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**CHRONIC FATIGUE SYNDROME / MYALGIC ENCEPHALOPATHY:  
A KNOWLEDGE-BASED APPROACH TO AN  
INDETERMINATE ILLNESS**

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A thesis submitted in fulfilment of the requirements for the degree of Master of Arts in  
Anthropology, The University of Auckland, 2013.

## ABSTRACT

In this thesis I argue for a knowledge-based approach to CFS/ME, one that considers multiple types of knowledge (embodied, scientific, clinical, interpersonal) and asks what these can tell us about the lived experience of this condition. CFS/ME is a contested illness, meaning that science and medicine, the stewards of authoritative knowledge of illness, have yet to resolve it; its causes, course, and cure are presently uncertain. Drawing upon interviews and immune biomarker information from fifteen New Zealand sufferers I show how this condition plays out across multiple sites: the body, the mind, in daily life, and in people's social worlds. In each of these domains new forms of knowledge are made and mobilised. Though they highlight different aspects of the illness, these different forms of knowledge consistently point to the variability that pervades individuals' experiences of CFS/ME. I argue that this variability, which is often described as an obstacle to understanding CFS/ME, could instead be considered a substantive and significant part of this condition – one that engenders flexible coping practices and repositions sufferers as key knowledge producers. Living with CFS/ME reconfigures relationships between individuals, their bodies, their families and friends. Explanations are developed piecemeal, as my participants pull together bits of information they have learnt, lived, and been told. Normative ways of coping are challenged, and sometimes fail; alternatives are sought. Considering the types of knowledge that emerge in such instances not only elucidates the experiences of CFS/ME sufferers, but also elicits questions of credibility and expertise. These speak back to work on delegitimisation and stigma, highlighting the role of destabilised medico-scientific authorities in producing social uncertainty. The knowledge-based approach advanced here thus invites new ways of seeing CFS/ME alongside the existing medical perspectives that cannot fully account for it.

Keywords: Chronic Fatigue Syndrome; Myalgic Encephalopathy; contested illness; knowledge; embodiment; explanatory models; care; local worlds; New Zealand.

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## ABBREVIATIONS

ANZMES	Associated New Zealand Myalgic Encephalopathy Society
CFS/ME	Chronic Fatigue Syndrome / Myalgic Encephalopathy
CRP	C-Reactive Proteins
DBS	Dried Blood Spots
EBV Ab	Epstein Barr Virus Antibodies
IACFSME	International Association for Chronic Fatigue Syndrome/Myalgic Encephalopathy
IgG	Immunoglobulin G
mg/uL	Milligrams per microliter
PHO	Primary Healthcare Organiser
SD	Standard Deviation
U/ml	Units per Millilitre

# INTRODUCTION

In early April 2013 I made my first venture into the local Chronic Fatigue Syndrome, or Myalgic Encephalopathy (CFS/ME), community, attending a meeting of an Auckland support group. Seated in the group leader's lounge, the curtains drawn for those who were sensitive to the daylight, were about a dozen people. Most were suffering from CFS/ME; a couple were parents whose children were sick. It seemed to be a tight knit group, with everyone catching up on each other's health and families. The members were very informed, avidly discussing the latest research, and were similarly enthused by my project, full of suggestions and questions. The talk I gave rapidly turned into a group discussion, as everyone shared their stories and raised issues they thought I ought to address. My six months of reading had not equipped me for that meeting. Though people alluded to the delegitimation and stigma that the social science literature addresses, they also spoke of their turbulent bodily experiences, the frustrating lack of answers for CFS/ME, and the makeshift answers they had worked out on their own. The breadth of their concerns reflects both the uncertainties of CFS/ME, and the many struggles that sufferers face. Despite the enormity of these struggles, however, and the wealth of experience that is their result, very few studies have looked at this illness from the perspective of those who have it.

This thesis is my attempt to fill that gap. By exploring the different ways my participants explain and make sense of their illness, I argue that CFS/ME as lived is characterised by its indeterminacy. This indeterminacy plays out across individuals' bodies and webs of social relations; it provokes new ways of understanding ones' health and body, and also new techniques for coping with the illness. It allows new forms of knowledge to build up around this condition, and these coexist alongside normative biomedical perspectives due to the scientifically unresolved position of CFS/ME. From that very first meeting I was being told of the many ways in which people with CFS/ME come to know their illness.

## **An overview of CFS/ME**

CFS/ME affects approximately 20,000 New Zealanders (444 per 100,000)(ANZMES 2012; CDC 2012; Lorusso et al. 2009), predominantly adult women (66-75%) who fall ill in their early thirties and stay ill, on average, for three to nine years (Gallagher, Hamilton and White 2004, Jason 2011, IACFSME 2012, Prins, van der Meer, Bleijenberg 2006). The main symptom is extreme fatigue, which to obtain a diagnosis must last for six months or more and not be ameliorated by rest. Accompanying this fatigue is generally a host of non-specific symptoms, which may include muscle pain (myalgia), sleep problems, headaches, tender lymph nodes, impaired memory or concentration, psychological symptoms, and exhaustion after moderate



exertion (CDC 2012, Lorusso et al. 2009, Wessely, Hotopf, and Sharpe 1998). Because these symptoms are common amongst 'healthy' people, and because no biomarker has been identified, diagnosing CFS/ME is difficult (Buchwald, Pearlman, Kith, and Schmaling 1994; IACFS/ME 2012; Lorusso et al 2009). Even once a diagnosis has been granted, there is no cure for the illness itself, though some of its symptoms and underlying features (viral infection, allergies, neuroendocrine issues etc) can be treated (de Becker 2002). Though most people with CFS/ME improve over time, the majority never return to their pre-illness health, suggesting that the meaning of 'recovery' for CFS/ME requires some thought (Brown, Bell, and Bell 2012; Prins, van der Meer, and Bleijenberg 2006).

The majority of CFS/ME research is based in Europe or the United States. As with most of those countries, the dominant ideologies of health and illness in New Zealand are biomedical (Abel et al 2001)<sup>1</sup>. However, more work is needed to identify the local particularities of CFS/ME, both to open up locally specific aspects of this condition to analysis and comparison, and to develop appropriate responses. There have been three anthropological, New Zealand-based Master's theses of CFS/ME in the past twenty-five years (Bell 2012, Gibbons 2010, and Horne 1990), the first of which addresses identity change and illness narratives, and the other two delegitimation and stigma. A bioscience study aiming to find diagnostic biomarkers of CFS/ME is also presently underway (University of Otago 2013).

The CFS/ME community here is represented by the Associated New Zealand ME Society (ANZMES) which, founded in 1980, was the first such collective in the world. The society provides information and support for New Zealanders living with CFS/ME, though it is taking on an increasingly political role. Smaller support groups throughout the country provide a venue for sufferers to meet, talk, and share support and information. In Auckland, where this project took place, there are five such support groups, which this year merged into an incorporated society. Their motivation for doing so was primarily to enhance their financial potential with a view to hiring a support worker who could assist Aucklanders struggling with CFS/ME. Unfortunately an exploration of collective movements around CFS/ME and the political objectives of local sufferers are beyond the scope of this research, but I include this information to give a sense of the social context in which my informants are situated.

### *Nomenclature*

Courtney: Do you prefer ME?

Harry: ME.

Courtney: ME?

---

<sup>1</sup> Though a plurality of perspectives on health and illness coexist in New Zealand my informants subscribed to a predominantly biomedical outlook, as is typical of most New Zealanders (Dew 2000).

Harry: Yeah but even that doesn't feel like something you can communicate to people. Myalgic encephalomyelitis.

Courtney: Mm, bit of a mouthful.

Harry: You're gonna lose the conversation within the first 30 seconds [laughs] and CFS is like, nah that's not what it is. But it has helped me to understand how I got there.

Courtney: The CFS?

Harry: Yeah the- the term CFS but um it's not the right term for it. I don't know what we would call it. 'Crazy disease' sounds better to me [little laugh].

The above interchange, which kicked off my interview with Harry (35 years old, 10 years with CFS/ME), delineates some of the naming issues around CFS/ME as they appear to sufferers. The title 'CFS' has been in common use since 1988, but is somewhat misleading, over-emphasising fatigue at the expense of other symptoms (Jason et al 2001). My own informants felt that 'CFS' was too easily confused with everyday tiredness; as one participant put it, "think about the name 'Chronic Fatigue Syndrome'... literally, it means *on-going tiredness disease*". Proposed alternatives include Myalgic Encephalomyelitis, which indicates an underlying neurological impairment (encephalo-) that 'CFS' glosses over somewhat (Carruthers et al 2011). However, the suffix '-myelitis' signifies inflammation of the brain and spinal cord, which is not ubiquitous with CFS/ME (CFS/ME Working Group, as cited in Bell 2012). In response, Myalgic Encephalopathy has been proposed, referring more generally to neurological impairment (Jason et al 2001).

The Associated New Zealand Myalgic Encephalopathy Society presently uses this latter suggestion in their name, and refers to the illness as both ME/CFS, though they are presently re-evaluating their title (ANZMES pers. coms. 2013). Also working in New Zealand, Bell (2012) found that her participants almost exclusively used 'ME' when referring to their illness, but many explained that they would switch between titles according to the situation, which my own work corroborates. I asked participants at the outset of our interviews what term they would prefer, and most opted to use CFS. I use the joint term CFS/ME throughout this thesis to encompass the divergent perspectives on this issue.

### *A brief history*

CFS first appears in medical records in the mid-1980s, when practitioners attributed it to the Epstein-Barr virus (Wessely, Hotopf, and Sharpe 1998). Although in this sense a relatively new illness, the literature suggests it is derived from neurasthenia, a very similar condition with a longer medical history. American neurologist George Beard discovered neurasthenia in the late nineteenth century, and it quickly became a common malady of the upper classes (Cohn 1999, Lee and Ching Wong 1995, Wessely, Hotopf, and Sharpe 1998). Fatigue was the primary indicator of neurasthenia, accompanied by more than seventy possible physical and

psychosomatic symptoms (Lee and Ching Wong 1995). Beard blamed the strains of modern civilisation for its emergence, paralleling similar explanations sometimes offered today (Wessely, Hotopf, and Sharpe 1998). Attitudes toward neurasthenia evolved with the social norms of the time: it began as an ailment of the wealthy, described with economic metaphors and treated with rest, but gradually became associated with the lower classes and women, whereupon diagnoses declined. As the field of psychology emerged in the early 1900s explanations turned to mental problems or idleness, and treatment regimes prescribed gradual exercise and psychotherapy (Wessely, Hotopf, and Sharpe 1998). By the 1960s neurasthenia was considered a somatisation of anxiety and was consequently removed from the DSM-III, though it remains in use in some countries today, including China (Lee and Ching Wong 1995, Ware and Kleinman 1992, Wessely, Hotopf, and Sharpe 1998).

While neurasthenia diagnoses were waning in the first half of the twentieth century, several unusual 'epidemics' occurred (Cohn 1999). In 1934, two hundred Los Angeles hospital staff came down with extreme fatigue, and in some cases paralysis. In 1948/49 a similar outbreak was reported in Akureyi, Iceland, and in 1955 another in London. In each case hundreds of people were afflicted. The cases were uniformly framed with reference to hygiene and disease, echoing scientific concerns of the time, and when initial suspicions of polio were disproven, *The Lancet* coined the name 'benign myalgic encephalomyelitis' (Cohn 1999). The predecessors of CFS/ME thus have a history of debate and uncertainty that persists in contemporary debates around the illness. Tracing the history of this condition reveals shifting ideas over time, not just about CFS/ME or its precursors, but also notions of risk, work, social roles, and for whom it is acceptable to be fatigued. Popular and professional understandings of CFS/ME convey historically and locally specific cultural logics, which recreate the illness today as much as they have in the past.

#### *The natural sciences on CFS/ME*

The historical emphasis on psychological and hygienic causes of CFS/ME has given way to the molecular and systems-based explanations that characterise contemporary science (Ford and Lerner 1992, Kay 1996, Novas and Rose 2000, Rose 2007, Oyama 2000). Biomedical researchers have looked at the interaction of hormonal, endocrinological, immunological, neurological, and genetic features of CFS/ME in seeking to explain its development and character (for example, see Bains 2008, Dietert and Dietert 2008, Fletcher et al. 2010, Lorusso et al. 2009, Norheim, Jonsson, and Omdal 2011, Ortega and Zorzaneli 2010, ter Wolbeek et al. 2007). These studies describe an enormous range of results, often disagreeing, which I will touch on briefly to give a sense of the breadth of bioscientific work on this illness.

The expression of some 88 genes appears to be affected for CFS/ME sufferers, and the functioning of each has been used to group patients into seven “genomic subtypes” (Kerr et al 2008). The central nervous system is hypersensitive (Nijs et al 2012) and corresponding damage to the peripheral nervous system is suggested by autonomic disturbance (that is, disturbances to what are ordinarily automatic bodily processes – breathing, sweating, heart rate regulation etc.) (Newton et al 2011). These factors may affect sufferers’ sensitivity to exertion, which is further compounded by mitochondrial dysfunction, suggesting that insufficient energy is being produced at the cellular level (Myhill, Booth and McLaren-Howard 2009). Additionally CFS/ME sufferers appear to have poor cardiovascular function, evidenced by severely reduced red blood cell mass, lower plasma and total blood volume, and abnormal blood pressure variability (Frith et al 2012, Streeten and Bell 1998). Hormonal misregulation is also evident, as indicated by the consistently reduced cortisol<sup>2</sup> excretion of CFS/ME sufferers (Cleare 2003), and the significant overlap between CFS/ME and other endocrinological diseases (Baschetti 2003)<sup>3</sup>.

Studies on immunity and CFS/ME have produced an inconsistent array of results (Carter and Marshall 1995, ter Wolbeek et al. 2007, Wessely, Hotopf, and Sharpe 1998), to the extent that Lyall and colleagues (2003:88), in a comprehensive review of the field, stated “the CFS literature now contains papers with the results to support virtually any conclusion about the nature of the immunological abnormalities [of CFS/ME]”. A decade on the field continues to flourish, but with little consensus beyond the fact that the immune system plays a critical role in CFS/ME (Dietert and Dietert 2008). The most compelling recent findings suggest that this might be an autoimmune disease (Bradley, Ford and Bansal 2013, Brenu et al 2013, Fluge et al 2011, Morris et al 2013), meaning that the body misrecognises its own tissue for that of a pathogen, a foreign substance, and defends against it, damaging itself in the process.

The heterogeneity of immune function in CFS/ME has led some to suggest that a subtype approach, perhaps related to illness onset (i.e. viral trigger versus gradual onset)(Bansal et al 2012), might be necessary. The incommensurate results from the scholarship in this field may, in fact, be due to the neglect of subtype approaches, if patients with the same illness in distinctly different forms are being grouped as a single study sample (Lyall et al 2003). In all likelihood, various bodily systems collectively contribute to the fatigue and other symptoms that CFS/ME sufferers experience (Snell et al 2013). The complexity of CFS/ME at the molecular level exceeds even its symptomatic variability, and has brought about an awareness of the need for integrative work that can account for the interactions between different bodily systems, specific to the nature of individuals’ illness (Klimas et al 2012).

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<sup>2</sup> Cortisol is a hormone excreted as part of the stress response (Sapolsky 2004).

<sup>3</sup> CFS/ME has 42 shared characteristics with Addison’s disease, an endocrine disease (Baschetti 2003).

One area that is becoming less opaque is the psychology of CFS/ME. Depression and anxiety are more common amongst CFS/ME sufferers than other people, but the illness is increasingly recognised as a physical one with psychological components, rather than the other way around (Wessely, Hotopf, and Sharpe 1998). Some practitioners do still fail to recognise this, and several of my participants had received incorrect psychological diagnoses before having their physical suffering formally acknowledged. On the whole, however, research is repeatedly confirming the physiological basis of CFS/ME. The accompanying psychological illnesses may be cause, consequence, and/or comorbidity of CFS/ME, but they are only one part of a broader biological whole (Wessely, Hotopf, and Sharpe 1998). This complex biology filters into the lived experience of CFS/ME, which this thesis, and other social science work, has begun to examine.

#### *An anthropology of CFS/ME*

Anthropological studies of CFS/ME have primarily addressed the social challenges that face CFS/ME sufferers, looking particularly at delegitimation (Cohn 1999, Sachs 2001, Ware 1992, 1999), stigma (Åsbring and Närvänen 2002, Sachs 2001) and identity (Bell 2012, Clarke and James 2003, Sachs 2001). Ambiguity arises as a key issue from this literature. The inability to identify and label an origin of the condition, or even sometimes the condition itself, becomes for many people a source of confusion, frustration, and social exclusion. Ambiguous symptoms make a clear diagnosis impossible, which has social consequences since diagnosis is a key way in which patients legitimise their illness (Clarke and James 2003, Ware 1992). Legitimising an illness based on fatigue can be problematic in itself; as Sachs (2001) explains, fatigue lacks the “moral authority” of other diseases, and may thereby be socially rejected as a cause of debilitating illness. Sufferers may be perceived as lazy, or suspected of misleadingly exaggerating a common experience (‘tiredness’). Accordingly, they may be blamed in a way that sufferers of other illnesses would not. The commonness of CFS/ME symptoms often see it labelled as a “yuppie flu”. This title implies exaggeration and frailty, suggesting larger scale social tensions at play, such as the class prejudice mentioned in relation to neurasthenia (Cohn 1999). The difficulty of having mundane symptoms taken seriously was problematic for my participants as well, and I discuss this later as an impediment to social understanding of CFS/ME.

Cross-cultural research on CFS/ME, though scarce, suggests that comparative approaches to the illness might be especially illuminating. In one case, a vignette designed to tacitly represent someone with CFS/ME was given to groups of European Americans and South Asian immigrants to the USA (Karasz and McKinley 2007). 72% of the European Americans identified the vignette as a health problem, compared to only 31% of the South Asian group,

who often passed it off as 'just' tiredness or boredom (Karasz and McKinley 2007). Another study found that although the prevalence of CFS/ME was similar between England and Brazil, it was less likely to be clinically recognised in Brazil (Cho et al 2009)<sup>4</sup>. The one anthropological cross-cultural comparison I have found highlights the ways in which Americans with CFS/ME and Chinese with neurasthenia attribute and express their illnesses in relation to their local social worlds (Ware and Kleinman 1992). Despite differing symptoms, both groups used their illness as a medium for expressing discontent with broader cultural issues of their time (the former pressures regarding work and productivity, the latter the Chinese revolution). These studies indicate that cultural interpretations of CFS/ME vary significantly, warranting further anthropological study.

This thesis contributes an experience-near account to anthropological scholarship on CFS/ME, placing sufferers at the centre of analysis to examine the illness as lived. Doing so has allowed me to highlight the different forms of knowledge that circulate around CFS/ME on multiple planes (the body, the mind, the social world, the everyday), and to add to the CFS/ME literature in several ways. Being based in New Zealand this thesis adds to an incipient body of regionally specific work. I address aspects of CFS/ME that have received little other scholarly attention. The body, to give one example, is a central concern of medical anthropologists, and is likewise central to CFS/ME. Despite this only one study to date has addressed the lived body in CFS/ME (Lombaard and Mouton 2005). By exploring such under-assessed topics I have been able to elucidate some aspects of CFS/ME that have until now been overlooked, and raise new questions about the illness in doing so. My material has also prompted me to question my theoretical approaches and in some cases to take them in slightly different directions. For example, I had to rethink my use of Csordas' embodiment paradigm, since the mind-body dualities he seeks to rescind with embodiment turned out to be valuable to my participants. Additionally, this research speaks to the contested illness literature. Although I do not explicitly deal with the contestedness of CFS/ME, this pervades the experiences of my informants, and therefore also my findings. Credibility and uncertainty, both central to contested illnesses, emerge repeatedly as people try to make sense of CFS/ME with knowledge that is ordinarily not granted authority.

### **CFS/ME as a contested illness**

Contested illnesses, of which CFS/ME is one, are those that are subject to social and scientific uncertainty and/or scepticism. Questions of knowledge inevitably arise around such conditions, and I address these by looking at the many facts, assumptions, and ways of knowing that circulate around CFS/ME. Since its formal emergence in the 1980s, every

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<sup>4</sup> I would note that the authors of the former study here are psychologists, and most of the latter psychiatrists.

aspect of CFS/ME has been subject to contestation: the name, cause, diagnosis, treatment, and the very reality of the illness. The consequences are not only frustrating and offensive to CFS/ME sufferers, but also have practical implications. Individuals who find the medical legitimacy of their condition refuted may be unable to get a diagnosis, and thus unable to access further treatment; they may be cut off from financial support in the form of sickness benefits, or (where issues of culpability arise) compensation<sup>5</sup>.

Given these difficulties it is not surprising that the literature tends to focus on the socio-political origins of and response to contested illnesses (Brown 2007, Brown et al 2012, Kroll-Smith et al 2000). Seeking recognition and recompense, contested illness sufferers form collectives to lobby the state, corporations, and other institutions, and to engage in scientific decision-making as participants, rather than just patients (Dumit 2006, Brown et al 2004)<sup>6</sup>. Dumit (2006) talks about the strategic use of facts by various parties (patients, physicians, institutions), who frame and mobilise them differently according to their aims. I want to expand this, to look beyond facts at the broader epistemic matrix that is often implicit in studies of contested illness. I examine how the incomplete medico-scientific foundations of CFS/ME bring to light forms of knowledge that are ordinarily overlooked or disavowed, and how these operate in the everyday lives of sufferers.

Writing of nuclear test veterans trying to prove genetic damage from their service, Trundle and Scott (2013: 510) say that contested illness sufferers are in a position of “bearing the burden of proof while having little access to information”. In their work the condition in question is marked (or rather, unmarked) by a resounding scientific silence. Comparatively, Joseph Dumit (2006: 578) writing on CFS/ME and Multiple Chemical Sensitivity, argues that “with these emergent, contested illnesses, the social problem is the apparently intractable uncertainty at each dimension. There is often not enough research and at the same time too many facts”. Of these two remarks, the first describing an absence, the second an inchoate mass, CFS/ME aligns more with the latter. In either case the afflicted individual is responsible for making use of what information there is, either by sifting through an excess of facts, or by “making do” with whatever is available (Dumit 2012, Trundle and Scott 2013). Also in either case the knowledge available (partial, conflicted) is open to multiple readings and reconfigurations. These take place within the context of individual lives and experiences, and raise another distinction, between formal and informal knowledge; between the socially and scientifically sanctioned, and the improvised everyday (Trundle and Scott 2013). This opens

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<sup>5</sup> For a discussion of the legal obstacles to claiming compensation for contested illnesses that originate in the workplace see Engel et al (2002) on Multiple Unexplained Physical Symptoms, and Phillips (2010, 2012) on Multiple Chemical Sensitivity.

<sup>6</sup> See also Epstein (1995) on the collective movement of AIDS sufferers and associates. Though AIDS is not a contested illness per se, Epstein shows how when medical knowledge of the illness was in a formative stage, social groups were able to take up roles as participants in the knowledge-making process.

up questions of credibility and the relative value of different kinds of knowledge – questions that must be attended to in order to understand the challenges sufferers face in negotiating their illness in both public and private spheres. I address these questions by showing how the value and authority of different kinds of knowledge differs according to individual aims and circumstance.

## **Theoretical engagements**

### *Knowledge*

Knowledge has long been a concern of anthropologists, who have demonstrated its plurality and contingency (Lindenbaum and Lock 1993, Worsley 1997), and problematized polemics of abstract versus concrete, or knowledge versus belief (Geertz 2002, Pelto and Pelto 1997). In 1982 Allan Young put forth a call to go beyond demystification “to critically examine the social conditions of knowledge production” (1982: 722). This constructivist perspective has gained prominence in social studies of science and medicine, with the work of Bruno Latour (1987) and others (Hacking 1999; Jasanoff 2013) examining not only the social conditions but also the social practices through which facts are produced and made mobile. As Andrew Lakoff (2005:3) explains, “the solidification of a fact requires the ongoing stabilization of the network of actors and techniques through which the fact is produced.” Haraway (1988) both tempers and reinforces the constructivist approach by arguing for knowledge as partial and situated. For Haraway, multiple perspectives are essential to gain a truer account of things. It is beyond the scope of this research to examine scientific knowledge production in CFS/ME, but I focus instead on how sufferers work the little established evidence that exists into their own ways of knowing CFS/ME – those that they learn by living with the illness day to day.

Acknowledging the above contributions, I want to proceed with a more open notion of knowledge. In particular I look to Barth’s (2002:1) use of the term as that which “a person employs to interpret and act on the world... feelings (attitudes) as well as information, embodied skills as well as verbal taxonomies and concepts: all the ways of understanding that we use to make up our experienced, grasped reality”. The wide repertoire of knowledge types Barth allows for is essential, in my mind, to analysing the lives of people with CFS/ME. As I will show, sufferers understand CFS/ME through a number of lenses, of which facts are but one. Factual knowledge is pieced together from whatever information appears most relevant to the individual: that which aligns best with their pre-existing factual knowledge, their experience, and their cultural logics. Embodied knowledge verifies the reality of the condition through its intense physicality, and at times overrides the institutionally sanctioned knowledge of doctors and research. Barth’s knowledge allows for the multiplicity Haraway (1988) argues for, and this multiplicity is inherent to CFS/ME.



Medical and scientific knowledge has an aura of 'truth' (or at least objectivity) that invests it with a largely unappraised cultural authority (Lindenbaum and Lock 1993, Starr 1982). However, scientific endeavours are inevitably political ones (Collins and Evans 2002), shaping and shaped by human interests, and caught amongst shifting power relations (Lindenbaum and Lock 1993). Recognising this invites questions of authority and credibility. For example, within the natural sciences, evidence is the currency of value, and the nature of evidence is stipulated in the language of science (Barry 2006). Evidence is produced and reified through institutional practices like the randomised clinical trial, governed and legitimised through ideals of standardisation. The rhetoric of evidence is then deployed to manage clinical medicine through the acceptance and exclusion of difference practices (Barry 2006). Exploring this in the case of alternative therapies and biomedicine, Barry (2006: 2655) points out that "the biomedical focus on evidence in the forms of standardised statistical forms of knowledge, and the anthropological focus on evidence as local and particular, are to some extent worlds apart". However, biomedical evidence too can be treated as local and particular (or, as above, partial and situated). The challenge "is to preserve the individuality of things, and enfold them in larger worlds of sense at the same time" (Geertz 2002: xi).

The larger world of sense for my participants comes in the form of bioscientific logic. The supposed 'sense' of this world is destabilised, however, when facing CFS/ME, and it is this that allows sufferers' composite ways of knowing to emerge, to fill in the gaps the biosciences are leaving and making. My participants make and mobilise various types of knowledge in seeking to understand and explain their illness. They defer to scientific findings, to their doctors, and selectively adopt the knowledge those sources produce and disseminate. They can do this because though the natural sciences have not found answers for CFS/ME, they have created facts. These facts comprise the existing body of medical knowledge of CFS/ME, which my participants draw upon to make sense of their illness. By incorporating such credible information into their existing corpus of knowledge, sufferers can assume a degree of authority that is otherwise off limits. This epistemic infiltration of the medical world reconfigures relations according to expertise. To give one prominent example, AIDS activists in the mid-1980s placed themselves at the centre of public and specialist debates about AIDS by learning and speaking in the biomedical language in which those debates were conducted. Doing so not only gave the patient population a voice, but a voice of authority (Epstein 1995). This has significant implications for lay participation in scientific decision-making<sup>7</sup>, but my

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<sup>7</sup> "Activist movements, through amassing different forms of credibility, can in certain circumstances become genuine participants in the construction of scientific knowledge [and] can (within definite limits) effect changes both in the epistemic practices of biomedical research and in the therapeutic techniques of medical care" (Epstein 1995: 409).

interest here is at the individual level. By invoking the work of particular authorities or referencing certain studies and evidence, my participants argue for the legitimacy of their illness in a way that resonates with their own experiences, but still carries the stamp of scientific approval.

The formal medical knowledge my informants appropriate is imbricated with their pragmatic, everyday understandings of CFS/ME. Everyday knowledge is that which develops through living out the minutiae of life and illness. It is a getting used to oneself with illness, getting to know oneself again on a shifting biological terrain, and within the constraints of the day-to-day. This latent knowledge emerges most prominently from my participants' accounts when they talk about how they cope with CFS/ME, often describing a process of small shifts in routine or habit that reflect a new awareness of their capabilities.

These adjustments are also informed by my participants' embodied knowledge, their ways of knowing with the body. Embodied knowledge arises from lived experiences, somatically stored and expressed in bodily action and practice. Stoller (2007) has written of embodied knowledge using his own experience with cancer as a lens that illuminated his past sorcery apprenticeship with the Nigerian Songhay. To the Songhay learning is writ on both body and mind, and Stoller argues that the embodied knowledge they acquire over time is reflected in the ways they go about their world. There is considerable overlap here with writing on embodiment, which I address in Chapter One. The knowledge part of this embodied process is the repertoire of ways of being that individuals have at their disposal, which enables them to cope with the hardships that are an expected part of Songhay life<sup>8</sup>. The bodily experiences of people with CFS/ME can be similarly conceptualised. By living with illness people develop intimate understandings of their bodily capabilities and limitations, which are expressed in practice, as they allow their daily goings on to adjust to the state of their body. What is important is that this knowledge resides within the body.

Of course factual, pragmatic, and embodied knowledge are not mutually exclusive – rather they inform and affirm reciprocally, producing a composite knowledge. Pols (2013) has recently proposed the notion of 'patient knowledge' to account for the overlap between practical and medical knowledge in patients' everyday lives. The idea of patient-experts, she argues, implies a simple transferral of medical knowledge from the clinic into the day-to-day, concealing the creative work patients do in bringing together and applying multiple types of knowledge. She privileges instead the "messy knowledge" (Pols 2013: 3) that patients piece together in practice – an approach that I find particularly useful when thinking through my participants' understandings of CFS/ME. However, this thesis explores two other types of knowledge that do not quite fit under the 'patient knowledge' rubric.

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<sup>8</sup> Stoller (2007) says that misfortune is an expected regularity of Songhay life.

I adapt from education studies the term interpersonal knowledge (Collinson 1996) to denote the types of knowledge that are expressed and produced between sufferers and their social peers. The social field is a volatile epistemic space, where the knowledge of CFS/ME sufferers is open to revision and refutation. Interpersonal knowledge is distinct (rather than patient knowledge shifted to a public site) in that it ceases to be just about understanding, and becomes instead a resource for debate and education. My participants would express their knowledge differently according to their audience or agenda, and where they would usually use this knowledge to make sense of their condition, my participants here used it to prove their illness, or to relativize it.

Another part of this project was to assess my participants' immune function by taking blood samples in dried spot (DBS) form, with the aim of gaining some insight into their biology. These tests provide a different perspective on CFS/ME, one grounded in biomedical techniques, and resulting in a certain type of biomedical information. The results are fine grained enough to offer bodily information that occurs below the level of perception, i.e. information that individuals themselves cannot possibly know without such a test. Moreover, this evidence is not usually accessible to CFS/ME sufferers: this is not a method that has been used before for this illness; this is not information that the average CFS/ME sufferer would be aware of, or have the opportunity to incorporate into their lives. What it is, is an alternate window into a different facet of CFS/ME, one that reveals some continuity with the knowledge my participants describe, by highlighting the immunological flatness of CFS/ME. These forms of knowledge are not incommensurate.

Just as my participants drew upon multiple sources and experiences to make sense of their illness, so too did I in carrying out this research. The people I worked with are very much at the front and centre of this thesis. Our interviews, carried out one-on-one in people's homes, gave them a chance to reflect at length on their thoughts and experiences. Listening to what they said (which often differed from what I had expected to hear) prompted me to rethink my focus and adjust my direction. The outcome is a text that has been shaped as much by my informants as by myself, one that reflects their concerns as much as my interests, though that is, I think, a happy compromise between the two. We have contributed to a nascent type of knowledge of CFS/ME: one that addresses people with illness, rather than illness that happens to affect people. Perhaps knowledge of this sort will help to round out the biological checklist by which CFS/ME is made knowable clinically. In pulling together different parts of my interviews, alongside the DBS and the various bodies of literature on CFS/ME, I have produced a deliberately complex knowledge, one that does not try to make things simpler, but rather to open up new ways of knowing CFS/ME. This thesis has also

contributed to anthropological knowledge more broadly, bringing new material to various theoretical approaches and asking what this can tell us about, for example, the body.

### *Embodiment*

It is hard to ignore the role of the body with a condition as physically imposing as CFS/ME. This thesis starts with the body, moving from the molecular level out to the lived, embodied experience. As I will show (Chapter One), life with CFS/ME transforms the state and experience of one's body, and as a result transforms the ways one goes about being-in-the-world. To frame this, I work with a theory of embodiment in the manner of Thomas Csordas (1990, 1993). His is a phenomenological notion of embodiment that focuses on the sensory and experiential. The body here is not only as an object of study, but a site of culture and all experience, mediating the engagement between the individual and the world through sensory perception and practice. The body is essential in perceiving the world (Merleau-Ponty 1945). Bodily experience occurs in a world that is infinitely more expansive than our experience can encompass: "A more-than is always woven into the fabric of existence that constantly shifts as we attend to particular aspects of reality, while ignoring others. Uncertainty, ambiguity, and indeterminacy are the norm here" (Desjarlais and Throop 2011:90). Bodily experience, from this view, is both constituted by, and constitutive of, culture. As culture shapes bodily experience via perception, the body recreates the cultural and the social through practice (Bourdieu 1972, Comaroff 1985, Csordas 1990, 1993, Desjarlais and Throop 2011). The relationship between body and world is thus central to studies of embodiment.

This is but one use of embodiment. The concept has been used elsewhere to refract ethical debates about organ trading through reflection on ownership and ontology (Cherry 2002), and to explore how the material world is physiologically imprinted on the body through pathways such as stress (Gravlee 2009, Krieger 2001, 2005). Others have expanded the concept, using the embodied mind to situate cognition in the sensorial and emotional workings of the body (Lakoff 2003, Lakoff and Johnson 1999), or the embodied world to conceptualise human-environment relationships (Scheper-Hughes and Lock 1987). Recent work has integrated phenomenological approaches and cognitive linguistics with the objective of developing a "genuinely cultural theory of embodiment" (Kimmel 2008:77)<sup>9</sup>.

The approach I use here can be traced back to both the phenomenology of philosopher Edmund Husserl, and early work on the body begun by Mary Douglas (Csordas 1995,

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<sup>9</sup> See also Mascia-Lees' 2011 volume for an excellent selection of work on the body and embodiment, and van Wolputte (2004) for an overview of this body of literature.

Desjarlais and Throop 2011)<sup>10</sup>. Over the past four decades the body has come to be seen as plural, plastic, and historically and locally specific. With these changes came an emphasis on experience, complementing earlier perspectives of the body as semiotic and representational (Comaroff 1985, Csordas 1993, Desjarlais and Throop 2011). The body-of-meaning has been augmented by the body-as-lived. I work with the latter of these due mainly to the nature of CFS/ME: viscerally disruptive, variable, and largely unvoiced (or unheard). Exploring the bodily ways of being that CFS/ME engenders gives a sense of the lived experience of this illness, and this experience is one of the grounds from which people's understandings of CFS/ME emerge. Investigating CFS/ME through embodiment thus illuminates how it feels to live with CFS/ME, while also beginning to hint at what this might mean to sufferers.

### *Explanatory models*

The embodiment approach elaborated in my first chapter is built upon in the next, where I explore how my informants make sense of their illness. I frame this analysis with explanatory models, as outlined by Arthur Kleinman (1978, 1980, 1987, 1988, Kleinman et al 1987, Kleinman and Benson 2006). Kleinman developed the explanatory models framework to draw out the cultural logic that underlies people's understandings of illness, an objective grounded in his belief that explanatory models "are tied to specific systems of knowledge and values centered in the different social sectors and subsectors of the health care system" (Kleinman 1978:88). Individuals' social, political, and historical circumstances are thereby accounted for in Kleinman's framework. Explanatory models are designed to elicit comprehensive commentary upon illness, which Kleinman (1988, 2006: 1674) attains with a prescribed set of questions: "What do you call this problem? What do you believe is the cause of this problem? What course do you expect it to take? How serious is it? What do you think this problem does inside your body? How does it affect your body and your mind? What do you most fear about this condition? What do you most fear about the treatment?" The categories these questions address may be understood very differently by patients and medical practitioners, particularly since the former are thought to trade in illness and the latter in disease. Disjunctions between the two, Kleinman argues, produce obstacles to efficient and efficacious treatment.

Despite their original clinical purpose, explanatory models have enjoyed wide ranging application by social scientists. Poss and Jezewski (2002) use them to show how *susto*, fright, features in Mexican American diabetics' understandings of their health and susceptibility. Another study used explanatory models to compare how rural and urban Tanzanians

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<sup>10</sup> See Desjarlais and Throop (2011) for a comprehensive review of phenomenological scholarship within anthropology.

understood stroke, finding, contrary to expectations, that rural populations more commonly gave physiological or behavioural explanations, whereas urbanites were more likely to attribute stroke to witchcraft (Mshana et al 2008). Working with mental health patients who were in the process of being diagnosed, Williams and Healy (2001) argue explanatory *maps* might be more useful than models, given the changeable nature of their participants' opinions.

The original explanatory models framework has been revised and expanded since its inception. Kleinman himself has identified shortcomings, noting (Kleinman and Benson 2006) that explanatory models are often misused in medical practice. The authors show that they are often treated like a technical tool rather than as entry points for personally engaging with patients, and in doing so they flatten patients' experiences into a factorial checklist (Kleinman and Benson 2006). Weiss (2001) shows that the model has taken on a more causal focus, with greater emphasis on patients' explanations of why their illness transpired. He also points out that other concepts have been brought to the conversation: illness experience, causal explanations, and talk of the different rationalities underlying experience (Weiss 2001). Pols (2005) argues that explanatory models (and other patient-perspective approaches) reify the separation of lay and medical knowledge, and fail to challenge the authority of the latter. She also comments that a perspective-based approach, which of necessity prioritises what is verbally articulated, cannot account for the performative aspects of communication – and what is unsaid is often equally or more informative than what is.

My own use of explanatory models does indeed privilege the descriptive. Unlike Pols', however, my participants took up the task of explaining their illness with great enthusiasm<sup>11</sup>. My informants' descriptions were rich, detailed, and carefully thought over. Most of them had been formulating their views for years. Rather than separating patient and medical perspectives, the explanatory models shows just how blurred the distinction between lay and medical perspective is. Kleinman's model acts here as an ordering device: a way of organising my informants' explanations of their illness that allows me to draw out the similarities and inconsistencies between them.

### *Self-Management and Care*

If explanatory models help order people's thoughts on CFS/ME, ideas of responsabilisation (Rose 2007) and care (Mol 2008, Mol, Moser, and Pols 2010) allow me to analyse how that knowledge is applied in practice. 'Responsibilisation' denotes the expectation that individuals must accept and enact responsibility for their present and future health (Rose

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<sup>11</sup> Pols (2005) was working in a mental health facility, where several of the residents whom she worked with did not speak at all, and others were very uncomfortable in the interview situation.

2007). This expectation arises as part of broader shifts toward individuation and autonomy that characterise 'advanced neoliberal democracies' (Novas and Rose 2000, Rose 2007). Novas and Rose (2000) have written about this in relation to genetics. They argue that individuals who learn that they carry an enhanced risk of the hereditary genetic disorder Huntington's disease are expected to act responsibly: to learn about their condition and to make their reproductive decisions accordingly. With CFS/ME responsabilisation is evident in the recommendation of self-management approaches to illness management – those that place the patient as the primary enactor of their treatment.

What self-managing patients face, and what responsabilisation opens up, are issues of choice. Choice, as Anne-Marie Mol (2008) argues, places the onus on patients to make appropriate decisions about their health, and in doing so exposes them to inadequate treatment, and blame if they choose poorly. The alternative that Mol proposes is a logic of care<sup>12</sup>. The argument for care is an argument for localised, responsive coping, and for interaction as well as independence (Mol, Moser, and Pols 2010). Care raises questions of what is 'good' (a term often conflated with efficacious) which Mol, Moser, and Pols seek to problematize. Goodness implicates an ethical stance, linking to Foucault's (1986) work on self-care amongst the Greco Romans, for whom regular attendance to ones' body and mind was an ethical imperative, integral to developing a wholesome self and being a good member of society. Those ideals gave way as Christianity emerged and self-cultivation took on egocentric connotations. We have, then, a historical trajectory of shifting degrees of connectedness and independence, apparent today in notions of the responsabilised individual<sup>13</sup>. I use these ideas to think through my informants' experiences, particularly with respect to their coping strategies, and to argue that care may be a more analytically useful concept than self-management.

### *Local worlds*

In the final chapter of this thesis I take a step back and consider my participants in the context of their local social worlds. The concept of local social worlds comes from Ware and Kleiman (1992), for whom it is a flexible term used interchangeably with 'local worlds of experience', 'local worlds', and 'local worlds of interpersonal experience'. The purpose of local social worlds is to frame the dialectal relationship between individuals' bodily health or suffering and their macro-social context, using the immediate interpersonal sphere as the

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<sup>12</sup> See also Roberts (2012), who deals with intersecting ideas of autonomy and care in Ecuador, where, she argues, the latter has much greater significance than the former, in contrast to America.

<sup>13</sup> Care theory has also recently expanded into the realm of science and technology studies, where its role in the production of research and scientific knowledge is being discussed. See Friese (2013), Jespersen, Bønnelycke & Eriksen (2013), Pols (2013), and Schwennesen & Koch (2012) for some such discussions.

connection between these. This concept was developed in response to unilinear sociosomatic models, which look only at the effect of the social on the somatic; local social worlds look also to the effect of the body on the local world, considering how illness influences social experience. They elaborate this with a comparative example of Americans with CFS/ME, and Chinese with neurasthenia. Illness for the former served as a commentary against larger cultural pressures valorising work and success, and enabled them to instigate change in their local worlds by re-evaluating their lives, changing professions, or making time for rest. For the latter, illness was attributed to the Cultural Revolution, which saw families separated and people displaced. Neurasthenic symptoms, such as dizziness and pain symbolise the emotive experience of the revolution, but illness for this group was less ameliorative than for the Americans.

I borrow local social worlds with more of an emphasis on interpersonal experiences than the shared social experience that Ware and Kleinman (1992) focus on. The local social worlds of my participants were sites of intersecting knowledge and strategic adjustment, as my informants sought to educate their friends and families on CFS/ME to preserve their relationships. I show how the invisible, apparently common symptoms of CFS/ME, especially fatigue, foster misunderstandings and destabilise the social field, and I argue that this is indicative of the marginal social position of CFS/ME sufferers more generally.

## **Methodology**

### *Participants*

This project was originally designed to investigate CFS/ME among young adults (between the ages of 18 and 29), but I decided to expand this age bracket before I began interviewing. This decision was prompted primarily by the insistence of one individual, a middle-aged man from the first support group I visited, who politely but emphatically asked to be interviewed. I realised that limiting my study to young adults meant excluding a wealth of experience from older CFS/ME sufferers, plus preventing them an opportunity for expression, which was apparently much desired. Removing the age restrictions also made it significantly easier to find participants. By the end of my fieldwork I had interviewed fifteen people aged between twenty-one and seventy. Three were men, and twelve women, reflecting the higher rates of CFS/ME amongst women. Illness duration ranged from one to twenty-five years. All but one participant had received a clinical diagnosis of CFS/ME at some point, and many had had CFS/ME for months or years before being formally diagnosed. Only one of my participants was not of New Zealand European descent, and I have removed any references to ethnicity for them to protect their anonymity. One person, Toby, had recurrent post-viral fatigue rather than CFS/ME. His symptoms were similar to those with CFS/ME, but of a lesser



intensity, and intermittently occurring. Post-viral fatigue often precipitates, and is sometimes considered a variant of, CFS/ME. I have chosen to include Toby in this text for this reason, and for the fact that he considered himself to be experiencing chronic fatigue. The resulting group of participants thus comprise a fairly broad sample of CFS/ME sufferers generally, though without any children or adolescents. Those who participated are also those who were well enough to endure an hour or more interview, which many people with CFS/ME could not; my informants thus represent a slightly more able group than the CFS/ME population as a whole. A control group of twenty individuals was also recruited as a comparison for the DBS testing, and these individuals ranged in age from twenty-two to fifty-seven.

My participants came to the study from a variety of avenues. The organiser of the support group I attended kindly put out notifications through her e-mail list on my behalf, and many of my participants made contact after that. Four people expressed an interest in participating after hearing about the project through mutual friends, and one person contacted me in response to a newspaper advertisement. Most control group members were snowball sampled from various contacts of my own, and in line with my ethics agreement I did not solicit anyone directly.

This project received ethics approval from the University of Auckland Human Participants Ethics Committee in April 2013. My participants were all recruited on the understanding of informed consent. This meant supplying prospective participants with Participant Information Sheets (Appendix 3), usually via e-mail, and discussing any questions or concerns that arose from these. Those participants who chose to take part based on this information gave written consent verifying that they understood the purpose and procedures of the project (a sample consent form is in Appendix 4). All participants were informed that they had the right to withdraw any information until July 1, 2013, though none chose to do so. For the purposes of anonymity I use pseudonyms throughout, and have removed identifying characteristics where necessary.

### *Methods*

As the aims of this project required detailed insight into people's understandings and experiences of CFS/ME, I chose to obtain my ethnographic material through semi-structured interviews. I conducted fourteen such interviews with my fifteen participants<sup>14</sup>, taking between 45 minutes and three hours each. I began each interview with a list of questions, but rarely ended up following them, instead allowing people's answers to redirect our discussion as they saw fit. In doing so we typically covered all of my listed questions anyway, but in an

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<sup>14</sup> In one case I spoke with two people in one interview, as convenient for and agreed upon by all.

order that seemed more intuitive to my informants. The questions began with basic demographics, moved to how people developed CFS/ME, their lives before and after diagnosis, their thoughts about the illness, and some questions about the biology of CFS/ME. The full list of interview questions is in Appendix 1.

I also devoted some time to examining online forums for CFS/ME sufferers to get a sense of how reflective my participants' perspectives were of the patient community on the whole. This generally served to confirm that the responses I was receiving in interviews were not discordant with the experiences of most people with CFS/ME. My method was informal, as I skimmed through discussions on a wide range of topics. CFS/ME sufferers use forum discussions to ask questions, (particularly it seems when recently diagnosed), to share difficult experiences and find out how others have coped in similar situations (dealing with difficult doctors is a highly discussed issue, for instance), and to debate new research or disseminate resources. Information on forums is publically accessible<sup>15</sup> and almost always posted under pseudonyms, minimising privacy issues. Moreover, as I do not draw upon specific comments or entries from forums in this text, ethics approval was not required for this aspect of the project. There are some potential problems with this medium, most importantly the absence of information about the people involved (Dumit 2006). It is impossible to say if the people whose opinions I was reading did in fact have CFS/ME, what the nature of their illness was (duration, severity, etc.), and who they were aside from this (in terms of nationality, sex, occupation, age, etc.). Nonetheless, forum analysis proved useful as an additional method with which to contextualise my ethnography.

To get an alternative perspective on CFS/ME, one at the molecular level, I also collected Dried Blood Spots (DBS) from my participants and a control group of twenty individuals without CFS/ME. My aim was to assess individuals' immune function by looking at C-Reactive Proteins (CRP) and Epstein Barr virus antibodies (EBV Ab), two markers of inflammation. These analytes have been verified for assessment using DBS, and are not subject to diurnal variation (McDade 2007, McDade et al 2007, Meier-Ewert et al 2001, Wander 2009). At the end of each interview I took the dried blood spots (DBS) from my participants following the procedure described by McDade (2007, et al 2007). I would don latex surgical gloves and use an isopropyl-soaked pad to sterilise the finger being pricked. Using a disposable lancet, I then pricked the fingertip slightly to one side and waited for a drop of blood to well up. This first drop was wiped away with a sterile gauze pad, and up to five subsequent drops were collected on filter paper marked with circles for accuracy. McDade (2007, et al 2007) cautions that the finger must not touch the paper in case it smears the sample, so to avoid

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<sup>15</sup> Some forums require an account or profile to access, however I only made use of those that were completely open and freely available.

this I waited until a big drop had gathered, then lightly touched the tip of this to the paper, whereupon it usually absorbed without the finger making contact. This was usually easiest by keeping the hand still and moving the card to the blood. Once all the spots were collected, any residual blood was wiped off the participants' finger and a plaster applied. The DBS were marked with anonymous identifiers and left out to dry for at least four (but no more than twenty-four) hours, before being stored in a fridge set to 4°C.

In the interest of expediency and security, DBS were couriered<sup>16</sup>. The blood spots were packaged individually in small plastic bags to minimise the risk of cross-contamination, with desiccant sachets, as stipulated by the Centre for Disease Control guidelines. These were then put together into a larger plastic bag with absorbent cloths, and packed with chiller pads to protect samples from degrading on the journey. Core director at the University of Washington (UW) Biodemography Laboratory, Dr. Eleanor Brindle, carried out the DBS analysis. The UW was chosen for testing due to the lack of local facilities, but also due to an existing connection with the lab, and the expertise of the UW team. The analytes examined, CRP and EBV Ab, indicate inflammation, thereby serving as proxies of immune function<sup>17</sup>. The full method for the two assays, as supplied by Dr Brindle, is in Appendix 2. The results were returned with values for each analyte assigned to the appropriate anonymous identifier<sup>18</sup>, and basic descriptive statistics were run using SPSS.

### *Negotiating a biosocial approach*

At its outset this project had a strong biosocial orientation. I set out to explore the interaction of individual biology, particularly immune function (as evident in the DBS described above), and people's social worlds. I wanted to know how my participants' relationships, work lives, ambitions, and upbringings got 'into' their bodies. How, then, did the sick body reiterate these factors biologically, and come to occupy the world differently because of this? Over the year however the focus of my research changed significantly, and this thesis draws primarily from social anthropology. Each interview I conducted prompted me to rethink the questions I was asking and to ask if the approach I had chosen was really the best way of addressing this illness. This work is a product of this on-going reflection and reorientation. However, I sustain an interest throughout in the power and problems of people's underlying biologies, of their profound effects on individuals' experiences of CFS/ME, and of the knowledge being constructed around them. This is where my DBS tests have proved most useful, as an

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<sup>16</sup> DBS can be shipped by standard postal services due to their status as 'exempt human specimens'.

<sup>17</sup> For an excellent example of both CRP and EBV use in DBS see Wander's (2012) evaluation of the hygiene hypothesis in Tanzania.

<sup>18</sup> This is excluding two samples, which could not be tested due to insufficient blood having absorbed.

alternate window into the body with CFS/ME, one that offers a glimpse of the invisible biological processes at play.

Biosocial projects usually strive for a synthesised analysis of social, political, biological, and ecological factors that interact in a mutually constitutive fashion (Goodman and Leatherman 1998, McElroy 1990). Biosocial work in anthropology is seen by different parties as both an approach and a subfield (McLennan 2013). My own preference is for the former, which enables research that caters flexibly to concerns of both biological and social anthropology according to specific cases. Over the past three decades various scholars have proposed specific approaches to biosocial study, including, *inter alia*, adaptationist (Wiley 1922) and ecological (Alley and Sommerfield 2013, Armelagos et al 1992) models, political economy (Goodman and Leatherman 1998, Leatherman 2005), and syndemic theory (Singer and Clair 2003). These (and other) approaches have been fruitfully put to use teasing out the complexities of topics including race (David and Collins 2007, Gravlee 2009), infectious disease (Alley and Sommerfield 2013), epidemics (e.g. Singer 2009, on swine flu), chronic illness (e.g. Brewis 2011, on obesity), and drug resistance (Porter and Farmer 2013), amongst many others<sup>19</sup>. The diverse methodological and theoretical resources of both biological and social anthropology equips the biosocial medical anthropologist well for such endeavours.

An inevitable epistemological tension arises when taking a biosocial, mixed methods approach. The majority of this work privileges the subjective experience of my informants, which I have collected empirically. It acknowledges the uniquely individualised position of each informant, and how enriching the subjective is as data. I have tried to be attentive to the sentiments expressed by many, whilst retaining individual voices. My analysis itself is interpretive. The biomarkers bring a positivist perspective on CFS/ME – or as close to positivism as it is possible to get whilst acknowledging the inherent contingency of science<sup>20</sup>. The varying epistemologies in which this work is grounded are not exclusive; rather, I hope they prove complementary, and I have tried to let each illuminate parts of the other.

## **Chapter overviews**

I begin this thesis by exploring the individual and their body with CFS/ME. Moving outwards, I examine how my informants understand the condition, how they cope day-to-day, and how their existing social relations are reconfigured with CFS/ME. The first chapter takes as its focus the body, inquiring into the somatic changes wrought by CFS/ME, both as lived, and as

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<sup>19</sup> For further insight into the conversations that arose around biosocial anthropology in its formative years, see *Medical Anthropology Quarterly* (1994, Volume 4, Issue 3), a special edition devoted to the topic.

<sup>20</sup> The inclusion of a biological test was well received by my informants, who on the whole wished for greater 'scientific' understanding of their illness, and more options for testing aspects of CFS/ME

reflected in immune measures. Using a phenomenological theory of embodiment (Csordas 1990) I show how my participants' bodies became unfamiliar with illness, and in so doing how they come to occupy the world in new ways. A tension arises from Csordas' approach, which aims to collapse dualities, particularly those of the body and mind; in a finding that parallels work on chronic pain (Jackson 2005) I show that the mind-body distinction has value for CFS/ME sufferers as they try to locate and explain their illness. Exploring CFS/ME as embodied reveals the deep indeterminacy that sufferers experience, and I argue that is characteristic of CFS/ME.

In chapter two I examine how people make sense of CFS/ME, given the conflicted medical and scientific perspectives on the illness. People describe their condition with composite explanations, moving between medical research, everyday experience, and professional advice to understand CFS/ME. Many of my informants gave two-tier explanations, referring to various aspects of their lives when explaining how their own illness transpired, but invoking a sophisticated and selective medical dialect to explain what causes CFS/ME more generally. I argue that this serves to situate a complicated condition cogently within people's lives, whilst also claiming medical legitimacy.

People's explanations of their illness help frame Chapter Three's discussion, where I address how my participants cope with CFS/ME. Here I argue that though self-management is often fruitfully enacted by my informants, this can only account for one part of their coping. For this reason I argue that we instead think of coping with CFS/ME through notions of care, as has been suggested by Anne-Marie Mol for diabetes (2008, 2010). This is particularly salient in the case of CFS/ME because there are times when sufferers are so physically incapacitated that they are unable to self-manage. Care would allow for the intersubjective coping that such times necessitate, and can also account for the affective aspects of living with chronic illness, which self-management practices neglect.

In the fourth chapter my perspective turns outward from the individual, to consider the social relations they are entwined in, and how these shape and are shaped by CFS/ME. I argue that people's immediate social relations are not only an important part of the lived illness experience, but also raise broader social concerns about the place of people with CFS/ME. Using the concept of local social worlds I show how the invisible, apparently common symptoms of CFS/ME, especially fatigue, foster misunderstandings and destabilise the social field, and I argue that this is indicative of the marginal position of CFS/ME sufferers as a whole within society.

Together these four chapters comprise an exploration of CFS/ME as it plays out on the body, in everyday life, and in people's social lives. Different forms of knowledge circulate amongst these domains, sometimes as resources with which people can cope or justify their

illness, and sometimes as barriers, inhibiting understanding. Considering these types of knowledge reveals the instability and variability that so thoroughly permeates the experiences of people living with CFS/ME. My participants were constantly adjusting to the shifting states of their bodies and their worlds. However, rather than letting this hinder work on CFS/ME this ought to be treated as a feature of the illness – one worthy of attention and analysis. This thesis is my contribution to such an endeavour.

# CHAPTER 1: CFS/ME AND THE BODY

## Introduction

The body is central to CFS/ME, and I argue here that it is defined by its continual instability. My discussion of the body with CFS/ME begins at the cellular-level as I analyse my participants' immune function, and moves out to look at their lived experiences. I frame this discussion using Csordas' (1990, 1993) theory of embodiment, which looks to perception and practice to analyse how people go about being-in-the-world. Symptoms such as brain fog and sensory sensitivity change individuals' most immediate experience of the world, and elicit new ways of inhabiting the world and using the body within it. CFS/ME changes the body at both the cellular and symptomatic levels prompting people to notice their bodies anew, and occupy the world in different ways. As they tried to make sense of these changes, my participants often relied upon mind-body dualisms to locate and explain their illness, a finding that aligns with work on chronic pain (Good 1992, Jackson 2005, Kleinman 1992). This challenges the primary aim of Csordas' embodiment paradigm, which is to collapse dualities, including those of the body and mind. While exposing the very dualities it seeks to collapse, embodiment proves to be a productive way of conceptualising the lived experience of CFS/ME. This approach highlights the many roles of the body with CFS/ME: as something to be known by afflicted individuals, as partner to the mind, a medium between individuals in the world, a source of embodied knowledge, and a biological entity. The many roles of the body with CFS/ME emphasise its centrality to this condition, and invite further appraisal.

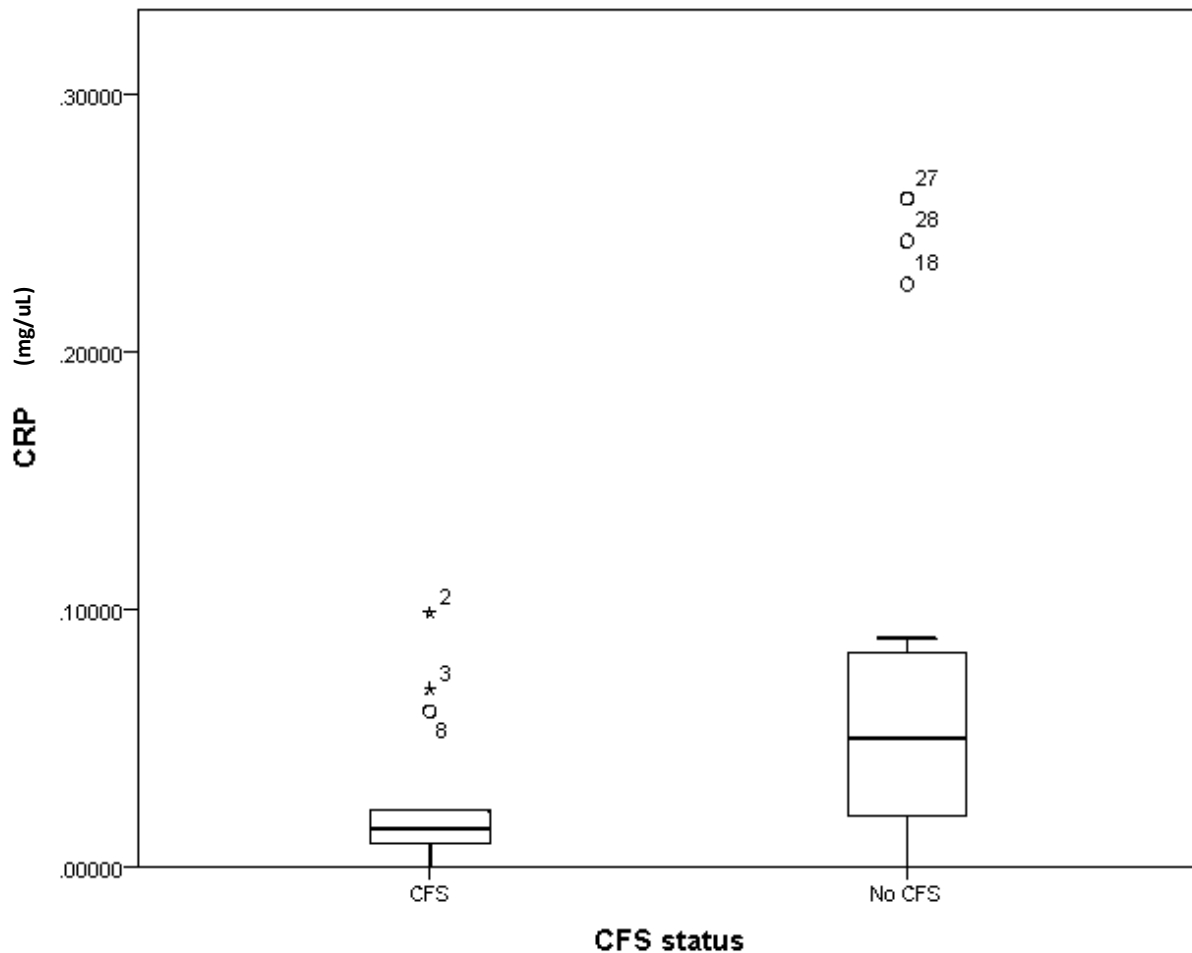
## The body as seen through blood

Though most of this thesis addresses the lived experiences of my participants, I begin my discussion by looking at an aspect of CFS/ME that cannot be known experientially: immunity. I assessed my participants' immune function by taking dried blood spots (DBS) from my participants and measuring two analytes, C-Reactive Proteins (CRP) and Epstein Barr Virus antibodies (EBV Ab), which indicate inflammation and thereby act as proxies of the immune response (McDade 2007). DBS can detect inflammation at a sub-clinical level. That is, inflammation that may be having significant biological effects without producing symptoms, and without the person in question being aware of it (Wander 2009).

Unfortunately the EBV analysis proved uninformative, with no statistically significant difference in measures between the CFS/ME (mean EBV Ab 24,105 U/ml, SD 21,000) and control groups (mean 42,836 U/ml, SD 65,257). In her work with Tanzanian children, Wander found that EBV Ab was similarly uninformative and hypothesised that this analyte may be masked by other physiological processes; factors such as infection status and

nutrition may also influence or bias EBV Ab readings (McDade 2007). Given the precarious and fluctuating state of health of CFS/ME sufferers, I suggest that EBV Ab is likely not the best measure of immune function in this group.

The most notable result from my DBS testing was that the participants with CFS/ME had considerably lower CRP levels than the control group (those without CFS/ME) (Figure 1). Mean CRP value for the former was 0.0256 mg/uL (SD .030) as compared to .1072 (SD .175) for the latter. The range of CRP values was also smaller in the CFS/ME sample than the controls (range .0089-.0151, compared to .0059-.7761 mg/uL). Following Wander (2012) I used a CRP measure of .2000mg/uL as the threshold differentiating normal immune response and acute infection. The entire CFS/ME sample and all but three controls fall below this value, suggesting they are not in a state of infection. Complicating this however is the fact that three of the total twelve CFS/ME sufferers for whom I have CRP results<sup>21</sup> were outliers,



<sup>21</sup> Two individuals were unable to be tested for CRP due to insufficient blood having been absorbed.



and sat well above the rest of this sample. There was no relationship between immune function and marital status, presence of children, socioeconomic status, socioeconomic status relative to parents, or age.

Though the significance of this test is limited by the small sample size, it is possible to make some tentative suggestions. Firstly, the immune response of these CFS/ME sufferers appears to be suppressed relative to 'healthy' people. Were this the case before these individuals contracted CFS/ME (which I have not explored, but has been suggested elsewhere (Dietert and Dietert 2008)) they may have been more susceptible in the first place. This result also supports suggestions that CFS/ME may be characterised by impaired cell-mediated immunity, a part of the adaptive immune response that provides specific defence against pathogens (Lloyd et al 1992). Other studies have found that people with CFS/ME have higher CRP levels than healthy controls, though in at least one case results were not statistically significant (Klimas et al 2012). Discrepancies like this between studies may be because of confounding brought about by not using subgroups, which is a limitation in my own work and many others (Jason et al 2005). The tightly clumped values of nine participants alongside the three outliers is intriguing, and should be investigated in future work to see if this pattern carries across larger samples, perhaps measuring CRP in tandem with other immune biomarkers<sup>22</sup>. For now, I suggest this may serve as (modest) support for a CFS/ME subtype based on immunity, as has been suggested elsewhere (Jason et al 2005).

These immune measures provide a different perspective on the body from the personal information recounted by my participants, which is carefully thought out and articulated. The DBS tap into biological processes operating below the level of perception; those that may not register in peoples' conscious minds, but that contribute to the overall physiology and experience of CFS/ME. They confirm (tentatively) some biological discrepancy between CFS/ME sufferers and their healthy counterparts, apparently manifest as a blunted immune response in those with CFS/ME. This supports general arguments for immune dysfunction in CFS/ME, but also suggests that this might not be generalisable across the whole patient population. At the very least the immune information produced by the DBS analysis suggests that the body with CFS/ME may be consistently different to the body without, and if this is so at the cellular level, it supports differences at the symptomatic level as well.

### **Talking about CFS/ME and the body**

How do people experience CFS/ME? What does a body with CFS/ME feel like? How does one articulate their experience with an illness that is equal parts unknown, unpredictable, and

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<sup>22</sup> Wander (2012) measures CRP and AGP (acid glycoprotein) together (also using DBS), and uses the relative values of each to develop a more complex picture of the immune function than either could provide alone.

invisible? The body is central to CFS/ME, both medically and experientially, and is also a key concern of anthropologists. Despite this the lived body has only been addressed in one study that I am aware of (Lombaard and Mouton 2005). This chapter demonstrates how through our interviews my participants and I came to share an understanding of CFS/ME based in their bodies. References to the body, overt or implicit, permeate my informants' descriptions of CFS/ME. Jess, who at 26 had had CFS/ME for three years following a swine flu infection, told me, "your body feels a bit light, your head feels light, you're not quite present". In contrast Tess (31) describes her body as feeling like concrete, and another person said it felt like "every cell in my body was made of lead". Mandy (47) who had had CFS/ME for almost six years, described an insidious pain that affected almost every part of her body, badly enough for her to be taking painkillers most nights. The pain is so unremitting that "you just want to escape your body", she said. In all of these examples the body provokes attention, sometimes subtly, and at other times more obtrusively. The following account expands on this.

Harry, 35, was diagnosed with CFS/ME seven years ago, though he thinks this would have happened several years earlier had it not been for a string of misdiagnoses first. He was in a minority amongst my participants in that his illness began inexplicably, not developing from a virus or infection. He was also one of the most severely afflicted. Before developing CFS/ME he had been building a career in marketing, but had since given up on his past ideals of a steady job, house, and family. My interview with Harry turned into an afternoon, spent in the little flat he rented, which clung to the side of a hill overlooking the harbour. He told me how when he was in a bad spell he couldn't actually make it up the steep driveway, and when he got too sick to look after himself (which happened fairly regularly) he would move back to his parents' house. He had returned there last year during a particularly bad 'crash'<sup>23</sup>, and whilst there his dad had spontaneously decided to have the house professionally cleaned. One of the symptoms Harry experiences as part of his CFS/ME is chemical intolerance, which in this particular instance kicked in after the cleaners had been:

I remember that night feeling asphyxiated, I couldn't breathe, and when I woke up the next morning I was spaced out as, like I'd be moving my leg, I know I'm moving my leg, but I can't feel I'm moving my leg, but I can feel [gripping his thigh] that I'm moving my leg, so you have this hyper-stimulated sense of being, you can hear things from a mile off – I think Peters [his doctor] calls it hyper stimulated immune reaction. I kept hitting my leg and grabbing my arms 'cause I didn't feel like I was *in* my body... it's more than intolerance, it makes my immune system go berserk.

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<sup>23</sup> 'Crash' is a term used by my informants as synonymous with the notion of relapsing, typically denoting a serious and often sudden deterioration of health. For most of my participants these are the times when they are confined to bed and struggling with basic needs, such as feeding themselves.

In these few sentences, Harry patches together the sensations, the observable bodily reaction, and the physiological mechanism he is told underlies it, to make sense of this singular experience elicited by his CFS/ME. He has similar reactions to bug sprays, perfumes, and food additives, so carefully avoids these daily products.

Another of my informants, Tess, who had worked in the fashion industry before getting sick, described the onset of her CFS/ME thus:

I... went to an A&E doctor 'cause I thought I was being paralyzed or something, 'cause my body was slowing down, it felt like concrete basically, every move was just so hard, even scratching my head... and I had all these weird nervy symptoms [and] aches and headaches and pains throughout my body.

Tess was in her third year with CFS/ME, and her concerns hark back to a childhood illness that had left her paralysed for a month and in recovery for years. She not only describes the physicality of this early encounter with CFS/ME, but also the associated anxiety and uncertainty, and how it fit with her existing knowledge of her body and health.

These descriptions raise two points. First, the experience of CFS/ME in these instances transcends both symptoms and soma, though especially the former, verging instead on the metaphysical. Though some might try and classify a 'hyper-stimulated sense of being' in medical terms, it is clear from Harry's account that his experience is infinitely more complex than such categories can capture. Such a description is hard to reconcile with the physicality of disease in the traditional sense. The immediate state of affliction described by Harry here is that of a profound ontological dissociation, which is not particularly amenable to classification or communication. Another of my informants, Lisa (29), who had had CFS/ME for three years, described one of her symptoms as feeling like "cold icy fingers in your brain" and a "band in your mind, that gets tightened". Trying to relate to how this might feel, I asked her if this was a physical sensation, a kind of pressure, and she responded, "well it's kind of physical and kind of – is the word metaphysical? I don't know". She also told me about getting sleep paralysis:

...that's just another thing that kinda throws you... it's when [sigh] sometimes when you're sleeping and then you wake up but your body is still frozen, and things can happen... the first time it happened to me I felt like I was being attacked, that something was like pressuring my chest and I couldn't breathe, and like you're trying to scream and stuff but you can't scream.

Lisa's comment communicates not just the physical pressure on her chest and the immobility of her body, but the fear and panic, and the even less communicable idea that 'things can happen'.

Second, in this intense immersion in CFS/ME (or one moment of it, at least) the body emerges as an object of observation and a site of phenomenological experience. Illness permeates the body. It elicits all manner of unfamiliar sensations, be they 'hyper-stimulated', or so dulled as to be mistaken for paralysis. As the body expresses pain or ceases to fulfil its ordinary functions, like breathing, it comes to the fore of peoples' attention. The state of the body is questionable and confronting. My informants' most immediate response was awareness, followed by action, as with Tess taking herself to the A&E. I would note here that those who had had CFS/ME for longer often did not act upon even their stranger sensations. Jess, a lawyer, said "I got so used to my body doing weird stuff that I would just go with it". Moreover, those who had been sick for even longer often ceased to notice the peculiarities of their body; in these cases health becomes the notable bodily state. As Mandy said, illness "just becomes your new normal". What is important here is that CFS/ME engenders intense bodily experiences, which in turn prompt people to become aware of their bodies<sup>24</sup>.

### **The end of the absent body**

It's like my body used to carry me around, in a way, and now I have to carry my body... everything used to be effortless and now it's not... Now it's my will that gets my body going, before it was like my body would be going and my mind would be catching up.

Rosa (57), who gave the above quote during our interview, was the most severely affected CFS/ME sufferer I spoke to. Before getting sick she had been a busy single mother; returning to New Zealand with \$13 and the two children her ex-husband had tried to take to Australia, she took up nursing study, began several small business ventures, and had bought a house within six months of being back. When she met Peter, her husband, they had another three children, whom she spent much time looking after alone due to his work as a pilot. She developed CFS/ME after a bad flu and had had CFS/ME for twenty-five years by the time we met. In her worst period Rosa was barely able to turn over or open her eyes. She ate with her hands and, once she began to improve slightly, drew a tiny graph on the wall by her head so she could track how she was doing. There was a time, she told me, where for three days she did not sleep; she lay awake reciting the same line of scripture, counting the passing time in five-minute increments. She remarked that in times like that, "it would be easier to be in a coma, but your mind just keeps thinking and trying to work out ways of getting through". Rosa had improved significantly by the time we met, but it had taken over two decades to get

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<sup>24</sup> Lombaard and Mouton (2005) make some similar observations of their four South African participants. These individuals express confusion and frustration at the changed and changeable state of their bodies with CFS/ME, and the authors say their response is to attend increasingly to their bodies.

that far. Though far from full health she was able to get up each day, work on her business here and there, and participate in the local CFS/ME community.

I spent close to five hours with Rosa on the day of our interview, and as we spoke she drew together a range of actors and incidents to construct her story of CFS/ME. She moved easily between medical and emotive dialects, peppered the interview with anecdotes about particularly hard moments or unusual symptoms, and frequently referred back to her body to express herself. When I asked her to compare her life now to when she was in her worst period, she spoke about how her body, which had then been so fragile and easily exhausted, had become much stronger and more resilient. Recounting a particularly bad relapse in which she could not eat properly for several weeks, Rosa says “my body basically was starving”; her doctor told her they had to “calm [her] whole body down”; and the medication she was prescribed “gave my mind a break, gave my body a break... it gave me time out and let my body rest”. Talking about CFS/ME through the body gives Rosa a measure of certainty when describing the unstable illness and her subjective encounters with it. She traces the trajectory of her illness through the changing state of her body, summarised in the opening quote, where she explains that what used to be effortless was now wilfully driven.

If Harry, Lisa and Tess showed how CFS/ME pulls the body to the fore of attention (even before it is diagnosed), Rosa’s account illustrates how her illness reshapes her use and understanding of her body. What merely “used to carry me around” now requires carrying. CFS/ME incapacitated Rosa to such a degree that she had to adopt a consciously custodial role. My other informants said similar things. Mandy told me that before getting sick she had been quite detached from her body; though she never abused or deliberately neglected it, nor did she think she had given it enough rest. To cope with her illness Mandy used mindfulness, a practice in which people refocus their attention to the state of their body in order to better manage their health. This, she said, had attuned her to what was going on with her body now that she was unwell, and gave her the perspective she needed to get through the tough times. Similar sentiments were expressed by others: Tess, who said “anything I notice, whereas before when I was healthy, unless it was really persistent I wouldn’t pay too much attention to it”; and Beth (21) who told me it had been easier before she had been formally diagnosed with CFS/ME, because she was able, to some extent, to ignore how she felt and carry on with her normal life<sup>25</sup>. This pre-disease state of imperviousness ruptures with the development of CFS/ME, as the physicality of the illness permeates the body and stops it fulfilling its previous functions.

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<sup>25</sup> Beth’s thoughts on diagnosis stand in contrast to most of my participants’, many of whom fought for years to be diagnosed. This may reflect her relatively well state of health (she was sometimes able to work and go out at night) in comparison to those who were, for example, bedridden much of the time. The important point here is that before developing CFS/ME, Beth more or less ignored that state of her body.

As sufferers are subjected to the diffuse host of symptoms that comprise CFS/ME, the body goes from being an unconscious accompaniment to an object of awareness, reflection, and care. This process of emergent bodily awareness is discussed by philosopher Drew Leder in his 1990 monograph *The Absent Body*. Leder writes in the phenomenological tradition of philosophers Husserl and Heidegger, and engages debates between Merleau-Ponty (1945) and Sartre (1956) to reflect on the ill body. Sartre (1956) advocated a consciousness-based mode of engagement between people and the world, which was contested by Merleau-Ponty (1945) who argued instead that the body is the critical medium in such relations, a point I return to later. Agreeing with Merleau-Ponty that the body is the *site* of all experience, Leder sets out to explore how it is so rarely an object of experience itself; rather, in the words of Sartre, it is “perpetually the surpassed” (Sartre as cited in Leder 1990: 20). Drawing upon notions of the lived body (*Leib*) and the physical body (*Körper*), Leder argues that in a state of health or normality the body does not garner attention; only when some dysfunction occurs, pain, fatigue and so forth, does the body become an object of appraisal, as absence again becomes the desired state.

This argument does lose sight of alternative ways the body emerges; as Sartre (1956) points out it is prominent in moments of physical incompetence, disability, or when aware of how others see you (for example when sexualised, or discriminated against), and the body is similarly conspicuous in pleasure (Zeiler 2010). Despite these oversights, Leder’s work has been used fruitfully by other scholars, and proves likewise useful here. Phinney and Chesla (2003) use the ‘lived body’ to develop an account of dementia that acknowledges the embodied character of what is typically understood as a cognitive, disembodied disease. In doing so they show how the bodily changes wrought by the disease fundamentally alter people’s way of being-in-the-world, as their long established habits and actions are forgotten or slowed, and their worlds become disorienting and hard to keep up in. Here, I use Leder (1990) to different ends, to show how the trajectory of CFS/ME (erratic as that is) incites a sequential emergence and recession of the body.

Beth’s remark that she used to ignore any discomforts in her body, and Mandy’s professed inattention to her own, testify to their disregard for their bodies before illness. I found that remarks like this generally preceded a description of growing bodily awareness. Increasingly, there occurred this painful and imposing presence that demanded my participants’ attention: the body was no longer absent from their field of attention. This progression, from blithe to acutely aware, reflects Leder’s argument of two absences. The first is that of the body in a state of normality, in which it is absent from awareness; the second absence comes about by the body’s ‘dys-appearance’, where it is absent from the desired state (Leder 1990). Here, the body with CFS/ME is far from desirable. Of course, as suggested by Sartre (1956), it is

unlikely that the body was entirely unnoticed before CFS/ME. People are often aware of their bodies' cyclical fluctuations: hunger, needing the bathroom, menstruation, pregnancy, tiredness (Moran 2010). Illnesses such as CFS/ME, however, bring forth the body in more dramatic and irrepressible ways. The accounts provided by my participants suggest that Leder's secondary absence, when sustained for long enough, reverts to a primary absence. That is, when they have had CFS/ME for a certain length of time (usually years) a new state of normality emerges, in which pain, fatigue and strange symptoms are the norm, and this perpetually disrupted body recedes into absence again. Mandy told me that every now and then she would have a moment where she suddenly realised she was in no pain at all, and this was such an uncommon occurrence that it brought her body again to her awareness (and amazement).

Anthropologist Lisbeth Sachs (2001) makes a similar case for CFS/ME, looking at patient-practitioner relations. She argues that through the clinical encounter patients' dysfunctional bodies are recast as pathological ones, and their suffering newly rendered as disease. The clinic is the point of transformation here, and this transformation is propelled by the physicians' view of the body as a medical object. Sachs' argument is a valuable reminder of ways in which others can shape the body of oneself, and particularly others in positions of authority. For my participants, however, the body in fact emerges as an object of suffering long before it is pronounced so by a doctor. Thinking with Leder (1990) about my informants' experiences of CFS/ME highlights the interaction between individual, illness, and body over time. The increasing bodily awareness that CFS/ME provokes prompts people to be more attentive and active in caring for themselves. I will return to issues of care later (Chapter Three) but for now, suffice to say that during CFS/ME the body has a stronger and more erratic presence than in health.

Another absence arose during my interviews: the absence of the body from participants' imagined future recovery. When I asked my informants what recovery would mean to them, not one referred to the state of their body. The most common answer was that recovery would be the ability to return to work and the old life, often expressed alongside a sense of energy and wellness. Such sentiment is reflected in the following interchange I had with Beth, the youngest of my participants, and also the most recently diagnosed, having had CFS/ME for approximately one year.

Courtney: What would recovery mean to you?

Beth: Oh it would be amazing! I would get back to my life, the way it was, and then a lot of people say "oh if you do get better Beth, you want to be careful, you don't want to have a relapse" ... but I just want the busy life I had [laughs].

Courtney: Do you think if you got better you'd just jump straight back into it?

Beth: Oh yeah, 'cause last week I started feeling really good and I was working like full time<sup>26</sup> so yeah totally, definitely, and that's something you've really got to watch ... 'cause you get so excited.

As in this exchange, recovery is frequently characterised in functional and affective terms. When well, CFS/ME sufferers want to return to full time work, resume their social lives, renew their gym memberships, and so forth. They want to feel well and energised. What they do not want is to continue thinking about their bodies. Of course a healthy and functioning body is implicit to all these responses, but the very fact that it is implicit suggests that the recovered body is a silent one. CFS/ME changes the body in such a way, and to such an extent, that it becomes a prominent object of consciousness and concern. Sufferers become aware of their bodies both without choice, since they are often in pain or incapacitated, and of necessity, since awareness of oneself is essential to coping with CFS/ME. As we will see, this refocused awareness engenders both novel conceptualisations of the body and self, and new relations between them.

### **The emergence of agentive bodies**

One of the most illustrative ways in which people reconceptualise their body and its relationship to themselves is in descriptions of the body as agentive. Not only does the body appear to act independently in such depictions, it typically does so in opposition to the individual. Though such descriptions discursively divide self from body, the issue is in people's inability to divorce themselves from the suffering body. Two of my informants report the onset of CFS/ME through the body in remarkably similar ways. Carol (58) said, "I just got overwhelmed really, and then my body said 'enough, collapse, go to bed'". Similarly, Mandy explains that she feels she never abused her body, but says "I probably haven't given it enough rest, that's the only thing, so it's decided that 'right, well I'm going to give you *years* of rest now!". In both cases CFS/ME is presented as a capricious catalyst for the body's rebellion, after a lifetime of being taken for granted.

Other participants envisioned their bodies more cynically. Lisa told me her body was "rebellious, I think it like, mounts an attack on my self". I asked Toby, a 47-year old doctor, what he thought was happening in his body when he had post-viral fatigue<sup>27</sup> expecting a medical answer; however, he replied with the following:

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<sup>26</sup> This week of work had pushed Beth into a crash, which she had been recovering from for several days when we met.

<sup>27</sup> Toby was the only one of my informants who did not technically have CFS/ME. He suffers post-viral fatigue, which for him is a recurring condition that usually affects him for around six months after a viral infection.



...it's like the body's fooling me into thinking that I'm having another illness, a worse illness, so basically there's no pathology, there's no um virus, there's no bacteria, there's no cancer, there's no autoimmune disease charging on in the background, but ... the brain is saying that you're unwell.

The body (and brain) here is a trickster, and is placed in opposition to Toby, he being certain "there's no pathology", and his body insisting there is – or behaving as though there was regardless. Two of my participants provided similarly agentive descriptions, though with somewhat less animosity. Both of them utilised the imagery of machines to convey their thoughts on their bodies. Kate, 25, told me with traces of both humour and empathy:

I kind of imagine that my body is actually just trying to do its best while it's pretty much like running on a third of a tank, you know instead of a full tank... I imagine my brain as being something that kind of lies there and gives off a few electronic sparks in this tub of water that's a bit murky.

Mandy imagined her body as an engine that had not been properly tuned, and was thus too inefficient to collect all of the nutrients it needed. Implied in both of these accounts, particularly Mandy's (and notably missing from those above) is that the inefficient engine that is the body is reparable. Given a tune up or a full tank of gas, the engine will resume "chugging along like an engine's meant to". The body, if provided with enough rest, nutrients, and medicinal supplements, might likewise return to a state of wellbeing. This mechanistic imagery is deeply ingrained in popular and professional thought, first appearing in the prescient writings of eighteenth century physician-philosopher Julien Offray de la Mettrie, who wrote of *l'homme machine*, man as machine (Smith 2001). This has been elaborated in recent years, in Martin's (1987) discussion of women as reproductive machines, and Lakoff's (1987) mind as machine paradigm, wherein the mind is abstracted and endowed with algorithmic qualities. Machine motifs make CFS/ME knowable, and logical. I argue that these provide a way for people to make sense of their bodies as they are being disrupted and alienated by illness.

### **Being-in-the-world with CFS/ME**

Living with CFS/ME destabilises the mutual engagement between sufferers, the afflicted body, and the worlds they inhabit. Symptoms such as sensory sensitivity and brain fog disrupt individuals' most immediate perceptions, which in turn shape the ways in which they conduct their lives, as daily routine, basic bodily action, and social interaction all shift accordingly. Individuals with CFS/ME occupy the world differently because they *encounter* it differently, living through a body reconstituted by illness. My informants' accounts, which follow, illuminate the subtle ways CFS/ME manifests in the minutiae of daily life; drawing

upon the work of Thomas Csordas (1990) I analyse this as an embodied way of being that shapes, and is shaped by, both perception and practice, from the body out.

Many of the symptoms associated with CFS/ME alter individuals' most immediate experience of the world. For example, sensory sensitivity is a common symptom of CFS/ME. Several of my participants are acutely sensitive to light and sound, to the extent that for Daniel (41), the sound of a dog barking down the street – to me distant and muted – can be physically painful. Harry told me that recovery would be not having “to feel confronted by someone’s perfume”, highlighting how everyday substances can have disproportionate effects on the body affected by CFS/ME. To people like Daniel and Harry, a bright day or ambient noise are no longer unnoticed aspects of one’s environment; they become instead pervasive influences that infiltrate the body and amplify pain and fatigue. Often the only way these people can cope with such an assaulting environment is to shelter themselves. Rosa was so light sensitive during her worst period that she was confined to bed, the curtains drawn, unable to even see her children. At the support group meeting I attended, the leader drew the blinds and turned off the main lights so as not to discomfort any attendees.

In the opposite vein, brain fog dulls people’s awareness of their surroundings. As Daniel explained, “why people refer to it as brain fog is because the interface between me and the real world is getting foggier and foggier”. This, coupled with the physical incapacities of CFS/ME, helps to understand Jess’s comment that “your day just gets smaller”. Jess shared a small, multi-storied townhouse with her boyfriend in an affluent Auckland suburb. I met her in the shared courtyard outside before our interview, and walking through the front door was immediately faced with a set of stairs. For some time while suffering from CFS/ME, Jess had been unable to walk up these stairs without resting halfway. She would have her groceries delivered and cook her dinner with rests during the process. This, she explained, became the focus of her days. Daily routine, and the physical layout of people’s homes can become challenges in and of themselves.

People’s engagement with their worlds are interrupted in less tangible ways as well, and perhaps the most salient example of this is individual’s perceptions of time. The body with CFS/ME experiences time differently, both in the immediate present, imagined future, and remembered past. Rosa describes the painful passage of time from when she was first diagnosed, after the doctor had told her it would take her two years to recover, saying “I can just remember thinking, two years? I don’t think I can get through the next five minutes!”. That was almost three decades ago, and she was still not fully recovered when we spoke. Describing the period in which she was bedridden, she told me “I had a clock, and I used to watch it and think, ‘if I can get through the next five minutes’ – and I used to do that all day, to get through the days”. Time for Rosa was achingly slow, and in the depths of CFS/ME, awake

and aware but hopelessly exhausted and in pain, she was acutely conscious of every moment. Objective measures of time gave Rosa a comfort, and also a seemingly unattainable promise – two years until recovery, three days until a crash would be over, five minutes closer to the end of another day of suffering. Harry, reflecting on the world from his often-lonely little cottage, simply said, “where have the last ten years gone”.

Byron Good (1992) discusses this sense of time in relation to chronic pain, saying, “the building blocks of the perceived world – time, space – begin to dissolve”. Time and space are the materials with which people construct their world and their lives within that, and when these are shaken by pain or illness, people are ontologically uprooted. Drawing on the work of Elaine Scarry (1985) Good says later that “pain slows personal time, while outer time speeds by and is lost... space and time are overwhelmed by pain, and the private world not only loses its relation to the world in which others live, its very organising dimensions being to break down. Pain threatens to unmake the world”. CFS/ME likewise ‘unmakes the world’, in diverse ways that often originate in the body. In the passage above, Rosa and Harry described their distorted sense of time, and the conflict this entails. Elsewhere Rosa explained that when she is tired she loses the sense of where her hands and feet are. Unless she is looking directly at them, she is unable to locate these parts of the body. This suggests a spatial disruption like that which Good (1992) discusses, as CFS/ME disorients sufferers both temporally and spatially. Here, as with chronic pain, CFS/ME not only unmakes the world, but also the body within it.

Good’s reflections cannot be applied to CFS/ME unproblematically, however. Time, for my participants, was closely bound up with their sense of energy. Most people described how they would plan their weeks so that they had only one commitment every few days. They closely monitored the state of their body, specifically their sense of energy, and conducted their lives accordingly. Thus, time for my participants is not only something uncontrollable and disorienting; the organising capacity of time is not always lost in CFS/ME. Rather, my informants draw on their embodied sense of wellness or illness, and make use of time accordingly. They use time in the most efficient manner possible to them, say, by scheduling their activities for the time of day they feel their best. Or, they use time as a gauge, to monitor their improvement or decline, as Rosa was doing with her bedside graph mentioned earlier. Good’s statement that “pain slows personal time, while outer time speeds by and is lost”, is true in a sense for CFS/ME – time certainly seems to slow for many of my informants, and its loss is poignantly lamented by Harry. However, if pain (or here, fatigue) does threaten to unmake the world (and often it succeeds, at least in bouts), people also rebuild their worlds and reorganise their lives. Bringing together their embodied knowledge with objective measures of time, or an awareness of their surrounds, they press on within the constraints of

their illness, adapting to the new limitations of their bodies, their time, and the worlds they inhabit.

The experiences I have just recounted describe a process of abrupt change and adjustment common to most of my participants. Illness disturbs the normal contiguity between the body and world, by making ordinary phenomena affronting. In response, people withdraw or adapt, developing a repertoire of techniques (e.g. moving more slowly) that gradually become second nature. This can be further elucidated using the concept of embodiment, as proposed by Csordas (1990, 1993). For Csordas the body is “the existential grounds of culture” (1990:27), the site of ones most immediate encounter with the world, and an agent for acting within it. This dialectic of body and world, framed through embodiment, is broken down by Csordas (1990) into two components, perception and practice, which he elaborates with reference to Merleau-Ponty (1945) and Bourdieu (1972), respectively.

From Merleau-Ponty, Csordas (1990) borrows the notion of the pre-objective, to describe the purely experiential moment before the conscious mind begins to make sense of a phenomena. With the pre-objective, Csordas (1990) seeks to account for “perceiving in all its richness and indeterminacy” (Merleau-Ponty as cited in Csordas 1990: 9). The pre-objective makes perception an embodied experience, since perception takes place in the body before the mind. In the case of CFS/ME perception may be muted by brain fog, overwhelmed through sensory sensitivity, or more subtly shaped, as the fatigued body is oriented anew in time and space. As individuals’ perception alters so too do their operational ways-of-being, through bodily practice. Here Csordas (1990) adopts Bourdieu’s (1977) concept of *habitus*, those unconsciously acquired dispositions that structure, and are structured by, one’s engagement with their social and material world. The *habitus* is embodied, manifest in the habituated mannerisms of the body, in one’s movement, conduct, perception and posture. These dispositions operate below the level of consciousness for most people, and are typically shared between members of certain groups, being culturally patterned. It is thus through the *habitus* that practice is embodied.

These categories show just how thoroughly sufferers embody CFS/ME. Their foremost ways of apprehending the world are reshaped by their illness: muted by brain fog, overwhelmed through sensory sensitivity, or more subtly shaped, as the fatigued body is oriented anew in time and space. As individuals’ perception alters so too do their operational ways-of-being, through bodily practice. Practice too changes: my participants repeatedly described the ways they refined their bodily, behavioural actions in accordance with their physical limitations. I found that this was actually observable in my interviews, especially with the people who had had CFS/ME the longest. Harry, for example, walked very slowly

down his driveway and around his house. He was one of the first people I interviewed, and at the time I had thought he just seemed like a very peaceful person. It was only later, when listening back on our discussion, that I realised his slow movement and supposedly calm manner were, at least partially, a product of his illness. Several of my participants lay down while we spoke, and one, who had trouble sitting for long, stood up almost unconsciously and stretched as she answered my questions. My participants' ways of being in the world alter as CFS/ME permeates their bodies. They are forced to reorient themselves in the world through their bodies, overcome with symptoms and newly constrained. Their most immediate modes of apprehending the world are transformed by illness, and this manifests physically as the long-habituated proclivities of the body shift.

An embodiment approach can enhance our understanding of the lived experience of CFS/ME by tracing the shifting connections between the afflicted body and the world in which it resides. However, in one respect this concept is problematic for CFS/ME. One of Csordas' primary aims in developing his theory of embodiment is to improve "the study of culture and the self" (1990:5) by collapsing the dualities of body and mind, subject and object. Embodiment, for Csordas, is a tool to enable this collapse. My problem is with the dissolution of a body-mind duality, because as I have shown, these categories are important for CFS/ME: my informants objectify their bodies in novel ways (as machines, as agentive), just as they work to connect and uncouple these with their minds. From the perspective of my participants these dualities are all but collapsed.

### **Disentangling the body and mind in CFS/ME**

Conceptualising and untangling the notions of 'body' and 'mind' is something theorists have grappled with for years, and something my participants also sought to figure out by making connections between their bodies, minds, and illness. Jess touches on this in the statement below, where she discusses how she was uncomfortable with her doctor's suggestion that she go on antidepressants immediately after diagnosing her. She said:

I was quite averse to that because I knew the issue was not psychosomatic and it – well it's an interesting thing because I do feel like it's neurological but I just didn't see how the drugs would help me... I didn't take them until about 18 months ago, so maybe about halfway through, when I went into relapse phase, and it has such an emotional effect on me, because I'd been doing so well and then I went into relapse phase – so there was a breaking point for me where relapse was just so heart-breaking that I thought, ok maybe now I'm at the point where I needed to take this medication, and [my doctor had] described it as acting like a buffer in those times of relapse when the emotional side of the illness gets too much, so I'm taking it more as an emotional support rather than a physical support, but I didn't like the fact that my doctor thought that would

be a good cure to start with, 'cause I think it's unrelated to the physical symptoms.

For Jess, trying to figure out what part of her CFS/ME is physical and what part is emotional has consequences for the treatment she will adopt. The physical symptoms of her illness are the source of her emotional distress, which she considers to be neurological, but not necessarily in her mind. Hers is one of many instances in which my informants sought to unravel psychological and somatic aspects of their illness, and resurrected the body-mind dichotomy in doing so. CFS/ME runs its course along multiple planes, of which the body is but one.

The mind serves two important roles in my informants' descriptions. First, it is a site on which symptoms play out, just like the body. Brain fog is one example, and the majority of my informants also reported psychological symptoms. In contrast to previous studies of CFS/ME (Surawy et al, 1995; Cohn, 1999; Asbring and Närvänen, 2002) I did not find that my participants were particularly averse to the notion of having psychological comorbidity with their illness; in fact most of them freely discussed any accompanying anxiety or depression they had experienced. Recent years have seen prominent campaigns in New Zealand aimed at reducing the stigma around mental illness, and I would speculate that perhaps my participants' relative ease with this aspect of their illness might be due to a greater acceptance of depression and anxiety than CFS/ME itself. Issues arose only when people were given a psychological diagnosis in the place of a physical one. For example, Lisa was diagnosed with depression by her doctor despite her conviction that she had a physical illness. This misdiagnosis not only left her sleepless for a fortnight due to the antidepressants she was prescribed, but caused her to doubt herself and her sanity. Some of my other participants had similar experiences being misdiagnosed by doctors who they say did not know of, or believe in, CFS/ME, and instead resorted to explaining their problems as mental illness. Swoboda (2006) also found this in her study of contested illness: her participants acknowledged a psychological component of their illness, but felt that this was not the primary cause or symptom. This conviction is often hard-won, however, as continually being told they are mentally unwell by authoritative figures (i.e. doctors) pushes people to wonder if they really are losing their minds (Ware 1999). My participants did not deny that they had the prescribed mental illness *per se*, but took issue with the fact that this masked the underlying condition, CFS/ME. Most of my participants, however, were very accepting of their psychological symptoms, which were often spoken about in the same breath as all their other symptoms. Thus the mind, like the body, is susceptible to medical impairment by CFS/ME.

Moreover, the wellbeing of each is directly connected, and a worsening of physical symptoms will often precipitate an emotional or psychological slump. Rosa tells how this sequence plays out for her when talking about the depression she sometimes got with CFS/ME:

...this wasn't a pervasive depression that was there all the time, this came specifically when my body had done too much and I started to crash again. I could feel this hopelessness coming on and it would lift as I started to improve and I found that I could feel myself going down, that was the scariest because you never knew how far down you would go before you'd stop.

In Rosa's account a physical deterioration brought on a depressive spell (which itself was anticipated intuitively), but she differentiates between the depression she gets as part of her CFS/ME and that which she felt years earlier when suffering from post-natal depression. Another informant, Vicky, who at 44 was a similar age to Rosa, also emphatically distinguished between Depression, seen by her as an illness in its own right, and the depression she experienced alongside CFS/ME. What seems to occur is not so much the comorbid CFS/ME and mental illness that appears in much of the literature (ter Wolbeek et al 2011), but a convergent physical and psychological deterioration that is harder to tease apart. This idea of a physical crash precipitating an emotional one was common to many of my participants. For many it simply seemed logical: of course you will get depressed if you have to spend months bedridden and in pain. Julia (55) referred to the fatigue component of CFS/ME as "soul destroying". Emotional and physical distress are in many cases different facets of a single experience.

The mind's second role in this illness is as a medium by which people can take control of their wellbeing. Mandy explained this in detail, telling me her process of coming to terms with her illness, reconceptualising her depression as a part of her illness instead of her self, and trying to distract herself and accept her state of health at any given time. Similarly Kate (25) spoke about the importance of not dwelling on the negative aspects of the illness, saying that "if you concentrate on what you can do and what you enjoy ... you have freedom in that". Beth and Tess had both tried lightening therapy, a somewhat controversial treatment that engages the power of the mind to overcome CFS/ME by focussing on (and supposedly thus manifesting) energy and positivity, and refusing to concentrate on negative symptoms<sup>28</sup>. Though neither had completely recovered, both of them credited this as a turning point in their time with CFS/ME. In these ways my participants engaged their minds to help cope with the suffering brought on by the illness.

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<sup>28</sup> Lightening therapy is a British practice, brought to New Zealand by a woman who used to have CFS/ME and says she was cured by this practice. It is run in small groups as a three day course, costing \$1300NZD.

At times the dualistic mind-body model recedes, as my informants sought out more holistic ways of describing CFS/ME. One person said she used the term ‘yucky’, then went on to say “the best way to describe it is you feel ‘off’”. Another, Carol, said:

I find it very hard to explain symptoms, it’s such a funny thing. People think you just feel tired all the time but you actually feel *sick* and tired. You get this sick feeling, so ... in the beginning when I got sick I was very hypotensive, I got a bit of fibromyalgia<sup>29</sup> down my arm, I felt nauseated and I was off my food, and I was tired of course, and anxious about everything ... but it’s a feeling of being sick.

Carol lists both physical and cognitive symptoms, but concludes by blurring the distinction between them: *it’s a feeling of being sick*. Such an account suggests that the CFS/ME cannot be fully communicated within the strictures of a mind-body duality. Here, the illness is too pervasive to be contained by either body or mind, and instead produces a feeling of sickness.

Another way people circumvent the traditional mind-body duality is by endowing the often-abstracted mind with a corporeal quality. This is exemplified in Mandy’s statement:

...when you’re in those states, in that brain fog and in that depressive state it’s like, ok this is how I describe depression, it’s like, when you have a broken leg you can’t run on a broken leg, it’s the same as when you are depressed, the chemicals in your brain – your brain is broken, that part of your brain is actually not working, it’s actually broken – you can’t use your brain to get yourself out of it, you can’t, it’s just the same as you can’t walk on a broken leg, you actually need to just let it, kind of heal really...

Likening the depressed mind to a broken leg confers a sense of tangible injury and goes some way to explaining the difficulty of having this depression. Concepts of the ‘mind’, ‘brain’, ‘neurology’, ‘cognition’, and even ‘head’ all appeared in my interviews, and blur together the psychological, emotional, cognitive, and conscious aspects of CFS/ME. Attributing aspects of CFS/ME to neurological impairment gives the intangible mind a biological grounding. As Harry said “they say it’s all in the head, well yeah, I think there is something wrong in the head [laughs] but it’s not in your imagination”. What is ‘in the head’ ranges from the oft-cited mental illness, the more ambiguously labelled emotional distress, cognitive issues like concentration and memory, and the actual biological processes of nerves, synapses, and so on. As my participants made clear time and again, the mental and physical aspects of their illness are equally legitimate, and can be equally incapacitating. They need not always be distinguished in people’s descriptions, but the mind-body distinction clearly has both conceptual and pragmatic utility for CFS/ME sufferers.

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<sup>29</sup> Hypotension is low blood pressure, and fibromyalgia here refers to the pain in Carol’s arm, though this is an illness in its own right.



The finding that the body-mind dualism has some value for CFS/ME aligns with Jean Jackson's (2005) work on chronic pain. Chronic pain, she notes, is both physiologically expressed and subjectively experienced. As in the case of CFS/ME, this transgression of boundaries confounds traditional biomedical models, which define disease as either physiological or psychological, but rarely both. She also notes the tension in how patients articulate this duality, explaining that though "patients' understanding of mind-body integration was often relatively sophisticated and nuanced" they often fell back upon a "hyper-Cartesian idiom" to validate their illness in the eyes of others (2005: 344). A complaint that cannot be squarely located in the body may be viewed as suspicious, and thus throws a suspicious shadow over the complainant. In my work participants move between modes of explanation, sometimes moving beyond dualisms, and other times returning to them to emphasise the nuances of their illness.

In the case of CFS/ME then, Csordas' endeavour to collapse mind-body dualisms does not quite fit. The mind-body dichotomy is a flexible construct that people actively engage to understand and articulate their experience of illness. Sometimes this means emphasising the divide between body and mind, and other times surpassing it; the important point is that it cannot be collapsed once and for all for CFS/ME sufferers, because it is useful. However, this does not make the endeavour of embodiment void. The concept illuminates the nuances of CFS/ME, revealing the minute bodily changes that cumulatively transform sufferers' being-in-the-world. Thinking of CFS/ME as embodied deepens our understanding of the lived experience of sufferers. Additionally, I would argue that by acknowledging the significance of mind-body dualisms in CFS/ME, we improve "the study of culture and the self". Doing so highlights just how culturally ingrained Cartesian imagery is, and how CFS/ME, as a cultural object, necessitates its resurrection in order to be understood. Csordas' theory of embodiment cannot be transposed onto CFS/ME unchanged, but remains a useful theory with which to critically reflect upon the lived experience of this illness.

## **Conclusion**

Experientially rich, biologically variable, and symbolically potent, the body is central to CFS/ME. This analysis began with the biological body, with my immune assessment affirming a contrast between the bodies of my participants and bodies of those without CFS/ME. The DBS CRP results suggest a physiological correlate of CFS/ME of tightly clumped, suppressed immune function, and several distant outliers. Just as the DBS results suggest a distinct biological character of CFS/ME, so too do my participants describe a distinct bodily experience of their illness. My participants expressed deep, if conflicted, engagements with their bodies, which were transformed by their illness, made unfamiliar and oppositional. The

body with CFS/ME is volatile, its energy peaking and dropping, subject to strange symptoms and sensations. People make sense of this through metaphor (the machine) and in relation to the mind, the two being at times conflated, and elsewhere emphatically distinguished as people argue for the biological grounding of CFS/ME.

The body is made meaningful by comparing the past body – quiet, compliant – to the present one that is obtrusive and in pain. The change from healthy to ill body, invisible to overt, has been characterised as forms of absence (Leder 1990): the body absent from attention in health; the body absent from wellness when ill. I expand on this, arguing that as my informants adjust to the constraints of CFS/ME, they develop a ‘new normal’, and the body (in its sick state now) recedes again to the background of their consciousness. Considering my participants’ experiences as embodied highlights how CFS/ME reconfigures the most immediate encounters between individuals and their surrounds. Symptoms like sensory sensitivity destabilise the body, which thus inhabits the world differently. My informants adjusted their conduct to cope with the physical limitations their illness imposes, and in doing so they would accumulate embodied knowledge, a type of knowing that resides in the body, and feeds back into their ways of being-in-the-world. This embodied knowledge is also drawn upon in people’s explanations of their illness, which I turn to in Chapter Two.

## **CHAPTER II**

### **EXPLAINING CFS/ME**

#### **Introduction**

In this chapter I examine how my informants make sense of their variable bodily experiences in a context of medico-scientific uncertainty. CFS/ME is a contested illness (Dumit 2006). The scientific knowledge of this condition is conflicted, and though the International Association for CFS/ME (IACFSME) disseminates information to practitioners, none of my informants described treatment along the lines they recommend. The uncertainties around CFS/ME, and its individual variability, make it hard to apply what *is* known, but also make space for patient-driven explanations. My participants brought together embodied knowledge, personal experience, and medico-scientific research to construct composite explanations of CFS/ME that align with their own experiences and beliefs. Drawing selectively upon a conflicted body of scholarly literature enables CFS/ME sufferers to ground their illness in the dominant biomedical paradigm of our society, and thus stake a claim for medical legitimacy; referring to embodied knowledge, key illness moments, and circumstantial detail enables them to situate their condition cogently in their own lives. These explanations thus fulfil both a personal function, helping people make sense of what is happening to them, and a social one, by articulating CFS/ME in a way that others can understand and accept. Despite its unpredictable and variable nature, individuals' experiences of CFS/ME overlap, eliciting shared understandings and explanations of the illness. Anthropologist Simon Cohn says such overlap arises "not directly from communicating with each other but from an affliction that generates common responses from pre-existing shared cultural values" (Cohn 1999: 197).

I use an explanatory models framework (Kleinman 1978) to order and analyse my informants' illness explanations. Doing so allows me to tease out the types of knowledge that people pull together to understand their condition, and to get at their underlying logics. What this reveals is a two-tier explanation used by many of my participants, wherein they first explain CFS/ME as a result of various influences specific to individuals' lives, then later in the interviews expand this to draw upon extensive biological detail.

#### **Getting to know CFS/ME**

##### *Embodied knowledge*

When living with an illness as variable as CFS/ME, the irregularities of the body come to constitute a type of certainty. As discussed in the previous chapter, the body is transformed by CFS/ME and informs new ways of being. Months or years spent living with the illness

produce a type of knowledge that is grounded in the processes and form of the body. Lisa alluded to the embodied knowledge that began to develop right at the beginning of her CFS/ME. She told me she would go to the fridge to get an instant breakfast drink, and walking back to her room she “just knew” she had to sit down immediately, or else she would collapse. She would sit, and stay on the ground until she felt strong enough to get up and return to bed. Similarly, Rosa sometimes got painful big lumps up her arms when unwell, and she said that before they appeared she could feel the pressure building up her arms, warning her to stop using them and rest until the sensation subsided. The embodied knowledge that prompts Lisa to sit before she collapses, and Rosa to rest before her arms swell, is a tacit type of knowing, evident in these women’s actions before they come to consciously understand it.

Rappaport (2001:100) underscores the salience of embodied knowledge, saying “it is surely true that no other knowledge matches the potential self-knowledge that the body possesses, the body cannot know something other with anything approaching the subtlety and complexity, the immediacy and inescapability that it can know itself”. The experiential nuances of the body comprise a robust source of knowledge that only the individual is privy to. This intense bodily knowing, like that which Lisa and Rosa recount, helps people develop an understanding of their illness that is located primarily in their bodies. Doing so affirms for them the biological reality of a condition that has historically been passed off as ‘in the head’, and acts as a deeply personal claim that fills out the medical explanations they also invoke. Though all states of health entail some forms of embodied knowledge, CFS/ME sufferers may rely more heavily upon their embodied knowledge given the uncertain medico-scientific perspectives that would ordinarily take precedence. As Jordan (1977) argues, multiple ways of knowing can coexist in the absence of one hegemonic, authoritative knowledge. The developing biomedical knowledge of CFS/ME coexists with individuals’ lived ways of knowing, allowing my informants to produce explanations of their illness that bridge the bodily and biomedical. All of these factors are placed in the context of everyday life, and are thereby made specific to the individual in question.

### *Invoking the everyday*

In my interviews, once the standard demographic questions were out of the way, I launched into the topical part of the conversation by saying, “do you want to tell me about how you first found out you had CFS/ME<sup>30</sup>?” I wanted this question to be open-ended, so that people could answer in whatever way seemed most logical to them. Not a single person attributed their CFS/ME to simply a virus, or stress, or any one cause. Instead they cited a whole host of

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<sup>30</sup> I used CFS in most interviews, as this was deemed agreeable by participants at the outset. This title was often agreed upon despite a mutual understanding of its inadequacy.

factors, which explicitly or not were drawn into their story of CFS/ME. Carol began her answer by talking about the various health issues she had had the previous year, shortly before developing CFS/ME. A practice nurse, she had contracted bronchitis during the winter, and had a recurrent urinary infection that was proving hard to clear. The physician she worked for prescribed her the wrong antibiotics (“there was a bit of mismanagement there”) and she ended up on others for a month as a result. When she returned to work in November she felt faint and dizzy, “and then one day – well I didn’t collapse at work but I just sort of thought, ‘something’s wrong here, something’s not right’”. The locum at her practice attributed this to stress, which Carol substantiates by citing pressure from the primary healthcare organisation (PHO) that oversaw her practice, the fact that she was the only nurse in the clinic, and her own perfectionist tendencies. She went home, and on the locum’s advice took some citalopram<sup>31</sup>, which only exacerbated her symptoms. The following day her boss made a house call, whereupon he diagnosed her with post-viral fatigue with an efficiency she attributes to him having had post-viral fatigue himself. A local specialist later diagnosed her with CFS/ME when it became clear that her condition was persisting.

This is a fairly straightforward explanation, and was recounted in one go. Over the course of our 90-minute interview, however, Carol elaborated upon this account. She cited a teenage episode of glandular fever, and speculates that perhaps this had weakened her immune system and increased her susceptibility to CFS/ME. She has allergy problems (which she refers to as genetic) and thinks this has given her poor lung function, making it hard to exercise. She had a little laugh admitting that she didn’t exercise as much as she ought to anyway, which probably does her respiratory health no favours. Yearly flus were also a common feature of Carol’s life, and more recently the bronchitis, which together she thinks might have been the trigger for her CFS/ME. On top of all this she told me of a relationship that “broke up a couple of years ago in a not very nice way, really”, leaving her feeling sad and exhausted. This compounded her work stress as the PHO imposed more and more administrative duties, while she also tried to pick up after the ageing doctor and deal with the sometimes-difficult patients. On top of all this, at fifty-eight Carol was feeling her age, and at the same time dealing with menopausal symptoms that many nights left her sleepless. At one point in the interview she funnelled this diffuse explanation down, saying:

It’s sort of like a line of ducks sitting in a row and I got chronic fatigue because of those three factors... I felt that I had suffered emotional stress with the relationship breaking up, I had suffered mental pressure from the challenges of work, and I had physical symptoms. I think it was a combination of the three.

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<sup>31</sup> Citalopram is a pharmaceutical anti-depressant, frequently prescribed off-label for a range of conditions.

Carol's account is typical of many of my informants'. All acknowledge some biological basis of CFS/ME, but when explaining how it transpired in their own lives the illness is portrayed as a product of many interacting social, familial, occupational, *and* medical factors. CFS/ME becomes meaningful to people only in context; it is not an isolable illness, but one deeply embedded in a full and complex life. Invoking such a wide range of influences makes a perplexing condition logical in relation to people's lives.

#### *Medico-scientific knowledge*

Accompanying the above explanations, where people situate CFS/ME in their own lives, were repeated invocations of a sophisticated medical dialect. Toward the end of my interviews I asked people what they thought caused CFS/ME, inviting them to speculate or guess at its origins. The answers I received departed significantly from those given earlier, when people were talking exclusively about their lives. Carol, who identified so many different influences that contributed to her illness, offered the following explanation when I asked about the cause of CFS/ME:

Well I'm not a particularly academic nurse, I always say this, I'm a practical nurse so the whole physiology of it is all beyond me, but basically I understand that *it is a hypersensitivity of the immune system, that the immune system has gone haywire, and so that's why I have the hypersensitivity to the chemicals and that's why I can't have the flu vaccine* because it will actually stimulate my immune system even more and my immune system is over stimulated at the moment, it needs to calm down, so yeah just in a nutshell that's what I would say it is, it's like overstimulation of the immune system, the immune system's gone haywire. But I know there's a lot more to it than that.

In this explanation Carol draws on considerably more 'scientific' detail than in her earlier one; her relationship, her job, and most of her health problems scarcely feature at all here, replaced instead by a focus on her immune system. From the enormous body of evidence on CFS/ME, Carol selects the hypersensitive immune system as the explanation that best aligns with her own illness experience. To her mind the fact that she is chemically sensitive and cannot receive vaccinations supports an immunological cause of CFS/ME. This manner of explaining CFS/ME was fairly typical of my participants. Rosa's response, though differing in the details, followed a similar pattern. She told me:

I think it's gotta be something to do with – it comes from the outside, it changes the blood or something because *why else have we had the outbreaks?* You know we've had the outbreaks in Western Australia, we've had them in London, we've had a couple in America, one down in Tapanui, these whole outbreaks where people come down with fairly similar symptoms...

...and I remember saying to [my specialist], “if I had a blood transfusion, would I feel better?” And she said, “yep, for 8 hours you would feel perfectly normal”, and she said “then all your symptoms would return” so to me it’s gotta be something that’s carried around in the blood or circulating in the blood, I mean I know that there’s abnormal – *the latest research that backs up other research* that’s been done before, is that the muscle tissue is abnormal, lactic acid levels are high and recovery rates longer<sup>32</sup> and things...

...and sometimes, even with me you know *that little tablet that helped me that was an antioxidant* so basically what that did was cleaned up my blood and cells so it took out whatever toxins were being produced.

Citing recent published research, the expertise of her physician, and historical outbreaks, Rosa develops an explanation for CFS/ME based on biomedical logic that makes sense in relation to how her own illness has played out. In this case, she justifies her claim that it is “in the blood” by recalling the fact that an antioxidant had significantly improved her condition. Carol and Rosa show how a huge amount of very complicated scientific research can be judiciously appropriated to develop an explanation that aligns with both their own lived experience of CFS/ME, and medical explanations imbued with cultural authority. This two-tier explanation proved characteristic of my informants, who often used specific bodily systems to connect their lived experience and their knowledge of the biology of CFS/ME.

### **Stress, immunity, and neurology: linking biology and everyday life**

References to stress, immunity, and the brain were recurring features of my participants’ illness explanations. These three bodily systems (in the medical literature referred to as immunological, neurological, and endocrinological) feature prominently in research around CFS/ME, and likely interact to produce the illness (ter Wolbeek, van Doornen, Kavelaars, van de Putte, Schedlowski and Heijnen 2007; Dietert and Dietert 2008; Lorusso, Mikhaylova, Capelli, Ferrari, Ngonga, and Ricevuti 2009). Participants’ references to the brain, immune system, and stress all serve to explain people’s subjective experiences of CFS/ME in a manner that aligns with the biomedical model. My participants generally cited at least one of the three when explaining what causes CFS/ME. Biomedical explanations are key sources of validation for which contested illness sufferers strive (Dumit 2006, Ware 1992). Here, they do so by appropriating a medical dialect that carries cultural authority, and using this authority to argue for the legitimacy of their own illness.

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<sup>32</sup> These statements are grounded in a conflicted body of literature, some of which supports Rosa’s interpretations, and some of which refutes them. Lactic acid, for example, has been shown by some studies to be unusually high (Vermeulen et al 2010) and in others to be the same as in controls (Jammes et al 2005, Sargent et al 2002) leading Jammes and colleagues (2005) to suggest that perhaps this is characteristic of a sub-group of CFS/ME sufferers, but not all.

The immune system was often spoken of as a way of reconciling CFS/ME with other aspects of people's health. Several of my participants described a propensity for catching colds, or an unusual resilience to them, and from this concluded that their immune systems were either over-active or suppressed, which they then claim has contributed to either their developing the condition in the first place, or their symptoms since. Also writing on New Zealanders with CFS/ME, Bell (2012) made a similar finding, arguing that the immune system served to absolve people of blame by linking their present illness to past health patterns, producing a coherent narrative to fit CFS/ME into. Recent biological research indicates that the immunological picture of CFS/ME is more complicated than previously suspected, with contradictory evidence supporting both over- and under-active immunity (see ter Wolbeek et al 2007 for the former, and de Becker et al 2002 for the latter).

Several people also broadly invoked stress as a causal factor in their contracting CFS/ME. Tess's job as a fashion buyer was so stressful that she was having heart palpitations at work, and Beth described a hectic pre-illness life juggling two jobs, full time study, and a busy social schedule. When I asked her about the cause of CFS/ME, she said with certainty that stress was a huge part of it. In my informants' accounts 'stress' subsumes many life factors: relationships, work, health, and more. To my participants, stress describes the distressing experience of pressure or strain, often due to an overwhelming number of obligations and expectations. These colloquial meanings of stress differ significantly from the biological perspective, where it refers to a "state of homeostatic imbalance" that the body rectifies by activating neurological and endocrinological resources (Sapolsky 2004: 393). Biologically speaking, the stress response is an efficient adaptive mechanism that enables individuals to cope with dangerous or taxing situations. In the case of CFS/ME, however, stress is conceptualised as anything but adaptive – in fact, it is damaging.

Both immunity and stress serve a very specific connective function, acting as links between people and their worlds. In this way people can point to aspects of their lives – be that their job, their family circumstances, their personality type – and argue for the influence of these factors on their CFS/ME using notions of stress or immunity. Furthermore, these explanations tie tidily into people's embodied knowledge, given the visceral experiences of stress or feeling run down. For example, before he got CFS/ME Harry was playing a lot of gigs with his band, and he told me that someone would always have a cold. They would be up late at night in smoky bars, coughing and continually passing on their sickness to each other. He too thought that his immune system was important to his CFS/ME, and it provides for him a way of linking his health to his lifestyle: his work – the long, late hours and unhealthy environment – was undermining his health, first to a fairly minor degree with recurrent colds, and later more seriously when he developed CFS/ME. Stress similarly provides a



connection between people's lives and illness, both in its development and over the course of the illness. While my informants spoke about their immune systems like a material part of their body that was broken down by CFS/ME, stress was described with less specificity, as a force that overwhelms and increases susceptibility. Carol said:

Some days I just thought I'm too busy and I'm too stressed, is this actually good for me, and I think that contributed to me getting the bronchitis, I think that again the – I often say that *when I used to get stressed, I got physically sick* – like other people might get mentally sick, but what seemed to happen with me was physically sick, so work stress would mean that I got bronchitis, it meant that I got the flu, it meant that I got a urine infection, whereas other people would start to sort of unravel up the top, I seem to unravel physically

Stress, in this explanation, is directly responsible for Carol's poor health. Stress makes her sick, and since work, her relationships, her other health issues cause her stress, these things are also causes of her CFS/ME. Stress also appears in discussions online, and in the literature (Ware and Kleinman 1992) as cause of CFS/ME proposed by sufferers.

Neurological references are used somewhat differently, not so much as a channel by which the world gets into the body, but as a way of unequivocally identifying a biological foundation of this invisible illness. By arguing that it has a neurological basis my informants make a claim for the objective reality of their condition. So much of the brain's workings are still mysterious that neurological explanations may accommodate some of the stranger, perceptual symptoms that people experience with CFS/ME. For example, Tess sometimes used to feel like she had hot water running down her leg when there was none, a disconcerting sensation that she said "has *got* to be neurological". Such an incomprehensible symptom, which could be passed off as completely fictive, is made understandable by locating it in the opaque yet objective brain.

These references to the brain, the immune system, and stress reflect our unquestioned ways of understanding the world and the body, through the lens of biology and medicine. By drawing them out of the scientific realm and into their daily lives, my participants align these scientific models with their affective, bodily experiences of CFS/ME. Sometimes however they turn the tables and identify medical care itself as the cause of their suffering.

### **Iatrogenesis: Attributing CFS/ME to medical treatment**

Iatrogenic illness explanations are those that identify medical treatment as the cause of illness or suffering, and they appear in a surprising number of my interviews. They do so only when people are talking about their own illness, not CFS/ME in general, and my informants never attributed their condition to this alone. However, the diversity of explanations, and the

readiness with which people speculated about the possible contributions of medical care to their CFS/ME warrants attention. The most striking instance of this was recounted by Lisa, who began the story of how she got CFS/ME as follows:

So I was going out with a guy who was diagnosed with cancer, and because he had to have chemotherapy and that makes your immune system really vulnerable, I decided to have the flu injection so that we could still be hanging out and everything while he was going through his treatment, so I had the flu injection in May 2010 and then a day or two later I just went pwoo [crash gesture with hands] and I was in bed for about three weeks and I just – it was really sudden and I didn't know what was going on.

Lisa went on to say that she was in a stressful job, which she struggled to cope with when unwell, and that she later went to her doctor who inappropriately prescribed her antidepressants. There are, therefore, multiple factors that she sees contributing to her getting CFS/ME. However, it is the flu injection that is presented as the precipitating force. In this example a preventative medical product brings on chronic illness, and she develops this further when talking about how subsequent mismanagement by her doctor only exacerbated her problems. Other participants also alluded to medical causes of their CFS/ME. Mandy developed CFS/ME after being hospitalised with vasculitis, but in the following excerpt appears to find it just as plausible that it was the treatment, rather than the infection, that made her sick:

I ended up in hospital with vasculitis ... so they basically just gave me a massive dose of steroid ah prednisone or whatever, I think it was prednisone, and I kind of, they'd obviously kicked that, the vasculitis, but I haven't been the same since. So I don't know if it was the vasculitis, or if it was the prednisone itself...

Carol talks about a mistreated urinary tract infection when explaining the beginnings of her CFS/ME; an imperfect surgery features in Toby's explanation; and though she begins by talking about a bad flu, Rosa adds to her story with a series of wrong medications, beginning with a treatment she received as a baby that eroded her stomach tissue, and saying how right before the onset of CFS/ME a psychiatrist prescribed her a dangerous combination of drugs that saw her hospitalised with scarred kidneys. Contributors to online forums list causes that range from standard pharmaceuticals, stressful clinical encounters, and in one case nerve damage from dental work.

The inclusion of iatrogenic instances in my participants' explanations of CFS/ME does not reflect a wholesale opposition to biomedicine, nor even a sense of blame or resentment. My informants still expressed hope and faith in the medical world to one day cure their ills, even when they disagreed with how this was being done or how long it was taking. I include these

iatrogenic explanations to illustrate both the persuasive power of biomedicine, and its shortcomings as perceived by my participants. Invoking iatrogenesis enables my informants to work with the common language of health in New Zealand, biomedicine. By engaging and appropriating the language of biomedicine my informants acknowledge its authority; by musing upon its capacity to cause illness in an instance where it is unable to cure, they challenge its all-enveloping dominance. CFS/ME sufferers have spent years seeking out medical recognition of their illness, and they are now in a position of having a medically-accepted illness (accepted by most anyway) without the technological means of diagnosing or curing it. The place of CFS/ME is still indeterminate, and CFS/ME sufferers continue to puzzle out their place in the medical world by both requesting its help and questioning its authority.

### **Kleinman's Explanatory Models**

To understand CFS/ME my participants switch between a vernacular of everyday life, and a selective, sophisticated medical dialect, piecing together different types of knowledge to create a logical explanation of their illness. Doing so enables them to situate CFS/ME in their individual lives, whilst retaining the sense of legitimacy the latter imparts. Approaching these explanations as explanatory models, as outlined by Arthur Kleinman (1978, 1980, 1987, 1988, Kleinman et al 1978, Kleinman and Benson 2006), furthers our understanding of how these illnesses are made more coherent. Kleinman's aim with explanatory models is to "operationalize the concept of culture in the health domain" (1978: 85), and highlight misalignments between patient and practitioner opinions on health and illness that may hinder healthcare delivery. His motive in this endeavour is clinically-oriented, but as many scholars point out the explanatory models framework is useful for illuminating the implicit knowledge systems and value judgements that underlie sufferers' understandings of illness (for an example of such work see Cohen et al 1994, Good 1987, Gregg and Curry 1994). Typically an explanatory model encompasses ideas about aetiology, symptom onset, pathophysiology, illness course, and treatment (Kleinman 1978), and whilst I covered each of these in my interviews, my focus here is primarily on causal explanations.

#### *The cultural logic of CFS/ME*

The way my informants spoke about CFS/ME reveals just how embedded the biomedical model is in everyday ideas about illness. Biomedical explanations are not only produced by my participants to strategic, legitimising ends; in most cases they simply fit with people's existing ways of understanding the world and their bodies. My participants invoked ideas of immunity, neurology, and stress to link their illness to biomedical work, and broader cultural influences can be read from these references. Immunity, as a dynamic and malleable bodily

system, is firmly rooted in Western thought (Martin 1994). Martin (1994) shows how metaphors of battle and war characterise people's descriptions of their immune systems, drawing out ideas of illness, protection, and the body under siege. Likewise, the brain has provoked fascination in popular thought for centuries. Pickersgill and colleagues label it a "cultural motif" (Pickersgill, Cunningham-Burley, Martin 2011: 347), while Frazetto and Anker (2009: 815) proclaim "we are witnessing the rise of a neuroculture (or neurocultures) in which neuroscience knowledge partakes in our daily lives, social practices, and intellectual discourses". These scholars argue that the power of the neurological lies in the idea that the essence of our selves – our identities, our subjectivity – is found in the brain, waiting to be unveiled. Sophisticated biomedical ideas filter into the everyday lives of the populace, offering CFS/ME sufferers a distilled body of knowledge with which to make sense of, and claims for, their illness. Though Pols (2005) argues that explanatory models divorce lay and specialist knowledge, in this case they illuminate the blurring of these categories.

The joint use of medical, contextual, and embodied evidence in my participants' explanations does not simply serve to explain CFS/ME. It also functions as a commentary upon the nature of the illness in the context of a technocratic, medicalising society. Irrevocably variable, CFS/ME defies codification and is consequently denied full legitimacy (Dumit 2006). By invoking medical facts in their descriptions of CFS/ME, my participants situate their illness in an explanatory framework (biomedical) that it is (at present) technologically excluded from. Many spoke with concern and frustration about the lack of diagnostic or therapeutic technologies for CFS/ME, which cannot be identified through blood tests or x-rays, and cannot be treated pharmaceutically or surgically. In a society that relies upon technology for finding and fixing disease, CFS/ME is marginalised. Constructing these composite explanatory models allows my participants to account for their illness in a way that validates their own experiences and understandings without exonerating the medical world from the task of assisting them.

#### *Explaining continuities in explanatory models of CFS/ME*

My informants' explanations almost uniformly share the two-tier structure and biological bridging I have described above; such continuity is not unprecedented. Returning to Cohn's quote from the start of this chapter we can think of these as a result of "an affliction that generates common responses from pre-existing shared cultural values" (Cohn 1999: 197). The 'common responses' Cohn alludes to are evident in the foregoing discussion: in peoples' use of everyday life, medical advice, scientific research, and their own embodied knowledge as evidence with which they build their explanatory models of CFS/ME. The 'affliction that generates' these does so by virtue of two key consistencies. All my informants have in

common the symptom of severe fatigue, but the variable, unpredictable nature of the illness is perhaps the more defining feature for most. As Daniel told me, “there’s no way I can predict ahead of time what’s going to happen”. The variability of CFS/ME resists simplistic explanations and necessitates a flexibility in coping that most of my informants were familiar with, producing a shared experience of CFS/ME.

One of Cohn’s ‘pre-existing shared cultural values’ that stood out in my interviews was the emphasis my participants placed on the importance of work. Only one of my participants was working full time, and he had post-viral fatigue as opposed to the full CFS/ME my other informants had. The rest were either unemployed, or working little jobs from home that took only a few hours per week. Such was the case for Vicky, who had a PhD in English literature and had worked as a high school teacher before getting sick. When we met she was working a “very part time sub-editing job” that she would chip away at for an hour or so a day. Telling me about this, she said:

I do value having it even though I don’t love the job itself, but I do because I would feel terrible if I wasn’t contributing to the economy at all, because you know I was a super high achiever before, and felt like I was doing important things and earning money and you know and it was really hard to lose my identity, so if I wasn’t working at all yeah I’d feel like absolute crap.

This was a common refrain amongst my informants. Most identified themselves as busy, ambitious, hard-working citizens before their illness, echoing other research on CFS/ME (Surawy, Hackman, Hawton and Sharp 1995, Ware and Kleinman 1992). They similarly lamented their inability to work fully at the time of our meetings; only one person said they had completely abandoned their previous career-oriented priorities. Some of my participants found ways around their illness to pursue work: Rosa, when she was bedridden, would iron her children’s clothes from bed; Tess would set up a stool in the kitchen so she could cook for her boyfriend; and Mandy had taken on some odd computer-based jobs on a voluntary basis, which she said is for “the fact that I feel that I’m contributing, that’s where I get the pay off, as opposed to [financial pay off]”. The ability to work clearly holds significant personal and social value to the people I spoke with, and I believe this collective priority underlies some of the common explanations I received from them. Thus when people cite a pre-illness life of heavy, stressful workloads as a likely cause of their CFS/ME, this resonates with a cultural perspective that valorises work, both for individuals and society. Likewise, when they explain the difficulties of having CFS/ME by saying how boring it is, how they wish they could return to work, they reveal their own inclinations in favour of productivity and achievement. These explanations may also lend sufferers some moral authority that is often lacking for contested illnesses like CFS/ME, by confirming that sufferers are not in fact lazy, but rather chronically

incapacitated (Sachs 2001). This contrasts with Ware and Kleinman's (1992) work however, where they argue that CFS/ME serves as a bodily protest against a culture of hard work. In both cases CFS/ME represents an inability to work. For their participants it was a way of resisting their role as workers, but for mine it was an impediment to their filling that role, which most of them very much wanted to resume.

Using an explanatory models framework it is possible to tease out the various factors that people blur together to explain CFS/ME. Frequent references to work and invocations of medical knowledge reflect broader cultural norms and values; they serve as both sense-making tools and as potent claims to moral or medical validity. When people talk about being hard working, they make a statement of their moral credibility, and argue, explicitly or not, for their *inability* to work. When they cite scientific explanations, they make a statement of the medical credibility of CFS/ME, by letting the cultural legitimacy of the medical dialect rub off on their illness. And when they refer back to their bodily experiences, or particular illness episodes, they connect all these arguments back to what has happened to them. From what is at face value an explanation based upon personal logic and experience, it is thus possible to extricate the underlying cultural knowledge, assumptions, and values that people use to make sense of CFS/ME.

## **Conclusion**

By constructing complex explanations that unite lived experience, embodied knowledge, and biomedical facts, CFS/ME sufferers make a case for the reality and severity of their illness, often in the face of contradictory, or outright repudiating medical opinion. An explanatory model approach highlights the diverse logics that underlie people's understandings of their illness, and how the different types of knowledge used therein work together to make sense of such a complex illness. Explanations of CFS/ME are a product of many types of knowledge – knowledge of one's medical history, one's stressors, one's body, of science, and of research on CFS/ME. They are also, however, a product of cultural values and assumptions that are implicitly present in their retellings. Here I have argued that my participants use these different types of knowledge, values, and norms to explain their illness in such a way that they can make it logical within the context of their own lives, and at the same time medically legitimate. In so doing, their explanations act as both a tool with which to make sense of their illness and a medium through which to challenge the shortcomings of biomedicine, which cannot yet fully account for CFS/ME. Here I have attempted to open up my informants' explanations to explore multiple ways of knowing CFS/ME, and how these work together to make a complex illness somewhat comprehensible. As I will show in the following chapters,

these explanations come into play in my participants' daily lives, where they guide their coping strategies and become social resources.

# CHAPTER III

## SELF-MANAGEMENT, CARE & COPING PRACTICES IN CFS/ME

### Introduction

Given the absence of curative treatments, *clinical care of ME/CFS involves treating symptoms and guiding patient self-management*. The goal is symptom reduction and quality of life improvement based on a collaborative therapeutic relationship. Although not all patients will improve, the potential for improvement, which ranges from modest to substantial, should be clearly communicated to the patient (IACFS/ME 2012: 18).

The above statement is taken from the International Association for CFS/ME ‘Primer for Clinical Practitioners’, which sets out *inter alia* the recommended clinical response to patients suffering from CFS/ME. This excerpt and subsequent report advocate joint, on-going management of specific symptoms, with suggestions as to how this may be carried out; for example, by having patients write out their symptoms for their doctors and taking notes that can be referred back to, and possibly administration of pharmaceuticals, which should “start low and go slow” (IACSF/ME 2012: 18). Of particular interest to me is the promotion of self-management, a form of health delivery wherein patients assume primary responsibility for managing their illness. Self-management is a product of neoliberalising health reforms that have shaped the local medical landscape in which my informants negotiate diagnoses and treatment (Trnka in press).

Self-management provides my starting point for the discussion that follows. I explore how my participants cope with CFS/ME in a political and scientific context that provides little help for sufferers of contested illness. I consider the role of medical experts and expertise in helping or hindering my participants, and explore how their traditionally vested authority is destabilized in the case of CFS/ME, where individual sufferers typically have as much or more knowledge than physicians. Equipped with this knowledge, my participants cope with their condition independently, by seeking out information on their illness, pacing their energy, and experimenting with different strategies. Many of these practices align with those promoted by self-management programmes; however, this approach is problematized by one critical shortcoming, leading me to argue that we consider people’s coping behaviours in a different light. To do so, I follow the suggestion of AnneMarie Mol (2008, 2010) that we turn to a theory of care.



### **Self-management: Context and history**

Self-management is a mode of healthcare wherein patients are seen as the primary agents of their wellbeing. Initiated for cost cutting purposes, self-management emerged alongside broader political shifts toward individuation that saw responsibility shifted from the state to practitioners, and onto patients themselves (Trnka 2012). The practice is based in the belief that through regular attendance to the body, individuals can improve their present and future health, not only by eliminating illness, but by increasing vitality (Rose 2007). Self-management typically entails two practices. First, monitoring, wherein patients regularly assess the state of their illness. This usually implicates a joint consideration of both how the patient feels (their subjective bodily experience) and some measureable assessment, often technologically mediated (Willems 2000). This monitoring, or self-assessment, is followed by self-treatment, wherein the individual responds in accordance with their assessment (Willems 2000). The patient is thus actively engaged with their condition and able to treat themselves, thereby reducing their reliance on professional help. Asthma patients exemplify this, monitoring their respiratory health through peak flow measurement, and adjusting the use of their inhalers accordingly (Trnka in press, Willems 2000). From a public health perspective, self-management is thus a programmatic means of healthcare delivery. The context in which it has emerged, however, and the new sets of relations self-management engenders, has seen self-management become a subject of social theorising.

Foucault (1986) describes the roots of contemporary self-management in his work on 'technologies of the self' and 'care of the self' amongst the Greco-Romans (Fornet-Betancourt et al 1987, Rabinow and Rose 2003). Self-care, to the Greco-Romans, was comprised of both knowing and seeking to improve oneself, "an act of self upon self, in which one tries to work out, to transform one's self, and to attain a certain mode of being" (Fornet-Betancourt et al 1987: 113). It is an active practice, requiring constant attention to both body and soul, and responsive adjustment, and this habitual pursuit of self-care was an ethical imperative. Health, and thus also medical care, were central to such practices (Willems 2000). Foucault traces the changing place of self-care over time, showing that as Christianity gained prominence the practice took on egocentric connotations, and the self, though still ideally a subject to be known, was reconfigured as something characterized by hidden truths.

Contemporary self-management programmes, with the rational, self-appraising individual at the centre, arise amidst a political climate in which state accountability gives way to individual autonomy. Sociologist Nikolas Rose (2007) writes of this shift as a product of advanced liberal democratic governance, where individuals are governed from a distance, through mediating commercial or professional bodies. Responsibility is displaced, being moved from the state to individual actors: patients, physicians, scientists and so forth. These

individuals are vested with responsibility for present and future health by a state that facilitates, without directly providing the means to enact such responsibility. One way this is achieved is through the promotion of certain self-care practices that are imbued with moral associations: hygiene or child rearing, for example (Rose 2007). This devolution of accountability is at its most prominent in the realm of health, where the physician becomes a physician-consultant, the patient a patient-expert, and patient-consumer. The latter Rose calls 'responsibilised patients': those patients empowered, or obliged, to look after themselves. Alongside this political context of shifting accountabilities is a scientific context of increasing, and apparently uncapped, discovery:

Over and above these shifts, perhaps, the novelty of contemporary biopolitics arises from the perception that we have experienced a 'step-change', a qualitative increase in our capacities to engineer our vitality... It is now at the molecular level that human life is understood... At this level, it seems, there is nothing mystical or incomprehensible about our vitality – anything and everything appears, in principle, to be intelligible, and hence to be open to calculated interventions (Rose 2007: 4).

This excerpt describes a new kind of somatic transparency, where the most minute details of individual biology become subject to appraisal and manipulation. However this produces a dilemma for the CFS/ME sufferer, whose illness remains opaque. Life with CFS/ME plays out against a political backdrop that promotes responsabilisation and self-care, but a scientific one that produces deeply conflicted information on which to act. This is the context in which my research took place, and the context my participants occupied and encountered in their many interactions with medical institutions and government bureaucracy.

### **Patient-practitioner relations**

The patient-practitioner relationship is central to self-management programmes, and faces a new set of challenges with CFS/ME. The profusion of conflicting information on CFS/ME complicates the physician's role, and presents new obstacles to diagnosis and treatment. In fact the medical endorsement provided by a diagnosis of CFS/ME is a necessary precondition of self-management. Until definitively diagnosed, sufferers cope with their illness without direction; they are managing, but are not told *what* they are managing. Lisa describes a frustrating year-long process between her first 'crash' following a flu shot, and her diagnosis of CFS/ME, and also spoke about how that affected her ability to cope later. She said:

One of my biggest concerns about the whole process towards diagnosis and then for lack of a better word recovery um it's that it's kind of designed to break down the person's resilience... you're made to question the state of your mind,

whether it's all just in your head, everyone's not believing you and it's like you get really broken down by the time you actually get a diagnosis and you kind of have to claw your way back.

The productivity and perceived value of the patient-practitioner relationship is foremost dependent upon the physician giving a quick and conclusive diagnosis. Delays in obtaining diagnosis can, as Lisa says, have long-lasting consequences for people with CFS/ME. Indeed two of my participants were told by the doctor who diagnosed them (the same doctor for both) that they would have had a better chance of full recovery had their illness been recognized earlier.

Those of my participants who were fairly unproblematically diagnosed expressed a sense of good fortune and an appreciation of their doctor's awareness. Anna, whose CFS/ME followed an episode of swine flu, said of her doctor:

I think I was really lucky that she knew about chronic fatigue, and ... once I was four months in she said, "if you're still feeling this way in two months, you *may* have Chronic Fatigue," and I think she didn't want to say it to me so I wouldn't get it in my head that I had it already, so she was very careful about it and very good about it, without planting a seed in my head and creating some kind of psychosomatic illness, but I was feeling so bad and she could see that I wasn't right. Then again, the same doctor hasn't ... really known how to treat, or deal with the issues in a - 'cause she uses a conventional sense - and I haven't found that to be very helpful. So yeah, but I'm pleased that she knew about it in the start, 'cause I know some people go from doctor to doctor to get a diagnosis.

Though Anna is appreciative of her doctor's assistance and understanding, she raises an issue that was acknowledged by many of my participants: the limited ability of GPs to actually assist their patients beyond diagnosis. For example, Mandy said, "the only reason I go to [my doctor] is to get my medical certificate every three months... he's been sympathetic, but he hasn't been any real help with CFS/ME". She sees her doctor for purely pragmatic reasons, and went on to say that she had been seeing a second, more holistic doctor, but he had been similarly little help. Beth likewise felt her doctor had a very limited ability to assist her, not due to unwillingness, but ignorance. One symptom of her CFS/ME is bad back pain, and her doctor had suggested she try swimming or pilates to ease this. However, Beth pointed out there was no way she could do such physical activities given her fatigue, and concluded that she thought her GP didn't really understand CFS/ME. Harry expands on these comments, saying:

I see [my GP] pretty much now just once in three months, I feel like there's nothing she can really do for me anymore other than ah until we can get - until we can get special tests done, until we can get access to ah all the special stuff

like there's so many of us who don't have private health insurance and don't have rich parents and stuff like that, where we should have medical thing tests done to rule out or even discover um other things that we're having that could be treated, like an endocrinologist, a neurologist, a muscular specialist and all that sort of stuff that all these specialists - um the stage where I'm at is I need to get tested through all those things, but a GP can't get that done for us...

After ten years with CFS/ME Harry sees his illness as falling outside the purview of his GP, requiring instead specialist attention that is unattainable given the technological limitations of current medical care, and his reliance on a government benefit for money. This lack of sophisticated technologies appears to compound physicians' already limited capabilities. Daniel reflects on this, saying:

It's probably like being in the 1800s and someone walks into the doctor and says "I've got a broken arm" – the doctor doesn't have an x-ray machine that many centuries ago to confirm or deny what the patient is saying. We're sort of in a technological conundrum a bit like that I feel.

Comments such as this reflect sufferers' understandings of the difficult situations both they and their doctors find themselves in when facing CFS/ME. It is not only physicians' knowledge or open-mindedness that limits (or enables) their ability to assist; they are constrained too by the limitations of existing scientific knowledge. In recognizing this, my participants shift and diffuse some of the blame from their doctors, absolving them at least partially of the responsibility to cure them, without necessarily taking up that responsibility themselves. Looking at patient-practitioner relationships – sometimes positive and collaborative, other times ineffectual or damaging – illustrates how medical practitioners can and have helped their patients: providing an expedient and informed diagnosis, helping them obtain financial assistance for their illness, and prescribing them medications to ease their symptoms. However, it also highlights the perceived inability of these same practitioners to really transform sufferers' condition, to fulfil their ultimate purpose as doctors: to cure. Where then does this place CFS/ME sufferers in terms of managing their illness?

### **Managing the mundane: CFS/ME as a self-managed condition**

I asked Julia, a composed woman in her mid-fifties, if she thought she could help herself recover from CFS/ME. She retorted, "Well no one else has. I've had to do it myself, and what I was like at the beginning – it was shocking". Julia had a repertoire of ways she managed her illness. Like many of my other participants, she had found her doctor had little to offer her. Over the course of her illness she had searched out information online, which had led her to the work of a prominent American CFS/ME specialist, whom she referred to various times

throughout our talk. She was on a complicated cocktail of hormonal medication and supplements, including vitamin D, fish oil, and probiotics. Julia was extremely sensitive to most supplements, telling me how she had ended up in A&E after a small dose of magnesium, couldn't take vitamin B tablets, and had tried anti-depressants once, which had left her frozen and shaking in her chair. Thus she had found her present intake of supplements through a prolonged process of trial and error. At the time of our interview she was also dieting, trying to eat more fruit, vegetables, and protein, and though she admitted it was difficult she felt that the weight loss she was achieving was helping with her CFS/ME, and was also emotionally beneficial. Julia had been very active and sporty before getting sick, and as having CFS/ME more or less prohibited any exercise the diet was her way of countering her present inactivity. She was continually turning down invitations and activities, in the interests of keeping her health on an even plane, and described this emphatically as "boring, boring, boring; it is so frigging boring".

Julia's case encompasses many of the ways my participants dealt with their CFS/ME, and a number of these strategies align with self-management practices – information seeking, for example. When their doctors were unable to provide them with sufficient help for their illness, my informants took the task upon themselves. They sought out information from the internet, books, and support groups, and often brought this material into the clinic for their doctors, or suggested possible avenues for treatment. Independently acquiring knowledge on one's condition may help in obtaining a diagnosis and creating an action plan; in the case of contested illnesses collecting facts may also enable people to frame their condition as biologically legitimate (Dumit 2006, Larun and Malterud 2007). This active acquisition of information is characteristic of responsabilised patients (Rose 2007). Sometimes my informants were too unwell to actually fulfil this role, however. Rosa and Jess both told me that when they were really sick, especially at the start of their illness, they had not been physically able to read; it was too exhausting, and consequently they had no way of finding things out for themselves. Though the ideal notion of a responsible patient may be one who seeks out and makes use of information on their illness, in the reality of CFS/ME there are times when this is simply impossible.

Another behaviour my participants practiced was 'pacing'. This is what Julia referred to when talking about how she would have to turn down invitations and limit her activities, and most of my other participants made similar statements. Pacing entails people keeping track of their wellness and energy, and adjusting their activity accordingly (not unlike the monitoring that is required by self-management). Daniel described how he paces himself thus:

I push myself two or three days a week, but the other four or five, when it's bad six or seven days a week, I live like a 60 to 80 year old. I shuffle around, I go to the letterbox when I'm good and ready, not when the postman's ready, like a 60 to 80 year old probably would.

Pacing requires an attentiveness to one's state of health and an awareness of one's limitations, but also considerable forward thinking. Most of my participants would plan each week carefully so as to be able to fit in the things that were most important. Jess said:

I haven't relapsed for at least a year now, but I still have to be very careful, I've learnt to pace my energy much better, so I look ahead and think if I've got a busy week ahead I'll just pull back on what I do today or tomorrow, just to make sure I've got energy in store. So I guess I've learnt to monitor my energy better than when I was first diagnosed, or first got sick.

She later returned to this, saying:

I'm quite cautious not to take on too much, I still say no to things if I know that that's going to be a busy day and I don't want to overload myself with that extra thing, or weekends I'll make sure I might be doing something one day but not the other day, so it's just now it's also a conscious effort on my part to make sure my energy's well-paced, before and after, so I kind of pre-load on energy. If I've been resting all day I can handle something at night time, you know.

Like Julia, and most of the others I spoke with, Jess paces herself by planning ahead, resting before engagements, by being attentive to how she feels, and how she expects to feel.

Pacing did not come readily to my participants, which is perhaps not surprising given how many portrayed themselves as "120-mile-an-hour" people, to quote Julia. Instead people often learnt to pace themselves after a turbulent phase at the start of their sickness. In such phases, my informants told me they would push themselves, crash, and then suffer through a long period of building their health back up. Beth was diagnosed with CFS/ME during the first semester of her art degree, and ignored the advice of her doctor and teachers, all of whom told her to drop out, rest, and recover. Instead, she says, "I just *pushed* myself to finish the semester, I *really* wanted to finish the semester, which would've been about another month, and I just was so stressed, I had so much work to do". She goes on to say that this undoubtedly exacerbated her CFS/ME, but she has since learnt to manage her energy better.

As a couple of my informants pointed out, pacing oneself sometimes entails a trade-off. Lisa explained herself in this way:

Part of managing it is – so like on the one hand you want to still have a great life, so sometimes part of managing it is knowing I'm doing something that's going to make it worse, because then the point where you have to pay back isn't at the

time where you do something that you shouldn't do, so it's kind of learning where the boundaries are and how to safely push them as well, to ensure that you're still having a cool life.

Tess, too, told me how:

The other day I was really naughty and I knew that I'd feel awful afterwards but I couldn't help myself, I just wanted to run [laughs] I just wanted to go for a run and I'm paying for it three days later, I'm still, my muscles are all kind of heavy feeling and I'm *exhausted*.

These excerpts show that people take into account more than just their CFS/ME when working out how (or whether) to manage their health. It is important, also, to "have a great life" as Lisa points out, and to indulge in whims, even on the understanding that they may be "really naughty". Such choices do not preclude attention to oneself – far from it. Instead the awareness of one's health is used to justify a choice that might not, from a medical perspective, be seen as the most judicious.

These decisions, where people choose how far to push themselves, when to schedule their obligations, and how much attention to devote to their illness, comprise a type of everyday management: a management of the mundane. Daniel, for example, told me that he did not shower daily, nor shave. He forgoes such routine habits in the interests of conserving energy. The normal aspects of most people's routines, like daily ablutions, are often too much effort for someone with CFS/ME. Others take care with their diets, going gluten free or just generally adopting more healthful eating habits. And, as mentioned above, my informants minimised the toll of their social lives and obligations on their health by limiting and scheduling what they chose to do. However, though people certainly deal with CFS/ME by managing the mundane aspects of their lives, they do so in a manner that is anything but mundane, instead testing and trying different ways by which they can cope with their illness.

### **Experimentality**

The strategies my participants employ to help manage their illness are a product of extensive experimentation necessitated by the indeterminacy of CFS/ME. The early period with CFS/ME, described above, wherein people crash, recover slowly, learn, and adapt, leads to a type of day-to-day experimentality; likewise the dietary adjustments some of my informants had made, where they tested out gluten-free diets, increased their protein intakes, or cut out food groups. As well as making behavioural or lifestyle changes they extended their experiments into the medical realm through therapeutic and pharmaceutical trial and error, sometimes accomplished in collaboration with their doctors, sometimes alone. Reflecting the

variability of CFS/ME itself, the medical regimes of CFS/ME sufferers are highly individualised. Though there is no pharmaceutical treatment for CFS/ME specifically, a host of medications can be used to manage symptoms associated with the illness. My informants between them took dozens of different pharmaceuticals, ranging from natural dietary supplements such as vitamins, to hormone replacement therapy, sleeping pills, and mood management drugs usually prescribed for clinical depression, anxiety, or psychosis. Despite the non-specific nature of many of these medications (or their specificity to other conditions) they often proved efficacious for my informants. For example, Toby took citalopram, an anti-anxiety drug that is widely prescribed for other conditions, and said this had completely transformed the irritability that accompanied his illness. The specific combination of drugs each of my participants took was either the result of a trial-and-error process of medication, or was in flux when we spoke, as they figured out what was working for them and adjusted their intake accordingly. This constant adjustment was common amongst my informants, several of whom professed a reluctance to take anything they didn't feel they desperately needed.

Vicky described the experimentation she and her doctor went through together:

Me: Do you not feel like [your doctor] could help much?

Vicky: Well no because from what I read you know there's nothing that helps. I mean she did try, was it B12 injections or something, that didn't help at all. She's given me a pill called Duramine, which is a diet pill, which has a side effect of giving you more energy, and she said I could have a try with that, but she warned me that the energy doesn't really come out of the blue, it all comes from inside me anyway so if I overdid it I would crash, sort of thing, which is exactly true, and I just couldn't – I found that pill – oh it was so rough, I can't believe some people would take that every day.

Me: What does it do?

Vicky: Oh it just makes me feel really kinda wired and tense and it- it has helped me sometimes in terms of having more energy but if I'm in a really really low energy state anyway it doesn't really do that, it just makes me feel on edge and things, but um currently I take one on Saturdays, because I go to my daughter's hockey game and I try to catch up on all my washing for the week and that sort of thing ... but when I'm sort of in a little bit of a better state I don't take it at all, because it does have a crash component afterwards so I only take one once a week, but she tried that, and she's tried giving me different sleeping things, but then I found I had um idiosyncratic reactions to Amitriptyline and Nortriptyline [both anti-depressants], they kept me awake all night, so I couldn't take them. Then she tried me on melatonin, I couldn't sleep on that, and then Circad-whatever, it's to do with melatonin but a slow release one and that didn't work, so I am reliant on Zopiclone<sup>33</sup>, which isn't a good one but it's the only thing I can

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<sup>33</sup> Zopiclone is a sleep-promoting drug. Though originally thought to be less addictive than others, cases of addiction are emerging, and withdrawal can be an issue, so it is not recommended as a long-term solution.



take. But I do make an effort to ah like when I'm feeling a little bit better I'm always cutting it down to the absolute minimum, but it does vary so within a month I will range from less than one pill to – well I'd need two if I was taking one of those Duramine pills, I'd need two, 'cause it keeps you awake so yeah. But I'm careful to try and keep it low, because it also makes me feel doopy and forgetful and stuff like that.

Vicky's extensive trial and error has taken her through at least the six drugs she lists here, and caused her some trouble, particularly when taking the anti-depressants that stopped her sleeping. Still, she is not completely satisfied with the result, acknowledging that neither the Zopiclone nor Duramine are ideal solutions. However, they are the best tools she has at present to manage her CFS/ME, and consequently are the ones she sticks with.

Lisa also spoke about her experimental method of managing her CFS/ME symptoms, specifically the sleep paralysis she and Harry (a friend of hers) experience. She said of this:

That's the weirdest thing [sleep paralysis], I think – thought that that could be related to the sleeping pills that we take, because I didn't realise because no one told me, the doctor didn't tell me that temazepam, temazepam? No, Zopiclone, which I take sometimes, is a hypnotic drug, I think, but see when I get sleep paralysis, it's not on the same night as – so I didn't make the connection 'til a little bit later, so it's maybe taking that time to come out of my body. But that's just a possible theory. I've gone off Zopiclone for now to test that [laughs].

Like Vicky, Lisa tries and rejects certain medications to deal with her sleep paralysis. Others enacted a similar type of experimentation with therapies, rather than medications. Most of my participants had stepped outside of orthodox biomedicine and tried alternative therapies, and Beth seemed to have done so most extensively. She had done Lightning Therapy, a CFS/ME-specific programme which, she told me, "is meant to be like a miracle cure" and had "definitely improved" her health. She had also tried kinesiology, which entailed a six-week dietary regime but did not help her much, and Su-Jok, which she describes thus:

[The practitioner is] like this Maori healer, and he does this thing called Su-Jok, which is on your hands, it's very weird [laughs] very weird and I have to say two days after I always felt really good after seeing him, he sort of did acupuncture in your ears with his hands on the back of your head, and he'd do around your hands with different coloured felt tip pens, but he had moxa, it's like this burning thing, you'd put [this] burning thing round your hands – oh! And then he'd cellotape like seeds or beans to you, yeah. But I actually felt better after two days. I don't know if it was like a mind-thing like oh I'm feeling fine, like it was in my head, but I always felt good, like the next day and the day after seeing him. And it was only twenty dollars. He was like, out of his friend's house type thing, it definitely wasn't a medical thing, he was just like a Maori healer that I saw.

Trying different therapies, as well as varying her supplement intake, enables Beth to find the most effective ways of treating her CFS/ME, and though some of the treatments she tried were costly and unhelpful, others brought relief and taught her how to cope in the future.

My participants' processes of testing and trying different ways of coping comprise a type of experimentality that CFS/ME necessitates. Experimentality (conceptualised as a social ordering technique *in sensu* Foucault's governmentality) has been pioneered in Petryna's (2005: 311) work on clinical trials, where, she argues, the line between care and research blurs. Towghi and Vora (2013) eloquently articulate the notion of experimentality, saying:

As experiments move beyond the biomedical laboratory and the clinic into everyday life we see that an orientation of experimentality in everyday practices is not only central to the production of bioscientific knowledge and social policies, but also to the very meaning of what it means to be modern.

Their treatment of experimentality as an orientation is particularly useful here, as I think less of an 'experiment' in the clinical sense, and more of a mode of engagement and way of being. Their excerpt also points to an important feature of experimentality: that it is generative, producing new types of knowledge from contexts of uncertainty (Petryna 2002, Towghi and Vora 2013). Where usually evidence would inform intervention, experimentality means intervention produces evidence (Nguyen 2009). Thus my participants opt to try a new therapy or medicine, not because they know it will be effective, but because they know that it might be, and only once they have tried it do they know what the consequences are. The blurring of research and care (Petryna 2005) is also key to CFS/ME. My informants' experimentality was both a necessary way of coping, of caring for themselves with illness, and a way of learning about their condition. It is a simultaneous process of doctoring and discovery.

Though most writing on experimentality to date has focussed on the macro-social scale, the notion of experimentality is equally instructive in framing personal practices of illness management. Trnka (in press) elaborates this in her work on childhood asthma through the concept of 'domestic experiments'. She uses this notion to situate experimentality within familial regimes of care, showing how parents take up positions of expertise in relation to their child's illness, and actively experiment with medical management to sustain a normal life for their child. The experimental in this case is highly individualised, specific to a given family, and driven by the objective of normality. Like Trnka's asthma families, my informants' experimentality is highly individualised, situated in the everyday, and seeks to sustain the normal. Just as experimentality constitutes a *modus operandi* for global pharmaceutical companies (Petryna 2005) and humanitarian missions (Nguyen 2009), so too is it an

orientation toward illness. Though sufferers themselves enact experimentality in CFS/ME, I would argue that these individuals become experimental subjects by virtue of CFS/ME's indeterminate medical status. Because treatment options for this illness are open but uncertain, a degree of experimentality is inevitable. The supposedly self-managing subject thus also becomes an experimental one.

### **The limitations of self-management**

In the description given thus far I have shown the ways in which CFS/ME sufferers take on board ideas of individual responsibility to self-manage their condition, independently or in liaison with their doctors. My participants often align with the 'ideal' self-managing patient: they are active in seeking out information on their condition; they monitor their health and energy through pacing; they engage in experimental uptake of medication and therapeutic practices, thereby positioning themselves as autonomous patient-consumers (Rose 2007). However, what is equally or more important is the fact that almost all of my participants had been through times during their illness where they were physically unable to self-manage. Lisa described the worst part of her time with CFS/ME to me thus:

Me: So how have you coped with CFS/ME?

Lisa: Um a lot of times I haven't coped with it [laughs]. So I'm, I'm doing pretty good in that department these days, um I hope this isn't too much but I did actually just want to kill myself several times over the last – well no I haven't this year really, no...

Being bedridden for months had left Lisa with little hope, struggling to see the value in herself or her life. She got through this period with the support of a new friend, who helped her change her perspective and recognise the worth in living, but like most of my participants who had struggled with depression bordering on suicide, she doubted if she would have done so alone.

Rosa explains the physical impossibility that typified her CFS/ME by recounting how it feels to crash:

I could feel myself going down, that was the scariest because you never knew how far down you would go before you'd stop, but hopefully once you realise that was happening, you stop right away, you knew that it was going to stop somewhere hopefully and you could just stop doing anything –and *for me it meant absolutely nothing, it meant not turning over in bed, I couldn't open my eyes, I couldn't talk, I had difficulty even eating*, I didn't use a knife and a fork, I just shovelled what I could in my mouth with my hands and I had to lie very still and I had to turn very slowly if I wanted a drink of water, I had a straw, but I had to turn really really slowly, because quick movements use too much energy,

and so everything I did was very very slow, and *that was the only way I could cope*, by knowing that if I stopped and did nothing I would start to feel better, and that it would take three days, but three days from now I might not feel like I did.

Perhaps some aspects of self-managing could be read out of this – her awareness of “going down” and consequently ceasing everything. To do so, however, would do an injustice to Rosa, and fail to acknowledge to extremity of her experience. These are not moments of managing, but of raw survival. These are the times in which people are barely coping with the enormity of an illness that has transformed their bodies and lives. In such instances self-management is impossible.

How then do CFS/ME sufferers cope in the times when they cannot self-manage? Faith and religion are apparently important sources of support in such times. Several of those I spoke to were strongly religious, having returned to or newly discovered some form of faith through their illness. The sense of faith, and the philosophical reflection it elicits, seemed to ease their suffering somewhat, and some also spoke positively about the new contacts they had made, or the support network they had through their church. My participants also spoke of the indispensable importance of their family and friends in these times: those people who talked them off fatal ledges, who spoon-fed them their meals, and sought out medical help for them. In the moments they could not look after themselves, other people stepped in and did so for them. These networks of support (which I discuss in the next chapter) provide care when the self of self-management is unable to do so.

### **Caring for CFS/ME**

Self-management practices fracture when people with CFS/ME crash, as their ability to manage daily life, let alone illness, erodes alongside their physical health. To really understand then how people cope over years with CFS/ME, over the ups and downs, we need something more than self-management. I suggest we look to care. In making this shift I follow the work of Annemarie Mol (2008), who has critiqued the unquestioned value of choice and advocated instead a theory of care. Though I start from a position of self-management rather than choice, my argument is informed extensively by her writings, the most prominent in recent years to bring care into critical thought. Care may offer a more open and nuanced frame with which to consider the coping strategies undertaken by CFS/ME sufferers. Mol, Moser, and Pols (2010: 15), in a volume devoted to the subject, say that:

Care practices move us away from rationalist versions of the human being. For rather than insisting on cognitive operations, they involve embodied practices.

Rather than requiring impartial judgements and firm decisions, they demand attuned attentiveness and adaptive tinkering.

This describes well my participants' reported coping strategies, which were often guided as much by embodied knowledge and everyday experimentalism as by logic and fact. It is similarly suited to CFS/ME, the variability of which necessitates attentive and adaptive responses. The CFS/ME sufferers I have worked with move between these care practices and a more programmatic self-management. There is overlap: the attentiveness, and a readiness to alter one's practice based on this. However in several respects care is more flexible and personal than self-management. Thinking of coping through the notion of care allows us to step outside of the patient-practitioner relationship that is central to self-management, and also outside the confines of a programmatic, illness-oriented coping regime.

Care allows for an affective element that is absent from self-management but significant to CFS/ME sufferers. Learning to live with CFS/ME is an intensely affective process. It is frustrating, heart breaking, disorienting, and depressing (and these are my informants' words) but for many it also triggers a process of discovery, of acceptance, and of empathy towards oneself and others. An approach that accommodates affect will be better placed to understand the experience of CFS/ME as lived. It acknowledges the disappointment that may arise when a treatment fails, or another crash sets in; the hope that a treatment might be found or that a good day might be the start of recovery; the sense of loss: of friends, and freedom, and bodily vitality that inevitably dissipates with CFS/ME. This fluctuating emotional terrain of CFS/ME profoundly shapes how people cope with it, both by influencing the extent to which they can or will care for themselves, and whether they can or will accept care from others.

And this is another possibility the concept of care allows for: that care can come from outside of oneself, and the principle agent of care can shift. Care goes beyond the patient-practitioner relationship privileged in self-management, and instead travels along relational pathways, of individuals relating to their selves, and also to their social networks of family, partners, and friends. Mol (2008: 18) touches on the indeterminate, relational nature of care saying, "care is not a (small or large) product that changes hands, but a matter of various hands working together (over time) towards a result". Coping with CFS/ME is, ideally, and at least sometimes, a collaborative endeavour. For example, Mandy said:

I am pretty fiercely independent, um but there's definitely been times ... especially after I separated from my husband, I spent 7 months with my aunty ... and then after I don't know how many months it was, I crashed [laugh] and then I basically went and lived at my brothers place for another 7 months, so

there's been times when I haven't actually been able to look after myself for the daily physical stuff.

Despite her self-professed independence, Mandy could only cope (at times) with the care of these family members, and most of my participants recounted similar such instances.

Care is also oriented toward the self, as compared to self-management, which focuses on illness and symptoms as the objects of enquiry and improvement. Coping through care encompasses the entire individual, not apart from the illness but as inseparable from it. This illuminates Lisa's earlier comment, about coping sometimes involving doing something that is actually bad for your health. People's priorities can shift in ways that are not accommodated by self-management programmes. Mol (2008) touches on this as well, talking about how 'good care' is not necessarily reflected in good outcomes, but may instead be focussed on simply getting by over time. This describes a self-centred coping process, in which illness is only one part of the equation.

These three factors – the affect, the intersubjective coping, and the more open focus of care – are all integral to CFS/ME. By attending to such issues, a theory of care also invites new ways of knowing CFS/ME. The illness can be known as a new affective state; as a mutual construction; as a phenomena embedded in a larger life, rather than an isolable illness. Thinking of CFS/ME through care elicits a knowledge of the illness as unstable, for the illness no longer needs to check certain boxes in order to be dealt with in a certain way. The array of coping strategies enabled through care broadens the possibilities of what CFS/ME can be, and exposes dimensions of CFS/ME that would be overlooked by more clinical approaches such as self-management. Though self-management does prove both productive and desirable in many cases, there are times when something more is needed to understand how people cope. That something is care.

## **Conclusion**

CFS/ME sufferers are in a somewhat unique position when it comes to coping with their illness, as the medical profession has few answers and fewer people who are informed enough to offer them. The IACFSME primer sets out clinical guidelines for treating patients with CFS/ME, but these seem to be infrequently implemented in practice. When they are, the resulting strategy does align somewhat with self-management, emphasising an active patient, who, acting upon their physicians' advice, monitors their health and adjusts their behaviour or medication accordingly. When they were able, my participants filled this role eagerly: they sought out information from their doctors, and supplemented this with information from contacts, the internet, and reading; they kept track of their illness and attempted to maintain a steady level of energy by pacing themselves, limiting their activity

and getting ample rest. They also adopted an outlook of experimentality, testing out different habits, drugs, and therapies in the hope of finding a solution or salve for their illness. This experimentality appears to be in part a necessity, filling in the gaps left by doctors and biomedicine at large, and in part a practicality, a way of finding solutions that fit into individuals' lives. The irony of an active chronically fatigued patient is stark however, and CFS/ME entails acts of both self-management and care. The latter makes space for the affective and interpersonal aspects of coping with this chronic illness; it invites new ways of knowing CFS/ME, and allows different forms of knowledge to shape people's coping. Using both of these concepts to frame the experiences of my participants illustrates the pragmatic and the deeply personal aspects of living and coping with CFS/ME, and begins to trace the relational pathways that shape their experience. These relations are taken up further in the following chapter.

# CHAPTER IV

## “SORTING THE WHEAT”: THE SOCIAL WORLD OF CFS/ME

### **Introduction**

As I have described in the previous chapter, CFS/ME is a difficult illness to deal with alone. Sufferers are often too physically unwell to cope with their illness, and in those times rely upon the care and support of their families and friends. This chapter examines my participants' social worlds and shows that though care and support are critical to individuals with CFS/ME, they are often lacking; the social world of CFS/ME appears to be characterised as much by isolation and loss. My participants typically had busy social lives before getting CFS/ME, and most described friendships and familial relationships that were reconfigured or lost after falling sick, often in ways they would not have expected. Parental relationships are especially susceptible to change, whereas romantic relationships attract surprisingly little mention. To fortify their relationships my participants mobilised their existing knowledge to make CFS/ME relatable, to communicate its seriousness, or to educate people on how to be friends with a CFS/ME sufferer. Though in many cases problematic, the variability of CFS/ME allows my informants to portray their illness differently according to their audience or aim, and in doing so they can actively reshape their social worlds. My participants' relationships form spaces in which different forms of knowledge circulate, and where these intersect a type of interpersonal knowledge emerges, bridging the epistemic gaps between sufferers and their friends and families. I argue that by attending to sufferers' immediate social relations we can better get at the lived experience of CFS/ME, and use this to make sense of the broader social tensions this illness taps into. This argument aligns with that made by Ware and Kleinman (1992), also partly in relation to CFS/ME, which I draw upon using their local social worlds approach.

### **Theorising the social world of CFS/ME**

In this chapter I look at some of the many social challenges that CFS/ME brought into my informants' lives. Existing work on the social aspects of CFS/ME has focussed primarily on delegitimation and stigma, which have been shown to be key issues to CFS/ME sufferers (Åsbring and Närvänen 2003, Kleinman et al 1995). Stigma typically refers to aspersions based on either overt or absent-but-suspected abnormalities, which become the grounds for moralistic judgement and social exclusion. Previous studies have noted that CFS/ME



becomes stigmatised when burdened with psychological connotations (Åsbring and Närvänen 2003, Cohn 1999, Surawy et al 1995) or when taken at name-value, the title 'chronic fatigue syndrome' being easily trivialised (Jason et al 2001). My informants did allude to stigma at times, but they also spoke of loss, misunderstanding, the physical confines of CFS/ME, the vulnerability of existing relationships, and the promise of nascent ones. To account for these various aspects of peoples' relationships, I turn to Ware and Kleinman's (1992) notion of local social worlds.

Ware and Kleiman (1992) use this concept to round out sociosomatic models that look only at the impact of the social environment on illness expression, by asking how bodily suffering in turn shapes social experience. Thus they show that for Americans living with CFS/ME, their illness is a means for commenting upon broader cultural pressures relating to work and success, and enables them to negotiate change in their local world by re-evaluating their lives, changing professions, or making time for rest. This linking of individual sickness to societal commentary is a powerful way of conceptualising CFS/ME and one that I have touched on briefly myself in arguing for peoples' explanatory models as rhetorics of challenge to biomedical hegemony. The crucial midpoint between individuals and macro-scale social happenings is interpersonal relationships and shared experience. Ware and Kleinman (1992) deal primarily with the shared experience (though they do mention that broken families and difficult relationships were attributed significance by their informants), which they frame with their notion of local social worlds, a term I adopt to advance my own analysis<sup>34</sup>. My focus is more on my participants' relationships and immediate interpersonal experiences, and a local social worlds approach provides a lens through which social experience can be understood in relation to both illness and broader social context.

### **The social role of the CFS/ME sufferer**

People's mode of engagement with the world around them changes with CFS/ME, and so too does their engagement with others. The physical manifestations of CFS/ME have social consequences. Lisa, nearly thirty, was one of my more philosophical participants, and explained how her symptoms affect the way she interacts with people:

Before I had Chronic Fatigue Syndrome I was a bit of a shy person socially... I mean I would feel anxious in social situations right? If you have Chronic Fatigue then you're just bringing this whole other aspect to it... 'Cause when I get mentally exhausted or whatever I start slurring and start stuttering a bit, and

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<sup>34</sup> Ware and Kleinman (1992) use this term flexibly throughout their paper, and in subsequent work (Kleinman et al 1995, Ware 1999), using similar terms such as 'local worlds of social experience', 'local worlds of interpersonal experience', 'local worlds of experience' etc. For clarity's sake, and to retain this flexibility, I use the term local social worlds here.

that's not, you know, everyone has their impression management thing going on, and that's not your ideal first impression to give someone, is that your kind of looking a little bit loopy [laughs] and sounding strange. So it is a big issue I think.

Another of my informants, Harry, who worked occasionally in the music industry, told me how people would often mistake his ill demeanour for being high. For these two, the physical changes CFS/ME wrought on their conduct raised a whole new set of misunderstandings in social situations.

The physical limitations of CFS/ME also affect what social activities people can partake in. Julia, who at fifty-five has lost a lot of friends from her illness, explained that her limitations shaped how she could take part in social occasions, and consequently how people would engage with her:

You can't get out as much as you would want to, and you might be quieter and not quite so buoyant and not so life and soul of the party up there on the table going woohoo, you're probably a lot quieter than you used to be. I stopped drinking. I just find alcohol doesn't agree with me now... because I don't drink some people don't come around, and to some people it's not a problem.

The physical constraints of CFS/ME prohibit relationships based on certain activities, like drinking in Julia's case, and sufferers also feel this has repercussions for how people will interact with them. Lisa, who had been a gymnastics coach before developing CFS/ME, said:

It's always freaky meeting new people when you have CFS/ME because it's kind of like you have this dark secret in a way ...But you go out and meet people and it's all cool, and then they're like, "hey do you want to come out and do this hike, this three day hike?" and you're like "... NO I don't [laughs]"... so then you've gotta try and educate people on how to be friends with a person who has CFS/ME.

This comment touches upon some of the apprehension involved in being a social actor with CFS/ME – apprehensions that people take pains to ameliorate. Marcia, a 66-year old former ballerina, had alopecia as one side effect of her CFS/ME. She said to me, "I'm very careful how I go out or I see somebody, I will always get dressed, and thank the lord for makeup". Marcia felt that CFS/ME compromised her appearance, and she would always make an effort to present herself well when seeing people, donning her wig and doing her makeup neatly. These insecurities troubled my participants, but they did not stop them participating socially as has been suggested elsewhere (Arroll and Howard 2013, Larun and Malterud 2007). Though my informants speculated about how they appeared to others, and at times seemed

to be self-conscious of this, most of them would still go out when physically able, and many expressed a desire for a fuller social life.

The desire for more social interaction was often at odds with what my informants could physically tolerate, much to their frustration. Social situations can easily be exhausting and overwhelming when experienced through CFS/ME. Beth, who worked part time (very infrequently now) as an events photographer, described how recently at a busy function she had worked, she had had to step outside as the sound of people's talking, with the music, was sickening her and making her head spin. Daniel, who experiences sensory sensitivity as part of his CFS/ME, said:

I don't know whether its true of everyone who suffers the pain aspect of Chronic Fatigue but for me personally the withdrawal from society – somewhere in society is a lot of the trigger for the pain... I'm much more productive in that sort of isolation.

Social participation takes a toll on Daniel and most of my other informants, sometimes to a painful extent. Rosa told me that those individuals who fall within “the 25%”<sup>35</sup> are usually too sick to bear people being in the same room as them, as the simple awareness of someone's presence is intolerably exhausting. Rosa herself could not see her children for several months during her worst period. CFS/ME sufferers occupy a different social world from others, one that appears and in which *they* appear differently. The physical manifestation of CFS/ME thus shapes the social world of my participants; social experience and the state of the body are tangibly bound.

### **Reshuffling relationships: “Sorting the wheat”**

So, what happens is you start getting sick. Because there are no biomarkers, people find it hard to believe that there's something wrong with you. During that whole process towards actually getting a diagnosis you get really, really frustrated with your friends and family 'cause they're not believing you, it's like the trust is broken between you, and then even when you do have a diagnosis it's actually normally more helpful for them than it is for you, because you know what's been going on all this time, but having that label for some reason changes things for people, but by that point you have- you feel very betrayed by your friends and your family, by the disbelief and the in- what's the word? The totally inadequate responses to what's happened to you... And then that just creates lots of issues to deal with, 'cause then you have to get to a point of being able to forgive everybody because when it comes down to it they really do love you and they do want to help you and they've just been really confused because nobody really understands Chronic Fatigue. (Lisa)

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<sup>35</sup> Rosa is referring here to the estimated 25% of CFS/ME sufferers who are too sick to leave their beds and are thus often completely unknown of.

The above account touches on many of the interpersonal problems that living with CFS/ME entails. Lisa describes disbelief, broken trust, betrayal, and forgiveness, and in doing so she begins to show how friends and family are brought into the world of CFS/ME: how the diagnosis, that transformative moment where a complaint is registered as a disease, is in fact sometimes less important to the sufferer than to their family – although of course its significance to others becomes by turn significance to the sufferer. What Lisa describes is a process wherein an individual with a whole and presumably satisfying social life falls ill, and their friends and family scatter (some far, some not), leaving the sufferer to reassemble their social world with a hard-won combination of fact and faith.

Lisa's is an especially erudite explanation, but most of my informants spoke of ruptures in their social worlds brought about by CFS/ME. With the severe immediacy of illness onset, the period of uncertainty in obtaining diagnosis, and the long process of actually living with the illness that follows, peoples' previous relationships shift and collapse, often along lines that surprised people in hindsight. One of my participants, Mandy, described this as 'sorting the wheat' (though the sorting seems to have occurred with little of her own input). 'Sorting the wheat from the chaff' is an expression that describes a process of sifting through a mass (of chaff, if being literal) to find the valuable components (the wheat). Mandy uses the phrase to describe how many of the people she was close to when healthy fell away during her time with CFS/ME, and how a few especially valuable people remained, providing crucial support for her in times of need. She spoke to this further, saying:

You really understand who are the people who are there for you and who aren't. For example, my parents, love them to bits, but they were useless, and they still are useless as far as supporting me and they don't kind of understand it and they don't, almost like they don't want – it's just like too hard for them? I don't quite – I just don't, I still don't get it. There's quite a lot of hurt there because ... that's probably the first time in my life that something really bad has happened and I've kind of needed people, you know. But then on the other hand, my ... aunts were amazing, and my cousins who I didn't used to be close to, I've become really close to them, so it's really interesting how- and like my brother you know the fact that I could stay there for that amount of time<sup>36</sup> and even though – and he tried really hard to understand, and his wife... there's some people who kind of get it, even though they might not have experienced it themselves, but they can kind of put themselves in your situation, and almost like seeing you as you really are. And then there are other people... as close as your family, as your parents... who... just couldn't cope with it, or it was just too much.

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<sup>36</sup> Mandy lived with her brother and his wife for seven months during a crash.

This commentary also draws attention to the fact that these strands of loss and support often fall apart (or come together) in unexpected ways. It came as a surprise to Mandy that her parents, the people she had most expected to be there for her in difficult times, could not cope with her illness as well as her brother, aunts, or the cousins she had never been close to.

### *Family*

Julia experienced a similar abandonment by her mother and sisters who left her to nurse her injured father alone, during which time she got CFS/ME:

I think the biggest lesson I learnt was when I first got chronic fatigue... and when my father got kicked in the head by a horse, was who was there and who wasn't there for you. And I'm not meaning doing things for you, doing your housework or washing or whatever, I'm talking about being there for you, just coming in and having a cup tea, or giving you a phone call, or inviting you out for dinner or around for a cuppa or whatever, it's that sort of stuff that I found hardest, that was the thing that I found really hard, and *I realised that my family, I could not rely on them to be there for me for anything. And I had a totally different vision of family. I thought when chips were down family would pull together for the common good, to help whatever member needs a lift, needs that support at the time. That's what I thought. I was obviously wrong.*

Her family's failure to support her is a source of great pain for Julia, compounded by the fact that it was not only her they were abandoning initially, but her father too. The family context is one of the most significant sites of social change for people with CFS/ME. Individuals' family roles – as sons or daughters or parents – and their associated expectations and responsibilities, are often made problematic by CFS/ME. For example, two of my informants, both middle aged women, spoke of how they felt bad for not being able to take better care of their elderly parents. One, Carol, said:

I felt very sorry that I wasn't able to help my sister, my older sister ... who had full time responsibility of our elderly parents and I feel guilty that I haven't been able to help out more and I think that they wonder when I'm actually going to get out of bed and get better. The day that I did go to [the retirement home] compounded with a couple of other things and I had a relapse. So I just have to be very careful...

Carol was in a tricky position in that she occupied a familial middle ground, having the aforementioned obligations to her parents, but responsibilities toward her adult children as well. She told me although her daughters do not yet have children of their own, she feels that they expect her to be able to help them once they do, "to be a helpful grandmother". Her sense of obligation thus extends beyond her own parents and children, to encompass a

generation of her family that does not exist yet, her grandchildren. Carol's illness disrupts her role as a caregiver in every direction, and all of these obligations vie with her concern for her own wellbeing, which is so easily compromised by over exertion.

The parental role in CFS/ME is easily disrupted, partly due to people's expectations about how they ought to parent, and partly due to the immense work that parenting requires. Vicky described a typical afternoon with her adolescent children to me thus:

The children come home and I feel sort of stressed and I feel bad that I've been at home all day and they think I'm – they might think I'm lazy and I just find it really difficult coping with them getting home and telling me all the stuff they've – like all their problems to do with school and what work they've got ah 'cause especially my daughter has bad dyslexia and she's always got problems and then my son is quite sensitive and indignant so he's always got something unfair to tell me about um, by then I just want to go crash in my room [laugh] and sometimes I don't manage to help them with their homework and [my husband] has to do everything really, makes their dinner...

Keeping up with the children requires a concerted effort for Vicky, and several times during our conversation she reiterated the fact that her husband took on the majority of practical responsibilities toward the children. 'Keeping up' was also something Toby<sup>37</sup> spoke about, saying how despite really needing his weekends for rest, he wanted to make the most of the time with his young family, and would often push through the exhaustion to do so.

Parental relationships may also be changed when one's adult child falls sick. Jess spoke of how when she crashed, her parents had stepped up and gone back to looking after her like when she was a child:

My parents, my relationship with them would have strengthened, because I'd been independent for so many years, I'd been off to uni, lived away from home for six years, and now suddenly I needed them again, and needed them to make my dinner and make my bed and do my washing [laughs] so there was a real – and they stepped up to it and gave everything so that was a real close, that brought us closer together.

Though they had always been her parents, the onset and severity of Jess's CFS/ME prompted them to resume *parenting*. They took on anew the responsibility of caring for Jess, both through their solidarity and emotional support, and pragmatically, by feeding her and such. A similar situation transpired for Rosa, though she notes that they were perhaps not so well equipped to look after her:

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<sup>37</sup> Toby, a doctor, was the only one of my participants who was working full time when we spoke, and had been throughout his illness.

My folks were really good, and my sisters just didn't understand, and because my parents were older and they looked after me for three months, and I guess my sisters were worried that it was too much for my parents to be looking after me, and it probably was but there just wasn't anywhere else for me to go... yeah so they got it, Mum and Dad really understood, but I don't think they felt that they – I think they could have coped better if they'd had more support, you know from everybody, but it wasn't there, so they were trying to explain to people – they were piggy in the middle, trying to explain to people why they still had me there when I was 39, why they had to be looking after me, why I wasn't home, and really it wasn't fair on them.

Rosa's situation falls somewhere between Carol and Jess's. Like Jess, for a time she became reliant upon her parents again, and like Carol she alludes to a sense of obligation toward her parents, who in this description take it upon themselves to care for her despite being somewhat compromised themselves. Moreover, Rosa's own children often had to look after themselves, and her. Her daughter Kate, the youngest of five, has CFS/ME herself, and said:

With Mum being sick and stuff there was a lot that everybody in the family had to handle, and we were all kids, and then Dad [a pilot] would come back and he'd be tired from flying so we knew we could not – oh we were just sensitive that we couldn't ask a lot of people...

With an unwell mother and a father whose work saw him travelling much of the time, Kate and her siblings became fairly self-sufficient. Despite her extreme illness however, Rosa told me she would sometimes iron her children's clothes from bed, wanting to send them out looking neat and tidy; even when bedbound, Rosa prioritised her maternal role. Nowadays she is in better health than Kate, and has resumed a motherly type of care for her daughter, making her breakfast and bed most mornings. Their relationship is defined by the type of empathy that arises only from a shared experience of suffering. Family dynamics alter in the wake of CFS/ME, as a previously able family member becomes dependant upon those who would otherwise be their dependants. The traditional roles of responsibility and care need to be recalibrated according to who is capable of what, and this recalibration is an on-going process, changing as children grow up, parents grow old, and sufferers' illness wanes or worsens.

### *Friendships*

Similar reshuffling was described by my informants with respect to their friendships, though neglect by friends seemed to be a somewhat lesser issue, perhaps due to greater significance and expectations placed on familial relations. Most people had experienced a range of reactions to their illness from their friendship circle, and most had also lost a number of

friends. Though one of Carol's friends had been quite disbelieving of her illness, others had been supportive:

Some good friends are very interested in this journey I'm on, they're looking at it as quite a novel thing, you know what's happened to their friend has all been, though unfortunate, quite interesting. And so some friends have been quite interested in the ins and outs of what's happened to me. Other friends just don't really want to know any longer. So it varies a lot.

She also told me that having CFS/ME and not being able to work had actually allowed her to spend more time with some friends, and she felt grateful that she had been able to invest in these relationships as she approached retirement. Jess, an ambitious 26-year old, had had a busy social life and wide circle of friends before getting sick. However, she was philosophical about those friends who moved away, explaining:

Friends are hard to keep when you keep breaking promises to them that you're going to catch up. ... I'd try to squeeze friends in to my limited capacity life, so maybe I'd – some friends would come over and bring a meal, which was great for me 'cause that meant I could use my energy talking to them ... So yeah, friends come and go when you're ill, and I'd say that anyone whose had serious illness would say that to you.

Loss of social contacts appears to go hand in hand with the loss of physical ability that accompanies CFS/ME. However, many of my participants spoke about one particular friend or companion who had provided invaluable support during their illness. Often, it seems, the solidarity of one person more than compensates for the absence of many. My informants valued these friends for different reasons. Carol, for example, had a good friend, Therese, who had also had CFS/ME, and for much longer. Carol mentioned how much she valued her friend several times during our interview, saying:

Knowing Therese, I can't stipulate how valuable it was because everything I was experiencing she said "I had the same"...everything that happened to me I ran by Therese, and because she's a bright lady and she had had such a struggle herself with her son and herself [both had CFS/ME], I know it was 20 years ago, but because of the fact that she's interested in her own health, and she said do this, do that, don't do that, don't do the other, and so I was guided straight away by someone I felt was terribly experienced and [who gave] terribly good advice.

Another of my participants, Tess, had been living with a friend who had once had CFS/ME when she fell sick herself. She was emphatic about how good it had been to be with someone who understood the illness, and her friend also sent out an e-mail to their mutual friends explaining what Tess was going through. Tess and Carol's friends could be thought of as



pragmatically supportive; or, perhaps more accurately, they are valued for the pragmatic support they provide. It may be worth noting that in both of these cases the friend who was so highly regarded had had previous experience with CFS/ME, which is perhaps in part why their support was so useful to my participants.

Others valued their closest friends for less pragmatic reasons. Mandy said:

I'm so lucky I have a best friend whose been a massive support in my life um even to the point that when you're severely depressed you start thinking like "oh she doesn't, you know, want to talk to me... it'd just be a pain for her to want to have to talk to me" whereas it's just like when you're in - I know for a fact she'd be there in a heartbeat for me whatever - she *has* been there for me, in fact she ... if I'm honest she probably saved my life [getting teary] um because I was very depressed, you know like, suicidal, a couple of times...

Mandy describes a relationship with someone that preceded her developing CFS/ME, who knew her before the illness and stood by her throughout. Lisa describes a similarly profound relationship with a friend she made during her time with CFS/ME:

Ugh this is gonna sound really cheesy but this is what happened. Um so I met a person who's now my best best friend... So I met this person who just - we hit it off and um they just welcomed me into their life really easily and it turns out that she has a completely different thing going on, and I didn't know this for ages, but she has seizures sometimes, and every time she has a seizure she has all these cognitive issues, getting back, as her body recovers from it, so she totally understands all that, and um... So I started going to this church and that's where I met this person and they kept, every time I was like "I don't know what the point is" they'd just be like, "you are so so loved, and you are so lovable^" and um and like saying that she could see all the qualities that were in me and I was just like [belligerent voice] "I don't know how you can see that 'cause I am a zombie" and she was like "no you're not, you're awesome, you're Lisa", and I just kept trying to hold onto that...

Lisa credits this new friend with transforming her perspective on her illness and life, giving her hope and confidence in her own ability to live with CFS/ME. This is a different manifestation of support from that detailed by Carol and Tess - a more personal and intangible form, though no more or less valuable for it. The support of one friend like this can bring respite (both physical and emotional) to sufferers, introducing some stability into their volatile local social worlds.

#### *A note on partners & spouses*

Approximately half of my participants were either married or in long-term relationships, yet references to partners were sparse. All of those who were married had developed CFS/ME

well into their relationship, whilst the others had begun their relationships whilst having CFS/ME, thus making it “part of the deal when he signed up”, as Jess put it. Two of my single informants mentioned relationships that ended before, or around the time their CFS/ME began, but none of them spoke of wanting or having any romances otherwise. People made occasional remarks about their partner taking on extra domestic responsibilities, or being generally supportive, but only one spoke in any detail about her husband. She said that her illness had placed immense strain on their relationship, pushing the couple to seek counselling. Others have found that romantic or marital relationships are the foremost concern for people with CFS/ME (Dickson, Knussen, and Flowers 2007). However, it seems that romantic relationships feature less prominently in the minds of my participants than do familial, or even sibling, relations. It could be that my informants were actually less willing to speak openly about their intimate relationships, but given the sensitivity of some of my interviews I feel that this is improbable. Perhaps, instead, marital relationships are simply expected to be more enduring than others, and thus occasion less commentary or reflection. In any case, this is a topic that would benefit from further enquiry.

### **The invisible and mundane: isolating features of CFS/ME**

Many of the struggles people faced in their social worlds are attributed, explicitly or not, to misunderstandings. A crucial issue for CFS/ME sufferers, one that is emphasised by my own participants, is the isolating engendered by the illness (Brooks, King, and Weardon 2013). Physically incapacitated and frequently misunderstood, CFS/ME often sees sufferers socially stranded. The isolating effects of CFS/ME are often exacerbated by the fact that many people who suffer from CFS/ME were extremely sociable before falling ill. Vicky, for example, had been a teacher, and told me that after being in contact with over 100 students and colleagues per day, the solitude of her illness was extremely frustrating. Jess’s comment here also points to this stark social contrast:

When I got sick I went to a naturopath and she said, “what do you do for me time?”, and I said, “well I have my friends over”, and she said, “what else?” And I said, “I meet my friends for coffee” – “what else?” – “I go to the gym” – “what else?” She said, “do you ever just stay at home and close the door and not see anyone”, and I was like *no!* To me that sounded socially retarded [laughs] who would do that? But I think the illness has now taught me, probably to be more self-reliant, and also to be able to do that, kind of come to enjoy it a bit more now, so it’s certainly changed my day to day routine in that sense, kind of enjoying my own company a little bit more now.

Jess was fortunate, and the isolation of CFS/ME had actually elicited a more comfortable relationship with herself. For many, however, being alone, exhausted, and in pain for days on end was a purely devastating prospect. Lisa offers some insight into this, saying:

It's a very isolating illness when you're spending a lot of time just in bed, and I spent days and days not really seeing beyond four walls, so that's just the perfect storm to get really really depressed.

Isolation is clearly a critical issue for CFS/ME sufferers, who are frequently housebound and estranged from their social network. Obviously the physical inability to get up and enter the world of others is central to this. However, equally (or perhaps more) important is people's misunderstandings of CFS/ME, which are often more isolating than the physical exclusion it entails. Given the many unknowns of the illness it is perhaps unsurprising that misunderstandings around CFS/ME are rife. Many people have never heard of CFS/ME, and those that have often know very little. In fact, several of my participants acknowledged that it was a hard illness to comprehend, and some admitted that they would probably not understand it themselves, had they not lived with it.

The primary reason most people identified for misunderstandings of CFS/ME was the fact that it is an invisible illness. CFS/ME is not a self-evident condition. Sufferers rarely look like they are suffering from a chronic illness, particularly because in their worst times, on off days or in crash periods, they are not seen socially, being in bed. Tess said of this:

I think what my friends struggle with is... when I do see them I'm fine, and it kind of lifts me when I see them anyway, 'cause that's just my personality, I get energy off other people, and so when I see them you know I'm excited to see them 'cause I'm alone most of the day unless I organise to go out and do things with other people so when I see people I want to chat and it lifts me, yeah.

Jess offers a similar explanation:

The hardest part about this illness is it being an invisible illness, and it's that scepticism from people, people forget too... but yeah *you feel different inwardly, but you look exactly the same outwardly, and sometimes the most hurtful things people would say are "you look fine"* and that can be – while they're trying to be nice to you, um it doesn't always go down the way they wanted it to, 'cause it can make you feel agh so frustrated that you look fine when you feel terrible, so yeah the fact that it's invisible is probably the hardest thing I've had to come to grips with.

What many people said was that nobody thinks about the time in between social occasions, where CFS/ME sufferers return to bed, to recover and prepare for their next engagement or

appointment. Additionally, when trying to communicate that they had a serious illness to others, CFS/ME sufferers have no visible evidence to support their claim; the people they speak to can only take their word for it, or not. Jess said “I don’t have a cast on my arm or a bandana on my head<sup>38</sup>”, pointing to the lack of sickness symbols for CFS/ME as an obstacle to claiming a sick role.

Another vehicle for misunderstandings is the commonness of CFS/ME symptoms, which can compound the isolating effects of the aforementioned invisibility (Brooks et al 2013). My participants attest to the difficulties of having such mundane symptoms with anecdotes of trivialising remarks made by healthy contacts, who also claim to be tired, or jokingly remark that they must have CFS/ME as well. (In fact, I can attest to this myself, having provoked dozens of such comments in the last year of this research.) CFS/ME is comprised of painfully mundane symptoms, resulting in it being easily dismissed as trivial or exaggerated. In either case, the legitimacy of CFS/ME as a medical condition, and the acceptance of those diagnosed, is compromised. To give one example, Julia told me of the following encounter with an ill-informed friend:

I’ve got another friend here that basically says to me that [sigh] she hasn’t got chronic fatigue and she’s lazy and unmotivated too, that’s the way she puts it to me, and she thinks I do more than she does. And I said, but I’m not lazy and I’m not unmotivated. I’ve got all the motivation in the world physically *I can’t do it*. And this is where I feel I have the battle [crying]... So it’s people’s ignorance and lack of understanding, and not willing to sit down and actually ask, you know.

Misconstruing Julia’s exhaustion as laziness, her friend not only denies her illness, but makes a judgement of Julia’s character that is deeply at odds with how she wants to be – how she would be if she were healthy. In encounters such as this sufferers’ knowledge of CFS/ME is placed in direct opposition to their friends’ understandings of what makes an illness, and the point of contact becomes a point at which knowledge is mobilised and transformed.

### **Mobilising knowledge to right misunderstandings**

In efforts to right misunderstandings, my participants often expressed a wish that their friends were more open to simply talking about CFS/ME. This can be read from the last part of Julia’s statement above, and also from Jess, in the following interchange:

Me: Do you tend to tell people that you have ME?

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<sup>38</sup> In New Zealand bandanas are also sold as fundraisers each year for CanTeen, a charity that support young people with cancer. They are a popular item among school children, and highly recognized.

Jess: Yeah I do because I think it's important that we talk about it to make it less invisible. If people know that I've got that, it may mean nothing to them, but down the road they may bump into someone else who's got it and think "oh it's not as uncommon as I thought it was" you know? So if anyone has the time to listen I'll explain it to them... But yeah I just decided that if that is going to be one of the greatest challenges, that it's invisible, then I'm going to talk about it, and if people want to not believe then that's fine. But more often than not people are willing to listen.

Jess was emphatic about the importance of openly discussing CFS/ME, and felt that she had enabled some of her friends to come to better understand the illness and her life by doing so. To communicate their illness to friends and families, my participants would mobilise various types of knowledge in various ways. Carol distributed brochures and books amongst her contacts, and said of her adult children:

One of the things that helped them was that - you might have heard us talk about that evening they had ... this [awareness] evening, so that was good for [the children], so they came and they heard a little bit more about Chronic Fatigue, and the [doctor] put out a little pamphlet and I wanted all my family to read the pamphlet and once they'd read the pamphlet there was a definite change in how they saw me...and once they know what they're dealing with they're a lot more sympathetic...now they have got more knowledge about the condition um they are definitely more sympathetic.

Carol chooses to share knowledge that is imbued with facticity (published, medicalised) to educate her family and friends, communicating with them in the biomedical language that bears cultural authority in New Zealand, and in which she as a nurse is also well versed.

A part of teaching others about CFS/ME meant educating people on how to be friends with a CFS/ME sufferer. Harry, a sociable man, had invested a lot of thought and care into his friendships. He said, "I've always tried to help my friends understand as much as they want to understand, but give them the tools to ... be able to interact at whatever level". Most of his friends were busy young professionals (as he had been himself a decade before) and he was aware that their time for socialising was limited. Moreover, he had discovered that a lot of friends were not comfortable spending time with him if that encounter was based on his need to see people. Instead he had to engineer an engagement in which his illness could take a back seat. He would organise to have a meal with friends, or to play music together, constructing encounters in which attention was not on his illness. He would, however, explain everything to those friends who were willing to learn about CFS/ME and how it affected him. These were the friends who knew that he could only walk so far if they were going out, that he could only handle short car rides, and could not eat certain foods. For Harry CFS/ME necessitates new ways of interacting with people. Sometimes CFS/ME needs

to be at the centre of these, so that it is clear what he is and is not capable of, and sometimes it needs to be veiled. Harry's astute awareness of the social fields he inhabits enables him to construct his relationships in a different form for each of his friends. Social knowledge here shapes his experience with CFS/ME as much as his knowledge of the illness itself. The combination of the two is an interpersonal knowledge, shaped collaboratively by Harry and his social network.

My informants also often drew on 'common knowledge' to make CFS/ME understandable through analogy. Harry explained his illness to friends by using relatable anecdotes: exhaustion from stressful work cases or the gym were two frequently used explanations that made CFS/ME less alien to the people he was talking to. Another recurring comparison was with the flu, with several of my participants saying that CFS/ME felt like having a bad virus that wouldn't go away, and two participants likened it to having a bad hangover. In these ways they harnesses the ordinariness of CFS/ME, which so often acts as an impediment to people's belief, and instead turn that into a tool for explaining the illness.

If explanations such as these are used to make CFS/ME relatable, there are other instances in which the illness is compared to conditions that may be socially perceived as more serious. Rosa recounted the following incident, from one of her first encounters with a local CFS/ME specialist, Dr Parson:

We had Dr Parson come in, she was very good, she talked to Mum and Dad, she said, "Rosa's as sick as someone in the final stages of cancer" she said "that's how bad her body is", and that was really good 'cause ... [getting teary] that kind of really helped me to understand for the first time – it let me understand that somebody actually knew how bad I felt.

By likening her CFS/ME to cancer this specialist confirmed for Rosa herself that she was indeed seriously unwell (as she said, "that I wasn't putting it on") and also helped her family comprehend the severity of her condition. Ware (1992, 1999) reports similar anecdotes; in one case a patient speculatively said that it might be easier to have cancer than CFS/ME, because at least then they would know what was wrong, and how to go about coping with it. Harry and Rosa, using different words in a similar vein, said they felt as though they were poisoned, with Rosa likening her condition to that of chemical warfare victims. Harry, saying how hard it has been to be stuck in his flat for years as life goes by, told me "you *feel* crippled, you know?" alluding to the functional helplessness he feels with CFS/ME, at odds with a body that is, to all appearances, healthy. Mandy cited an internationally renowned CFS/ME specialist, Nancy Klimas, who publicly stated that she would prefer to have AIDS than CFS/ME.

These references give people a way to communicate the severity of their illness by drawing upon the social capital of diseases with a powerful public image, like cancer and AIDS, as well as the 'common knowledge' of these conditions as being serious and indisputable. As Dumit (2006: 578) notes, CFS/ME and other contested illnesses require "tremendous amounts of hard work by patients to achieve diagnosis and acknowledgement", with the diffuse symptoms and often absent diagnosis compounding the difficulties of gaining social acceptance and/or understanding. By judiciously combining their own personal knowledge of CFS/ME with the common knowledge of other diseases and shared, everyday experiences, my informants construct CFS/ME in a socially acceptable and significant form. I adapt the term interpersonal knowledge from education studies (Collinson 1996) to describe this composite knowledge, deployed for social purposes and shaped by the beliefs of both my informants and their peers. This knowledge is constructed intersubjectively with the aim of bridging the epistemic gap between sufferers and those they share their social worlds with, and provides a useful way of delineating the social negotiations CFS/ME sufferers undertake.

My informants' depictions of CFS/ME also convey discontent with the social indifference afforded their illness thus far. Juxtaposing their condition with cancer and AIDS highlights the differential respect granted these diseases, and voices support for the inclusion of CFS/ME in the echelons of the medical world. Again this speaks to broader social tensions about the place of people with CFS/ME. As I have shown, a lack of support (be it pragmatic or emotional) can be devastating to CFS/ME sufferers, and these local social challenges are not dissimilar from those faced by CFS/ME sufferers collectively. My participants' cited obstacles like bureaucratic exclusion from receiving sickness benefits, and hostile public attitudes as influences that directly damage their health. Daniel, for example, told me that dealing with Work and Income to try and obtain financial support while unable to work had been stressful enough to break down his mental health. Accounts like this tap into macro-scale socio-political obstacles that CFS/ME (and other contested illness) sufferers face collectively. The efforts individual CFS/ME sufferers make to negotiate their place in their local social worlds thus mirror the broader efforts of CFS/ME sufferers collectively to situate themselves in society.

## **Conclusion**

As with the bodily experience of CFS/ME, my participants' local social worlds are volatile and easily disrupted. They had all seen relationships dissolved or disrupted by their illness, and such losses only compound the physical difficulties of CFS/ME. In my informants' local social worlds knowledge is both a resource and impediment. My participants sought to preserve their relationships by appealing to factual knowledge and 'common knowledge', illustrating

yet another way knowledge is created and conveyed in an attempt to ease the experience of living with CFS/ME. Their social peers come to their relationships with pre-existing ideas, not only about CFS/ME, but also about what constitutes illness, or the role of a friend. Social relationships thus become spaces in which different epistemes collide, creating an interpersonal knowledge that is shaped by both, though not necessarily in the form of either. I have argued that these interpersonal relations warrant attention. They shape the lived experience of CFS/ME, affecting how people feel about themselves and their illness, and how they represent this socially. Furthermore these individual social worlds can be seen as a microcosm in which broader societal tensions around CFS/ME play out. Issues of recognition and misunderstanding track almost seamlessly between the collective and the individual, once more drawing attention to the types of knowledge that circulate in and amongst such spheres.



## CONCLUSION

By exploring the lived experience of CFS/ME from the body out, into the realms of the social and everyday, knowledge in its many different forms and uses has emerged as a central aspect of this condition. In this thesis I have explored some of the types of knowledge that make up CFS/ME for sufferers, and argued for the importance of each to the lived experience of the condition. I have considered the knowledge that resides deep within the body alongside that produced by the medical world; the ways of knowing that come about through personal experimentality, and those jointly created through social interaction; the knowledge suffused with a sheen of facticity, and that which would ordinarily lack authority. By drawing upon these different pieces of knowledge my participants construct explanations of CFS/ME that cohere with their lived experiences, and fill in the gaps left by medico-scientific explanations.

What these various ways of knowing CFS/ME point to is its irrepressible variability. Very little about this illness is certain or consistent, and this consequently becomes its defining feature. The bodily experience of CFS/ME changes from day to day – my participants spoke about their health being utterly unpredictable, with crashes coming from nowhere. The indeterminacy of CFS/ME requires a correspondingly open ended way of coping, which I argue is best conceptualised with notions of care. And the social world of CFS/ME sufferers is similarly inconsistent, as people's relationships shift, break down, and are rebuilt. This variability is important, and instead of fixating on how it hampers understandings of CFS/ME, I suggest that it might be more productive to think *with* this indeterminacy, to ask instead *what does this tell us about CFS/ME?* Pursuing this question in my analysis I have realised that the uncertainty is, in fact, a kind of openness. Though a source of frustration to sufferers, the indeterminacy of CFS/ME also make space for personal understandings to take on authority; it invites alternative ways of knowing.

These alternative ways of knowing are especially important to contested illnesses, whose facticity is in the process of being solidified (Dumit 2006, Lakoff 2005). The juncture of these ways of knowing also tap into issues of credibility and authority that are particularly fraught for CFS/ME due to its marginal place in the realms of biomedicine and science. Though scientific knowledge on CFS/ME is rapidly accumulating, it is conflicted and often contradictory. The medical establishment is vested with the authority to answer questions of health and illness, but when it comes to CFS/ME it cannot. As with most of the Western world New Zealand society relies on biomedical technologies, with their continual processes of refining and revealing, to diagnose and treat illness (Abel et al 2001; Trundle and Scott 2013).

Medical diagnosis plays a central role in ensuring social acceptance and bureaucratic support, and individuals are expected to act responsibly and manage their health. In such a context people with CFS/ME are at an impasse, and my informants were acutely aware of this. I have shown how in response they make and mobilise new forms of knowledge, which are deeply grounded in their own experiences. These forms of knowledge tie together facts, practices, culturally vested beliefs, the body, and extensive social networks, and my informants used these to both make sense of their condition themselves, and to help cope with it.

In delineating these ways of knowing, I have followed my informants' lead in bringing together different forms of knowledge with which to understand CFS/ME (Chapter Two), and thus have been able to explore the condition in ways that have largely escaped the attention of previous social science studies. For example, CFS/ME can be considered in light of blood-based biomarkers, which produce a cellular-level knowledge, and show how the body with CFS/ME appears characterised by suppressed immune function. Alternatively, it can be viewed from a lived perspective, which reveals the embodied nature of CFS/ME, and also the importance of a mind-body distinction to sufferers. The embodied knowledge produced here influences the practices people employ to cope with CFS/ME, and when looking at such coping strategies we encounter a different kind of knowledge again: a knowledge in practice that contradicts the prescriptive treatment advocated by self-management programmes.

This knowledge-based approach equips me to revisit existing work on CFS/ME that has addressed issues of stigma and delegitimation (Åsbring and Narvänen 2001, Cohn 1999, Sachs 2001, Ware 1992, 1999). Though these are important issues, the lived experience of my informants exceeded these. This thesis has shown that the social field of CFS/ME is defined not only by judgement and exclusion, but also by support and reciprocal negotiation. Further, the social experiences my participants describe are inextricably tied to their bodily experience, their ways of understandings and communicating their illness, and the coping practices they can or will engage in. Framing the connections between these factors in terms of knowledge continues an anthropological tradition of the epistemic that has yet to be applied to CFS/ME. The knowledge produced through this thesis answers Haraway's (1988) call for partial and situated knowledge. While the medico-scientific world continues to ascertain the facts of CFS/ME the sufferers of this illness are creating their own facts. I have discussed here the many types of knowledge that emerge around CFS/ME sufferers, illustrating their partiality, as a type of knowledge that privileges the lived experience of CFS/ME, and their positionality, located in the individual, who themselves is positioned in an unstable epistemic and intersubjective terrain.

Attending to these forms of knowledge demonstrates how CFS/ME sufferers continually shift and negotiate their position between the spheres of the everyday and the scientific. Just

as the body can be known both biologically and experientially, so too do sufferers come to know their condition through a composite of lived and learnt knowledge, and to cope by moving between medical practices and everyday care. The place of CFS/ME sufferers in New Zealand will continue to shift. I feel it is safe to say that they face an increasingly politicised future as attempts to engage politicians, raise awareness, and attract financial support gain momentum. These will be important topics for social scientists to address and I believe studies such as this one, which address sufferers' perspectives of the illness, can inform such future work by establishing a foundation in the variable lived experiences of CFS/ME.

# APPENDIX 1

## INTERVIEW QUESTIONS

### Demographics

How old are you?

How many siblings do you have?

Are they older or younger than yourself?

What ethnicity do you identify with?

Are your parents married/divorced/etc?

How would you describe your family's economic means?

As compared to your own?

### Background information

Tell me about how you first discovered you had CFS/ME?

How old were you?

Had you been sick before?

With what?

What did you know about CFS/ME before you developed it?

How did you learn more about it?

Did you know other people with CFS/ME before being diagnosed?

Can you describe what it's like to have CFS/ME?

What are the challenges?

How are you coping with CFS/ME?

### Questions about CFS/ME

What do you think causes of CFS/ME?

Ask to expand on any explicitly biological, psychological, or anthropological explanations that may arise.

How do you feel about psychological explanations of CFS/ME?

Do you think CFS/ME can be prevented or overcome?

How?

What's it like seeing your doctor about your CFS/ME?

Can you tell me about a recent encounter with your specialist/GP about your CFS/ME?

Is that quite typical of how your specialist/GP treats you?

### Before and with CFS/ME

What was your occupation before your diagnosis?

Are you still working now?

Do you feel like your attitude toward your work has changed?

What were your primary responsibilities?

Can you describe how your health was before you first developed CFS/ME?  
Could you describe what a typical day for you was like before contracting CFS/ME?  
How does that compare to your life now?  
Has having CFS/ME affected your relationships with family/friends/colleagues?  
How do you think other people perceive CFS/ME?

### **Reflections**

Has CFS/ME changed the way you live, on a day-to-day basis?  
Have your priorities changed, having CFS/ME?  
What do you think of your ability to manage your CFS/ME?  
Do you think you can help yourself recover from CFS/ME? How?  
What sort of support do you have for dealing with your CFS/ME?

### **Biology of CFS/ME**

How do you see your immune system affecting your CFS/ME?  
How does your general health affect your CFS/ME symptoms?  
How does your CFS/ME affect your general health?  
Can you describe what you think is going on in your body when you have CFS/ME?  
The Dried Blood Spots I'll be taking after this might be able to show sub-clinical inflammation –would be useful or interesting? How?

### **'Wrap up' question**

What would you like to say about this condition to someone who doesn't know about CFS/ME?

## **APPENDIX 2**

### **DRIED BLOOD SPOT ANALYSIS**

The following section details the assay protocol carried out on my DBS samples by Dr Brindle, of the University of Washington biodemography laboratory.

#### *CRP assay method*

A microtiter plate-based sandwich enzyme immunoassay was used to measure CRP in dried blood spot specimens. The assay, described in full elsewhere (Brindle, Fujita, Shofer, & O'Connor, 2010), uses capture (clone C5 anti-CRP MAb, cat.no. M86005M) and detection (clone C6 anti-CRP MAb, cat.no. M86284M) antibodies purchased from Meridian Life Science, Inc. and calibrators purchased from Fitzgerald Industries International, Inc. (cat.no. 30-AC10). All specimens, calibrators and controls were assayed in duplicate. Colour reactions were quantified at 405nm (test) and 570nm (reference) using a Synergy HT microtiter plate reader (Bio Tek Instruments, Inc.). Concentrations are estimated with a four parameter logistic calibration curve fit (Gen5, Bio Tek Instruments Inc.). In validation studies, within and between assay coefficients of variation for plasma in-house quality control specimens were 3.5% and 9.4% respectively for the low (0.0033mg/L) control, and 2.7% and 9.9% for the high (0.0063mg/L) control (n=11 plates). Analytical sensitivity, defined as the concentration 3 SD above the zero dose calibrator, is 0.00007mg/l (n=20 plates). Functional sensitivity, estimated as the concentration at which the within-assay coefficient of variation is consistently less than 10%, is 0.00015mg/l (n=230 duplicate specimens across 8 plates). In tests for independence of volume, linear mixed effects models showed no differences between slopes of the liquid calibration curve and of ten serially diluted plasma specimens (p=.9). Analytical recovery, evaluated by adding known amounts of CRP to plasma specimens, averaged 105%, 101%, and 106% for low, medium, and high doses respectively. The assay shows no cross-reactivity with two compounds related to CRP, human pentraxin 2 and human pentraxin 3. The CSDE Biodemography Lab has used this assay method previously for a number of studies (Fujita et al., 2009, 2011, 2012; Wander, Brindle, & O'Connor, 2008, 2012; Wander, O'Connor, & Shell-Duncan, 2012)

#### *EBV VCA IgG assay method*

IgG antibody to Epstein-Barr viral capsid antigen (EBV VCA IgG) was measured using a commercial ELISA kit supplied by IBL International (Hamburg, Germany; IBL catalog #

RE57351) that allows quantification of the antibody in arbitrary units. All specimens were run in duplicate. The kit manufacturer reports that the assay shows no cross reactivity with antibodies to other common viruses tested (parvovirus B19, VZV, HSV 1, CMV, measles, mumps, toxoplasmosis and rubella) and that the assay demonstrated linearity (recovered values 85% - 111% of the expected values). Precision tests for high (68 U/mL), medium (23 U/mL) and low (9 U/mL) resulted in intra-assay CVs of 7%, 6% and 9%, respectively, and inter-assay CVs of 19%, 8% and 18%, respectively.

# APPENDIX 3

## SAMPLE PARTICIPANT INFORMATION SHEET (PIS)



Department of Anthropology  
University of Auckland  
PO Box 92019, Auckland  
Phone 09 3737599 ext. 87662

### PARTICIPANT INFORMATION SHEET

#### **The Biological Expression and Social Origins of Chronic Fatigue Syndrome (CFS): Immunity, Stress, and Individual Encounters with a Contested Illness.**

Dear [name]

My name is Courtney. I am a graduate student of Anthropology at The University of Auckland, enrolled in a Masters of Arts.

I would like to invite you to participate in this research and would appreciate any contribution you may be able to make. My research aims to investigate how New Zealanders with Chronic Fatigue Syndrome (CFS) or Myalgic Encephalopathy (ME) understand and experience their condition. I am conducting this project under the joint supervision of Dr. Susanna Trnka and Dr Judith Littleton.

I would like to interview you about your experience with CFS/ME, at a time and place convenient for you. The interview will take one to two hours, but can be ended at any time you wish. This interview will be about your own understanding of CFS/ME and its causes, how CFS/ME has affected your life, and how you deal with having this illness. With your consent I wish to record our interview electronically, but the recorder can be turned off at any time.

At the time of the interview I would also like to collect dried blood spots from you. To do this I will use a sterile, disposable lancet, like those used by diabetics, to prick your finger and collect up to five drops of blood. This will allow me to biologically assess the state of your



immune system, and your physiological stress<sup>39</sup>. This is not a very painful procedure, but may be slightly uncomfortable. There is a chance that incidental findings may arise from this procedure. If you would prefer not to be notified in such a case, I will unfortunately have to exclude you from participating.

Please understand that you have no obligation to participate in this research. If you do agree to take part, you may withdraw your participation or any data you have contributed at any time until July 1, 2013.

The result of this research will be a thesis written for my Masters. I may also use the results for publication in academic journals, and presentation at academic conferences. Every measure will be taken to preserve your anonymity and confidentiality. Pseudonyms will be used to protect your identity. I can provide you with a summary of my findings once this project is complete if you wish.

All research papers – consent forms, data, and so forth – will be securely stored for six years. After this time they will be destroyed via secure paper destruction and electronic cleaning. Dried Blood Spots will be tested and stored in a laboratory at the University of Washington, where they will be destroyed following analysis.

Please feel free to contact me on the below details with any questions you may have. If you agree to take part I will arrange a meeting with you to arrange consent.

Thank you for taking the time to read this, and for considering this research project.

*Courtney Addison*

Graduate Student  
Department of Anthropology  
The University of Auckland  
Private Bag 92019  
Auckland.  
Email: [cadd006@aucklanduni.ac.nz](mailto:cadd006@aucklanduni.ac.nz)  
Mobile: 021-0494367

My Supervisors are:

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<sup>39</sup> At the outset I planned to measure people's cortisol levels, which reflect the stress response, as well as immune function, but decided against this later after realizing that multiple measures of cortisol taken over days or weeks are really needed to produce informative results.

**Dr Susanna Trnka**

Department of Anthropology  
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Tel. + 64 9 373 7599 extn. 85316

**Dr Judith Littleton**

Department of Anthropology  
The University of Auckland  
Private Bag 92019  
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The Head of Department is:

**Associate Professor Simon Holdaway**

Department of Anthropology  
The University of Auckland  
Private Bag 92019  
Auckland.  
Tel. 3737-7999 extn 83947

For any queries regarding ethical concerns you may contact:

The Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142.

Telephone 09 373-7599 extn. 87830/83761  
Email: [humanethics@auckland.ac.nz](mailto:humanethics@auckland.ac.nz).

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 4 April 2013 for (3) years, Reference Number 9100.

# APPENDIX 4

## SAMPLE CONSENT FORM



THE UNIVERSITY OF AUCKLAND  
NEW ZEALAND

Department of Anthropology  
Level 8 Human Sciences Building  
10 Symonds Street  
Auckland

The University of Auckland  
Private Bag 92019  
Auckland, New Zealand

### CONSENT FORM

THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS

#### **The Biological Expression and Social Origins of Chronic Fatigue Syndrome (CFS): Immunity, Stress, and Individual Encounters with a Contested Illness.**

Researcher: Courtney Addison

I have read the Participant Information Sheet, have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

I agree to take part in this research.

I understand that I am free to withdraw participation at any time, and to withdraw any data traceable to me up to July 1, 2013.

I agree / do not agree that my sibling may also be approached, regarding dried blood spots contributions.<sup>40</sup>

I agree / do not agree to be audiotaped.

I wish / do not wish to have my tapes returned to me.

I wish / do not wish to receive the summary of findings.

---

<sup>40</sup> At the outset I had hoped to use my participants siblings as the control group for the DBS testing, to minimise potential confounding by genetic factors. I did not end up working with any siblings however, primarily due to availability.

I wish / do not wish to be notified of any incidental findings that may arise.

I understand that the researcher will take every measure possible to preserve my anonymity and confidentiality, by way of secure data storage, pseudonyms, and personal confidentiality.

I understand that data will be kept for 6 years, after which they will be destroyed.

If you would like to receive a summary report, please include your e-mail address here:

\_\_\_\_\_

Name \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS  
COMMITTEE ON 4/4/13 FOR (3) YEARS. REFERENCE NUMBER 9100.

## REFERENCES

- Abel, S., J. Park, D. Tipene-Leach, S. Finau, and M. Lennan. 2001. Infant care practices in New Zealand: A cross-cultural qualitative study. *Social Science and Medicine* 53(9): 1135-1148.
- Alley, C. and J. Sommerfield. 2013. Infectious disease in times of social and ecological change. *Medical Anthropology* (forthcoming).
- Armelagos, G. J., P. J. Brown, and B. Turner. 2005. Evolutionary, historical and political economic perspectives on health and disease. *Social Science & Medicine* 61:755.
- Arroll, M. A., and A. Howard. 2013. 'The letting go, the building up, [and] the gradual process of rebuilding': Identity change and post-traumatic growth in myalgic encephalomyelitis/chronic fatigue syndrome. *Psychology & Health* 28:302-318.
- Åsbring, P., and A. L. Närvänen. 2002. Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research* 12:148-160.
- ANZMES (Associated New Zealand Myalgic Encephalopathy Society). 2012. "ANZMES Homepage." Retrieved from [www.anzmes.org.nz](http://www.anzmes.org.nz).
- Bains, W. 2008. Treating chronic fatigue states as a disease of the regulation of energy metabolism. *Medical Hypotheses* 71:481-488.
- Bansal, A. S., A. S. Bradley, K. N. Bishop, S. Kiani-Alikhan, and B. Ford. 2012. Chronic fatigue syndrome, the immune system and viral infection. *Brain, Behavior, and Immunity* 26:24-31.
- Barry, C. A. 2006. The role of evidence in alternative medicine: Contrasting biomedical and anthropological approaches. *Social Science and Medicine* 62:2646-2657.
- Baschetti, R. 2003. Chronic fatigue syndrome: An endocrine disease off limits for endocrinologists? *European Journal of Clinical Investigation* 33:1029-1031.
- Becker, G. 2004. Phenomenology of health and illness. In *Encyclopedia of Medical Anthropology*, Carol R. Ember and Malvin Ember, eds. Pp. 125-126. New York: Springer.
- Bell, L. J. M. 2012. *The disrupted and realigned self: Exploring the narratives of New Zealanders with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis* (Masters thesis). Wellington: Victoria University.
- Bourdieu P. 1972. *Outline of a theory of practice*. Cambridge: Cambridge University Press.
- Bradley, A. S., B. Ford, and A. S. Bansal. 2013. Altered functional B-cell subset populations in patients with chronic fatigue syndrome compared to healthy controls. *Clinical & Experimental Immunology* 172:73-80.
- Brenu, E. W., L. Tajouri, K. J. Ashton, D. R. Staines, and S. M. Marshall-Gradisnik. 2013. Chronic Fatigue Syndrome/Myalgic Encephalomyelitis and Parallels with Autoimmune Disorders. In *Genes and Autoimmunity - Intracellular Signalling and Microbiome Contribution*. S. A. Stanilova, ed. Pp. 205-235. Rijeka: InTech.

- Brewis, A. A. 2011. *Obesity: cultural and biocultural perspectives*: Piscataway, N. J.: Rutgers University Press.
- Brindle, E., M. Fujita, J. B. Shofer, and K. A. O'Connor. 2010. Serum, plasma, and dried blood spot high-sensitivity C-reactive protein enzyme immunoassay for population research. *Journal of Immunological Methods* 362(1-2):112-20.
- Brooks, J., N. King, and A. Wearden. 2013. Couples' experiences of interacting with outside others in chronic fatigue syndrome: A qualitative study. *Chronic Illness* (forthcoming).
- Brown, P. 2007. *Toxic exposures: Contested illnesses and the environmental health movement*. New York: Columbia University Press.
- Brown, M. M., D. S. Bell, L. A. Jason, C. Christos, and D. E. Bell. 2012. Understanding Long-Term Outcomes of Chronic Fatigue Syndrome. *Journal of Clinical Psychology* 68:1028-1035.
- Brown, P., R. Morello-Frosch, and S. Zavestoski. 2011. *Contested illnesses: Citizens, science, and health social movements*. Berkeley: University of California Press.
- Brown, P., S. Zavestoski, S. McCormick, B. Mayer, R. Morello-Frosch, and R. Gasior Altman. 2004. Embodied health movements: New approaches to social movements in health. *Sociology of Health & Illness* 26(1): 50-80.
- Buchwald, D., T. Pearlman, P. Kith, and K. Schmaling. 1994. Gender differences in patients with chronic fatigue syndrome. *Journal of General Internal Medicine* 9:397-401.
- Carruthers, B. M., M. I. van de Sande, K. L. De Meirleir, N. G. Klimas, G. Broderick, T. Mitchell, D. Staines, A. C. P. Powles, N. Speight, R. Vallings, L. Bateman, B. Baumgarten-Austrheim, D. S. Bell, N. Carlo-Stella, J. Chia, A. Darragh, D. Jo, D. Lewis, A. R. Light, S. Marshall-Gradisbik, I. Mena, J. A. Mikovits, K. Miwa, M. Murovska, M. L. Pall, and S. Stevens. 2011. Myalgic encephalomyelitis: International consensus criteria. *Journal of Internal Medicine* 270:327-338.
- Carter, B. D. and G. S. Marshall. 1995. New developments: Diagnosis and management of chronic fatigue in children and adolescents. *Current Problems in Pediatrics* 25(9):281-293.
- CDC (Centre for Disease Control and Prevention). 2012. Chronic Fatigue Syndrome (CFS) symptoms. Retrieved from <http://www.cdc.gov/cfs/symptoms/index.html>.
- Cherry, M. 2002. Bodies and minds in the philosophy of medicine: Organ sales and the lived body. In *The Philosophy of Medicine: Framing the Field*. H. T. Engelhardt, ed. Pp. 57-78. New York: Kluwer Academic Publishers.
- Cho, H. J., P. R. Menezes, M. Hotopf, D. Bhugra, S. Wessely. 2009. Comparative epidemiology of chronic fatigue syndrome in Brazilian and British primary care: Prevalence and recognition. *The British Journal of Psychiatry* 194:117-122.
- Clarke, J. N. and S. James. 2003. The radicalised self: The impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Social Science and Medicine* 57:1387-1395.

- Cleare, A. J. 2003. The neuroendocrinology of chronic fatigue syndrome. *Endocrine Reviews* 24:236-252.
- Cohen, M. Z., T. Tripp-Reimer, C. Smith, B. Sorofman, and S. Lively. 1994. Explanatory models of diabetes: patient practitioner variation. *Social Science & Medicine* 38:59-66.
- Cohn, S. 1999. Taking time to smell the roses: Accounts of people with chronic fatigue syndrome and their struggle for legitimisation. *Anthropology and Medicine* 6(2):195-215.
- Collins, H. M. and R. Evans. 2002. The third wave of science studies: Studies of expertise and experience. *Social Studies of Science* 32(2): 235-296.
- Collinson, V. 1996. *Reaching students: Teachers' ways of knowing*. Thousand Oaks, C.A.: Corwin Press, Inc.
- Comaroff, J. 1985. *Body of power, spirit of resistance: the culture and history of a South African people*. Chicago: University of Chicago Press.
- Csordas T. 1990. Embodiment as a paradigm for anthropology. *Ethos* 18(1):5-47.
- Csordas T. 1993. Somatic modes of attention. *Cultural anthropology* 8(2):135-156.
- Csordas, T. 1994. Introduction: the body as representation and being-in-the-world. In *Embodiment and experience: the existential ground of culture and self*. T. Csordas, ed. Cambridge, N.Y.: Cambridge University Press.
- De Becker, P., N. R. McGregor, K. De Smet, K. De Meirleir. 2002. Current advances in CFS therapy. In *Chronic Fatigue Syndrome: A Biological Approach*. P. A. M. Englebienne, ed. Boca Raton: CRC Press.
- Desjarlais, R. and C. J. Throop. 2011. Phenomenological approaches to embodiment. *Annual Review of Anthropology* 40:87-102.
- Dew, K. 2000. Deviant insiders: Medical acupuncturists in New Zealand. *Social Science and Medicine* 50(12): 1785-1795.
- Dickson, A., C. Knussen, P. Flowers. 2007. Stigma and the delegitimation experience: An interpretive phenomenological analysis of people living with chronic fatigue syndrome. *Psychology and Health* 22(7):851-867.
- Dietert, R. R., and J. M. Dietert. 2008. Possible role for early-life immune insult including developmental immunotoxicity in chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME). *Toxicology* 247:61-72.
- Dumit, J. 2006. Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses. *Social Science & Medicine* 62:577-590.
- Dumit, J. 2012. *Drugs for life: How pharmaceutical companies define our health*. Durham: Duke University Press.
- Epstein, S. 1995. The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology, and Human Values*. 20(4):408-437.

- Fletcher, M. A., X. R. Zeng, K. Maher, S. Levis, B. Hurwitz, M. Antoni, G. Broderick, and N. G. Klimas. 2010. Biomarkers in chronic fatigue syndrome: Evaluation of natural killer cell function and dipeptidyl peptidase IV/CD26 (biomarkers in CFS). *Plos One* 5:e10817.
- Fluge, Ø., O. Bruland, K. Risa, A. Storstein, E. K. Kristoffersen, D. Sapkota, H. Næss, O. Dahl, H. Nyland, and O. Mella. 2011. Benefit from B-lymphocyte depletion using the anti-CD20 antibody Rituximab in chronic fatigue syndrome. A double-blind and placebo-controlled study. *Plos One* 5(5):e6358.
- Ford, D. H., and R. M. Lerner. 1992. *Developmental systems theory: An integrative approach*. Newbury Park: Sage Publications, Inc.
- Fornet-Betancourt, R., H. Becker, A. Gomez-Müller, and J. D. Gauthier. 1987. The ethic of care for the self as a practice of freedom: an interview with Michel Foucault on January 20, 1984. *Philosophy & Social Criticism* 12:112-131.
- Foucault, M. 1986. *Care of the self: The history of sexuality Vol 3*. New York: Random House.
- Foucault, M. 1993. About the beginnings of the hermeneutics of the self. *Political theory* 21:198-227.
- Frazetto, G., and S. Anker. 2009. Neuroculture. *Nature Reviews: Neuroscience* 10:815-821.
- Friese, C. 2013. Realising potential in translational medicine: The uncanny emergence of care as science. *Current Anthropology* 54(7):129-138.
- Frith, J., P. Zalewski, J. J. Klawe, J. Pairman, A. Bitner, M. Tafil-Klawe, and J. L. Newton. 2012. Impaired blood pressure variability in chronic fatigue syndrome—a potential biomarker. *QJM* 105:831-838.
- Fujita, M., E. Brindle, A. Rocha, B. Shell-Duncan, P. Ndemwa, K. A. O. Connor and K. A. O'Connor. 2009. Assessment of the relative dose-response test based on serum retinol-binding protein instead of serum retinol in determining low hepatic vitamin A stores. *The American Journal of Clinical Nutrition*. 90(1):217-24.
- Fujita, M., E. A. Roth, Y. J. Lo, C. Hurst, J. Vollner, and A. Kendell. 2012. Low serum vitamin A mothers breastfeed daughters more often than sons in drought-ridden northern Kenya: A test of the Trivers-Willard hypothesis. *Evolution and Human Behavior* 33(4):357-364.
- Fujita, M., B. Shell-Duncan, P. Ndemwa, E. Brindle, Y. J. Lo, Y. Kombe, and K. O'Connor. 2011. Vitamin A dynamics in breastmilk and liver stores: A life history perspective. *American Journal of Human Biology* 23(5):664-73.
- Gallagher A.M., J. M. Thomas, W.T. Hamilton, P.D. White. 2004. Incidence of fatigue symptoms and diagnoses presenting in UK primary care from 1990 to 2001. *Journal of the Royal Society of Medicine* 97:571-575.
- Geertz, C. 2000. *Local knowledge: Further essays in interpretative anthropology*. New York: Basic books.



- Gibbons, R. 2010. *A table of metaphors: The visual representation of chronic illness*. (Masters thesis.) Palmerston North: Massey University.
- Good, B. 1987. Explanatory models and care-seeking: A critical account. In *Illness Behavior*. S. McHugh and T. M. Vallis, eds. Pp. 161-172. Boston: Springer.
- Good, M. J. D. V., P. E. Brodwin, B. J. Good, A. Kleinman (eds). 1992. *Pain as human experience: an anthropological perspective*. Berkeley: University of California Press.
- Goodman, A. H., and T. L. Leatherman. 1998. Traversing the chasm between biology and culture. In *Building a new biocultural synthesis: Political economic perspectives on human biology, linking levels of analysis*. A. H. Goodman and T. L. Leatherman, eds. Michigan: University of Michigan Press.
- Gravlee, C. C. 2009. How race becomes biology: Embodiment of social inequality. *American Journal of Physical Anthropology* 139:47-57.
- Gregg, J., and R. H. Curry. 1994. Explanatory models for cancer among African-American women at two Atlanta neighborhood health centers: The implications for a cancer screening program. *Social Science & Medicine* 39:519-526.
- Hacking, I. 1999. *The social construction of what?* Boston: Harvard University Press.
- Haraway, D. 1998. Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies* 14(3):575-599.
- Horne, S. 1990. A daily battle with despair: the social and psychological effects of myalgic encephalomyelitis in New Zealand and the problems of recognition. (Masters thesis.) Palmerston North: Massey University.
- IACFS/ME (International Association for CFS/ME). 2012. *A Primer for Clinical Practitioners*. 2012 Edition.
- Jackson J.E. 2005. Stigma, liminality, and chronic pain: Mind-body borderlands. *American Ethnologist* 32(3):332-353.
- Jammes, Y., J. G. Steinberg, O. Mambrini, F. Brégeon, and S. Delliaux. 2005. Chronic fatigue syndrome: Assessment of increased oxidative stress and altered muscle excitability in response to incremental exercise. *Journal of Internal Medicine* 257:299-310.
- Jasanoff, S. 2004. *States of knowledge: the coproduction of science and the social order*. London: Routledge.
- Jason, L. A., R. R. Taylor, Z. Stepanek, and S. Plioplys. 2001. Attitudes regarding chronic fatigue syndrome: The importance of a name. *Journal of health psychology* 6:61-71.
- Jason, L. A. 2011. Natural history of chronic fatigue syndrome. *Rehabilitation Psychology* 56:32-42.
- Jespersen, A. P., J. Bønnelycke, and H. H. Eriksen. 2013. Careful science? Bodywork and care practices in randomised clinical trials. *Sociology of Health and Illness*. Forthcoming:1-15.

- Jordan, B. 1977. The self-diagnosis of early pregnancy: An investigation of lay competence. *Medical Anthropology* 1(2):1-38.
- Karasz, A., and P. S. McKinley. 2007. Cultural differences in conceptual models of everyday fatigue: a vignette study. *Journal of health psychology* 12:613.
- Kay, L. E. 1996. *The molecular vision of life: Caltech, the Rockefeller Foundation, and the rise of the new biology*. Oxford: Oxford University Press.
- Kerr, J. R., B. Burke, R. Petty, J. Gough, D. Fear, D. L. Matthey, J. S. Axford, A. G. Dalglish, and D. J. Nutt. 2008. Seven genomic subtypes of chronic fatigue syndrome/myalgic encephalomyelitis: A detailed analysis of gene networks and clinical phenotypes. *Journal of Clinical Pathology* 61:730-739.
- Kimmel, M. 2008. Properties of cultural embodiment: Lessons from the anthropology of the body. *Body, Language, and Mind*. 2:77-108.
- Kleinman, A. 1978. Concepts and a model for the comparison of medical systems as cultural systems. *Social Science & Medicine* 12:85-93.
- Kleinman, A. 1980. Orientations Three: Core Clinical Models and Explanatory Models. In *Patients and healers in the context of culture: an exploration of the borderland between anthropology, medicine and psychiatry*, vol. 3. A. Kleinman, ed. Berkeley: University of California Press.
- Kleinman, A. 1987. Explanatory models in health-care relationships: A conceptual frame for research on family-based health-care activities in relation to folk and professional forms of clinical care. In *Encounters between patients and doctors: An anthology*. J. D. Stoeckle, ed. Pp. 273-283. Cambridge, M.A.: The MIT Press.
- Kleinman, A. 1988. *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.
- Kleinman, A., and P. Benson. 2006. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Medicine* 3:1673-1676.
- Klimas, N. G., G. Broderick, and M. A. Fletcher. 2012. Biomarkers for chronic fatigue. *Brain, Behavior, and Immunity* 26:1202-1210.
- Krieger, N. 2001. A glossary for social epidemiology. *Journal of Epidemiology and Community Health* 55:693-700.
- Krieger, N. 2005. Embodiment: A conceptual glossary for epidemiology. *Journal of Epidemiology and Community Health* 59:350-355.
- Kroll-Smith, J. S., P. Brown, and V. J. Gunter, eds. 2000. *Illness and the environment: a reader in contested medicine*. New York: New York University Press.
- Lakoff, A. 2005. *Pharmaceutical reason: knowledge and value in global psychiatry*. Cambridge: Cambridge University Press.

- Lakoff, G. 1987. *Women, fire and dangerous things: What categories reveal about the mind*. Chicago: University of Chicago Press.
- Lakoff, G. 2003. The embodied mind and how to live with one. In *The nature and limits of human understanding*. A. J. Sanford, ed. London: Continuum.
- Lakoff, G., and M. Johnson. 1999. *Philosophy in the flesh: The embodied mind and its challenge to western thought*. New York: Basic books.
- Larun, L., and K. Malterud. 2007. Identity and coping experiences in chronic fatigue syndrome: A synthesis of qualitative studies. *Patient Education and Counselling* 69:20-28.
- Latour, B. 1987. *Science in action: How to follow scientists and engineers through society*. Boston: Harvard University Press.
- Leatherman, T. 2005. Space of vulnerability in poverty and health: Political ecology and biocultural analysis. *Ethos* 33:46-70.
- Leder, D. 1990. *The absent body*. Chicago: University of Chicago Press.
- Lee, S. and Ching Wong, K. 1995. Rethinking neurasthenia: The illness concepts of shenjing and shuairuo amongst Chinese undergraduates in Hong Kong. *Culture, Medicine and Psychiatry* 19:91-111.
- Lindenbaum, S. and M. Lock, eds. 1993. *Knowledge, power and practice: The anthropology of medicine and everyday life*. Berkeley: University of California Press.
- Lloyd, A., I. Hickie, C. Hickie, J. Dwyer, D. Wakefield. 1992. Cell-mediated immunity in patients with chronic fatigue syndrome, healthy control subjects, and patients with major depression. *Clinical and Experimental Immunology* 87(1): 76-79.
- Lombaard, A. and J. Mouton. 2005. Chronic fatigue syndrome, the body and the self: A qualitative analysis. *South African Journal of Psychology* 35(2): 286-307.
- Lorusso, L., S. V. Mikhaylova, E. Capelli, D. Ferrari, G. K. Ngonga, and G. Ricevuti. 2009. Immunological aspects of chronic fatigue syndrome. *Autoimmunity Review* 8:287-291.
- Lyall, M., M. Peakman, S. Wessely. 2003. A systematic review and critical evaluation of the immunology of chronic fatigue syndrome. *Journal of Psychosomatic Research* 55:79-90.
- Martin, E. 1987. *The woman in the body: A cultural analysis of reproduction*. Milton Keynes: Open University Press.
- Martin, E. 1994. *Flexible bodies: Tracking immunity in American culture from the days of polio to the age of AIDS*. Boston: Beacon Press.
- Mascia-Lees, F. E. 2011. *A companion to the anthropology of the body and embodiment, vol. 22*. West Sussex: Blackwell Publishing Ltd.
- McDade, T. W. 2007. Measuring immune function: Markers of cell-mediated immunity and inflammation in dried blood spots. In *Measuring stress in humans: A practical guide for the field*. J. E. Ice, ed. Pp. 181-209. New York: Cambridge University Press.

- McDade, T., S. Williams, and J. Snodgrass. 2007. What a drop can do: Dried blood spots as a minimally invasive method for integrating biomarkers into population-based research. *Demography* 44:899-925.
- McElroy, A. 1990. Biocultural models in studies of human health and adaptation. *Medical Anthropology Quarterly* 4:243-265.
- McLennan, A. K. 2013. Book review: Human diet and nutrition in biocultural perspective: Past meets present, T. Moffat and T. Prowse. Obesity: Cultural and biocultural perspectives, A. A. Brewis. *Medical Anthropology Quarterly* 27(2): b15-b18.
- Meier-Ewert, H. K., P. M. Ridker, N. Rifal, N. Price, D. F. Dinges, J. M. Mullington. 2001. Absences of diurnal variation of C-Reactive Protein concentrations in healthy human subjects. *Clinical Chemistry* 47(3):426-430.
- Merleau-Ponty, M. 1945. *Phenomenology of perception*. Translated by Colin Smith. New York: Humanities Press.
- Mol, A. 2008. *The logic of care: Health and the problem of patient choice*. New York: Routledge.
- Mol, A., I. Moser, and J. Pols. 2010. *Care in practice: On tinkering in clinics, homes and farms*. Bielefeld: Transcript Verlag.
- Moran, D. 2010. Sartre on Embodiment, Touch, and the "Double Sensation". *Philosophy Today* 54:135.
- Morris, G., M. Berk, P. Galecki, and M. Maes. 2013. The emerging role of autoimmunity in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *Molecular Neurobiology* Forthcoming:1-16.
- Mshana, G., K. Hampshire, C. Panter-Brick, and R. Walker. 2008. Urban-rural contrasts in explanatory models and treatment-seeking behaviour for stroke in Tanzania. *Journal of Biosocial Science* 40:35-52.
- Myhill, S., N. E. Booth, and J. McLaren-Howard. 2009. Chronic fatigue syndrome and mitochondrial dysfunction. *International Journal of Clinical and Experimental Medicine* 2(1):1.
- Newton, J. L., J. Pairman, K. Hallsworth, S. Moore, T. Plötz, and M. I. Trenell. 2011. Physical activity intensity but not sedentary activity is reduced in chronic fatigue syndrome and is associated with autonomic regulation. *QJM* 104:681-687.
- Nguyen, V. K. 2009. Government-by-exception: Enrolment and experimentality in mass HIV treatment programmes in Africa. *Social Theory and Health* 7(3):196-217.
- Nijs, J., M. Meeus, J. Van Oosterwijck, K. Ickmans, G. Moorkens, G. Hans, and L. S. De Clerck. 2012. In the mind or in the brain? Scientific evidence for central sensitisation in chronic fatigue syndrome. *European Journal of Clinical Investigation* 42:203-212.
- Norheim, K. B., G. Jonsson, and R. Omdal. 2011. Biological mechanisms of chronic fatigue. *Rheumatology* 50:1009-1018.

- Novas, C. and N. Rose. 2000. Genetic risk and the birth of the somatic individual. *Economy and Society* 29(4):485-513.
- Ortega, F., and R. Zorzaneli. 2010. The cerebralization of fatigue: An analysis of the cerebral hypothesis in the case of chronic fatigue syndrome. *História Ciências Saúde-Manguinhos* 17(2):289-305.
- Oyama, S. 2000. *The ontogeny of information: Developmental systems and evolution*. Cambridge: Cambridge University Press.
- Pelto, P. J. and G. H. Pelto. 1997. Studying knowledge, culture, and behavior in applied medical anthropology. *Medical Anthropology Quarterly* 11(2):147-163.
- Petryna, A. 2005. Ethical variability: Drug development and the globalisation of clinical trials. *American Ethnologist* 32(2):183-197.
- Petryna, A. 2002. *Life Exposed: Biological Citizens after Chernobyl*. New Jersey: Princeton University Press.
- Phillips, T. 2010. Debating the legitimacy of a contested environmental illness: A case study of multiple chemical sensitivities (MCS). *Sociology of Health & Illness* 32:1026-1040.
- Phillips, T. 2012. Repressive authenticity in the quest for legitimacy: Surveillance and the contested illness lawsuit. *Social Science & Medicine* 75:1762-1768.
- Phinney, A. and C. A. Chesla. 2003. The lived body in dementia. *Journal of Aging Studies* 17:283-299.
- Pickersgill, M., S. Cunningham-Burley, and P. Martin. 2011. Constituting neurologic subjects: Neuroscience, subjectivity and the mundane significance of the brain. *Subjectivity* 4:346.
- Pols, J. 2013. Knowing Patients: Turning Patient Knowledge into Science. *Science, Technology & Human Values* (Forthcoming).
- Porter, A. S., and P. E. Farmer. 2013. Drug Resistance and Biosocial Analysis in Practice. In *A Handbook of Practicing Anthropology*. R. Nolan, ed. Pp. 354. Chichester, U.K.: Wiley-Blackwell.
- Poss, J. and M. A. Jezewski. 2002. The role and meaning of susto in Mexican American's explanatory model of type 2 diabetes. *Medical Anthropology Quarterly* 16(3):360-377.
- Prins, J. B., J. W. M. van der Meer, and G. Bleijenberg. 2006. Chronic fatigue syndrome. *The Lancet* 367:346-355.
- Rabinow, P., and N. S. Rose. 2003. Introduction. In *The essential Foucault: selections from essential works of Foucault, 1954-1984*. P. Rabinow and N. S. Rose, eds. New York: New Press.
- Rappaport, N. 2001. Towards a post-cultural anthropology of personally embodied knowledge. *Social Anthropology* 9(1):95-102.
- Roberts, E. F. 2012. *God's laboratory: Assisted reproduction in the Andes*. Berkeley: University of California Press.
- Rose, N. S. 2007. *The politics of life itself: Biomedicine, power and subjectivity in the twenty-first century*. Woodstock, N.J.: Princeton University Press.

- Sachs, L. 2001. From a lived body to a medicalized body: diagnostic transformation and chronic fatigue syndrome. *Medical Anthropology* 19(4):299.
- Sapolsky, R. M. 2004. Social status and health in humans and other animals. *Annual Review of Anthropology* 33:393-418.
- Sargent, C., G. C. Scroop, P. M. Nemeth, R. B. Burnet, and J. D. Buckley. 2002. Maximal oxygen uptake and lactate metabolism are normal in chronic fatigue syndrome. *Medicine and Science in Sports and Exercise* 34:51-56.
- Sartre, J. P. 1956. *Being and Nothingness*. H. E. Barnes, translator. New York: Philosophical Library.
- Scheper-Hughes, N. and M. Lock. 1987. The mindful body: A prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly* 1(1):6-41.
- Schwennesen, N. and L. Koch. 2012. Representing and intervening: 'Doing' good care in first trimester prenatal knowledge production and decision-making. *Sociology of Health and Illness* 34(2):283-298.
- Singer, M. 2009. Pathogens Gone Wild? Medical Anthropology and the "Swine Flu" Pandemic. *Medical Anthropology* 28:199-206.
- Singer, M., and S. Clair. 2003. Syndemics and public health: Reconceptualizing disease in bio-social context. *Medical Anthropology Quarterly* 17(4):423-441.
- Smith, C. 2002. Julien Offray de la Mettrie (1709-1751). *Journal of the History of Neurosciences* 11(2):110-124.
- Snell, C. R., S. R. Stevens, T. E. Davenport, and J. M. Van Ness. 2013. Discriminative validity of metabolic and workload measurements for identifying people with chronic fatigue syndrome. *Physical therapy* 93:1484-1492.
- Starr, P. 1982. *The social transformation of American medicine*. New York: Basic Books.
- Stoller, P. 2007. Finding a path in the village of the sick. In *Ways of knowing: New approaches in the anthropology of experience and learning*. M. Harris, ed. New York: Berghahn Books.
- Streeten, D. H. P., and M. D. Bell. 1998. Circulating blood volume in chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome* 4:3-11.
- Surawy, C., A. Hackmann, K. Hawton, and M. Sharpe. 1995. Chronic fatigue syndrome: A cognitive approach. *Behaviour Research and Therapy* 33(5):535-544.
- Swoboda, D. A. 2006. The social construction of contested illness legitimacy: A grounded theory analysis. *Qualitative Research in Psychology* 3(3):233-251.
- ter Wolbeek, M., L. J. P. Van Doornen, A. Kavelaars, M. D. J. Tersteeg-Kamperman, and C. J. Heijnen. 2011. Fatigue, depressive symptoms, and anxiety from adolescence up to young adulthood: A longitudinal study. *Brain Behavior and Immunity* 25:1249.
- Towghi, F., and K. Vora. 2013. Bodies, Markets, and the Experimental in South Asia. *Ethnos* Forthcoming:1-18.

- Trnka, S. 2012. Responsibility, care, and the self-managing subject: Familial regimes of coping with childhood asthma in New Zealand. Presentation delivered to the Association for Social Anthropologists of New Zealand Annual Conference.
- Trnka, S. 2014. Domestic experiments: Familial regimes of coping with childhood asthma in New Zealand. *Medical Anthropology* (Forthcoming).
- Trundle, C. and B. I. Scott. 2013. Elusive genes: Nuclear test veterans' experiences of genetic citizenship and biomedical refusal. *Medical Anthropology* 32(6): 501-517.
- University of Otago. 2013. (Website.) Biochemistry news and newsletters. Retrieved from <http://biochem.otago.ac.nz/news/lottery-health-grants>.
- van Wolputte, S. 2004. Hang onto yourself: Of bodies, embodiment, and selves. *Annual Review of Anthropology* 33:251-269.
- Vermeulen, R. C., R. M. Kurk, F. C. Visser, W. Sluiter, and H. R. Scholte. 2010. Patients with chronic fatigue syndrome performed worse than controls in a controlled repeated exercise study despite a normal oxidative phosphorylation capacity. *Journal of Translational Medicine* 8:93.
- ter Wolbeek, M., L. J. P. van Doornen, A. Kavelaars, E. M. van de Putte, M. Schedlowski, and C. J. Heijnen. 2007. Longitudinal analysis of pro- and anti-inflammatory cytokine production in severely fatigued adolescents. *Brain, Behavior and Immunity* 21:1063-1074.
- Wander, K., B. Shell-Duncan, T. W. McDade. 2009. Evaluation of iron deficiency as a nutritional adaptation to infectious disease: An evolutionary medicine perspective. *American Journal of Human Biology* 21:172-179.
- Wander, K., E. Brindle, and K. A. O'Connor. 2008. C-reactive protein across the menstrual cycle. *American Journal of Physical Anthropology* 136(2):138-46.
- Wander, K., E. Brindle, and K. A. O'Connor. 2012. Sensitivity and specificity of C-reactive protein and  $\alpha$ 1-acid glycoprotein for episodes of acute infection among children in Kilimanjaro, Tanzania. *American Journal of Human Biology* 24(4):565-568.
- Wander, K., K. A. O'Connor, and B. Shell-Duncan. 2012. Expanding the hygiene hypothesis: Early exposure to infectious agents predicts delayed-type hypersensitivity to candida among children in Kilimanjaro. *PLoS ONE* 7(5):e37406.
- Ware, N. C. 1992. Suffering and the social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome. *Medical Anthropology Quarterly* 6(4):347-361.
- Ware, N. 1999. Toward a model of social course in chronic illness: The example of chronic fatigue syndrome. *An International Journal of Comparative Cross-Cultural Research* 23:303-331.
- Weiss, M. G. 2001. Cultural epidemiology: An introduction and overview. *Anthropology & Medicine*. 8(1):5-29.
- Wessely, S., M. Hotopf, and M. Sharpe. 1998. *Chronic fatigue and its syndromes*: Oxford: Oxford University Press.

- Wiley, A. S. 1992. Adaptation and the biocultural paradigm in medical anthropology: Awiley critical review. *Medical Anthropology Quarterly* 6(3):216-236.
- Willems, D. 2000. Managing one's body using self-management techniques: Practicing autonomy. *Philosophy of Medical Research and Practice* 21:23-38.
- Williams, B. and D. Healy. 2001. Perceptions of illness causation among new referrals to a community mental health team: "Explanatory model" or "explanatory map"? *Social Science and Medicine* 53(4):465-476.
- Worsley, P. 1997. *Knowledges: Culture, counterculture, subculture*. New York: New Press.
- Yoder, P. S. 1997. Negotiating relevance, belief, knowledge, and practice in international health projects. *Medical Anthropology Quarterly* 11(2):131-146.
- Young, A. 1982. The anthropologies of illness and sickness. *Annual Review of Anthropology* 11:257-285.
- Zeiler, K. 2010. A phenomenological analysis of bodily self-awareness in the experience of pleasure: On dys-appearance and eu-appearance. *Medicine, Health Care, and Philosophy* 13(4):333-342.