body's materialisation, from childhood through to adulthood. Jean, aged 52, was diagnosed with 'severe' ME and bedridden for six and a half years, after having a number of viruses. She exemplifies the effects of socio-cultural constructions on her own understanding of her sick body. Jean describes how she negotiates her world-within-a-room when bedridden, her experience of living with ME and adjusting to her eventual, potential recovery. As with Vivienne, Jean's story has a relational context, although this is shaped, reshaped and reaffirmed through her own and others perceptions and beliefs about her illness. Her life story is, therefore, peppered with the continuous questioning search for the cause of her illness.

The chapter examines four elements, in which the intersection between discourse and society are configured and reconfigured, as Jean describes becoming ill and working on her recovery. The first concentrates on her search to find the cause of her illness. The second addresses the abstractions of living with ME through the discursive field, in which the medical experts withhold and dispense knowledge and expertise. The third examines expert regimes and the negotiations of supposed recovery. The final element extends the issues of living with ME through a letter and her photo-elicited diary (PED), oriented by her sensory modalities that reveal the interplay between outside and inside worlds, from her room to a 'new life' which puts her back in 'circulation'.

9.2 Modalities of Causation: Rationale for contracting ME

Jean situates herself as a happy child, yet blighted with infections as she enters the school system. Her early recollections make connections between childhood and

adulthood experiences of illness, as she moves through different institutional systems of control, attending school and work, whilst experiencing flu-like symptoms.

Extract 1

Happy, ermmm generally a very happy childhood, but I wouldn't say I was errrh 100% strong health wise as a child like when I went through primary school, if there was something going I caught it erm lots of colds lots of gland things ermmm so I had quite a lot of time off school when I went through primary school ermm yeah (1) [...] Also when I was Older I worked ermm for a secretary for a while ermm for the NHS and we used to have to have flu jabs. Whenever I had the flu jab I used to end up being off with the flu because it gave I had a reaction and I got strong symptoms from the injections [31] [...] but I always ended up being unwell for a few days after I had them. I never thought oooh have I got an immune problem (laughing) or anything [32] I thought that's funny why doesn't anybody else have THAT, you know and just carry on [33] [T1.31-33]

Jean's early recollections move from the institution of the family to that of school, then to her working life. Her earliest memories explicitly call forth a child who experienced illnesses. In addition, they also elicit a possible connection to her experiencing flu symptoms after a mandatory inoculation against the flu virus at work. The touches of laughter peppered through Jean's narrative seem to belie a parodic air to her explanation. Being a sick child and having compulsory flu inoculations place Jean in a vulnerable position, as she performs both child and working roles. It also offers a glimpse of Jean's reaction to the flu inoculations being different to the reactions of other people. So, although it caused her to feel unwell, she had to 'just carry on' like everyone else.

Jean goes on to highlight how her body responds poorly to intravenous injections [T1.39] and it would seem that she is storying a search for causation. She makes connections to events in her past, as she tries to establish some kind of causal relationship between her life practices and her illness symptoms.

Jean then goes on to explain the issues of being severely ill with ME, when she was bedridden for four and a half years, which impacted on personal relationships. In the following extract Jean reveals not only her own frustrations, but also those of her brother, as she is unable to fulfil her roles as sister and daughter:

Extract 2

I was sort of stuck in bed really ill and he came down to see me and my mum had been very severely ill with a heart problem and I hadn't been up to see her you see in hospital because I was too ill and ermm he came down and he really read me the riot act told me that it wasn't fair to my family that I had ME and that I was lying about in bed and that it was time I pulled myself together and (1) got on with life and that my mum needed me and I broke my heart [68] I KNEW exactly where he was coming from because if I hadn't had it myself, I would probably have thought the same thing AND THAT was [70] THAT was what I found a difficult pill to swallow [71]' [T1.68/70-71]

The intertextual elements centre on social judgements and assumptions made by Jean and her brother. The styles of discourse revolve around not only their power relations, but also how Jean frames her position as 'stuck in bed really ill'. Jean's brother has both a mother and a sister who are bed bound and seriously ill. However, the overall sense is that he believes Jean is able to control her illness (Fairclough 2003:41). The mother's serious illness has value, whereas Jean's illness is brought into question. Jean describes her brother's objectification of her illness, stating 'it wasn't fair to my family that I had ME and that I was lying about in bed'. Her repetitions of 'THAT' were in a raised voice, as her speech emphasised the rigid position that the sick role produces for herself and others. Jean's empathy for her brother's attitude to her illness is emphasised with 'what I found a difficult pill to swallow', which is perhaps not only a metaphor for Jean's emotions, but also indicates the difficulties of conforming.

Like Vivienne, Jean's narrative returns to her early life and her father's encouragement for her to become a secretary. Jean's family repertoire makes indirect references to her father's wartime experiences of the benefits of shorthand typing, whereby 'three generations erm learned shorthand typing' [T1.121]. Jean then charts the social practices within which her norms and values were formulated and, like Vivienne, expectations halted. Jean accepts commonly-held beliefs about the role of women, saying 'In those days (1) you wanted to get married and you wanted to have children and you wanted to be looked after' [T1.129-30].

For Jean, the lack of personal consensus about her illness seems to be related to trust and knowledge by and from others. She connects these stories through negative contractive connotations, such as the terms 'didn't' [R.67] and 'don't' [R.41], which appear often in her life story. This phonetic alteration may relate more heavily to her experiences of illness and suggests an inability to go forward, as opposed to her life before her illness which contains more positive connotations. The variation of word

usage and diachronic alterations is crucial here, as Jean moves from stories about her brother and father in relation to her illness and the understandings of others. This builds the context in which she presents her relational world of meaning, which is not merely social but also her personal world and who has the power to speak about it. Jean's world of meaning is thus seemingly and predominantly powered by her male relations.

Intertextuality offers a way to observe the negative aspects of how Jean explains her illness experience. She uses a relational judgement, correcting her speech from 'I wouldn't' to 'I mean We', which reveals a regulative pattern to her discourse genre (Kristeva 1980:68-69; Bakhtin 1981:35-38; Fairclough 2003). Jean's syntactic arrangement offers a glimpse into how she may not speak for herself, as she returns to her past relationship with her father, which she believes was 'broken' by her severe illness, and reveals how her husband became her 'vicarious voice' (Hyden and Brockmeier 2008). However, the use of 'We' indicates an implicit shared knowledge and understanding about her illness experience. This retraction in the order of discourse may reveal the dominant ways Jean comes to 'consider' herself (Fairclough, 2003).

9.3. Emotional and physical experiences of severe ME

The powerful configuration of self and other has been historically constituted in Jean's personal memory, anchored in her social space, which seems to be heavily linked to the institution of family. Yet the social practices that require her to take up particular social identities are difficult to maintain in the face of her illness. When asked, 'Who helped you develop your current understanding of yourself?', Jean declares, 'do you know, I think in some ways in some ways the staff at Castle and Queen's [hospital] erm they were really great' [T1.158]. As with her accounts of meeting another patient with ME, her story is configured around those who understand and those who do not. Jean was bedridden for over six years and issues of trust were overcome in order for her to attend the hospital. A stream of therapists, from occupational to psychological, managed her illness experience, as their treatments worked to reconstitute old and new ways to understand self.

Jean's life history is contextualised by social ruptures and her conflicting struggles to maintain her subjectivity. Yet the order imposed by the new medical treatment plan seems to schematise her cognition, possibly allowing her to read her body. Jean reflects on her past behaviour as a possible trigger for her illness, thus making herself accountable. She goes on to describe how she has learnt to accept herself by

reconstituting the self, restoring and re-instating her sense of self and agency via a system of medical and personal maintenance.

Jean's daughter Maria also took part in the study and was also bedridden for one year after glandular fever and being diagnosed with CFS. Jean is pleased that she is now well enough to assist with her daughter's care [T1.167] and then goes on to explain how her illness made her feel as if she 'went back into childhood mode' [T1:204]. She refers again to her mother's deterioration in health and the difficulties in visiting her when she was in hospital. Jean's husband organised an ambulance to take her to visit her mother. Medication helped her cope with the pain of travel, while her aversion to light and noise was modified by her wearing eye mask and earplugs. However, Jean was still unable to leave the ambulance:

Extract 3

I was too ill to even go in the wheelchair and go up to her room because I felt so weak but they Managed to get mum in a wheelchair and her down to me in the (2) so we had a cuddle and I had a GOOD CRY [218] and I saw her and she knew that I had taken the trouble to go up and see her she didn't understand how ill I was. She didn't have a concept of it but all the time she said I know from the basis for the rest of our lives together – that if you're not well enough to come up and see me you are not well enough to come up and see me it's not because you don't want to [219] So even though my brother went against me mum [220] [T1.218-20]

This offered Jean a chance to fulfil her role as a daughter. The closeness, the 'cuddle', allowed her to let go. She makes the point that her illness is not understood, but it is clear that both mother and daughter had satisfied their internal and external needs. Sadly, Jean's mother passed away and she was unable to attend the funeral. Although a tape recording of the day was made, her illness was so severe she was unable to listen [T1.231-33]. Jean's narrative revealed how fulfilling her duty as a daughter allowed her to uphold her subject position and reiterates her previous perceptions about the importance of maintaining social roles. Again, Jean's use of language alludes to the problems she has in fulfilling expectations, as her discourse denotes her need to maintain her social roles, while her body is causing her to detach.

Jean then accounts for the kind of symptoms that caused her to be bedridden, she described the extent of her suffering and how she was given conflicting diagnoses:

Extract 4

I had these lumps come up and I was so, in the end I was too tired to go to work and I had to take time off work. I went to my GP and because I had lumps they thought it might be cancer [252] Errr but by the time I went for the biopsy [254] I was starting to feel a bit better because I'd been at home, I'd been resting I'd been off by then for about a month and a half and I just started to pick up a bit but the symptoms I had were really like glandular fever symptoms [255] And I've been told since no you've never had glandular fever. Well I've had something very much like glandular fever and I possibly have had glandular fever and errrm (3) anyway I was ill for quite a long time but I got better went back to my part-time job and thought nothing of it but they did not tell me was what I had was chronic fatigue or ME or anything like that errrm they didn't tell me what I had. I went to a skin specialist because I had funny skin things erm and he said you've actually got an immune condition. I said what's it called and he said I'm not going to tell you what it's called, it's immaterial what it's called errr... [256] [T1.251-256]⁴²

Although this extract reveals her physical symptoms, it also offers a way to understand how the labelling, un-labelling and non-labelling of her illness is completely out of her power. Her quest to try and identify her illness is met with a kind of disregard. Jean states 'I had aching groins, I had lumps come up round here erm I had a lump behind my ear erm and oh I was so tired I was just so tired I didn't know where to put myself [239]' [T1.238-239]. Yet these symptoms are dealt with by the compartmentalisation of her body, from the cancer biopsy, to the skin specialist, she is told that it is an immune condition and the naming is 'immaterial'. This reveals who has the power, knowledge and truth of medical discourse through which Jean's embodiment is either validated or denied. The contestation of Jean's illness seems to rest on the power of medics to withhold and refuse to name her illness.⁴³

Jean is also eager to recount another possible cause of her illness, which relates to the contraceptive pill, as a possible trigger for 'this immune problem' or 'thing' [T1AR.4-6]. She continually pinpoints events in her life which may have played a part in her physical decline. The inability and subsequent refusal of the medical profession to name her condition has caused Jean to search her life history to make connections and, in this way, make herself accountable for her illness. Furthermore, it would seem that Jean is

⁴² Her daughter enters the room, the interview stops abruptly at a poignant moment.

⁴³ At this point, Jean has a break and her daughter, Maria, recounts her own life story.

discursively deconstructing her body, like the clinical gaze, by continually dissecting and analysing her experiences of illness [T1AR.76-77].

9.4 Quantifying ME: 'So it's all a bit political'

Jean's therapeutic treatment was carried out via an intensive programme where she was hospitalised for six months and then sent to a care home for a further 10 months. She eventually went home to follow the same regime, but it appeared that once she returned to her home and the needs of others, she inadvertently neglected the self-surveillance instilled by the therapies she was trained in. Importantly, Jean only agreed to tell her life history on the proviso that she could talk about her recovery rather than relive her bedridden years. Her storytelling glossed over the areas that do not comply with her story of recovery. In this way, her story is, at times, fractured and disconnected as she jumps between particular eras to repeat repertoires that she finds acceptable. Jean often seems to avoid the sheer depths of her experiences of being severely ill, when she retrospectively states that '...if I'd known then that I was going to be stuck in a bed for six and a half years well (laughs) it's as well I didn't know' [T1.AR.96].

Jean then recalls the process by which she was able to gain treatment. Her GP diagnosed ME and, eventually, a family member found out about specialist treatment where Jean was able to resolve her issues of trust and have her diagnosis confirmed. She talks of the ME clinic and the issues faced by GPs in gaining access to NHS clinics and getting authorisation from the Primary Care Trust, which grant access to hospital treatment centres [T1AR.101-102]. A full agreement on treatment was reached and granted via a medical team due to the extreme deterioration of Jean's body. She was unable to eat and could not listen or speak to people. Her body had almost completely shut down.

Due to difficulties eating Jean had lost weight and was in a 'life and death situation'. She declares that 'they [the medical team] were very worried' [T1AR.148]. The medical team, including Jean's GP and her specialist, became involved in her recovery. Although Jean had tried alternative therapies these were stopped when she embarked on a new regime, which focused on cognitive and general pacing techniques. Due the severity of her illness, Jean describes they:

Extract 5

put me on oxygen it didn't hurt to have people speak and I could listen for five to 10 minutes without feeling like death warmed up and I thought this is a miracle and all it is is oxygen (laughing) [T1AR.133]

Extract 6

I wasn't allowed to use up all my energy I needed some energy for healing so I wasn't allowed to talk for more than 2-3 minutes up to 6 times a day ermmm and the therapy sessions I could listen up to 5-10 minutes once or twice a day and that was it I wasn't supposed to talk any more than that [140] Because and I was fed I was too tired to feed myself. They fed me and ermm (1) and then slowly they built up and I was allowed to talk for 5 minutes a few times and like that [141]' [T1AR.140-141]

The treatment not only restores her health but gives her a credible space within the hospital and care home. For Jean, this social validation gave a powerful message to those who did not understand her illness:

Extract 7

It sort of given it credence if you like like my brother now realises that I was quite ill because when he came to visit me in the hospital they said well you can have 10 minutes with her now and if she has a rest you can maybe come for 10 minutes later on OHH well the nurses said I can come and see you for 10 minutes yeah but that's really you know (tut) and the next time he came to see me and when he came back I was looking a bit tired and he said you're looking a bit tired we won't stay for the second 10 minutes well I nearly fell off the bed I couldn't believe it you know because but because the medical people agreed that I actually was ill it was all a bit different [T1AR.274]

Once Jean's illness is under the control of the medical institution, her lying still is no longer seen as immoral or ethically divergent. She has been given permission to be ill.

Jean's desperate feelings of fear and guilt are dealt with through CBT, medication and counselling. The Primary Care Plus (PCP), who funded her treatment, also agreed to pay for her rehabilitation to continue in a nursing home closer to her own home in order for her to continue recovery and offer her husband respite.

Jean then explains that she still takes medication and, although she is better, she declares that:

Extract 8

I had a little bit of a blip recently because I got a bit overconfident because I was feeling so well and Maria had just come out of hospital and I wanted to do everything for Maria. I wanted the house to look nice and we had people coming and I wanted to make lots of things myself [174] and I started a dance class and [175] And I was getting tired and I was getting low and I thought and then I went down with a throat infection and I thought I was getting ill again and I thought ohhh hang on a minute [178] So I cut everything back and I started walking. I used to walk I was walking for an hour (1) 2-3 times a week (1) so I cut all that back and I've cut back and I'm walking for sort of 20 minutes or half an hour 2-3 times a week if that now and but I'm slowly building it up and I'm I'm alright do you know what I mean [179] but I had a wobble [180] [T1AR.174-175/178-180]

It would seem that, as Jean returns to her role in the family, symptoms of her illness have returned. She believes that physical activities, which include dance classes, led to an eventual throat infection. Jean describes the reappearance of her symptoms as a 'blip', a word she mentioned twice, which implies a temporal irregularity in her new regime, as does the word 'wobble'. The emphasis seems to suggest Jean has merely strayed from her chosen path. The style of discourse reflects her need to minimise her recent symptomology. The central articulation is on her need to fulfil her social roles and there is a sense that, by proclaiming she was overconfident, she was to blame for her symptoms. She had to hold back time, 'ohhh hang on a minute', and return to her regime of pacing and sequentially timing her lifestyle. The level of abstraction and general context of her discourse centres on her negotiation to control the elements of space and time, evoking both social and personal issues (Fairclough 2003:126). Arguably, the social practices in which Jean performs her roles are juxtaposed with her new regime in which time is measured.

9.4 Literal account of 'having severe CFS/ME...'

Before we proceeded with the second interview on Jean's PED, Jean requested I include a typed letter in which she describes points which she felt may have been omitted from or need reaffirming in her life story interview. This typewritten personal statement contextualised and authorised life in her room. As with Vivienne's journal, Jean's letter offers an alternative orientated style in which to amplify her world of meaning (Fairclough 2003). This particular letter provides insight into the everyday practices,

emotional and social issues of being bedridden and the therapeutic regime that offered a means to reconstitute her life.

The letter:

...Having severe CFS/ME was a bit like having a bad dose of flu, while feeling winded, having run a race. The smallest physical tasks became mammoth activities. I was confined to bed, unable even to manage sitting out in a chair without suffering great exhaustion. Noise was agony. I was unable to read, listen to music, or watch TV, as my concentration was so affected. I also reacted to some foods and was hyper-sensitive to medication. I also couldn't stand strong smelling washing powders on my clothes. It was a nightmare not just for me, but the whole family.

I don't know how my husband kept going for so long caring for me.

I was unable to prepare meals, wash myself. It was so scary, being totally reliant on John for my every need. I did not have the strength to get to the kitchen if I needed a drink or something to eat. He used to prepare food so that I had some available next to the bed in case he was delayed getting back home. I couldn't lift a whole 1.5 litre bottle of water, so I had to have some of it poured out first, then managed by using both hands and tipping the rest as needed.

I also forgot to mention how the staff at the specialist CFS unit taught me about pacing. I was taught to take regular half hour relaxations. For these I was to lie down, eyes closed, in a quiet place (in hospital I wore ear plugs). The idea was to give my brain a rest, in order for renewal of energy and healing. Initially I had a period of relaxation every two hours.

Rehabilitation was very slow and structured. Activities were gradually introduced, (sitting in bed looking round the room counted as an activity), and slowly increased. The more tiring activities, i.e., washing myself, or walking a few paces would not be put in the same 'activity slot' (the time between relaxations) in order to spread energy output and try to avoid a cycle of "boom and bust". The idea was to not go to bed at night totally wiped out.

I was put on medication, which included vitamins and minerals. This was introduced in small amounts and gradually increased to the required level, or the level my body could cope with. The secret seems to be introduce things slowly, then when no longer needed, gradually decrease.

The configuration of the first three paragraphs of the letter offer a particular chronotope which validates Jean's experiences of severe illness. Her discourse offers glimpse into 'suffering' that is all-encompassing, as everyday activities constitute survival within one room (Bakhtin 1981:97). The impossibility of managing is described in terms of how Jean's space is dialectically interconnected to her carer, as her existence is dependent, which is 'scary'. The latter three paragraphs detail her world through her interactions with space and time which are managed and negotiated by outside forces, this time through the interventions of medical specialists and therapists. Although in her life

history Jean referred to the CFS unit as the ME clinic, the congruency and confusion over naming the illness is one which seems to run through all the narrations. Jean represents herself as a pupil being taught a new way to live her life. In Hyden's study on the CFS school, the regimes are focused on the mind controlling the body's output. Jean appears to identify with this structured approach where she declares that the need is to manage 'energy output' and avoid the cycle of 'boom and bust'.

9.5 PED

Jean took short notes on each image in her PED, which she grouped within an overall theme of ‘freedom’. The PED centred on the boundaries between inside and outside, which links to her subjective and objectified experience of illness. The sensory modalities are touched on as Jean shows how she is reconnecting with the natural elements. Although the emphasis is to portray recovery, the images also allowed her to discuss the extremely debilitating effects of illness.

9.5.1 *‘I couldn’t get over the beauty of trees’*

Figure 1

Extract 9



And erm now I love it even more this is another one you see (.5) I couldn’t I’ve written down I couldn’t get over the beauty of trees after being indoors for so long erm and I’ve put and I was given my life back (.5) by Professor Green [T2.38]

It is not only the image of a tree in bloom that is poignant, but also the inference in her narrative that the instrumental figure who gave her back her life was the medical consultant. There is a juxtaposition of power and the reconstitution of the self via the expert.

In the following extract, Jean starts by using the phrase ‘back to basics’ to introduce the image of her toilet. This is used to endorse her narration of progress. It is particularly significant as she shows this picture after the tree in bloom that represents new life.

9.5.2 'Back to basics'

Figure 2



Extract 10

But now this one this is back to basics this is I was going to take a picture of a commode cause I hated using a commode I absolutely hated it But we couldn't find it we tucked it away somewhere and don't particularly want to get it out so I just put it was so wonderful to use a loo after having a commode for so long [T2.44]

At first glance, the toilet seems to represent a backward narrative, but when it is coupled with the story about how Jean had to use the commode for more than five years, we see the toilet as part of this progress narrative. She actually uses the word 'wonderful' to refer to her experience of sitting on the toilet seat after such a long time. So the toilet for Jean is a new life, a liberation from immobility and an improvement from her previous state. Following this she refers to her experience of relying on other people, particularly for 'private' matters, which she finds very scary.

9.5.3 'This is freedom'

Figure 3



Extract 11

this is freedom right I took that in case these other two didn't come out but they did I carefully didn't get the er number plate in case you're not supposed to have number plates in erm but I've recently started to drive again I took two in case they didn't come out properly [52] And I have a real sense of achievement sitting behind the steering wheel it was the freedom [54] [T2.52-4]

Jean took three images of her car to portray the sense of achievement and freedom of being able to drive. Two shots were taken from the passivity of the passenger seat, positioning Jean the photographer as a spectator observing the active position from which Jean the driver will have the pleasure of control. This may denote the experience Jean has had of being a passenger in her life. The final image (Figure 3) is a full shot of

the car, which symbolises the socio-cultural technology connecting Jean's notion of freedom to movement. This concludes the series of pictures which show her progress, her new and active self. The car symbolises mobility and speed, in contrasting with her immobility in bed for five years. It could be argued that this represents assimilation, as Jean is slowly acknowledging her need to rejoin the dominant culture which values movement.

9.6 Conclusion

Jean's chapter contributes to the research questions on the doing, being of illness, the depth of meaning for living with severe illness and the dilemmas, resistance of possibly recovering, surviving chronic illness. The narration offers an opportunity for her to outline her struggles and eventual recuperation. Her story does not always follow a sequential path, moving back and forth through reflective musings. Jean's story of living and negotiating illness becomes the milieu for her to discuss the ways in which she constitutes and reconstitutes her lifeworld. Micro level readings offered an opportunity to focus on language usage, as well as the themes of blame and accountability. There is a sense of the inter-discursivity and intersubjectivity that signifies how Jean experiences the production and reconstitution of her identity. Jean's letter provides another layer of meaning to her life story, to add details she had forgotten or embellish areas that required further explanation, while her PED tells a clear progress story.

The extracts have been analysed in relation to events in which Jean attempts to fulfil various social roles. The interconnections reveal how Jean consistently re-evaluates herself and re-conceptualises her perceptions of self and others in relation to her illness experience. For Jean, there is always a negotiation about what others' perceptions of her illness are. Her discourses and social practices reveal the power relations at play, as her performance is disrupted due to various illnesses. For example, she needs her husband to become her vicarious voice when she loses her physical voice. Jean retrospectively explores the causation of her illness, which is directly and indirectly linked to relationships between self and other. Her emphasis initially is on the physical symptoms of her illness, but as she is unable to name the condition she looks within herself to find alternative causes. Memories trigger childhood and adulthood experiences of 'flu-like' symptoms and the dynamics between the intersections of body/self/other.

Jean's story revolves around how experts withhold and provide medical knowledge to form her understanding of the self. Jean experiences the fears associated with the materialisation of her illness through her body, which eventually comes under the control of others. When she becomes bedridden, her belief patterns are questioned as she subordinates adult social roles and returns to 'childhood mode'. Jean's narrative responds to the questions on the conflicts of living with chronic illness as it charts the tensions between mind and body, family and medical institutions, as she constitutes her subjective understandings of how to live with ME. She discusses the political battle which led to her being denied medical treatment, with authorisation only issued when she required palliative care. Jean's experiences demonstrate the political lottery between local councils and the NHS, which dispels the notion that the health service can be accessed equally by the whole population.

Jean describes how she adhered to the eventual regime of CBT and GET treatment, as she sets her narration on the path to recovery, although intransitive verbs allude to setbacks as she negotiates her 'new life and describes the pleasure and benefits of feeling better. The research questions on the practices of doing illness whilst being ill are addressed as she refers to a blip, as she begins to ignore her physical limitations, and accuses herself of having deviated from the imposed treatment regimes doing illness. For Jean, the becoming of a self is triggered through the eyes of others, within familial, educational or medical institutions. Her narrative reveals how the values and obligations to fulfil social roles are governed by a network of power relations that produce, reproduce and reiterate lived experiences.

Chapter 10: Masking ME – ‘putting on a front’

10.1 Introduction

This chapter uses performative narrative analysis and CDA to explore the masquerade and aesthetic investment involved in negotiating lifelong symptoms of ME. It interrogates the production of identity, cultural values and social practices within a field of relations between control and normalisation, power and desire, which mask and unmask life with chronic illness. This study supports literature that describes how, in the negotiation of intolerable symptoms and social expectations, uncertain and unpredictable conditions produce different levels of biographical disruptions that oscillate between *good days* and *bad days* (Bury 1982; Charmaz 1993). However, as the stories so far demonstrate, women often encounter deeper levels of medical disbelief in their search for diagnosis (Werner and Maltreud 2003). Helen’s narration follows those of Vivienne and Jean, who both appeared to be confronted with a more profound and disparaging medical disbelief than Robert.

In this chapter, the notion of disbelief is developed in relation to the problems of negotiating illness from childhood through to adulthood. Although, like Vivienne and Jean, Helen experienced childhood illnesses, it is her moving account of being disbelieved at the age of seven that influences how she comes to understand herself and interact with her social world. Helen was 23 when she was diagnosed with ME in the 1990s. At the time of the interview she was working part-time as an art teaching assistant and attending a college course. The central element in this narration is Helen’s focus on masking and unmasking her unhealthy body, as she deals with the strain of being believed and the problems of performing a healthy role. Due to the ways in which her illness disrupts her social roles as daughter, child, patient, colleague and friend, Helen takes part in value-laden cultural practices of trying to present the appropriate self. This chapter focuses on four elements from Helen’s life history. The first two are early accounts that position her within social practices of normalisation and alienation, where she attempts to fix and control her world. The last two are concerned with maintaining the allegorical mask, which symbolises how she comes to live with her

illness. Finally, in her photo-narrations, she continues to demonstrate how it is possible to metaphorically face her illness.

10.2 Medical disbelief and personal mistrust

Helen's narration begins by describing a good childhood juxtaposed with bad memories of her parents' separation. She does not necessarily construct herself in relation to this event, but situates herself as a 'negative strange person' not a 'normal child' [T1.14]. Her socio-historical context differs from Vivienne and Jean, who began their stories with accounts of childhood, followed by work and marriage (and, for Vivienne, divorce). Helen's experience of illness offers points of abstraction for her to separate and constitute her roles as child/pupil. She positions herself as 'a complex child' [T1.22] and begins to appropriate a normalising binary between self and other. Helen's intertextual relations surround her ideological role of the child with adjectives constituting herself as 'strange' and 'weird', 'different' and 'not like everybody else'. Her discourse indirectly produces a deviant social identity, which seems to portray her as being at odds with social relations and cultural values. However, like Robert, Helen describes the importance of performing and achieving the roles of captain and prefect at school (Fairclough 2010) and, like Jean, she enjoys physical activities like swimming, drama and dance.

Importantly, Helen's exposure to a doctor's disbelief as a child seems to instigate a mistrust of medical institutions:

Extract 1

small illnesses but just more regularly than most of the other kids like headaches, earaches, sore throats I can't really remember the specific things I moaned about but I know I often went to the doctors erm (1) and erm when I was like dancing and stuff and after swimming I would always have to eat something (1) erm (1) yeah I don't think there was nothing specific that I erm other than headaches that I know I definitely suffered with a lot but the doctors never believed me so er there was a big issue there my mum would want obviously the more my mum took me the more they thought I was making it up then the less she would want to take me because she then I suppose I don't think she ever questioned me but she did think well you know where is this leading they weren't really err they weren't saying much they like asked me to leave the room and

told my mum they thought I was making it up so I think that caused a bit of issue from the beginning really [T1.30].

The tentative relationship between doctor and parent was played out in front of Helen, as she observes their battle over her illness experience. The doctor's attitude reflects the approach to medical treatment in the 1990s, as children and parents were expected to follow instructions, while barriers to treatment were associated with a lack of compliance by patient-child and parent (Fielding and Duff 1999). Her dialogue begins with her describing her suffering and ends with 'things I moaned about', as if her material symptoms and cries of pain were not noticed or heard. The doctor's polemic established a particular truth, which subjugated Helen's utterances to those of a deprivileged child-patient (Bakhtin 1986; Fairclough 2003:42). For Helen the dynamics of the doctor/patient relationships are broken down, as she is excluded from the medical dialogue and later told that her experiences were an act. The propositional persuasive phrase 'making it up' questions the existence of her illness experiences, while the value-laden assumptions of doctor and parent position Helen as untreatable and portray her sick role as a performance.

The recollection of her early experiences foregrounds her passionate beliefs about the power of medical professionals. As with the previous three life stories, Helen's ability to seek a private referral seems to be a turning point. Once again, the notion of naming her condition is uncertain, as the expert denies the existence of one illness, glandular fever, in favour of another, ME. Yet, for Helen, the notion that she is not believed leads to a desire to reinvent herself:

Extract 2

Owh I hated it I hated going to the doctors ever since then and I was really quite young when that happened I think my mum and dad were still together when they accused me of lying and then I stayed at the GP practice for right up until a couple of years ago when finally I managed to use my boyfriend's address and pretend I'd moved house so that I could change doctors when I erm (.5) decided to make a fresh start so they didn't know any of my history hoped they wouldn't be able to keep the notes so that they wouldn't judge me really on thinking that I'd made stuff up because that always worried me I remember I read one of the notes once that he sent to erm when I had it was sent as a referral and the way the letter was written was if I had made it up so it was something along the lines of you know Helen has been suffering with this this and this over however many years but erm from what we found there doesn't seem to be anything

wrong with her we're not sure if whether it's I can't remember the exact terminology but you know something along the lines as if they was implying that I was making it up erm (.5) when I was I can't remember I think it must have been when I was 7 erm... [T1.32]

Helen's discourse continues to convey vulnerability and unhappiness associated with visiting the doctor, which seems to have produced an unstable sick role. The accusatory tone used by the doctor to her mother prejudices Helen against any future dealings with him. She seems to be aware of the interactions between hegemonic and ideological structures, that produce socio-political mechanisms of control between doctor/patient via the documentation of the patient's history (Fairclough 2003:55). Her childhood memory of visiting the doctor elicits a later recollection associated with illness in her teens. Helen attempts to 'pretend' and, thereby, reinvent her medical history, in an effort to protect herself from the normalising judgement of the medical gaze (Turner 1995; Foucault [1963] 2003:13). Her effort to counter the power difference and mystify the bureaucratic surveillance that silenced her disordered body has forced her to lie to escape judicial boundaries (Lupton 1994:119). The switch between the present and past tense of the verb 'to make' illustrates how medical intervention started a process of producing what was already constituted as a prefabricated sick role for Helen, as her illness experience seems to be outside the borders of medical knowledge and is, therefore, perceived to be non-existent.

10.3 Towards a diagnosis of ME

Helen described how she contracted ME-like symptoms as a child. As her symptoms continued she sought professional medical help through private health care, which was paid for by her father for a limited period of time. The following extract exemplifies how the private doctor worked not just to validate her illness but also to sympathise with the unrecognised suffering that seems to accompany contested illnesses of this nature.

Extract 3

in the end I got a private referral and he said that the doctor said he thought it was disgusting that they never worked out what it was why I was suffering from such bad headaches I had a really swollen face and glands to the point he said he didn't even need to give me a blood test he knew I had Glandular fever there and then erm and that I must

have just had a weak immune system and stuff and erm that the whole time I had been suffering with that up until then and then (1) I think (1) after that (1) I can't, can't remember what happened after that yeah was until then, I was then, diagnosed again with ME a lot later on that they are not sure if I even did ever have Glandular fever they don't really know what it was they don't know if the doctor just assumed and didn't test for it and really it was something else owh I don't know [T1.32]

The supposed indignation expressed by her private physician disputes her previous medical treatment. The act of naming her illness without following procedures means the gaze of the medic is able to penetrate and reinstate Helen's sick role. The loss of power, which alienated and disempowered her subjective experiences of illness, has been restored and her sick body validated by the private physician. Helen's realisation that her illness was nameable is superseded later in her teens with the further diagnosis of ME. Like Jean, Helen finds her diagnosis of glandular fever in the 1990s questioned by an expert in 2007. In the above extract the subjective pronoun 'they' is used as an antecedent to syntactically assemble and pluralise the pathological gaze upon the object 'it' – her body. Although Helen is given a diagnosis, the uncertainty associated with her illness is clear.

Unlike Robert, Vivienne and Jean, Helen has not followed the CBT and GET treatment programmes, but is finding her own way to manage her chronic illness through routine and artwork:

Extract 4

I think that I've learnt that there is underlined drive in me to do this kind of thing that I'm doing now like it's to discover something or to try and fix something or control something or create something and I don't know what it is but there's something like constantly in me that's searching for something and I think that's why I do art and I think when I had a lot of problems (.5) erm psychologically that I realised you've just kind of got to depend on yourself to fix them because if something influences you to become like that that there is also a route back from it as long as it's not erm a biological reason in your life that you born like it and you've become like it for some reason you can undo it so I think I've learnt that you can fix things and control things and I kind of think that that's what I'm about really [T1.66]

This extract demonstrates how, in order to engage with and perform social practices, Helen has learnt to adopt different subject-positions, suggested by her propositional phase which alludes to her decision to act upon herself. She reveals the unknown nature

of her illness by using the indefinite pronoun ‘something’, in order to reconstitute or reinvent her illness experience. Helen shows her desire to move from her previous experiences, in which she was disempowered, to a position where she has agency. Throughout her narration Helen seems to employ vague and unspecified terms such as ‘something’ [R.43], ‘sometimes’ [R.18] and ‘somebody’ [R.9]. These intertextual words may be linked to her possible feelings of being displaced or unstable within her social, temporal and material spaces (Fairclough 2003:61). The sense that Helen feels she is on a journey to find ‘a route back from it’ alludes to the alienation she seems to have experienced in her interactions with others. Dominant ideological structures appear to have mapped a path that Helen is constantly aware of, as she attempts to adjust and present different performances of self in the negotiation of her illness. Her fragile self or, as Shilling (1993) describes it, her ‘unfinished body’ battles with physical, social and psychological limitations. It could be suggested that Helen believes she may have found a way to control the psychological in her search for self knowledge. It may therefore be assumed that she constantly works on her physical and social self, inspecting her self-identity in order to penetrate social networks and appropriate an ideological space in which to live.

10.4 The masquerade of a healthy subject

Themes associated with Helen’s struggles with time and space re-emerge as she attempts to study, work and socialise. The issues raised by her illness seem to rupture and challenge her performance as a healthy subject. The following extract exemplifies the issues of ‘doing’ illness that appear to require constant surveillance:

Extract 5

I’ve had to struggle more recently with stresses of being ill and erm college and stuff like that I’ve been less and less able to adapt who I am but I feel like the person I’m stuck being isn’t someone I want to be erm and that’s starting to worry me so I’m concerned that I don’t want to start getting into a downward spiral again things like I’m getting worried I can’t be a certain way [T1.90]

The proposition of the extract reveals the temporal problems Helen has in performing a healthy role, as her subjective experiences of illness seep through her facade. The elaboration of ‘being ill’ with the additive concerns of how ‘to adapt’ demonstrate her frustration, while the contrastive ‘but’ shows that Helen is seemingly unable to present a

healthy self, as she is 'stuck' (Fairclough 2003:90). The extract demonstrates the tension between the two elements of 'being' unhealthy and 'doing' healthy subject-positions, the first appearing to be out of Helen's control and the latter being unobtainable whilst she experiences severe symptoms. Helen uses a figure of speech for her fear and struggles and the unrelenting impact of chronic illness on her life, as she is unable to act a 'certain way' and perform a healthy self (Radley 1993:109).

The way in which the wearing of a healthy mask provides Helen with an image that she feels is acceptable to self and others is elaborated on in the following extract:

Extract 6

I think there is only so long you can keep putting on this erm (.5) you can keep being fake well not fake but trying realise who you are and when you constantly feel unwell you run out of energy and so that person that person I'm becoming is a person that tries to avoid situations that's going to make me ill or someone that's putting on a image that shows that I'm not ill so I'm either someone that's acting really quietly and boring or somebody that just doesn't go out at all and I don't like either of them people I just want to be well so I kind of realise who I'm supposed to be rather than erm (.5) I just don't think I've got the energy any more to be' [T1.92]

This shows how heavy the healthy armour can be to wear, which affects Helen's ability to adapt and present a healthy image. There is a real sense that Helen is constantly battling the 'biographical disruption' (Bury 1982) of her illness, through the lack of certainty and difficulty with reconstructing her narrative self. She reveals how she moves in and out of the persona of her sick self, which contextualises the issues she has in normalising her position (Williams 1984). Helen makes assumptions about her sick self, as if she is closed off from society – 'acting really quietly and boring'. This juxtaposes her healthy and unhealthy self, as Helen poignantly explains how she works at doing illness in order to 'be'.

Asked about the possible reasons why she masks her illness from the outside world Helen responds with examples of how she would be treated if 'they' (her employers) knew she had ME. She recounts possible scenarios in relation to the question of severity of symptoms, which offers a way to legitimate the processes of performing as a healthy subject.

Extract 7

I think that they would treat me differently if I did have ME if they did know I had it even erm (.5) they would either think that I wasn't able on doing the job or they would question whether or how severe it actually was if I felt ok one day and then if I wasn't the next day it my one or two specific symptoms of that day wouldn't really seem legitimate enough to say I had ME erm I just think that they probably wouldn't have employed me because we are actually there to support people if they did have ME as well and erm (.5) I just don't like the whole thing that comes along with it and I think if they don't think I've got it and I pretend I haven't got it then I can get on with things better if I feel like I've been put into a category then I'll get treated like that and I'll treat myself like that and then I'll kind of conform to what's expected of me and erm I won't push myself as much and I won't get as much done and then I'll be annoyed at myself erm and I think it might affect my future as well the more people I tell now even the less people I tell now the less it will be on any form of record of piece of paper or reference or doctors note the longer I can pretend that I use to have it and I've just got symptoms now where as if I tell somebody and its somewhere that's evidenced then I might have to then say oh that was the last time I had it where as now I can say the last time I had it was the last time which was years and years ago [T1.114]

When asked about the social responses to her illness, Helen explains the issues of disbelief surrounding contested chronic illness to justify her reasons for pretending to be healthy at work. Her mitigation is that if 'they' did know about ME or the fluctuating nature of symptoms, 'they' would take issue with someone who exhibits an unstable position. The variation in symptoms and the inability to perform a consistent sick role causes Helen to believe that, if her employer knew, they would not employ her. Helen then describes the necessities of wearing the mask of the healthy subject, allowing her to resist the discursive mechanisms of control. By rejecting categorisation, Helen refuses to conform to the social rules of a disabled citizen offering her the 'conditions of possibility' for agency and self-control.

She again refers to the fear of documentation and the discursive trails through which doctors attempt to record her life. Unlike Vivienne, Helen sees documented evidence as a record of her illness that will stop her performing future social roles, such as teacher. Helen further justifies her actions by reiterating the potential for the social categorisation of disability in her workplace, which places an individual into certain boxes and causes them to be treated 'differently' [T1.122, R.2]. The notion of 'difference' [R.2] and being 'different' [R.13] appears throughout Helen's narration in terms of her illness experience. She then positions herself between complex social

systems where her independence is seemingly gained by distancing herself from the mechanisms that seek to control her. As her narrative states the need to ‘pretend’ [R.10] or ‘pretending’ [R.4] to be healthy may be a way to acknowledge the hegemonic power of conformity. The obligation Helen has to a medicalised identity is outweighed by her commitment to her future self.

Helen appears to wear different masks for different social interactions. From the ‘doing’ of gender, to the role of teacher, daughter and friend, the social arena requires multiple performances which are constantly under development. For Helen, major negotiations have to take place for her to take part in social events, such as with going out with friends and going on holiday. Like Jean, she enjoys the rewards of teaching, but finds social interactions difficult with her ME symptoms:

Extract 8

I think making decisions about going on holidays and stuff with the girls and erm whether or not to go out on a weekend is something that I’ll contemplate all week or for months because of my health whether or not I’ll be well enough whether or not I’ll stand up to the social expectations erm more than actually being physically ill I think I can try and manage that but it’s just now I can’t manage pretending to be well and be pretending to be this person that they’re expecting of me so now I think those kind of decisions I’m finding hard to make and it’s getting to me [T1.146]

Going on holiday becomes a process of shifting temporalities, as her health is measured. The propositional clause takes up a concern; her discourse complicates the action with the present tenses ‘going’ and ‘go’. Although the words are used to denote movement, the terms are juxtaposed with her concerns of illness and presenting a social image (Fairclough 2003:152). Helen’s conjunctive phrase ‘stand up to the social expectations’ uses the synonym ‘stand’ to describe her difficulties in rising up to her social expectations. Helen demonstrates how her biographical narrative, although often in crisis, is always in a state of reconstruction (Williams 1984).

10.5 The corporeality of ME

Helen goes on to explain how she not only wears a mask for others but also for herself. She describes the dialectical procedure in which she refuses to acknowledge her body and get on with ‘things’, ignoring her illness when possible [T1.164]. Like Robert, Helen

sees others as having an incorrect approach to work and a seeming lack of desire in the work place. She believes that illness has made her determined, yet the act of 'doing' a healthy identity becomes difficult and her vulnerability seeps through as she feels 'pathetic' [R.4]. The flow of relations between the production of a self who is ignored, to one who takes part in the social world, highlights the heterogeneous and contradictory issues Helen faces. Her possible exclusion is unhealthy, but the wearing of her healthy identity can also be too difficult (Fairclough 2003:214).

As her illness affects her life, Helen recounts how she confronts her lifeworld in the here and now. Her life is:

Extract 9

just a front and you just get like in a cycle erm and it probably is just revolved around health because if the health was if I was alright then I'd be able to just get on with it I wouldn't be having that constant battle every day and putting on a front [...] [T1.176].

For Helen the dialectical interconnection between space and time are contested, as she constantly monitors her lifeworld, reproducing her own structures in which to manage her everyday world. The continuous labour involved in her healthy performance is made in relation to the issues of control recounted on many occasions throughout her story, where the concern is:

Extract 10

if I get worse like I'm not in control anymore like at the moment I feel like I can control it I think that at the moment I know I'm like this so I'm going to force myself to go out at the weekend or whatever but when you get so far you can't can you anymore cause your physical symptoms get too bad you physically can't push yourself it's not about oh I'll just do it until I get ill you're already ill you can't push yourself any further erm and when you're in that state of mind you can't consciously make an effort to control it cause its already in control [T1.188]

The inter-discursivity in which Helen attempts to step outside of and structure her own lifeworld is constantly challenged. The production of text seems to take on a mnemonic pattern centering her spatiality throughout her life story with phases such as 'push yourself'. Her discourse signifies how she controls her interactions between others and the social space. Helen's narrative suggests an image of being a machine that requires 'force' and a 'push' and often being unable to reflexively 'push yourself' past the

unhealthy state. The use of different tenses reveals an ongoing need for motion, push, force, which is countered by the restrictions of control and fix (Fairclough 2003:152). A difficulty may be encountered in the ways Helen is trying to achieve, control and force productions of a self within what could be seen as an unmanageable machine/body.

The following extract extends her previous notions of social responses to her illness and holds some clue to why she is searching for medical support.

Extract 11

I think in general people see it as you're just a weak person I don't think they see it as a proper thing erm a lot of time people get confused with M.S. which is really severe and like then there like well you're actually well you don't seem ill erm (.5) you know I think I still think people just don't take it seriously they think (.5) just the word pathetic always comes to mind I know it's a horrible word I just think people are kind of like owh theres nothing really that wrong with ya you're just tired like pull yourself together get on with it you know and its just we pull ourselves together every day actually you know haha I don't know [T1.234]

The possible intervention of socio-political discursive practices, along with cultural understandings of her illness, causes Helen to declare a loss of self and question her own experiences and existence of ME as a chronic illness. As Helen evaluates her illness and takes on the language of medicine, she seems to delicately peel back the armour she has worn since her childhood and reveal her vulnerability. Being told 'there is nothing really wrong with ya', again confirms the power Helen believes the medical professional exerts to impose a 'truth' over her 'real' illness experience.

10.6 PED

The second interview was based on Helen's PED. As an artist, Helen found taking photos of her everyday experience difficult as she was used to working on 'creative subjects'. However, she found the experience provided an opportunity to tell a story, not necessarily 'the truth', but a visual construction of a life living with illness. The 24 images she took seem to enrich her life story as each represented the struggles of living with ME. The general themes emerging from Helen's images are feelings of isolation, sadness and battling daily struggles.

10.6.1 'Put on my mask'

Figure 1



Extract 12

first thing in the morning and I'm feeling really awful and now I've got to put on my mask not only does it mean I have to get up earlier but it seems to take so long and all my make-up seems really heavy as in like the actual process of putting it on and then when its on my face being really aware of it I hate doing [...] if I haven't got mascara on I look even worse because I've got blonde hair I look really ill so that's the one thing if I put a bit of mascara on I look so much better but I hate doing it (laughs) so I put it makes me look and feel normal so it's a love hate relationship. [T2.6]

Helen literally sees her make-up as a mask that she wears. The notion that she is wearing a different self does not, as in Bakhtin's carnival, offer freedom from a material body, but rather the 'grotesque' emerges through the recasting of her face, so that she can perform her female identity and hide her illness (Bakhtin 1984:370-371). The western custom of presenting a self 'made up' for others is heightened by Helen's mask. She also uses the mask to protect herself, as the make-up hides the vulnerability of 'being' unhealthy, as she attempts to 'do' a healthy performance in the public arena. Yet she also makes it clear that this is a labouring process and the actual energy used in applying make-up is not insignificant. However, these rituals work to normalise her performance of doing a healthy identity.

10.6.2 'Finding the balance between not looking too ill'

Figure 2



Extract 13

I stare at this image for so much that I'm surprised that I even need to bother looking in it I hate deciding what to wear and finding the balance between not looking too ill or too messy or too casual or not looking that I've tried to hard fitting in with the people that I'm going to be around that day without them judging me being comfy in case I feel sick or I'm hurting but not looking too frumpy not wearing something too revealing or tight as a result of not looking too frumpy and finally it being warm enough because I'm always cold... [T2.17]

Like Vivienne, Helen photographs her wardrobe, but her image is not about displaying the armour of a past life, but rather, demonstrating how Helen chooses what armour will best hide her pain. The judgements of others are the undercurrent of her choices about how much she needs to hide. The negotiations are based on the difficulties of balancing her ideals about what is acceptable in terms of fashion and illness symptoms.

10.6.3 'The mirror and thought NO...'

Figure 3



Extract 14

this is the last mirror on the way out and I looked in it and changed my mind and decided to stay in so that was quite a sad day I just felt rubbish I'd spent so much time I was still ill from the decorating and then I tried to find something to wear and I didn't feel right and I knew I wouldn't be able to put on a front so I just looked in the mirror and thought NO so I didn't. [T2.18]

The continual monitoring of Helen's social identities, governed by self and others, begin from the moment she begins her day, from make-up to wardrobe, to the final check of her appearance. The moment when the clothes do not hide her suffering starts a

process for Helen where ‘to put on a front’ becomes difficult. The mirror reflects an image for her that signifies a ‘no entrance’ sign to the outside world.

10.6 Conclusion

Helen’s chapter works from her earliest memories recall her position of being outside the norm. The question on the contested nature of her illness is a stark turning point for her to hide the being of illness. She seems to observe the assemblages of social order within social relations. Her childhood recollections describe her ability to disengage from the productions in which she was expected to perform the identities of pupil, daughter and patient. The penetrative gaze of the medical expert diverts attention from her sick body and, although there is disbelief in her illness, Helen seems to escape the field of medical knowledge that would constitute how her role as a sick child should be performed. The sense of disbelief is critical for Helen as it seems to place all social relations at risk, as the medical expert influences parental support and Helen is positioned as the ‘ill child’ in the family who is always ‘moaning’. Helen makes the decision to move away from the ‘all seeing eye’ of medical surveillance, as she resides between social borders of further uncertainty and risk (Foucault [1975] 1991).

Helen’s narrative responds to the research question on the dilemmas, contradictions, and conflicts of surviving with a severe chronic illness by taking us through her particular acts of resilience. She describes the way in which her physical and emotional experiences of illness become entwined with how she performs her social identities, as her performance seems to be alienated from the normalising gaze of social relations. Helen’s dialectic interactions seek to fix and control her social world through masquerade, although the mask of the healthy subject is not always achievable. Helen, therefore, attempts to alter the assemblages of control through a deterritorialization where she wears a mask and appears to assimilate, conform, ‘pretend’ to be healthy and thereby break the political connections of rhizomatic social networks (Deleuze and Guattari [1980] 2004). However, her actions are always intertextual, grounded in her performance of a gendered role, where the desire for wearing a ‘facade’ has ‘no authenticity’ (Bakhtin 1981:273) as her subjectivity is always discursively grounded between language and power (Fairclough 1989). Although she attempts to conceal a fabricated self, this demand seems at times more difficult to deal with than her physical symptoms. It would seem that Helen is always in a state of reflexivity, as her

performance of self is always carefully monitored (Goffman [1959] 1969). Living with chronic illness often causes Helen's mask to slip and at this point she becomes restricted and housebound, as she has to continually work on her 'unfinished body' (Shilling 1993).

Through the aesthetics of her work as a tutor and artist, Helen is able to explore possible freedom and release some of the stresses of living with her illness. She found the PED challenging as the mundanity of the images and lack of artistic content felt opposed to her usual approach to visual expression. However, her images were symbolic of her everyday struggles and sensitively map the difficulties she has in living with long term illness. Although the images pinpoint restrictions and challenges, they reply to the research question on depth of meaning as Helen demonstrates how she works to keep on keeping on as she 'makes up' her body/machine to negotiate 'being' unhealthy, 'having' ME and 'doing' healthy citizenship.

Chapter 11: Narrating the Discontents of a Contested Illness – ME/CFS

11.1 Introduction

This chapter clarifies major themes drawn from the seven data analysis chapters to respond to the research questions associated with how it is possible to live with and survive the severe symptoms of a contested chronic illness. It replies to the research questions by exposing how the heterogeneous nature of severe ME is governed by epistemological boundaries that define the *doing* of illness, whilst *being* ill taps into the ontological and creative processes required in negotiating physical symptoms. This thesis has also focused the question of depth of meaning for living with severe ME and the practices and processes of constructing healthy and unhealthy identities, whilst negotiating the subjective experiences of pain and suffering. It has touched on contentious debates into whether the illness should be classified as a disease or syndrome. However, rather than establishing a conceptual dichotomy between whether the illness is physical or psychological, the nine life stories elaborate on the journey towards becoming ill, in relation to language, space and representation. The thesis explored the bio-political and socio-cultural context for life with long term illness, drawing on notions of power, truth and knowledge that underpin the desire to be healthy and transgress the abjection that severe illness causes. In the critical discourse and narrative analyses, attention was given to discursive and material features that respond to the research question associated with depth of meaning by exploring how it is possible to narrate a severe chronic illness of this nature.

11.2 ME and its discontents

This section draws together major themes from the life stories and PEDs and clarifies the tension between performing healthy and unhealthy identities, whilst constructing ways to live with the subjective experience of a severe illness. Rather than invoking an oppositional account between medico-political definitions and treatments, it focuses on

the discursive processes and social practices of constructing identities and the socio-cultural dilemmas involved in managing a life with severe ME.

11.2.1 Constituting ME: the label and its associated affects

The life stories demonstrated how the various labels ascribed to this illness relate to the period in which a diagnosis was given, reflecting the concerns of specific medical disciplines, which influence government policies and control working definitions and treatment. For some of the narrators the labelling of their illness held powerful meanings whilst, for others, it was less important. Vivienne and Robert gave the term ME more weight than its counterpart CFS and reiterated the historical events in which the Latin term was produced, believing ME to be a more authenticated term. For Vivienne, the label offered a means to gain documented evidence, political legitimacy and cultural validation of the existence of her illness. However, Helen saw the official naming of the illness as a barrier to future employment and looked for ways to erase her past medical records.

For Jean, labelling highlighted the dilemmas of situating her contested illnesses, as different medical professionals either bestowed or withdrew the diagnosis of ME. Jean's desire to situate her illness was seen as superfluous by one doctor, whose refusal to name her illness situated Jean in 'a place of the other' (Shildrick and Price 1998:242). Her dramatic recollections suggested that her ill body became borderless, as the categorisation of her illness became uncertain. Unlike diseases with fixed labels, such as cancer, her illness typified the vigilant search to re-name and re-frame this illness. For Jean, the burden of not having a stable name produced a continual search for knowledge as she tried to determine whether her illness was caused by a virus, contraception or her lifestyle. The doing of illness is made vulnerable through the continuous contested rhetoric, the clinical gaze that changes its level of focus and challenges of managing severe symptoms. As Jean's illness moved between and within different medical and institutional borders it appeared to be nomadic in nature, as it was discursively controlled and encountered nosological barriers.

This forces us to ask: Can we ever truly establish meaning through nosological terms? As Foucault states in relation to the clinical gaze, 'disease is merely a name' (Foucault [1963] 2003:146). As the narrators searched for a name to give some resolution to their severe symptoms, the label of ME and/or CFS seemed to offer access to both political and social understandings. Yet, the label has the propensity to under-represent the depth

of the embodied experiences of severe ME, while the continuously fluctuating medical categorisations of disease and syndrome highlight how this illness in particular cannot be contained by its medical borders.

The stories identified how medical discourses work to situate the ‘dis-ordered body’ (Shildrick and Price 1998:246) and offered an opportunity to question the rigid distinctions that constitute how illness is categorised. Such stories substantiate how an illness such as ME is recognised through a moving set of political and social conditions that could ‘free us from the grasp of pre-given stable identity categories that slot all too easily into oppositional binaries’ (Shildrick and Price 1998:246). As the narrators reveal, gaining a diagnosis is not merely a personal quest, but a pragmatic necessity. Moss and Teghtsoonian (2008) point out that social citizenship requires its subjects to access the right to be unhealthy, as verification is accomplished by a political network of medical experts and state agencies who determine whether an illness can be supported (Moss and Teghtsoonian 2008:41-2). Indeed, Vivienne and Robert’s stories identified how their private health insurance validated their absence from work, providing consumer choice and certified support. Similarly, the diagnosis of Angela, Helen and Geraldine as children provided lawful permission for their absence from school. While for Jean, Maria, Paul and I, diagnosis led to an NHS-funded treatment plan. Therefore, while the quest to find a diagnosis arises from the personal desire to find out why one is ill, the permission to take on an unhealthy identity has to be politically and socially granted.

All the narrators described individual accounts of the often laborious journey to certify their condition via the bureaucratic spaces of doctor’s surgery and hospital, to fulfil legal tenancy as an unhealthy subject. As Vivienne poignantly stated, the journey to find a diagnosis represented the validation of her suffering, so that she had permission to seek treatment and had evidence that ‘it exists, it’s real’. The life stories described the events and experiences leading up to the diagnosis of ME/CFS and open up questions about the power to diagnose. Their narrations split open the fixation of the clinical gaze to label illnesses as diseases or syndromes. As the illness resisted categorisation, it forced many to become experts in their own illness experience. This search for validation and gaining a diagnosis was also the means by which treatment was granted and is elaborated on in the following section.

11.2.2 Constructing ways to manage the subjective symptoms of ME

As stated above, the narrators' first concern was to find a diagnosis which gave them a pathway to treatment. Their life stories illustrated how they moved between the heterogeneous identities of parent/child, pupil/employee. Within these social roles, the role of patient is individually experienced. Robert and Vivienne both worked within the fast-paced stockbroking world that rewarded those who performed, while Jean was a teaching assistant and I was a new mother. Our individual stories demonstrated how our childhood, adolescent and adult experiences influenced ways of doing illness and being ill. The narratives were positioned around how those diagnosed as adults had already acquired a work ethos that caused them to ignore the early signs of ME. This offered a means to account for how the narrators became severely ill and how their coping strategies were geared towards returning to the roles of child, employee or parent.

For seven narrators the CFS clinic, ME ward and, for three of the seven, subsequent intensive rehabilitation programme, became integral to improvement and recovery. The narrators captured distinct and varying ways to manage and engage with the treatment regimes. For example it was important for Jean and Maria to position their stories in terms of their recovery, situating their wellbeing within the context of balancing their lifestyles. In contrast, Angela and Helen, who had both been ill since childhood, focused on experiencing powerlessness in terms of others having control over their ill bodies. Paul, meanwhile, was immersed in such a strict regime of health management that it impacted on the minutiae of life, as every movement was strictly monitored. For example, he managed the interview by taking continual breaks to be silent/still. Paul spoke about his previous life experiences as highly energetic and focused on hedonistic pleasure, contrasting with his current recovery which was dependent on excessive control. The treatment was seen as a way for the narrators to gain equilibrium over energy and agency over their illness. The stories highlighted the reflexive action and hope of returning to their healthy identities as mother, daughter and employee. Although this was not necessarily fully realised, all managed to partly restore a sense of agency whilst experiencing often severe illness.

Seven of the narrators, who used coping strategies endorsed by the UK government (NICE 2007), described the process of managing and measuring energy/time output to slowly rehabilitate and restore balance. The self-management programmes were instrumental in their improved health, to a lesser or greater degree, with movement calculated on a minute by minute basis. For Jean, Maria and Paul, the treatment allowed

them to move from the inner space of a bedridden state of confinement to a rigid regime of self-surveillance, which provided a path out of illness through therapeutic compliance. Jean described the slow process of regaining a life from being bedbound to managing to sit, wash and use a toilet.

A number of the narrators also adopted discourses of accountability when deviating from the treatment programme. Jean revealed how she had been working hard to rebalance her life, but believed she was to blame for a 'blip' in her recovery. Meanwhile, Paul's fastidious control over time-management seemed to belie a need for complete self-governance, as he treated his body like a physical machine. As Jean, Maria and Robert demonstrated, the power to govern their bodies was granted through conscription to regimes which necessitated a continual focus on the body's energy. The implication being that any subsequent break in the equilibrium was one's own responsibility.

Importantly, while this study was underway the London CFS clinic/ME ward, which was central to eight of the narrators' recovery and/or improvement, closed in 2012 due to funding cuts. The extensive therapeutic programme which Jean, Maria and Paul experienced is no longer available and there are no similar private or NHS in-patient services for treating severe ME/CFS. NICE (2007) have made recommendations, including the implementation of support for severe sufferers of ME/CFS. However, currently, there are no treatment facilities and limited support for those who are severely affected. The narrators who were able to access private healthcare seemed to achieve earlier diagnosis and it also gave Vivienne, Robert and Helen quicker access to therapeutic treatment. Jean and Maria were also able access the intensive treatment programme available through NHS funding, which has since stopped.

The systems of treatment for the chronically ill tend to centre on coping strategies rather than finding a cure. The narratives outlined how treatment for ME is part of bio-power, a system of technologies that endorse therapeutic regimes as a means to manage the growing increase in chronic illnesses. The chronically ill are seen as an economic risk to society, requiring large scale administrative controls through government endorsed health programmes. This neoliberal approach is arguably about normalising coping strategies, through micro-politics of health that produces an ethics of self-surveillance to control the growing recognition of chronic illnesses worldwide. This medicalised assemblage has deterritorialized chronic illness into codes for coping and managing that

can be consumed by different intensities for other chronic illnesses to potentially replicate.

These stories highlight the exhaustive attempts to categorise ME, which reveal the time and funding spent on what can arguably be termed unworkable engineered biological markers. Blanket therapeutic regimes that lump all chronic illnesses together tend to omit the needs of those most severely affected. Arguably, as the stories demonstrate, the main issue with this kind of 'blanket treatment' is that the natural human instinct is to live life according to one's own desires, which can lead to a resistance to the required regimes of imposed treatments that seek to govern the body's energy. The clinical gaze seems to have turned its penetrating eye of power on the ill subject, making them wholly responsible for their own health, so that deviating from the regime causes them to question their own adherence to the obligations of self-management. The narratives show how the medical constructions of a chronic illness are based not only on defining and labelling, but also on whether treatment is made workable or unworkable for the severely affected. Whilst medical debates continue on whether ME is a disease or syndrome, rather than building a depth of knowledge, the high level of mobility between disciplines results in a continued medico-political battle over ownership, and a lack of focus on those who are severely affected.

11.2.3 Narrating ME

The narrations revealed the realities of living with severe ME and how discourses are used to communicate the nature of this contested illness to self and other. Unlike an illness with a stable medical definition and socio-cultural identity, there is a lack of understanding about ME, making continual interpretation of its vicissitudes necessary for those who suffer from the illness. Life stories and photo narrations offered a way to verbalise and visualise the disruptive nature of illness, highlighting how governing controls work to correct the unhealthy body through a set of political and social relations, making and unmaking social identities by plugging in and out of social mechanisms.

The stories described many different symptoms associated with pain and severe weakness, such as being unable to speak, stand, hold a drink or open the eyes, capturing the extent to which post exertion malaise affected their daily lives (Carruthers, van de Sande et al. 2011). The narrators illustrated the difficulty in finding the words to explain what it means to experience this level of weakness. Vivienne and Jean described their

illness in terms of being outside of commonly understood illnesses. Other chronic illnesses, such as multiple sclerosis, cancer and AIDs, cause chronic fatigue, yet fatigue is characterised as central to ME, not least in its renaming as CFS. As a result, the pain experienced by those with the illness is often sidelined, although more recent definitions state that both ‘pain and fatigue [are] crucial bio-alarm signals’ (Carruthers, van de Sande et al. 2011). As the stories in this study demonstrated, pain and fatigue go hand in hand, so that it becomes difficult to separate these embodied experiences.

The narrators demonstrated the difficulty of putting suffering into words and communicating an illness experience that continues to mystify medics and destabilising what it means to fulfil a diagnosis (Bulow 2008). The stories substantiate my assertion that language is unable to convey the *depth* of meaning for describing what it means for being severely ill. The fact that ME has no stable diagnosis or outward visual signs, means that the narrators described their illness via a cacophony of words to portray their suffering. Strategies such as laughter, intonations and deep exhalations and inhalations, often revealed the parody and uncanny nature of fluctuating symptoms. Metaphors and similes were useful aids to convey cultural meaning to self and other by combining words and images. When Robert says ‘it’s like putting a pin in a balloon’ and Vivienne refers to ‘*Archimedes screw*’, we gain cultural understanding of reduced energy and the cyclical nature of ME. Vivienne movingly revealed strategies for surviving with ME by shutting her emotions off, with terms like ‘closing the vault door’ and ‘archiving off’. These mechanisms of language colourfully portray the physical and suffering experienced by this illness.

The photo narrations elicited rich meaning, the images evoking a deeper level of understanding by combining images, as metaphors seemed to represent the plugging in and out of the social world. For example, Angela’s photos used street signs to demonstrate her past suffering and present recovery. These images revealed how Angela, who had been bedridden from the age of 14 to 18, struggled with re-engaging with the cultural practices within her social world.

As the signs and codes filtered in and out of the dialogic practices of the storyteller, I was able to decode the metaphorical symbols of the balloon, screw, vault and signposts. Interestingly, metaphors and similes are also used within therapeutic situations, as keywords which become bywords for managing illness. CBT and GET employ a discourse where the expulsion of energy takes up negative connotations; with slogans

such as having a ‘low battery’ and the ‘see saw’ affect. Some of the narrators then adopted these discursive terms, which became part of their own rhetoric about their illness.

The stories revealed how, in different ways, the desire to be healthy was matched by the obligation to become expert patients, as with those who followed complex rules about measuring time and energy. For example, Jean’s graded task was to monitor speech and limit time sitting up in bed. The stories described taking hold of these corporeal practices in order to return to their former everyday lives. This self-regulation denotes the powerful forces behind caring for the self, so that therapeutic techniques are merely the interventions bound by the power of medical knowledge and regimes, that rely on constant reflection on ‘oneself, to one’s body, to food, to wakefulness and sleep, to the various activities, and to the environment’ (Foucault [1984] 1990:100).

These acts of monitoring embodied experiences are then amplified to the extreme for those who are severely ill. When bedridden for many years, Jean relied on her husband to speak for her – or to speak for them collectively, as she denotes with her use of the pronoun ‘we’ – becoming her ‘vicarious voice’, as the carer is part of daily survival (Hyden and Brockmeier 2008:52). However, this vicarious voice can also be stifled, like the sufferer has been, when encountering a contested illness such as ME. Helen’s childhood recollections of having ME symptoms were that both mother and daughter were unable to effectively speak up about the illness when confronted with the doctor’s disbelief. The lasting effect of this experience is that Helen continues to mistrust the medical establishment and wider society to believe that she is ill.

The narratives of illness in this study eloquently made use of linguistic and literal pictures of what it means to survive a life with ME. Language, or more specifically our socio-cultural context, governs how it is possible to express meaning and arrive at shared understandings for self and other. Yet, the life stories and photo-narrations also alluded to the problems of achieving the depth of meaning needed to adequately describe the experience of living with the severe effects of ME.

11.2.4 Performing illness and navigating social spaces

This thesis has shown the strong desire of those negotiating and surviving severe illness to perform healthy subjectivities, as the narrators had to reconstitute notions of what it means to fulfil a ‘sick role’. The challenges of being house/bed bound and living with severe pain were often juxtaposed with the need to adhere to and resiliently negotiate

social relations and spatial environments. Those who were often completely removed from their social spaces due to severe illness had to find ways to plug back in and re-enter their social world.

Masquerading as a healthy subject allows those with illness to perform their public self, while the private self remains hidden away. Wearing a mask then offers the opportunity to be accepted at work and socially, providing a particular kind of freedom. The mask of health is then often used to hide the seemingly forbidden appearance of the sick self, to present a healthy image and plug back in to the social world. Paradoxically, one reason for the culture of disbelief around ME is the lack of visibility of the severe illness symptoms that cause many to be bedridden. Therefore, Helen's preoccupation with presenting an acceptable face to hide her illness unintentionally makes it difficult for others to understand her pain. While wearing the mask of a healthy subject, she effectively constructs a way to live with her illness and negotiate the tension between hiding and belonging to her social world.

The performative aspect is highlighted in different forms in the majority of the life stories. For Robert, the desire to 'keep on keeping on' necessitated the wearing of social armour, as he continued to work and ignore the physical symptoms of illness. The notion of 'pushing yourself' recurred in a number of the narratives, revealing how the reality of illness was overcome by ignoring or pushing through. Becoming ill with ME may cause a crisis of identity as it becomes increasingly difficult to return to previous social identities. Robert was a successful financial banker before becoming ill, but eventually had to leave his role as a manager within the financial sector and come to terms with his ill body. Equally, Vivienne talked about the need to hide her frailties and close down her sick self, mirroring some of the performative strategies she learnt as one of the first female stockbrokers in the 1970s. This demonstrates the importance of understanding life experiences when confronting long term illnesses.

11.2.5 Implications of severe illness on social networks

The stories and PEDs highlighted the practical implications of living with a long term illness, the narrations were predominantly linked to the presentations of self which often participants focused their stories around coping mechanisms thereby possibly avoiding the shared, often emotionally charged, painful areas of their lives where they may see their selves as lacking. Overall, the stories suggest that the hardest task to tackle may not be the inordinately physical impairments, but emotional pain of unfulfilled identities

and desires connected to the family home as a mother, daughter, sibling and partner, school, teachers and friends, workplace with employers and colleagues. These interactions are eluded too, but the emotive nature of these social networks seems on the whole to be avoided. Perhaps, the practical adaptations undertaken living with ME is easier to narrate than the social and emotional dislocation that long term illness causes. In support, Jean and Maria only agreed to take part if their accounts could be framed around their experiences of recovery. Taken overall, participants seemed to position themselves as ‘survivors’, wearing the mask of healthiness as Helen states becomes more important in the social arena- thus accounting for a surprising reluctance to speak about their personal intimate relationships.

Having said this there were instances where participants relayed, implicitly details of their social networks. Robert for example, revealed only one emotional glimpse of his sadness, not being able to work with his son. Vivienne’s life and photo narrations alluded to how she constantly worked at ‘hiding my frailties’ – ‘filing cabinet, archive, I’m off’ and her moving account of the spare room as a metaphoric Dorian Gray space revealed in these ‘private thoughts’ her attempts to actively disconnect from social networks that demand performative aspects of self. Given that these stories more often lacked explicit detail outlining the connections between disability and social networks, I felt it was beyond the focus of the current research, which aimed to allow participants to have a certain amount control and direction over their stories. Furthermore, probing obviously sensitive material may well have impacted on the emotional well-being of the participants whilst taking part in the study, in relation to aspects of their life they were clearly reluctant to discuss.

On reflection, during the analysis process I realised my own story was offering not a dislocation of my social roles, but the short gladiator extract omitted the often felt emotional desperation that accompanies not being able to walk your children to school and take part in family rituals such as eating a meal together or taking a walk in the park. I return to the issue of being both inside and outside the community I am studying, the nature of reflexivity may have influenced those aspects of the narrations that mirrored my own perhaps unspeakable, shared sadness associated with our social networks which may have been too difficult for participants to disclose in depth.

It is arguable that there could be an absence of focus on the inner workings of social networks but this was not the goal of the thesis. The research questions were open natured and organic allowing participant's full reign to take the stories in the direction and path of their own choosing.

11.3 Life stories and PEDs of severe illness

This section demonstrates the kaleidoscopic framework in action. This is woven into the following subsections. It is important to realise that this reflective view although explicated in chapter 2 into three diagrams, is in essence working at different levels and depth. This section therefore clarifies how storytelling assists in identifying discourses, social practices and interactions with social spaces by employing the kaleidoscopic lens to the discursive, material and dialogic contexts. Although it is impossible to achieve a singular account of these issues, the life stories offered significant insight into the social processes that constitute ways to survive a life with severe illness. As with Bakhtinian theory, it is the context and the relationship between language and the act of storytelling that offers a chronological and dialogic account of a life with illness. Meanwhile, a narrative analysis of life stories offers a means to examine the discursive and material events that precede the biographical disruption of chronic illness (Bury 1982).

11.3.1 Inscribing and the becomings of ME

During the act of storytelling, the focus was on 'who' was telling the story and 'how' they wished to transmit the events leading up to and associated with becoming seriously ill. When listening to these stories, I often recognised particular social practices of surviving severe illness, as some of our experiences were startlingly similar. As a researcher, I attended to 'how' to integrate individual and shared experiences of the discursive and social practices, which often lead to marginalised life styles. By employing life stories as a method, it was possible to explore how past events and contingencies worked to inscribe ways to live with severe illness in the present.

In his genealogical approach, Foucault recognised that the sick body is seen as a deviation requiring legitimation through the clinical gaze, which prods and pokes the body to judge whether an illness is a disease and/or syndrome. Those who remain ill, particularly with a contested illness, are placed outside of normative social controls, becoming marginalised subjects. While Foucault's work is important for understanding how social norms are made operational through language and can work to marginalise, these stories demonstrate how being ill is a deviation from the norm. Those living with

impairments and long-term illnesses are disabled within society and disabled by their illness state (Shakespeare 2013). Therefore, understanding disability is just part of the issue, as research needs to explore the states of discomfort that impairment causes every day, to delve into the discomfort of suffering and pain and find acts of resilience.

My reading of Deleuze and Guattari's concept of 'the refrain' offered a means to observe the movement of bodies, intensities at which physical illness, along with its emotional and social ramifications, impinges on life and transmits meaning. It allowed consideration of the implicit practices that bring together life history events and contingencies, where a life – a desiring machine – pulses and moves according to intensities that secure particular singularities and the multiplicities for existing. For example, as Helen was constrained by being bedridden, she resided in a space waiting, yet her mind worked to memorise, imagine and dream, revealing how the repetition of suffering produced a rhythm of difference to cope and survive.

The narratives explored the constructed understandings of what it means to live with a contested illness, along with the complex processes of becoming. In her life story, Jean described her journey to be diagnosed, but during her second PED interview, also brought along a letter to further explain her experience of doing illness. Her life story portrayed the events and power relations within the institutions of home, work and hospital that often controlled the ways she could express her illness. Jean was continually forced to ask medical professionals, 'what is the cause of my illness?', to substantiate her illness identity and provide a rationale for 'how to live with a contested illness', in her quest to find out 'who am I?'. This can be contrasted with Paul, who established and retained a diagnosis of CFS and, due to his life experiences and firm diagnosis, had no such concerns. He adheres strongly to his therapeutic regime and adopts an intra-corporeal outlook that governs his body's expenditure of energy. The desire to return and remain healthy is the key to a better future for both Paul and Jean, but their life stories reveal different complex relations. Jean already had the roles of mother, wife and daughter when she became ill, while Paul was able to return to his flat and be cared for by his parents.

Both Helen and Angela demonstrated the effects of power relations in their accounts of their childhood experiences and their later adult interactions as their subjective understandings affected how they negotiated social spaces and places. Helen and Angela's inability to conform to the requirements of socio-spatial establishments such

as school, due to their illness, meant they were denied peer relationships and other benefits associated with attending school. The norms that operate within the social fields of school, hospital and doctor's surgery caused these children to question their roles as compliant subjects and resist those who disbelieved their illness condition. For Helen, this was achieved by masking the illness and denying its existence, to evade the power behind the clinical gaze. Representing self was also a dilemma for Angela who assessed her audience before disclosing her illness, to the point that she often remained silent. These self-effacing acts demonstrate the continued self-surveillance associated with ME. These stories demonstrate that being excluded is part of being ill and reconstituting a self with recovering, surviving illness is a work in progress.

While the narrators articulated what it means to fulfil social norms within the abstractions of social expectations of health, their storytelling revealed the act of *doing* illness through the multiple and varied relationships between body, self and other. This revealed the contradictions that occur in constituting a self with a severe, yet contested, chronic illness. For me, the contradictions were apparent in the ways I performed my role as a mother, transgressing my bodily limitations and creating, within the space of my bedroom, an arena in which my son could play a game. These kinds of daily negotiations were common for those who were confined by their illness. For example, Jean felt sadness and guilt at being unable to visit her dying mother and failing to fulfil her role as daughter.

While our embodiment emerges through our mastery of social norms and practices, we recognise that aspects of suffering are rarely made visible or acceptable. We are, therefore, powerfully defined by our own systems of resilience. While severe illness rendered the narrators house/bed bound, the stories highlight the need to master illness in order to practice social roles. Although many had deterritorialized from the demands of physical roles, through social, spatial and relational contexts, they managed to reterritorialize into the spaces of home/bed and, in some cases, work. The mastery of severe illness shows how it is possible to transgress the social practices that determine our roles: while illness ravages the body, it cannot completely destroy agency.

The stories indicated the significance of moments of inter-corporeality, both in terms of the historical biographies that inscribed them and in relation to the desire to become healthy. Foucault used the term bio-power to discuss how the practices of socially dominant powers demand documented evidence of illness, not merely through the

clinical gaze as a surveillance system, but by requiring political validation so that you can prove your illness condition and are allotted the time and space in which to temporarily occupy the sick role, as experts grant permission to be ill.

This project has critically mapped the emergence of ME as a category and the scarce research and often neglected stories of those severely affected. The heterogeneity between the disabled and the chronically ill is vast and symptoms infinitely varied, yet the performance of unhealthy identities takes place in our rooms, in our beds, hidden away neatly from the social gaze. The norms that govern disability confound the issues of living with a contested illness, as the only socially recognisable guise is the mask of a healthy identity. The weight of this can often be too heavy to bear, as it is at times for Helen who, on surveying her appearance, opts to return to her bed and hide her ill-body. The narrations of being bedridden demonstrate how the ill body forces deterritorialization from the social world, producing discrete ways to achieve a rhythm of life, as a difference in tempo leads to a meeting between ‘doing’ illness and ‘being’ ill, in our beds, in our suffering, within our bodies.

11.3.2 Plugging in and plugging out

In the stories, it was the severe affects upon the (often bedbound) body that necessitated a continuous plugging in and out of their social world. Therefore, it is not enough to explore the epistemological basis for how people become diagnosed with ME; we must also learn how it is possible to ‘do’ illness whilst ‘being’ ill, as severe symptoms cause a clash of our constructed social identities with the intensities of our personal suffering. Deleuze’s notion of the refrain proved to be useful in examining what it means to live within the different intensities that occur for all organisms in the flow of life. In order to survive, there is always a creative process through which different assemblages are produced. The model of the rhizome describes the continuous nature of assemblages, as survival occurs through the ongoing life *process* of becoming.

The narratives illustrated how an assemblage sets out a series of different flows and intensities, which are constantly reterritorialized when being ill. The act of deterritorializing away from the body in pain is often activated through uplifting memories and dreams associated with being healthy. Therefore, what Foucault would call the power to resist is, in Deleuzian terms, based on these assemblages of becoming, in relation to performing healthy and unhealthy identities. The nature of ME, which produces symptoms that are not only uncertain but also continually changing, can mean

that the need to deterritorialize occurs with greater frequency and spontaneity. One example of this is the way in which Robert changes his social interactions and physical surroundings by removing himself to his bedroom when he starts to feel unwell. In this deterritorialisation, he plugs out of his social spaces to gain respite from his symptoms and the social roles of father/husband. The process of plugging in and out was also evident in the photo narrations, as Helen portrayed her 'resting' legs, Vivienne the 'waiting' to be well and I 'reading'.

It is important to state that, when plugging in and out of the social world, you never completely plug out. Lines of intensity remain connected, so that the wiring is present even when the plug has been removed from the social circuitry, awaiting a flow of energy to be restored in order to plug back in. This is especially poignant for people with severe ME, who experience both fatigue and pain. As productions of desire, our stories reveal a machine-like existence, made up of flux and flow, which can be likened to Deleuze's concept of a *Body without Organs*. We are interconnected with other animate and inanimate objects, to the extent that even when we do not appear to be part of something we remain part of a rhizomatic network. When bedridden the imperative is to survive our uncontrollable bodies, subject to space and time.

The thesis encapsulates what it means to hold 'outsider' and 'insider' positions, as the narrators literally plug in and out of their social world. Jean's photographs depict the process of plugging back in, as she illustrates the 'movement' from experiencing difficulty using a toilet, to enjoying the feeling of her feet on the ground, then being behind the wheel of the car adjusting to the pace of life. The narrators highlighted the experience of being housebound and bedridden, as illness caused them to retreat from their social spaces and become marginalised. The tropes associated with being bedridden were a point of contention for some, like Jean, who experienced the frustration of a family member when she was bedbound. The narratives demonstrated not only the issues of living with pain, but also how being bedridden deviated from the normative codes that decreed how the bed is constituted as a temporal place of rest. Their narrative formations offered a way to theorise how their enforced confinement produced a 'heterotopia of deviation' (Foucault [1984] 1998:180), making the place of the bed/bedroom 'other', disrupting their own understanding and that of others. Escape was physically impossible, but their virtual strategies of imagining other worlds countered the restrictions of being bedridden.

11.3.3 Spatiality and the subjectivity of severe illness

The life stories and photo narrations made connections between space, health and illness, determined by the relational aspects of suffering and the situational context of confinement. The narrators revealed how past events and experiences, hopes and dreams, accessed cultural memory (Tamboukou 2015:43), which constituted ways to resist and counter suffering. The narrative genre of escape and freedom was represented by the photo-narrations of windows. These literally and metaphorically opened up a view to the outside world, which triggered ways to imaginatively escape the 'inside' place of the bed and disavow physical pain. For Helen, the window appeared to signify emotion, while the moon represented light and ignited calm feelings associated with past memories. Geraldine was able to envisage a world 'outside'. Meanwhile, Maria wished her story to focus on recovery and set about redesigning her room to erase her view from the window and from the past, transforming the context from which she could view the world outside. The narrators built on their relationships to actual places in terms of time and memory, residing in both real and virtual worlds (Bakhtin 1981).

The photo narrations revealed the disruption of space in terms of inside/outside their home/hospital beds. The motifs of the window and the bed were heterogeneously experienced. For Angela, opening her eyes when bedbound was an act of resilience, while Jean's inability to speak meant that she often feared she would not survive. Outside places were like another world for the bedridden, a virtual world that moved to a different rhythm, as moving with minimal energy had to be mastered. The actual world for the bedridden is the bedroom, which constituted the conditions for escaping the sick body. To affect an ontological escape from the place of confinement, to counter the intensities of the neuro pathways which compute pain and weakness, Geraldine and Helen employed illusionary tactics. The window could be said to activate an assemblage for the intensities of living with the physical barriers of severe illness and escaping into a virtual imaginative world of memories and future worlds. Pain and imagination fused, allowing deterritorialization from the properties of physical confinement and reterritorialization in a world outside the static state of being bedridden. The window represented the conditions of possibility for living outside suffering.

The specificities of each story and photo narration highlighted how we individually shaped our world from inside and outside. The way illness differentiated our subjectivities, exposed us to the complexities of negotiating spaces and places whilst experiencing physical pain and suffering. Space and the place of the bed were

juxtaposed in terms of how the bed is to be used, but this inside space was for many a sanctuary from the power relations that dominated the spaces outside. The narrations also accounted for how specific spaces and objects, such as the window, bed and sofa, facilitated ways to live with the various manifestations of suffering and constituted ways to live with ill bodies.

The material and discursive effects of ME, as with disability more generally, demonstrate powerful connections between space and identity (Moss and Dyck 2003; Moss and Teghtsoonian 2008:159). All bodies are entwined within particular kinds of materialities, the implication being that the power to facilitate self is further fractured when we experience severe illness. Space and places are, therefore, principally organised in terms of personal resilience and social judgement. The narrations highlight how those with severe ME remain hidden away in their bedrooms, underrepresented and misunderstood, to the extent that the illness physically traps those affected in states of silence and stillness. Through discourse we are invited to cross the borders of the severely ill, not to negate their presence but to marvel at the stamina it takes to manage a life that is depleted of energy, at the same time as producing a poetics of suffering.

Concluding Remarks

Implications

The contested illness ME/CFS has remained a capricious case for researchers within the medical, social psychological and social sciences. Medical research has interrogated the risk factors (Pheby and Saffron 2009), as well as the effects of treatment programmes and the management of stress to decrease the burden of severe ME/CFS (Cox and Findley 2000; Lattie, Antoni et al. 2013). Medical and social researchers have continued to explore issues associated with uncertainty and controversy for ME sufferers and/or medical professionals and ask ‘what is it like to have ME?’ (Cooper 1997; Guise, Widdicombe et al. 2007). Whilst these approaches have begun to highlight the issues associated with ME/CFS, there has been little or no specific reference to those who experience severe symptoms over a long period of time. This failure exacerbates the lack of understanding within medical and social research and makes it harder for both scholars and laypersons to comprehend the full extent of the processes and practices that constitute a way to survive with a severe illness of this nature.

This study attends to research questions similar to those found in other studies (as mentioned in chapter 1), but goes further to incorporate the long term issues of living with a severe chronic illness. The study also departs from previous research in the following ways: Firstly, participants had been formally diagnosed with ME and/or CFS and experience/d ‘severe’ symptoms. Secondly, the method of investigation was primarily through life stories, which revealed the processes and practices that underpin the negotiations of their illness experience. Thirdly, photo-elicited-diaries provided another layer of meaning to daily life with ME. Fourthly, narrative and critical discourse analyses exposed the significance of agency in terms of language, navigating spaces and representing life with severe illness.

Previous medical and social research has attended to the issues of living with the contested label and unpredictable symptoms of ME/CFS (Carruthers, Kain et al. 2003). However, this study’s research questions have offered an opportunity to go further by combining practices and processes of doing and being chronic ill, to describe the profound meanings ascribed to living with the medical, social and personal uncertainties associated with a diagnosis of this nature, along with the physical instability of symptoms which impact on daily life and challenge familial, social and relational

practices. The narrators described isolation from their social worlds and the difficulties configuring and reconfiguring their social and physical spaces. The stories, in answer to the research questions, revealed the paradox of embodying illness while performing healthy/unhealthy identities and the multiple ways in which the narrators were rendered immobile and mobile, restricted and unrestricted, confined and unconfined, believed and disbelieved.

By employing a combination of critical discourse and narrative analyses the implications of 'doing' illness emerged. In terms of both epistemological and ontological standpoints, I explored how individuals constructed knowledge about what it means to become diagnosed with a contested illness, as well as the implications of 'being' physically and emotionally affected by severe illness. My analysis responds to the overarching question and the subsequent in-depth questions by working to reveal how doing illness emerged in relation to the problematic conditions of becoming severely ill, finding a diagnosis, negotiating suffering and resilience, public and private care, restrictions and freedom, and the relational impact on social identities. My findings in response to the research questions therefore reveal how a subject with severe illness plugs in and out of their social worlds and continues to demonstrate agency in the face of the physical barriers of ME.

Previous post-structural perspectives on women's accounts of ME and other chronic illnesses have attended to the relationship between corporeal space and embodied categories (Moss and Dyck 2000; Karfakis 2013), highlighting the importance of reading bodies marked with ME (Moss and Teghtsoonian 2008:158). These approaches suggest a need to examine how discourse and materiality constitute illness (Moss and Teghtsoonian 2008:19). Moss and Dyck (2003:168) have championed a radical body politics, to unsettle the dualisms that are prevalent in terms of discourse and materiality, which contributes to the ways in which body, identity and space are related to corporeal space and the embodied aspects of suffering and survival. My study draws attention to these approaches and goes further with the research question that was aimed at exploring the deeper aspects of living with a severe chronic illness. This study echoes the use of narrative in other studies to offer deeper understanding of the naming of a disability/chronic illness (Williams 1996:1194), and acknowledges feminists writing on disability who suggest that it is through dialogue that we see the personal and political struggles that provide ways to understand broken bodies (Shildrick and Price 1998:246). The use of CDA highlighted how language marginalises those with the illness, in terms

of the continuous contestation over naming, as well as the lack of words available to describe the extent of suffering.

My research focused on the social and physical impact of 'severe' ME and highlighted the processes and practices of moving between healthy/unhealthy identities and fulfilling social roles, such as the sick role. This is a departure from previous approaches to ME that focused on the discursive issues of uncertain labels and debates on whether the illness occurs within the mind or body. As highlighted in Chapter One, psychological research tends to focus on fatigue based symptoms, whereas social psychological research looks at social stigma. These studies tend to draw on socio-historical links and amplify the connections to neurasthenia and hysteria. The study has been able to chart the disappearance of the term ME as a standalone medical diagnosis. Confusingly, different definitions continue to emerge and co-exist, for example current government recommendations use the term CFS/ME, while many of those within the study used the term ME. Additionally, in most cases these definitions omit the severely ill. With limited discourses existing on the severest symptoms of this contested chronic illness, desolation is intensified when the media and popular discourse suggest that the illness is simply about being 'tired' and/or it is 'all in the mind'.

The research revealed ME and/or CFS as a nomadic illness as it continually moves between disciplines, as it is named and renamed, amplifying the contestation and ignoring the challenges of severe illness. This builds on the arguments for a call to rethink the sub-discipline of medical sociology as sociology of disability (Thomas 2012). Moreover, the thesis demonstrates a need for researchers interested in the sociology of chronic illness and the emotional effects of suffering to account for the processes that constitute the practices towards searching and living with a diagnosis of the mind (Brown 1995) and/or the body (Nettleton 2013:27). There is also a need to highlight a strategy for transforming the medically defined view of disability, not only through the social mode of disability, but also through social change which empowers those who live with impairments.

Although these issues remain, the aims were to attend to the research questions on living with an illness that is surrounded in contestation and can be experienced as a severe chronic illness. The narrators in this study focused on how they configured and reconfigured the contested and severe aspects of ME. In this way, the contested rhetoric and cultural disbelief became more profound as the stories revealed the intensity of the

search for a diagnosis and the struggle to manage a severe illness. Coping regimes featured as a means to intensify acts of self-surveillance to regulate ill bodies and provide ways to survive with a long term illness. The findings resonate with other interdisciplinary approaches, which have also established how it was possible to live with a chronic illness of this nature (Moss and Dyck 2003). The narrators who were severely affected as children experienced difficulties in constituting identities from childhood to adulthood whilst living with ME, whereas, those diagnosed as adults had to reconfigure previously formed social identities, often whilst living with severe symptoms of ME. These subject positions demonstrated how the sick role was not passive, but signified a need to override pain, to manage and mask, to hide their frailties in order to perform social roles.

This project has been concerned with how the subjective qualities of severe illness are socio-culturally storied and how the complex signs of illness are understood through discursive and social practices. These practices consist of the intra-corporeal and social relations of self and other that underpin how it is possible to recognise and attend to the physically embodied and subjective embedded acts of surviving with severe illness. Importantly, it includes the relations between physical bodies, spaces and places occupied in the material world. By attending to the research questions, this project has opened up how this chronic illness has been positioned as 'contested' and 'severe' and has been interpreted within discursive, corporeal and material fields. Attention has been given to the power relations that connect knowledge and desire. The life stories and PEDs produced acts of story-telling that positioned subjective experiences of ME alongside a crisis of formal identities, which required the reconfiguration of the self.

These life stories in response to the sub-question on the dilemmas associated with living with ME, described the confinement and the hope of freedom, in negotiating inside and outside spaces. These distinctions were markedly different depending on 'how' and 'when' the narrators were diagnosed with ME and/or CFS and whether they had early access to medical understanding. The variations in experience of severe illness are conditioned by the socio-historical context. Equally, the function of discourse is shaped by linguistic structures that connect space to time and memory and are consistently bound by both internal and external voices, which actuate material bodies in terms of the contextual and relational aspects of life stories. It is, therefore, important to link narrative theory to how storytelling positions a self through memory and events (Bruner 1986), but also how the narrative performance constitutes not simply storytelling

through reflections and past experiences, but sets out particular truths and operates emotive and imaginative modes that engage the listener (Riessman 2008). The analyses detailed the challenges, conflicts and personal negotiations that underpin struggles of 'doing' illness whilst 'being' severely ill. The simultaneous need to search for unhealthy identities (sick roles) and work towards healthy identities was heterogeneously managed whilst moving in and out of the social spaces of home/hospital.

By adopting a transdisciplinary approach I was able to narrow the research questions by drawing on both Foucault's and Butler's notion of performativity, which explores how the body is continually socially constituted. By using Foucault and incorporating CDA it was possible to identify how the narrators relate to the disciplinary systems that control through systems of power and knowledge, managing identities and possibly causing a crisis of subjectivity. Foucault also offers a way to see how plays of domination govern social spatiality, especially for those bedridden for long periods. The research question on depth of meaning to the everyday experiences of surviving with ME were more fully examined by incorporating Deleuze and Guattari's concepts that bring together body and self, I was able to recognise the subject within the networks that are born of discourse and desire, as the disruptive aspects of severe illness cause a need to *plug in and out* of our social networks, while the *masquerade* allows us to present healthy identities on the return. Applying my reading of Deleuze and Guattari's notion of the body without organs *BwO* to these stories, which document the process of becomings, demonstrates how the suffering of long-term illness can affect the desire to 'be'. In this way, the interest in the body/self - offers a means to account for the productions of 'doing', as the need to find ways of 'being' severely ill often falls outside the boundaries of normative behaviour.

The research questions facilitated a means for examining the life stories to explore particular detailed events and contingencies over a life span, which revealed the process of diagnosis, survival, resilience and, for some, restitution through discursive processes and social practices. Furthermore, the PEDs offered a means to elaborate on the cultural practices involved in living with a severe contested illness, as well as what it means to have an illness which is not visible but causes considerable pain and weakness. According to Bruner (2004), such narratives can be viewed not only as storied documents, but also as artworks or imitations of life, which creatively frame individual experiences, and as unique resources that manifest particular ways to story a self through our interactions with the world, self and others. As Riessman (2008:8) suggests,

stories are a unique way to process our different accounts of ‘who am I’ and ‘how’ social identities are uniquely constituted. The act of storytelling is not merely a way to produce meaning, but offers a way to reveal the struggles involved in these productions.

Research Limitations

This thesis acknowledges that the processes of constructing severe aspects of ME and/or CFS may vary substantially across, gender, sexuality, ethnicity, age and class, and for those who suffer different rates of disability. For example, the interactions with illness *per se* and the varied strategies for dealing with long term illness may operate differently depending on cultural demographics and the journey to becoming ill. Equally, this study has privileged those who have had been formally diagnosed with ME and/or CFS and therefore does not represent those who are in the process of finding, or are unable to find, a diagnosis for their severe illness experience. The cohort was gleaned mostly from one medical clinic and confined to two geographic areas. Subsequently, making generalisations about the diagnosis and experience of living with this severe illness needs to be approached with some caution.

Future Research

The study has identified the value of narrative in understanding the creative practices involved in living with a ‘contested’ and ‘severe’ illness. The use of narrative theory and narrative and critical discourse analyses provided tools to understand what it means to dialogue a life affected by contested severe illness. These theoretical and practical devices proved useful as a means to focus on the struggles and multiplicities of constituting healthy and unhealthy identities, whilst negotiating the subjective aspects of suffering and surviving with severe illness. This approach could, therefore, be used as means to substantiate further research into this field. As was noted in the study, the process of interviewing participants on two separate occasions for the life story and the PED narratives, provided additional insight into the capricious nature of ME. It is anticipated, therefore, that a longitudinal study on these nine cases, which took into account the changing nature of the illness over time, could offer additional insights into the continued productions of living with or recovering from severe symptoms of ME.

The combined life story and PED narrative methodology facilitated a breadth and depth of exploration into the subjective experiences of severe illness. This approach was able to overcome some of the problems faced by other studies that were unable to reach those who live with the most severe manifestations of illness, as well as offering a means for the narrators to both verbally and visually express their life experiences and everyday practices. The life stories demonstrated the importance of accounting for experiences from childhood to adulthood, if we are to understand long term severe illness. Furthermore, the PEDs allowed a view into the often hidden world of suffering and recovery. These combined methods could, therefore, be an important means for medical and social research to gain better understanding into severe illnesses. Rather than merely advocating for intervention and rehabilitation, this thesis supports Shakespeare's (2013:216) argument that there is a greater need to attend to what it means to live a life that is impaired, to listen to the uncomfortable tales of pain and suffering as these are part of [all] our biographies. Therefore, more medical and social research needs to include the voices of those who live with the severe impairments of chronic illnesses, as sharing stories can open up different ways of coping. Bury's (1982) ground-breaking work on the biographical disruption of chronic illnesses has been a cornerstone of understanding how narrators configure and reconfigure chronic illness. This thesis argues for an understanding not only of the contested and disruptive nature of the illness, but also the continuous flux, instability and debilitating affects the symptoms have on the individual.

Recommendations

The prevailing belief that ME and/or CFS is based on 'feeling tired' needs to be challenged and more attention is desperately needed into how it is possible that an illness can develop with such severity. Since ME as a diagnostic category emerged from the studies into the virus of poliomyelitis, there have been numerous changes into defining and understanding this chronic illness. A plethora of researchers have consistently sought to account for the aetiological basis of this illness and the lack of a cause has produced a focus on coping strategies. Rather than building a depth of knowledge the focus has been on defining this illness. This means that an understanding of the severe aspects of this illness is significantly limited and that those who live with severe ME are susceptible to further suffering. The experiences of those with severe and very severe ME remain under-researched, yet their experiences could provide a rich source for understanding a life with severe illness.

Recommendations arising from this thesis are:

- Although it has made steps towards disability inclusivity, the social model of disability has yet to build recognition for what it means to live with impairments, specifically, chronic illnesses. Disability policies and research mandates should include the missing voices of the severely affected.
- Participants in the study expressed surprise at what their photos revealed, stating that the process gave them a greater understanding of their own illness. Therefore, the combination of life stories and PEDs may serve both research and as a therapeutic aid for the chronically ill.
- The closure in 2012 of London CFS clinic and the ME ward in England and the lack of intensive therapeutic programmes for the severely ill, that was integral to five of the participants improvement is no longer available. Those with severe manifestations of the illness remain inaccessible for research due to ethics and the basic NICE treatment which requires attendance at an out-patient clinic or telephone contact. NICE needs to uphold its commitment to the severely ill, as a matter of urgency, as ongoing debilitation leads to devastation for many.
- More funding needs to be channeled into research within bio-medicine to find a cause and possible treatment for ME/CFS, so that attention during the early onset of symptoms might prevent the illness developing into severe ME.
- Current treatment regimes, such as CBT and GET are not intensive enough for the severely affected who require long-term specialist care. The present approach needs to be challenged as patients with severe ME are unable to adhere to outpatients programmes recommended by NICE (2007).

Contribution to Knowledge

My research substantiates the importance of understanding how uncertainty in the categorisation of illness impacts upon the biographies of those diagnosed. The research demonstrates originality in subject, theory and method of investigation. No previous social or medical research has adopted a trans-disciplinary perspective to life with severe symptoms of ME. By incorporating a kaleidoscopic approach to conceptualise the discursive, material and relational aspects of a life with long term illness, I have

formed a rational argument for how the present medical and social discourse of uncertainty affects those who live with ME and, by combining concepts, additional interpretations have been reached. In addition, the inclusion of photo-diaries offered a means of combining narrative and visual accounts of the everyday experiences of illness. This provided a further rich layer of meaning by producing new and important insights into how a contested illness is both constituted and experienced. Although there have been previous narrative inquiries into ME, no previous life histories and/or visual accounts of ME existed. Nor have previous studies on ME been completed by a disabled researcher living with the severe symptoms of ME which, I argue, affords further insight. This project has been able to combine a macro story of the categorisation of ME with a micro story of its effects on those who become diagnosed and live with a diagnosis. Therefore, my research goes some way to re-contextualise the slogan the “personal is always political”.

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Appendices

Appendix I: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocol (Carruthers et al. 2003)

DIAGNOSTIC PROTOCOL

Although it is unlikely that a single disease model will account for every case of ME/CFS, there are common clusters of symptoms that allow a clinical diagnosis.

Clinical Working Case Definition of ME/CFS

A patient with ME/CFS will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations; and adhere to item 7.

1. *Fatigue*: The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.
2. *Post-Exertional Malaise and/or Fatigue*: There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period, usually 24 hours or longer.
3. *Sleep Dysfunction**: There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.
4. *Pain**: There is a significant degree of myalgia. Pain can be experienced in the muscles and/or joints, and is often widespread and migratory in nature. Often there are significant headaches of new type, pattern or severity.
5. *Neurological/Cognitive Manifestations*: Two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances. e.g., spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload phenomena: cognitive, sensory .e.g., photophobia and hypersensitivity to noise and/or emotional overload, which may lead to crash.2 periods and/or anxiety.
6. *At Least One Symptom from Two of the Following Categories*:
 - a) *Autonomic Manifestations*: orthostatic intolerance neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea.
 - b) *Neuroendocrine Manifestations*: loss of thermostatic stability, subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change, anorexia or abnormal appetite; loss of adaptability and worsening of symptoms with stress.
 - c) *Immune Manifestations*: tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.
7. The illness persists for at least six months. It usually has a distinct onset**, although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

To be included, the symptoms must have begun or have been significantly altered after the onset of this illness. It is unlikely that a patient will suffer from all symptoms in criteria 5 and 6. The disturbances tend to form symptom clusters that may fluctuate and change over time. Children often have numerous prominent symptoms but their order of severity tends to vary from day to day. *There are a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except ME/CFS. A diagnosis of ME/CFS can be entertained when this group has an infectious illness type onset. **Some patients have been unhealthy for other reasons prior to the onset of ME/CFS and lack detectable triggers at onset and/or have more gradual or insidious onset.

Exclusions: Exclude active disease processes that explain most of the major symptoms of fatigue, sleep disturbance, pain, and cognitive dysfunction. It is essential to exclude certain diseases, which would be tragic to miss: Addison's disease, Cushing's Syndrome, hypothyroidism, hyperthyroidism, iron deficiency, other treatable forms of anemia, iron overload syndrome, diabetes mellitus, and cancer. It is also essential to exclude treatable sleep disorders such as upper airway resistance syndrome and obstructive or central sleep apnea; rheumatological disorders such as rheumatoid arthritis, lupus, polymyositis and polymyalgia rheumatica; immune disorders such as AIDS; neurological disorders such as multiple sclerosis (MS), Parkinsonism, myasthenia gravis and B12 deficiency; infectious diseases such as tuberculosis, chronic hepatitis, Lyme disease, etc.; primary psychiatric disorders and substance abuse. *Exclusion of other diagnoses, which cannot be reasonably excluded by the patient's history and physical examination, is achieved by laboratory testing and imaging. If a potentially confounding medical condition is under control, then the diagnosis of ME/CFS can be entertained if patients meet the criteria otherwise.*

Co-Morbid Entities: Fibromyalgia Syndrome (FMS), Myofascial Pain Syndrome (MPS), Temporomandibular Joint Syndrome (TMJ), Irritable Bowel Syndrome (IBS), Interstitial Cystitis, Irritable Bladder Syndrome, Raynaud's Phenomenon, Prolapsed Mitral Valve, Depression, Migraine, Allergies, Multiple Chemical Sensitivities (MCS), Hashimoto's thyroiditis, Sicca Syndrome, etc. *Such co-morbid entities may occur in the setting of ME/CFS. Others such as IBS may precede the development of ME/CFS by many years, but then become associated with it. The same holds true for migraines and depression. Their association is thus looser than between the symptoms within the syndrome. ME/CFS and FMS often closely connect and should be considered to be overlap syndromes.*

Idiopathic Chronic Fatigue: If the patient has unexplained prolonged fatigue (6 months or more) but has insufficient symptoms to meet the criteria for ME/CFS, it should be classified as idiopathic chronic fatigue.

General Considerations in Applying the Clinical Case Definition to the Individual Patient

1. *Assess Patients Total Illness:* The diagnosis of ME/CFS is not arrived at by simply fitting a patient to a template but rather by observing and obtaining a complete description of their symptoms and interactions, as well as the total illness burden of the patient.
2. *Variability and Coherence of Symptoms:* Patients are expected to exhibit symptoms from within the symptom group as indicated, however a given patient will suffer from a cluster of symptoms often unique to him/her. The widely distributed symptoms are connected as a coherent entity through the temporal and causal relationships revealed in the history. If this coherence of symptoms is absent, the diagnosis is in doubt.
3. *Severity of Symptoms:* A symptom has significant severity if it substantially impacts (approximately a 50% reduction) on the patient's life experience and activities. In assessing severity and impact, compare the patient's activity level to their premorbid activity level. Establishing the severity score of symptoms is important in the diagnostic procedure (46,45), and should be repeated periodically. While this numerical scale has been developed as a tool to assist the clinician and position the patient within the overall spectrum of ME/CFS severity, the severity and impact of symptoms should be confirmed by direct clinical dialogue between physician and patient over time.
4. *Symptom Severity Hierarchy:* Periodic ranking of symptom severity should be part of the ongoing evaluation of the clinical course. This hierarchy of symptom severity will vary from

patient to patient and for an individual patient over time. Thus, although fatigue and post-exertional malaise are universal symptoms of ME/CFS, they may not be the most severe symptoms in the individual case, where headaches, neurocognitive difficulties, pain and sleep disturbances can dominate, at least temporarily. Establishing symptom severity and hierarchy helps orient the treatment program.

5. *Separate Secondary Symptoms and Aggravators*: It is important to try to separate the primary features of the syndrome from those that are secondary to having a poorly understood chronic illness in our society such as secondary stress, anxiety and depression and inactivity. It is also important to consider symptom interaction and dynamics, and distinguish the effects of aggravators and triggers.

Discussion of Major Features of ME/CFS

Fatigue

The fatigue of ME/CFS comes in many ‘flavours’ (47). Patients learn to recognize the difference between ‘normal’ and ‘ME/CFS’ fatigue by its qualitative flavour, its temporal characteristics and its correlation with other events and activities. The patient must have a marked degree of unexplained, persistent or recurrent fatigue. The fatigue should be severe enough to substantially reduce the patient’s activity level, usually by approximately 50%. When considering the severity of the fatigue, it is important to compare the patient’s activity level to their premorbid activity level. For example, a former world class athlete could have a substantially reduced activity level and still exceed the norms for sedentary persons. Some patients may be able to do some work, but in order to do that they have had to eliminate or severely reduce other aspects of their life activities. Such interactive effects should be considered in the assessment of whether activity reduction is substantial.

Evidence of cognitive fatiguing should be sought in the history and may be evident during the clinical interview. Over the duration of the interview the patient’s responses may become slower and less coherent. The patient may begin to have difficulty with choosing the correct words, recalling information, or become confused. Occasionally asking more than one question at a time may make the fatiguing more evident. However these changes may be quite subtle, as patients have often learned to compensate for cognitive fatigue with hyper-concentration, and have often developed strategies for taking cognitive micro-rests such as changing the subject, taking postural breaks, reducing sensory stimulation, etc. They may be quite unaware of these strategies.

Post-Exertional Malaise and/or Fatigue

The malaise that follows exertion is difficult to describe but is often reported to be similar to the generalized pain, discomfort and fatigue associated with the acute phase of influenza. Delayed malaise and fatigue may be associated with signs of immune activation: sore throat, lymph glandular tenderness and/or swelling, general malaise, increased pain or cognitive fog. Fatigue immediately following activity may also be associated with these signs of immune activation. Patients who develop

ME/CFS often lose the natural antidepressant effect of exercise, feeling worse after exercise rather than better. Patients may have a drop in body temperature with exercise. Thus fatigue is correlated with other symptoms, often in a sequence that is unique to each patient. After relatively normal physical or intellectual exertion, a patient may take an inordinate amount of time to regain her/his pre-exertion level of function and competence. For example, a patient who has bought a few groceries may be too exhausted to unpack them until the next day. The reactive fatigue of post-exertional malaise or lack of endurance usually lasts 24 hours or more and is often associated with impairment of cognitive functions. There is often delayed reactivity following exertion, with the onset the next day, or even later. However, duration of symptoms also varies with the context. For example, patients who have already modified their activities to better coincide with the activity level they can handle without becoming overly fatigued will be expected to have a shorter recovery period than those who do not pace themselves adequately.

Sleep Dysfunction

Sleep and other diurnal rhythm disturbances may include early, middle or late insomnia, with reversed or irregularly irregular insomnia, hypersomnia, abnormal diurnal variation of energy levels, including reversed or chaotic diurnal rest and sleep rhythms. This results in lack of tolerance for shift work/activity or time zone shifts when travelling. Loss of the deeper phases of sleep is especially characteristic, with frequent awakenings, and loss of restorative feelings in the morning. Restless leg syndrome and periodic limb movement disorder often accompany sleep disturbance. A very small percentage of ME/CFS patients do not have sleep dysfunction, but do not fit any other disease criteria.

Sleep Study: It is important to rule out treatable sleep disorders such as upper airway resistance syndrome, obstructive and central sleepapnea and restless leg syndrome. Indications: the patient wakes up out of breath, or there is great disturbance of the bed clothes, or a sleep partner indicates that the patient snores and/or appears to stop breathing at times and/or has significant movement of her/his legs while sleeping. If poor sleep is a troublesome symptom, which does not improve with medication and sleep hygiene, it may be appropriate to have the patient assessed at a sleep clinic.

Pain

Pain is often generalized and nonanatomical, i.e., not confined to any expected structural or nerve root distribution. The pain occurs in unexpected places at unexpected times. There are pains of many qualities: sharp, shooting, burning and aching. Many patients have significant new onset headaches of many types, including tension and pressure headaches and migraines. There is often generalized myalgia and excessive widespread tenderness or pain that is usually perceived to originate in the muscles but is not limited to the classical FMS tender points. Patients have a lowered pain threshold or chronic, widespread allodynia. (48) with approximately 75% of ME/CFS patients exhibiting positive FMS tender points (49). Pain may also spread from pressure on myofascial trigger points (MTP). Arthralgia without joint swelling may be experienced but is not discriminatory for ME/CFS (45,47). A very small percentage of ME/CFS patients do not have appreciable pain, but do not fit any other disease criteria. ME/CFS should only be entertained as a diagnosis for this group when otherwise classical features follow an infectious illness, and where other diseases have been adequately ruled out.

Neurological/Cognitive Dysfunctions

The neurological/cognitive symptoms are more characteristically variable than constant and often have a distinct fatiguing component to them. Especially common are cognitive □fog□ or confusion, slowed information processing speed, trouble with word retrieval and speaking or intermittent dyslexia, trouble with writing, reading, and mathematics, and short-term memory consolidation. There may be ease of interference from concomitant cognitive and physical activities, and sensory stimulation. It is easy to lose track of things and/or many things are forgotten: names, numbers, sentences, conversations, appointments, ones own intentions and plans, where things are in the house, where one has left the car, whether one has brought the car, where one is and where one is going. The memory dysfunction tends to primarily affect short-term memory. There are selective deficits in memory processing arising against a background of relatively normal cognitive functioning in ME/CFS patients. They experience more difficulty in recalling information under conditions of greater semantic structure and contextual cues, the opposite of what is found in controls and patients with other sorts of CNS impairments. They also experience difficulty maintaining attention in situations that cause them to divide their efforts, e.g., between auditory and visual channels. *Perceptual Disturbances:* Less ability to make figure/ground distinctions, loss of depth perception or inability to focus vision and attention. One may lose portions of the visual field or one can only make sense of a small portion of it at a time. There are dimensional disturbances in timing which affect the ability to sequence actions and perceptions, and cope with complex and fast paced changes such as shift

work and jet lag. Spatial instability and disorientation come in many varieties, with gait tracking problems, loss of cognitive map and inaccurate body boundaries. e.g., one bumps into the side of the doorway on trying to go through it and/or walks off the sidewalk, where the ground feels unstable.

Motor Disturbances: Ataxia, muscle weakness and fasciculations, loss of balance and clumsiness commonly occur. There may be an inability to automatically 'attune' to the environment, as in accommodating footfall to irregular ground while walking and temporary loss of basic habituated motor programs such as walking, brushing one's teeth, making the bed and/or dialling a telephone. *Overload phenomena* affect sensory modalities where the patient may be hypersensitive to light, sound, vibration, speed, odors, and/or mixed sensory modalities. Patients may be unable to block out background noise sufficiently to focus on conversation. There is also cognitive/informational overload-inability to multi-task, and trouble making decisions. There is emotional overload from extraneous emotional fields that unduly disturb the patient. There is motor overload-patients may become clumsy as they fatigue, and stagger and stumble as they try to walk, are not able to keep a straight line, as well as showing generalized and local weakness, and need to slow down their movements. All of these overload disturbances may form symptom clusters characteristic of the individual patient such as dizziness, numbness, tinnitus, nausea, or shooting pain. These overload phenomena may precipitate a 'crash' where the patient experiences a temporary period of immobilizing physical and/or mental fatigue.

Autonomic Manifestations

Orthostatic intolerance is commonly seen in ME/CFS patients and includes:

- *Neurally mediated hypotension (NMH):* Involves disturbances in the autonomic regulation of blood pressure and pulse. There is a precipitous drop that would be greater than 20-25 mm of mercury of systolic blood pressure upon standing, or standing motionless, with significant accompanying symptoms including lightheadedness, dizziness, visual changes, sometimes syncope, and a slow response to verbal stimuli. The patient is weak and feels an urgency to lie down.
- *Postural orthostatic tachycardia syndrome (POTS):* Excessive rapidity in the action of the heart (either an increase of over 30 beats per minute or greater than 120 beats per minute during 10 minutes of standing); and a fall in blood pressure, occurring upon standing. Symptoms include lightheadedness, dizziness, nausea, fatigue, tremor, irregular breathing, headaches, visual changes and sweating. Syncope can but usually does not occur.
- *Delayed postural hypotension:* The drop in blood pressure occurs many minutes (usually ten or more) after the patient stands rather than upon standing.

Tilt Test: Further investigation by tilt test is indicated if there is a fall in blood pressure and/or excessive rapidity of heart beat upon standing, which improves when sitting or lying down. Patients often report that they experience dizziness, feeling light-headed or □woozy□ upon standing, or feeling faint when they stand up or are standing motionless such as in a store checkout line. Patients may exhibit pallor and mottling of the extremities. These historical symptoms and signs are sufficient for the initial diagnosis. As ME/CFS patients often have a delayed form of orthostatic intolerance, taking the blood pressure after standing may not be effective in diagnosis. Rather than having the patient stand for a period of time where there is a risk of him/her falling, we recommend using the tilt test where the patient is strapped down. The tilt test involves the patient lying horizontally on a table and then tilting the table upright to a 60°-70° angle for approximately 45 minutes during which time blood pressure and heart rate are monitored. It is recommended that orthostatic intolerance be confirmed by tilt testing prior to prescribing medication for it.

Palpitations with or without cardiac arrhythmias may be present. Further investigation by 24-Hour Holter Monitor may be indicated if a significant arrhythmia is suspected. Repetitively oscillating T-wave inversions and/or flat T-wave may be found. (Request to be

informed of this pattern as it may not be reported or subsumed under non-specific T-wave changes by the interpreter.)

Other common symptoms related to ANS disturbances include breathing dysregulation—holding the breath inappropriately, irregular breathing, exertional dyspnea; intestinal irregularities and hypersensitivity to pain-irritable bowel syndrome, diarrhea, constipation, alternating diarrhea and constipation, abdominal cramps; bloating, nausea and anorexia. Bladder dysfunction and pain sensitivity can manifest as urinary frequency, dysuria, nocturia, and pain over the bladder region.

Neuroendocrine Manifestations

Loss of thermostatic stability may be experienced as altered body temperature usually subnormal and/or marked diurnal fluctuation. Having patients take their temperature a number of times a day for a few days can confirm temperature fluctuation. It may be helpful to have patients note their activity prior to taking their temperature. Patients may have alternating feelings of hot or cold, sometimes in unusual distribution, e.g., feet are often cold, fingers may be hot, or the right side may feel hot while the left feels cold, or there may be localized feelings of heat and flushing. Many patients are intolerant of extremes in weather and experience worsening of symptoms. There are recurrent feeling of feverishness and sweating episodes. There is often a marked weight change a reduction in some patients with loss of appetite or anorexia and a weight gain in others and an appetite that is inappropriate to their activity level.

Dysfunction of the autonomic system and hypothalamic/pituitary/adrenal axis: bodymind crashing may lead to a general loss of adaptation to situations of overload. Excessive speed in the overloading situation or attempted response will aggravate these crashes. Anxiety states and panic attacks may also be part of the syndrome and coherent with the other symptoms. They may not be tied to environmental events that trigger them, or they may be secondary to the symptoms. When crashing, the patient becomes destabilized and disoriented, and thus is naturally frightened. Anxiety and panic may also appear without any external trigger. Patients with ME/CFS have worsening of their symptoms under increased stress, and with excess physical and mental activity. They also show slow recovery.

Immune Dysfunctions

Some but not all patients exhibit symptoms coming from immune system activation, which may or may not be in response to an appropriate stimulus. For many patients this type of symptom is prominent at the acute onset stage and then diminishes or becomes recurrent as the illness becomes chronic. There is often general malaise, flu like feelings of being □ill□ and feeling feverish. Tender lymphadenopathy in the cervical, axillary inguinal or other regions may be present. The patient may have a recurrent sore throat with or without faucial injection. Such clinical evidence of immune system activation may occur in the absence of demonstrable viral exposure and/or be associated with inappropriate events such as physical exercise and stress. New sensitivities to food, medications and/or various chemicals are common. Patients with an acute viral onset tend to show more immune dysfunction compared to those whose onset is gradual.

Positive Diagnosis Using Suggestive Signs

Faucial injection and crimson crescents may be seen in the tonsillar fossae of many patients but are not diagnostically specific. These red crescents are demarcated along the margins of both anterior pharyngeal pillars. They will assume a posterior position in the oropharynx in patients without tonsils. Oscillating or diminished pupillary accommodation responses with retention of reaction to light is also common. Cervical and axillary lymph adenopathy, often tender, may be felt. Positive fibromyalgia tender points and myofascial trigger points are common. Neurological dysfunction is often seen, including hypersensitivity to vibration sense, positive Romberg test and abnormal tandem gait. Simple mental status measures are often normal, but abnormal fatiguing on serial seven subtraction testing is common. Mutual aggravation when

tandem gait and serial sevens are done simultaneously, may be evident when the baseline serial sevens test and tandem gait are both normal. As more of these signs are elicited in the same patient, the diagnosis of ME/CFS is increasingly confirmed.

There are selective deficits in memory processing arising against a background of relatively normal cognitive functioning in ME/CFS patients. The results of neurocognitive testing will depend on the focus of the test as well as many variables including the test, the milieu, schedule, pacing and duration of the test. A well controlled study (50) showed patients significantly overestimated their memory (meta memory), their performance on recall tests significantly worsened as the context increased (e.g., recognition), they made more errors when rehearsal was prevented, and had delayed mental scanning as memory load increased. Neuropsychological testing is expensive and the cost is rarely covered by provincial health plans.

From 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols' Bruce M. Carruthers, MD, CM, FRCP(C), Anil Kumar Jain, BSc, MD, Kenny L. De Meirleir, MD, PhD, Daniel L. Peterson, MD, Nancy G. Klimas, MD, A. Martin Lerner, MD, PC, MACP, Alison C. Basted, MD, FRCP(C), Pierre Flor-Henry, MB, ChB, MD, Acad DPM, FRC, CSPQ, Pradip Joshi, BM, MD, FRCP(C), A. C. Peter Powles, MRACP, FRACP, FRCP(C), ABSM, Jeffrey A. Sherkey, MD, CCFP(C), Marjorie I. van de Sande, BEd, Grad Dip Ed, Journal of Chronic Fatigue Syndrome, Vol. 11, No. 3, 2003, pp. 7-36.

From <http://www.haworthpressinc.com/store/product.asp?sku=J092>, accessed 7 January, 2016.

Appendix II: The CDC Definition for Chronic Fatigue Syndrome (Fukuda et al. 1994)

Guidelines for the Evaluation and Study of CFS

A thorough medical history, physical examination, mental status examination, and laboratory tests must be conducted to identify underlying or contributing conditions that require treatment. Diagnosis or classification cannot be made without such an evaluation. Clinically evaluated, unexplained chronic fatigue cases can be classified as chronic fatigue syndrome if the patient meets both the following criteria:

1. Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (i.e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social, or personal activities.
2. The concurrent occurrence of four or more of the following symptoms:
 - Substantial impairment in short-term memory or concentration;
 - Sore throat;
 - Tender lymph nodes;
 - Muscle pain;
 - Multi-joint pain without swelling or redness;
 - Headaches of a new type, pattern, or severity;
 - Unrefreshing sleep; and
 - Post-exertional malaise lasting more than 24 hours.

These symptoms must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue.

Conditions that Exclude a Diagnosis of CFS

1. Any active medical condition that may explain the presence of chronic fatigue, such as untreated hypothyroidism, sleep apnea and narcolepsy, and iatrogenic conditions such as side effects of medication.
2. Some diagnosable illnesses may relapse or may not have completely resolved during treatment. If the persistence of such a condition could explain the presence of chronic fatigue, and if it cannot be clearly established that the original condition has completely resolved with treatment, then such patients should not be classified as having CFS. Examples of illnesses that can present such a picture include some types of malignancies and chronic cases of hepatitis B or C virus infection.
3. Any past or current diagnosis of a major depressive disorder with psychotic or melancholic features;
 - Bipolar affective disorders
 - Schizophrenia of any subtype
 - Delusional disorders of any subtype
 - Dementias of any subtype
 - Anorexia nervosa
 - Or bulimia nervosa
4. Alcohol or other substance abuse, occurring within 2 years of the onset of chronic fatigue and any time afterwards.

5. Severe obesity as defined by a body mass index [body mass index = weight in kilograms ÷ (height in meters)²] equal to or greater than 45. [Note: body mass index values vary considerably among different age groups and populations. No "normal" or "average" range of values can be suggested in a fashion that is meaningful. The range of 45 or greater was selected because it clearly falls within the range of severe obesity.] Any unexplained abnormality detected on examination or other testing that strongly suggests an exclusionary condition must be resolved before attempting further classification.

Conditions that do not exclude a Diagnosis of CFS

1. Any condition defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, including fibromyalgia, anxiety disorders, somatoform disorders, nonpsychotic or melancholic depression, neurasthenia, and multiple chemical sensitivity disorder.
2. Any condition under specific treatment sufficient to alleviate all symptoms related to that condition and for which the adequacy of treatment has been documented. Such conditions include hypothyroidism for which the adequacy of replacement hormone has been verified by normal thyroid-stimulating hormone levels, or asthma in which the adequacy of treatment has been determined by pulmonary function and other testing.
3. Any condition, such as Lyme disease or syphilis that was treated with definitive therapy before development of chronic symptoms.
4. Any isolated and unexplained physical examination finding, or laboratory or imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition. Such conditions include an elevated antinuclear antibody titer that is inadequate, without additional laboratory or clinical evidence, to strongly support a diagnosis of a discrete connective tissue disorder.

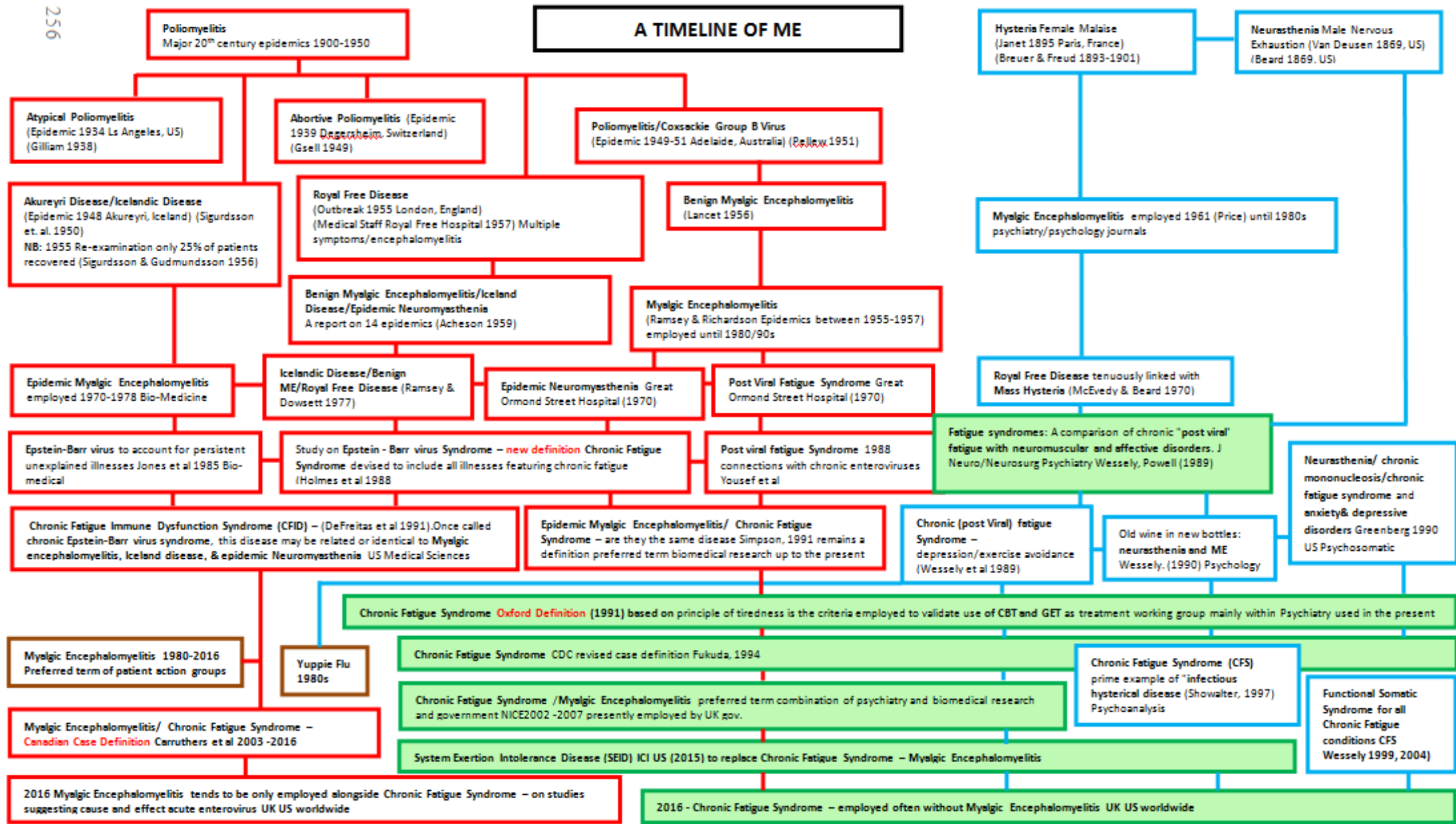
In clinical practice, no tests can be recommended for the specific purpose of diagnosing chronic fatigue syndrome. Tests should be directed toward confirming or excluding other possible clinical conditions. Examples of specific tests that do not confirm or exclude the diagnosis of chronic fatigue syndrome include serologic tests for Epstein-Barr virus, enteroviruses, retroviruses, human herpesvirus 6, and *Candida albicans*; tests of immunologic function, including cell population and function studies; and imaging studies, including magnetic resonance imaging scans and radionuclide scans (such as single-photon emission computed tomography and positron emission tomography).

From "The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study". Keiji Fukuda, M.D., M.P.H., Stephen E. Straus, M.D., Ian Hickie, M.D., F.R.A.N.Z.C.P., Michael C. Sharpe, M.R.C.P., M.R.C. Psych., James G. Dobbins, Ph.D., Anthony L. Komaroff, M.D., F.A.C.P. and the International Chronic Fatigue Syndrome Study Group. *Annals of Internal Medicine*, Vol. 121, December 15, 1994, pp. 953-959.

From the CDC's Website on CFS, "[CFS Revised Case Definition](#)", accessed 22 December 20

Appendix III – ME: Disease of 1,000 Names (Bell, 1988)

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Appendix IV: Definition of Disability Rates for CFS/ME (Cox & Findley 1998)

As stated, patients presented with a wide variety of ability and need. Each patient is categorised dependent on level of fatigue, daily activity level and general mobility into one of four grades, as devised by Diane Cox and Professor Findley (Cox & Findley 1998, Cox 1998).

- The patients in the **mild** category will be mobile and self-caring and able to manage light domestic and work tasks, with difficulty.
- The patients in the **moderate** category will have reduced mobility and be restricted in all activities of daily living, often having peaks and troughs of ability, dependent on degree of symptoms. Usually stopped work or limited capacity, requiring many rest periods.
- The patients in the **severe** category will be able to carry out minimal daily tasks, i.e. face washing, cleaning teeth, have severe cognitive difficulties and be wheelchair dependent for mobility. Often unable to leave the house except rarely.
- The patients in the **very severe** category will be unable to mobilise or carry out any daily tasks for themselves. They will be Bed-ridden and need full nursing care.

Patients in the **mild** to **moderate** categories, dependent on distance needed to travel, will generally be able to cope with outpatient management and therapy. Patients in the **severe** to **very severe** categories will generally require inpatient care.

From “Chronic Fatigue Syndrome: DIAGNOSTIC AND MANAGEMENT SERVICE – 2007-2009 *SERVICE SPECIFICATION*” CFS Team, Sahara A Ward, 2nd Floor, Queens Hospital, RM7 0AG, NHS Trust Hospital, Essex Neurosciences CFS Service, p. 3.

Appendix V: Consent Form

UNIVERSITY OF EAST LONDON

School of Social Sciences, Media and Cultural Studies,
Docklands Campus,
4–6 University Way,
London E16 2RD, UK.

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Researcher: Sharon Gallagher

Title of Research Project

Life history accounts of people diagnosed with ‘severe CFS/ME’

Aim of the Study

This study aims to redress the lack of research into the lives of people who have been diagnosed with severe CFS/ME, by examining the lives and experiences of four people who live in England. This will take into account their personal, social and physical environments. The Medical Research Council has recommended that future studies should aim to be more inclusive in relation to recruitment of participants. This study intends to fill the gap in research on severe CFS/ME by exploring whole life experiences of the severely affected.

Procedure

This study will use in-depth biographical interviews with people who have been diagnosed with 'severe' CFS/ME as a means of finding out about their life experiences.

Disposable cameras will be offered so that a photographic diary may be used to illustrate social, personal and physical space. These images (non-human) may be occasionally used to help clarify or expand upon specific points.

The number of interviews and their duration will be negotiated between you and the researcher. As a general guideline, an average interview will last 1–2 hours and in some instances, the researcher may ask to speak to you more than once.

Consent

If you give consent, the interview will be recorded on a digital voice recorder and these recordings will be copied on to discs and stored in a suitable archive at a later date. As the aim of this research is to demonstrate the life experiences of people with severe CFS/ME, it is hoped that you will give permission for any recordings and/if you chose photographs made during this project, to be used by the researcher for other educational purposes, including a PhD dissertation and related publications, presentations and exhibitions.

Transcripts of the interviews will be made available to you, if you wish, for perusal and to amend any biographical inaccuracies. The researcher will accredit your comments appropriately, in accordance with academic regulations. To protect your confidentiality your name will remain anonymous and the researcher will use a pseudonym for you.

Risks and Benefits of the Study

At no point will an interview be continued if you feel as though the process is too demanding and you need rest, or you need to discontinue and arrange another set time or you wish to stop your participation all together. You will not receive any

financial remuneration for participating in this project. Your participation will help to improve knowledge and understanding within academic and medical research and for the wider community.

Your Rights

You are not obliged to take part in this study and are free to discontinue your participation at any time or to refuse to speak on any topic during the interview. You also have the right to request personal confidentiality at any moment during recording and you may ask the researcher to stop recording at any time.

Do you have any questions about this form or your participation in this project?

Declaration of the Expert Participant:

I have read the above information, or it has been read to me. I have had the opportunity to ask any questions about it and am satisfied with the answers given.

Therefore (please delete as appropriate),

I consent/I do not consent voluntarily to participate as a subject in this study and to give an interview to be recorded on a digital recorder.

In consent/do not consent voluntarily to participate as a subject in this study by offering a photographic diary as evidence of (non-human) daily life.

I give/I do not give permission for any material arising from this interview to be used by the researcher for public purposes, including a PhD dissertation and related publications, presentations and exhibitions.

I give/do not give permission for photographs taken by me to be used by the researcher for public purposes, including a PhD dissertation and related publications, presentations and exhibitions. I confirm that these images will not record any human subject due to ethical regulations.

I give/do not give permission for the researcher to use my real name in this study.

I understand that I have the right to withdraw from the study at any time.

Signature of Participant _____

Signature of Researcher _____

Date:

Contact details

If you have any questions, concerns or comments about your participation in this study, you may contact me at any time on my current mobile phone (07866 946970) email address s.gallagher@uel.ac.uk

If you still have queries and concerns, you may contact -----,
the Secretary of the Research Ethics Committee of the University of East
London, at Stratford Campus, Romford Road, Stratford, London E15 4LZ.

Appendix VI: Life History Questions Guide (Atkinson 1998)

Generic list

- Why?
- How did that feel to you?
- What was that experience like for you?
- What happened next?
- Tell me more about that

Growing up

- What is your earliest memory? (*the leading question for all participants*)
- How would you describe your childhood?
- What were some of the things you did as a child?
- What was school like?
- How was your childhood different to your adolescence?
- Were you athletic?
- Did you join clubs, groups or organisations?
- What did you do for fun or entertainment?
- What was the most significant event as a teenager?
- Did you have any ambitions as a child or adolescent?

People in your life when you were growing up

- What special people have you known in your life?
- Who shared and influenced your life the most?
- Who are the heroes and heroines, guides and helpers in your life?
- Who most helped you develop your current understanding of yourself?
- What did you learn about yourself during these years?
- Did you achieve what you wanted or did your expectations change?
- What were your hopes and dreams when you entered adulthood?
- What events or experiences helped you understand and accept your adult responsibilities?

Family and Friends

- Have your relationships stayed the same throughout your childhood, teenage and adult years?
- How do you relate to your family, friends and colleagues? Has this changed at any time?

Work

- How did you end up in the type of profession you are in now?
- What did you do before?
- Why did you change your profession?
- Has your work been satisfying?
- What is important to you in your work?
- What comes the easiest in your work?
- What is most difficult about your work?
- Why do you do this work?

Not Working

- Why did you leave your profession? – Could you expand on this?
- How have you found it not working?
- What is important to you in your daily life?
- What are the easiest tasks you do in your daily life?
- What is the most difficult task to do in your daily life?
- What do you miss about being at work?

Now

- What do you do with your time?
- What, if anything, has changed for you?
- What transitions or turning points have you experienced?
- What changes would you say you have undergone since 20? 30? 40? 50?
- What were the crucial decisions in your life?
- What has been the most important learning experience in your life?
- What did it teach you?
- How have you overcome or learned from any difficulties in your life?
- What is your biggest worry?
- Have you had any struggles?
- Have these been physical, social and/or personal?

- What matters the most to you now?
- What were the most important things you have had to learn by yourself?
- How would you describe yourself at this point in your life?
- Is the way you see yourself now significantly different than it was in the past?
- How do you feel about your life now?

Closure Questions

- Is there anything that we've left out of your life story?
- Do you feel you have given a fair picture of yourself?
- What are your feelings about this interview and all that we have covered?

Atkinson, R., (1998), *The Life Story Interview – Qualitative Research Methods Series 44*, London, Sage Publications, pp. 41-53.

Leading questions not to use but to keep in mind for illness related questions

- How did you seek a diagnosis? How long did it take?
- How do you live with _____ME/CFS
- What attitudes do people have to your illness and do these affect how you live with ME/CFS?
- What ways do you manage living with ME/CFS?
- How does your illness experience affect your life?
- Can you tell me what ME/CFS is to you?
- How do the contested notions of 'malingers disease' and 'yuppie flu' make you feel?

(These questions were used in the pilot study and additional questions were included for possible use in the main study)

Appendix VII: Transcription Key

This is a self-devised transcription key based loosely on James Gee's 1991 social research on patient interviews.

(-) = Not quite 1 second pause

(3) = 3 second pause

(.) = Assumed sentence break

Fine (capital letter at the start of the word) = Emphasis on first letter

FINE (word in all capitals) = A laudable response

Italics = Rushed response

[] = Sic – Unsure of correct dialogue

Underline = Whisper

Appendix VIII: Pen Portraits of 9 Participants

Robert

Robert is 52. He was born in Essex, England and is the eldest of three siblings. Whilst attending school he enjoyed playing football and music. From the 1970s to 1980s Robert was employed within the financial sector as a stock broker. He is married with three grown up children and remains in the Essex area. In the early 1990s, Robert contracted pneumonia twice followed by mumps. Robert continued to work, eventually working intermittently. From this point symptoms of ME occurred; Robert was diagnosed with ME in 1998 as a private patient, paid for with medical cover that he had paid into at work for many years. Robert has remained symptomatic and has been unable to return to work. Although he has not been bedridden for extensive periods, he has experienced severe symptoms. At the time of the study he defined his disability as moderate, but had also been experiencing severe symptoms, which were chest pain, pain in his hands and legs and difficulty with concentration. The first interview with Robert on his life history was conducted in his home; the second on his PED was at the researcher's home.

Vivienne

Vivienne is 50. She was born in Essex and is the youngest of four siblings. She enjoyed drama and poetry at school, leaving at 16. Following a short form of post-secondary education she had a series of clerical placements in the 1970s. Vivienne was married during this period and later divorced and has remained living in the Essex area. By the 1980s, she worked from a secretary role in the financial sector to becoming one of the first female brokers. During this period, Vivienne contracted shingles whilst travelling which caused paralysis and internal ulcers. She recalls having vaccinations before travelling to the Far East and several months after her return, she 'completely crashed'. She was diagnosed with ME soon after as a private patient in an NHS hospital. Since her diagnosis, she has attempted to work and has continued to work on a very part-time basis. In 2005, at the same time as losing both her parents, Vivienne was also diagnosed and treated for cervical cancer. In terms of her ME Vivienne defines her disability as moderate, which manifests itself as reduced mobility and restricting all activities in daily life. Both interviews were conducted at her home.

Helen

Helen aged 28 was born in outer London and has a younger sister. Her parents divorced and she remained in the same area and lives with her partner, mother and sister. Since the age of 7 Helen has experienced severe headaches and sore throats was diagnosed as Glandular Fever. Helen managed to attend school, although due to health issues was unable to at the time, continue on into higher education. Helen continued to experience the above symptoms sporadically till at the age of 16 as a private patient, she was able to seek help and was diagnosed with ME. This private treatment was funded by her father, but due to his own disbelief about her illness, Helen was unable to continue visiting the consultant. Helen has since joined a college and studying art therapy, also being part of a local school, as an art teaching assistant as a special needs support. At her work place she refuses to disclose her condition as she is afraid they will not be employable as someone who has a disability to help with special disability needs. Although she would define herself as moderate, she is often challenged by her symptoms and has to stay confined to her bed until she feels able. Both interviews took place the researcher's private home.

Jean

Jean aged 52 was born in London and has an older brother. In her late teens, she began to dance competitively. From the 1970s she was employed as a secretary. On getting married and having two children, Jean stopped working and the family moved to a coastal area of Hampshire. When she was 30 and working as a special needs teaching assistant, she experienced glandular fever-like symptoms and a separate issue that was associated with a skin disorder, but felt unable to leave her employment due to work commitments. Later, after experiencing various symptoms including severe tiredness and swollen glands and was unable to work for four months. Jean wonders if there is a connection between vaccinations/contraception devices to contracting ME. Later she became a carer for her elderly mother and embarked on a degree course. After a short time, she became severely ill and her GP diagnosed ME in 2000. Jean deteriorated and suffered very severe symptoms which caused her to become bedridden for six and a half years. Her local council eventually funded a patient bed and she was sent to the ME clinic in London where she received various treatments for one year. At the time of the study she defined her condition as moderate. Both interviews were in the researcher's home. Her daughter Maria was included in the study.

Maria

Maria is 27 and was born in the outer London area. She enjoyed sport and academic studies at school, and during her childhood the family (Jean, mother) moved to a coastal Hampshire town. She describes her childhood as healthy and active and says that she was the stronger of the two children in the family competing in athletics and hockey club at school and playing netball nationally and internationally. She did a four-year teaching degree. At 19 she contracted glandular fever at university, but after a couple of weeks at home she returned to a full programme of teaching/training. She worked as a PE teacher for three years, was off work for nine months with glandular issues. Maria experienced a second bout of glandular fever and consulted a private neurologist who confirmed CFS but returned to part-time teaching for two years. A year and a half ago, she experienced an infection with viral-like symptoms and eventually relapsed. She became bedbound for approximately eight months. She applied to go to the ME clinic (funded by the PCT) and was there for three months following their therapeutic regime. After leaving she went to a nursing home where therapy was continued for a number of months. She currently describes her disability as moderate. Both her interviews were completed on the same day as her mother at the researcher's home.

Angela

Angela is 30 and was born in the outer London area and has younger sister. Angela has remained in the same area and lives alone. By the age of 12 she became ill with a viral infection where her illness symptoms were a sore throat and swollen glands. As her symptoms worsened her parents organised home schooling, but due to her concentration issues home teaching was stopped. By the age of 14 Angela had become bedridden and remained in this state for five years. She experienced severe issues with headaches, swollen glands and fatigue. Due to extensive issues with light, sound and eating, Angela was confined to a dark room. Medical authorities did intervene and force fed her by using a tube, this made her symptoms worse. A year later she was referred to Professor Findley's ME clinic where treatment was organised. Since this time, Angela has slowly progressed and, although she has to monitor her physical activities, she has improved enough to remain living alone with her cat. She has been in a long term relationship and has recently begun voluntary work. At the time of the study she defined her disability rate as moderate. Both interviews were completed at the researcher's home.

Geraldine

Geraldine is 27 and was born in coastal Hampshire town and remains in the same area. She is newly married and has a cat. At the time of the first interview she had just found out she was pregnant and on her second interview she brought the baby along. From the age of 7 she contracted Chicken Pox and other types of viral infections, which became progressively worse. She was diagnosed with ME at the age of 12. Her school had assumed she had school phobia, although they later became supportive. She was able to complete school GCSEs and college A Level exams through distance learning and is now doing an Open University degree course. Geraldine developed food intolerances at 19 and has remained symptomatic since. She attempted to work for a short while whilst studying but became too unwell to continue. Due to her illness she was unable to take part in sport and developed an interest in photography. She is now a semi-professional photographer and is also completing a degree. At the time of the study she defined herself as still experiencing severe symptoms. Both interviews took place in the researcher's home.

Paul

Paul is 34 and was born in a coastal Hampshire town where he remains today, living alone. Paul has a younger sister. Living an alternative lifestyle for many years, camping and living with different types of people, he enjoyed skateboarding, cycling and surfing. He was also a musician, playing music and part of a band. Later, taking up care work, he travelled internationally as a support worker and enjoyed the lifestyle. Due to spiritual experiences, his Christian faith grew and he stopped taking cannabis around this time, but continued with a busy lifestyle. At the age of 23 he contracted glandular fever. From 23-28 he contained his busy life style due to developing symptoms and was subsequently diagnosed with CFS. By the age of 34, symptoms became severe. He was bedridden for three years, sensitive to sound, light with tinnitus, fatigue and ulcers along with swollen glands and his weight dropped to only 6 stone. His local PCT funded a place to an ME clinic where it took ten months for him to learn to walk again. He returned home after a year. Paul continues a strict regime of pacing activities and follows a healthy diet. He describes previous disability rates as very severe and continues to oscillate between severe, mild and moderate at the time of the interview. The interview took place in the participant's home. After numerous attempts to make

contact for a second interview, I decided that it was unethical to continue perusing participation of the photo diaries.

Sharon

Sharon is 51 and was born in the East London area; she has a younger sister. Sharon experienced numerous bacterial and viral infections throughout her childhood and teenage years. During the 1970s, she worked as a secretary within the medical, financial and media sectors, also in the latter part living and working in Spain. In 1980 she experienced quinces, a throat bacterial infection, and by 1982 whilst working temporarily for a financial company contracted glandular fever. Whilst in the US around 1985, she again experienced severe swollen glands and fatigue-like symptoms and returned to the UK. By 1987, after the birth of her first son she began to experience severe problems with glands swelling, headaches, aching body and fatigue. Within a short while she became bedridden. She adapted to living with her illness and married in 1996 and had another son, along with two step-children. Her partner supports her and they live in London. She completed a degree in 2007 and presently, in the final stages of her PhD. She has experienced several very severe relapses intensifying both skeletal and muscular pain, fatigue, headaches and swollen glands. At the time of the study she would describe herself as experiencing very severe symptoms which she manages with painkillers and anti-inflammatory medications; at the time of the interview she was mostly bedridden. Self-interviewed in own home.