From Violation to Reconstruction:
The Process of Self-Renewal Associated with Chronic Fatigue Syndrome

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Declaration of Authorship

I hereby certify that this thesis is original work, and that, to the best of my knowledge and belief, it contains no material previously published and/or written by another person, nor material which to a substantial extent has been submitted for a degree or diploma to any other university or institution, except where due acknowledgement has been made in the text.

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Abstract

Chronic Fatigue Syndrome (CFS) is a contested condition that generates scepticism and occupies a marginalised position within medical and social contexts. The thesis examines the illness experiences, and specifically the experiences of self, for people affected with CFS. Using qualitative inquiry, a substantive theory related to the process of self-renewal and adaptation associated with CFS is explicated. The theory encompasses the trajectory of CFS from onset to chronicity, and in exceptional instances, recovery. Illness narratives were derived from in-depth, semi-structured interviews of 19 adults, including 16 people affected with, and 3 people recovered from, CFS. Data was coded and analysed using a grounded theory approach.

Analysis generated two parallel narratives that defined the illness experience of CFS: the narrative of the illness biographies and the narrative of self, specifically the struggling and diminished self seeking renewal. The illness biographies encompassed the stories of symptoms and their explanations, the encounters that ensued and their contentious milieu. The narrative of self was the primary narrative. It articulated the negative consequences to self and personhood associated with CFS, named the Violation of Self, and the consequent efforts of participants to decrease the struggle and violation by use of the Guardian Response and the Reconstructing Response. The Guardian Response provided protection and self-reclamation. The Reconstructing Response fostered self-renewal and meaning. The two narratives were bridged by the threats of CFS. That is, the illness biographies were accompanied by threats of disruption related to chronic illness, and by threats of invalidation that arose from CFS as a contested condition. In turn, these threats provided the catalyst to the violation and responses as described in the narrative of self. Under different conditions the relative strengths of violation, guardianship or reconstruction fluctuated, and it was these fluctuations that presented the participants with the ongoing struggle of CFS.
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Preface

The study is concerned with the illness experiences of chronic fatigue syndrome (CFS), with special reference to a narrative of self. While ‘self’ (and its dimensions) is a commonly used construct, it is not necessarily an agreed upon construct, and theoretical and conceptual differences are found within the literature. In this study the narrative emerged through the use of grounded theory methods, therefore it is the participants’ perceptions and definitions of self that have been used in the analysis.

Participants defined themselves in terms of past, present and future. The known-self was the before CFS, symptom free, and almost always preferred (past) self. The future-self was conceptualised in terms of possibilities and reflected the construct of possible selves as defined by Markus and Nurius (1986), that is, representations of what individuals could become, would like to become, or were afraid of becoming. Additionally, within the text, self-with-CFS is the term used to identify experiences of self while affected with CFS. The participants’ specific meanings of self are described in detail in Chapter 7.

The study included people who had a current diagnosis of CFS and were continuing to experience its symptoms and effects. These participants are referred to as “affected participants”. People with a past diagnosis of CFS who considered themselves to be recovered or significantly improved were also included, and are referred to as “recovered participants”. When the recollections of the recovered participants were found to be consistent with the experiences of the affected participants, findings were incorporated and presented as participant findings. Consequently, statements such as “pain was a common and ongoing symptom among participants” refer to the affected participants and the recovered participants recalling their CFS experiences.
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Chapter 1

Introduction

**Overview of Chronic Fatigue Syndrome**
This thesis is about the experience of Chronic Fatigue Syndrome. Chronic Fatigue Syndrome (CFS) is a debilitating, multi-systemic and distressing condition for which there is currently no known aetiology, an uncertain prognosis, no agreed-upon treatments or management strategies, and confusing recommendations for people affected with the syndrome. The condition presents a complex and puzzling picture for researchers and has been a focus of investigation from a number of disciplines. For people who have CFS, the illness remains a challenging and frequently overwhelming experience.

Debate and conflict surrounds the diagnosis, classification, treatment and prognosis of CFS. Medical disagreements are common and span the entirety of CFS from its legitimacy and credibility as an illness through to its outcomes. Specifically, there are marked differences in medical opinions regarding its existence, nature, possible causes, its natural progression as a syndrome, and ways to treat or manage it. There are also significant discrepancies in the symptoms, course, functional impairments and outcomes of the condition among the CFS population. This is reflected in a dissimilar, heterogeneous population that has proven problematic to diagnosis and research. Some researchers argue that the heterogeneity arises from an erroneous categorisation of unrelated and non-specific symptomatology that does not signify a single syndrome. Others argue that CFS is a distinct entity with a unique pathophysiology and that heterogeneity may reflect the presence of CFS subtypes (Fukuda et al., 1994; Jason & Taylor, 2002; Loblay, 1995).

Although the symptom cluster was first named Chronic Fatigue Syndrome by the Centers for Disease Control and Prevention (CDC, Atlanta, USA) in 1988 (Holmes et al., 1988), its existence as a new diagnostic entity has been contested (Kim, 1994). Internationally, a number of diagnostic criteria are in use including those from the
CDC, United States of America (Fukuda et al., 1994), Australia (Lloyd, Wakefield, Boughton, & Dwyer, 1988) and the United Kingdom (Sharpe et al., 1991). There is no specific diagnostic test and routine medical investigations usually do not find significant abnormalities. Therefore, CFS is defined clinically and diagnosed when other conditions associated with chronic fatigue have been excluded (Fukuda et al., 1994).

CFS is relatively common and affects people of all ages, with rates tending to peak during middle age. More women than men are affected and it is found across ethnic and socioeconomic groups (Jason et al., 1999). Typically, CFS presents as an acute viral or flu-like illness although onset can also be gradual (DeLuca, Johnson, Ellis, & Natelson, 1997). The symptom complex is diverse and unpredictable. It is characterised by extreme and disabling fatigue that is not modified by rest and that is exacerbated by minimal physical and mental activity. Contrary to the nomenclature, fatigue is not the only, or necessarily the most distressing, symptom. Chronic symptoms of post-exertional malaise, myalgia, arthralgia, muscle weakness, headache, sore throat, painful and swollen lymph nodes, non-restorative sleep, and neuropsychological symptoms such as difficulties in concentration and loss of short-term memory are commonly reported. Other symptoms include disturbances of balance, light sensitivity, speech disturbances, gastrointestinal disturbances, light headedness and perceptions of fever (de Becker, McGregor, & de Meirleir, 2001; Fukuda et al., 1994).

The symptomatic experience is complicated by unrelated and frequent variations in severity, intensity and type of symptom. Consequently, the person’s well-being can fluctuate markedly from day to day or within the same day (Dougall, Baum, & Jenkins, 1998). Typically improvement is slow, occurring over a number of years. The prognosis for CFS is not well understood with different definitions of recovery and the heterogeneous population proving problematic. Recovery is most likely in the early years but it is not always permanent and relapses of the condition appear to be common. It is clear, however, that many people remain, to varying degrees, chronically ill (Pheley, Melby, Schenck, Mandel, & Peterson, 1999; Reyes et al., 1999).
The causes of CFS have not been determined. Aetiological hypotheses, possible contributors and related findings have included central nervous system dysfunction (Evengard, Schacterle, & Komaroff, 1999), immunological abnormalities (Patarca, 2001), post-infection syndromes (White et al., 1998), psychiatric conditions (Wessely, 1997) and sleep disturbances (Fischler, Le Bon et al., 1997). Current thinking on causation suggests that no single or simple aetiology is likely to be found (Loblay et al., 2002). There are no treatments for CFS and management is aimed toward the relief of symptoms and gradual rehabilitation.

Research has indicated that CFS is frequently associated with a significant reduction in personal, social and occupational activities. Functional impairment, restrictions to social involvement, difficulties with relationships, decreased ability to fulfill social/familial roles, and disruptions in work practices have been commonly reported (Komaroff, Fagiolo, Doolittle et al., 1996; Tuck & Wallace, 2000). Additionally, people with CFS report a poor quality of life (Hardt et al., 2001).

CFS is a chronic illness and as such requires ongoing adaptation and management. CFS is also a contested illness that has been typified by opposing stances, medical and social debate, and frequently, conflicting multiple agendas among groups with vested interests in how the condition is understood and defined. Much of the controversy involves the perceived credibility of the syndrome. There is a strong school of thought that CFS is not a “real” or unique medical condition. There is also debate regarding the physical/organic versus mind/psychological explanations of causation. These differing viewpoints communicate, or are associated with, dichotomous attitudes or responses such as belief or scepticism, support or stigma. Further, given the absence of any defining physical pathology, there has been a tendency to hold individuals with CFS responsible for their condition with attributes of malingering or personal failings being ascribed to them. For example, the label of “yuppie flu” (Richman, Jason, Taylor, & Jahn, 2000, p. 178) that was popular in the 1980s and 1990s signified the disdain with which the condition and those affected have historically been viewed. It is this specific medical and social climate, in
addition to the general challenges of managing a chronic illness, which affects the lives of people with CFS.

**Foci of the CFS Research**

Although there has been a marked increase in the medical, psychological and sociological research related to CFS in the last 20 years, the literature has tended to focus on a number of defined areas. Medicine has focused on aetiologies, classification and diagnosis, prognosis, prevalence and outcomes, and neuropsychiatric status. To a lesser extent functional impairments and medical management have been investigated. Comparative studies have featured amongst the medical research, and include comparisons of CFS with Epstein-Barr virus, fibromyalgia, rheumatoid arthritis, multiple sclerosis, irritable bowel syndrome, repetitive strain injury, Gulf War syndrome, depression, and somatisation disorders. The psychological literature has concentrated on functional impairments (particularly neuropsychological and cognitive), psychosocial antecedents and predispositions, illness attributions and behaviour, and psychobehavioural characteristics and personality. There has been some work related to quality of life, coping, and management with cognitive behaviour therapy (CBT) accounting for most of the management focus. (The medical research on management has similarly focused on CBT.) Sociological research has addressed social course and process, social construction, legitimation, and the professional and popular views related to CFS. With a few exceptions, there has been limited research reported in nursing journals. The nursing literature has focused on updates, overviews and summaries, and personal accounts. Consequently, there is little that informs nursing’s view of CFS, nor how patients with the condition are nursed.

The different discipline perspectives have addressed the same research questions so that common issues and debates are evident. Research questions have mostly centred around the “what” (classification), “how” (causation), and “when and where” (epidemiology) of CFS, in addition to assessment of dysfunction. Measurement and quantification are most appropriate to answering these questions, and most CFS research has utilised a quantitative methodology. The dominance of quantitative
research, however, results in a CFS knowledge base that is derived from a singular and narrow perspective. The emphasis on aetiology, classification and dysfunction contrasts with the lack of research regarding the experiences of living with CFS. The daily lives of people with CFS, the everyday consequences, the personal and social worlds of CFS, and the meanings attached to the experiences of CFS have not been adequately articulated. In sum, qualitative aspects of living with CFS have attracted little attention. By neglecting the lived experiences and dimensions of everyday activities, the potential benefits of such a research focus remain unexplored. This research gap is of clinical and societal concern because of the chronicity, severity and intrusiveness of the symptoms, and the predominantly pessimistic outcomes, marked functional impairments, poor quality of life and consequent distress that is reported among people with CFS.

The present study helps to address this imbalance within the CFS research. The study examines the experiences of people with CFS, their everyday worlds, and the effects of the syndrome on their lives. The use of qualitative method aims to generate a fresh perspective and a different understanding of CFS to that which dominates the current knowledge base.

**Aims of the Study**

The general aim of the study was to explore the illness experiences of people affected by CFS, with a particular emphasis on exploring their sense of self. Specifically, the study aimed to examine the nature of the self-with-CFS, and the relationships between self and the illness experiences of CFS.

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1 In the main, the literature review of the thesis does not identify individual studies as quantitative, although most qualitative studies are identified as such. Generally, it is clear which studies are quantitative because reference is made to measures, standardised tests and so forth.
Need for the Study
Living with any chronic illness presents special challenges in societies that value independence, productivity, self-reliance and action. In addition, CFS presents a clinically complex picture that is complicated by the questions and doubts associated with the condition. It requires responses and a tolerance of uncertainty not easily accommodated within existing societal and medical frameworks. Consequently, experiences and perceptions of self are likely to be affected by the symptoms, course and outcomes, by the medical and social climates, and by the debates among researchers and clinicians regarding the essential nature of the syndrome, including its existence as a discrete condition. Additionally, the functional impairments that contribute to an often poor quality of life and the need for ongoing management in the absence of agreed upon protocols are also likely to affect experiences of self. To date there has been little research that examines experiences of illness and self for people with CFS.

Origins of the Study: My Experiences
My interest in CFS as a research topic was initially sparked from my personal experience of the syndrome. Additionally, it was consistent with my occupation as a university lecturer in nursing. CFS has affected me for 14 years, and I was at my worse for nine of those years. My medical specialist told me that I was moderately affected and had presented as a classic case of CFS. I am now markedly improved and the last 6 years have been typified by a slow recovery with occasional relapses. I still have periods of illness and experience some symptoms most days, but I am mostly able to live my life without the constant constraint of CFS.

Midway into the illness I enrolled as a part-time PhD candidate to investigate the psychosocial aspects of CFS. The motivation to do so and the choice of topic came from a number of sources. The process of immersing myself in such an intellectual endeavour had been a long-standing goal. I was also motivated to turn the presence of CFS into a positive force within my life. Studying for a PhD became a way to compensate for the losses associated with CFS while working towards an ambition that predated my illness. The belief that I was in a unique position to conduct research into CFS was an additional motivator. I had read much of the CFS research,
had a good grasp of its clinical status, was able to identify substantial gaps in the research, and was familiar with the controversies and discourses surrounding the syndrome. I believed that my qualifications and clinical and teaching experience would provide me with some of the skills and knowledge necessary to research the area. Additionally, my own experiences of CFS provided insights and glimpses of possibilities that perhaps only emerge from an insider’s perspective.

In retrospect, given how ill I was at that time and the marked limitations on my life, I am surprised at how little I thought about my physical, mental or emotional resources and whether these resources were adequate for a project the magnitude of a PhD. I purposefully adopted an expectation that my health would improve and the time frame afforded to part-time candidates seemed to be reasonable. Therefore I (naively) envisaged improvement in my health and progression with the study as achievable outcomes. At a deeper level, a self-evaluation of my capabilities was too great a threat, and to a large extent I refused to think about the possibility of failure or the potentially adverse effects on my already marginal health. I began with a mind-set of optimism, denial and a belief in my ability to persevere.

Given that the study originated from my experiences of being ill with CFS, it is important that aspects of my story are articulated. The insider’s perspective is of influence during the entire research process and throughout the thesis I have endeavoured to make explicit my place within the study. Therefore, my story is included as a context to assist the reader in understanding and evaluating the direction, method and analysis of the study.

I was 34 years of age when I became sick with a flu-like illness that was diagnosed as a viral infection. The treating medical practitioner recommended that I rest, treat the symptoms, drink plenty of fluids and come back if I did not improve. The symptoms of muscle aches and pains, headaches, tender lymph glands, sore throat and fatigue did not particularly worry me. Since the time I had worked in a respiratory Intensive Care Unit 10 years previously I had become ill with these symptoms, usually each winter. I had always recovered and it did not occur to me that this time would be any different. I was on annual leave when I became ill and
after a couple of weeks of resting I returned to work when expected. It was some months before I acknowledged to myself that I had not improved, that I wasn’t simply tired because I’d gone back to work, that my muscles ached regardless of whether I rested, and that the symptoms had remained a constant presence since their initial onset. Some symptoms such as the muscle pain were becoming worse. I went back to the medical practitioner.

I was now diagnosed with post-viral syndrome. It seemed that the defining quality of post-viral syndrome was a longer-than-normal recovery period and I didn’t know how to manage this, or indeed, what I was meant to manage or expect. The medical practitioner told me to rest and not over-exert myself but was unclear as to what and how much constituted rest or over-exertion. Specific questions such as “should I take sick leave” elicited vague responses. That was up to me, I wasn’t contagious, I should do what I could manage. But what was “managing”? When I wasn’t working I was in bed. The symptoms were unrelenting, my usual activities became impossible and I felt constantly ill. Was that managing? Meanwhile, diagnostic tests were carried out and although there were anomalies, they were mostly non-significant. During this time I felt my relationship with the medical practitioner changing. Previously I had consulted the medical practitioner infrequently, and considered the relationship to be one of collaboration and equality. I was familiar with the language and culture of medicine and possessed skills (and status) beneficial to the negotiation of medical encounters. To my confusion, numerous diagnostic tests continued to report mostly normal findings, yet my symptoms persisted, and I started to feel like a “bad” patient. I could see the doctor’s frustration and began to question whether she believed me. I dreaded consultations.

A sense of failing to meet my obligations began to pervade my relationships. Initially the ongoing nature of the symptoms had been associated with sympathy from others that I was still unwell, but as the symptoms continued and the tests remained mostly normal, I was aware of changing attitudes. I began to detect impatience, and inquiries regarding the results of diagnostic tests now included suggestions of stress or burn-out as possible causes. I was not threatened by these interpretations because I too had questioned such possibilities. Rather, feelings of
puzzlement and failure arose from my apparent inability to rectify the stress or burn-out.

After 11 months from the initial onset, the medical practitioner told me that she thought I might have CFS. There was some initial relief at having a diagnosis other than the vague post-viral syndrome, but I soon felt that one generic label had been swapped for another generic label that was also typified by an absence of information. The outcomes of CFS were unclear and the absence of treatment meant that my hit-and-miss attempts at management would have to continue. What little information was available was of small comfort (and as I found out, wildly inaccurate). I opened the first book I could find on CFS to the heading, “How to obtain a wheelchair”.

At the time I was diagnosed few people had heard of CFS. With an increase in media coverage, the syndrome and its controversies entered the public domain. CFS was rapidly becoming politicised, debated and associated with strong and opposing views. Usual social boundaries regarding the privacy of illness did not appear to apply to CFS and even strangers who (somehow) knew of my diagnosis automatically shared their beliefs with me about the causes of the illness. I was asked if I thought CFS was “just depression”, or a physical manifestation of not coping, or an unconscious strategy for “time out”. My behaviour, personality, values and existence were now subject to interpretation, discussion and judgement in ways that had not happened before my diagnosis. This left me feeling exposed and vulnerable within my relationships and interactions. I felt that for others I had become my illness.

The effects of CFS on my life were profound. Activities and interests that I had previously enjoyed were no longer possible. Relationships and friendships gradually faded and disappeared as my ability to participate in social activities diminished. Financial needs dictated that I maintain my employment for as long as possible, however, continuing to work was important for other reasons. My work was professionally and personally fulfilling and was a remaining link with my “healthy” life. To keep working I implemented many changes to my work practices, including
periods of part-time employment. Sometimes I felt myself to be a pale reflection of who and what I once was, while at other times I perceived myself as antithetical to the person I had been. It was a number of years before I realised that CFS might be contributing something positive to my personal development. CFS required me to examine and reflect upon my life and it was through this extended process that I learned different ways of being that enriched my everyday experiences.

In summary, my decision to study CFS formally was based on two factors. First, there was a desire and opportunity to create meaning and positive outcomes from my experiences of CFS. Secondly, I occupied a privileged position that was conducive to investigating CFS because research was crucial to the occupational culture I inhabited, it was a valued pursuit, and resources and support were available. Specifically, my personal experiences and knowledge of CFS, chronic illnesses and the social sciences influenced the choice of research questions for a major study into the experiences of people diagnosed with CFS.

**The Research Questions**
The aims of the present study fall within the realm of illness experience, and seek to provide insight into this largely unexplored field of how people experience CFS. Research that reflects what it means to live with CFS, how people construct meaning while living with CFS, and the consequent experiences of self-with-CFS have not been a foci of investigation. This subjective perspective is crucial to understanding CFS, particularly given that the condition remains an enigmatic illness located on the fringes of medical and scientific acceptance. As such, people with CFS are relegated to the status of fringe-dwellers, with a unique view of the experience of illness. Exploring their illness vantage-point, their subjective and everyday worlds, social location and ways of living with a contested reality, and the associated experiences and perceptions of self, is worthy of intellectual articulation.

In order to address the aims of the study as outlined in the introduction, three research questions were proposed.
1. What are the illness experiences of people affected with the condition of CFS? 
2. What are the experiences of self for people affected with CFS? 
3. What are the relationships, factors, contexts and processes important to experiences of self for the person affected with CFS? 

The first research question provided a broad and general perspective of the subjective world of CFS. Questions two and three focused on self as a way to further delineate and explore the illness experience of CFS and provided specificity in articulating that experience. In addressing these research questions the present study generated an understanding of CFS that is largely absent from the research to date.

**Organisation of the Thesis**

The thesis is arranged in 10 chapters commencing with a review and analysis of the ways in which CFS has been conceptualised, theorised and investigated (Chapters 2 and 3). Chapter 4 examines the methodology and design of the thesis. The data analysis of the study is presented and discussed in Chapters 5 through 9. Chapter 5 describes the narrative of the illness biographies, a contextual snapshot that provides insights into the symptomatic experiences of the participants. Chapter 6 articulates the threats of disruption and invalidation that are found within the CFS experience. The narrative of self is addressed in Chapters 7 (violation), 8 (guardianship) and 9 (reconstruction). Chapter 10 discusses the data analysis with reference to other relevant theories and research and identifies future research directions.
Chapter 2

Defining and Describing Chronic Fatigue Syndrome

CFS remains a mysterious condition that continues to be surrounded by controversy and associated with medical and social scepticism despite intensive investigation extending over two decades. This debate is evident in the large body of biomedical, psychological and sociological research related to CFS. Chapters 2 and 3 review this research in some detail and demonstrate the far ranging uncertainties and complexities surrounding the condition. The review of the literature provides a point of departure and context to understanding the experiences of illness associated with CFS. This chapter provides insight into the complexities of the condition of CFS by reviewing the research that addresses its definitions and descriptions.

The definition of CFS includes an historical account, the evolution of diagnostic classifications, and medical usage of the CFS diagnosis. The description of CFS encompasses the epidemiology, course and prognosis of the syndrome, and clinical presentation. The research related to fatigue and activity, and the effects of CFS on functioning, neuropsychological abilities and relationships are also discussed.

Contradictory findings and conclusions typify the CFS research. There is little that is accepted as undisputed knowledge and there is no clear picture of what constitutes CFS. It is a contested illness and the literature reflects this discord. A review of the CFS literature is, therefore, a review of contradiction, inconsistencies and ambiguity. As a consequence, nearly every statement regarding CFS requires qualification and little can be stated with any certainty. In some studies, variables have an effect. In other studies, the same variables have no effect. Accounting for differences, testing, measuring, refining, and challenging is, of course, essential to the research process. What is different with the CFS research, is that after 15 years of investigation basic and fundamental aspects of the syndrome remain in dispute. We are faced with a diverse body of research with vast disparities.
These contradictions are typical of contested conditions and reflect ontological, epistemological and methodological issues. Ontology is the theory of existence, and at its most basic, the dispute surrounding CFS is ontological – does it really exist or does it appear to exist while not existing? Epistemology, the theory of knowledge, underlies the disputes of what we know about CFS and how we judge it to be true. There are many ways of knowing CFS and these various ways of knowing and their underlying assumptions are frequently at odds with each other. The scientific community, for example, judges knowledge of CFS in a very different way to those affected with the condition. Indeed, even among the scientific community there is an absence of agreement and different scientists view knowledge of CFS differently.

Methodology refers to the principles and theoretical assumptions that underlie the choice of research methods. Science demands that knowledge is derived through a particular process, that is, the scientific method. To a large extent, however, CFS has not yet proven amenable to quantification through the scientific method, and this failure to fit neatly into an objective paradigm and in an observable manner has compounded ontological and epistemological differences.

Most of the CFS research is quantitative and the review highlights a number of common methodological limitations. The findings are methodologically constrained by heterogeneous samples, the use of different classificatory criteria, small sample sizes, selection biases (such as reliance on tertiary clinics and physician referrals), and the lack of criteria for measuring outcomes (for example, recovery). There is a reliance on cross-sectional designs, and in particular, an absence of longitudinal research (which, given the condition’s chronicity, is an important limitation). Comparative studies generally use a restricted number of illness groups, such as multiple sclerosis and depression.

The contradictions, ambiguity and uncertainty that are evident in the research findings discussed in Chapters 2 and 3 have real implications for the everyday lives of people with CFS. By addressing the experiences of people with CFS, this study explicates the effects of living with CFS and its associated uncertainties. The review begins with a discussion on the history of CFS that provides the background to defining CFS.
Defining CFS
Defining the criteria for an illness is a crucial precursor to diagnosis, and the conversion of symptoms into a diagnosis is crucial for legitimization. Fatigue symptoms are common and non-specific, and defining the symptom cluster that is currently labeled “CFS” has been problematic. These difficulties, such as isolating its essential features and defining a homogeneous population, are seen throughout the history of fatigue-illnesses.

The History of CFS
Chronic fatigue syndrome has been a diagnosis since 1988. While CFS was described as a disease of the 20th century (Wessely, 1997), fatigue-type illnesses that parallel the clinical picture of CFS have a long history dating back many centuries to include diagnoses such as febricula (1750s), neurasthenia (1870s to 1920s) and DaCosta’s Syndrome (1870s to 1940s). These various diagnoses for fatigue-symptom clusters each reflected the medical milieu, knowledge base and dominant concepts of the time, and were associated with ongoing debate regarding the organic or psychological/psychiatric determinants (Straus, 1991).

The previously common diagnosis of neurasthenia is the most frequently cited parallel, synonym or counterpart for CFS (Kim, 1994; Wessely, 1990). Neurasthenia was a popular diagnosis in the late 19th century and was derived from the work of George Beard, a neurologist. Neurasthenia, literally a lack of nerve force or nervous exhaustion, was characterised by a multitude of symptoms including profound mental and physical fatigue, nervous dyspepsia, mood changes, and prolonged post-exertional muscle weakness. No objective or measurable signs of disease were evident and patients generally appeared well. (Kim, 1994; Leitch, 1995). It was noted to affect more women than men, and to be predominant among the “upper-classes” and hard-working professionals (Kim, 1994). Neurological and psychological explanatory theories were proposed. Beard, however, maintained that neurasthenia was not attributable to psychological processes but was an organic disease that resulted from the competitiveness and stresses inherent to the modern, industrialised capitalist society to which the professional classes were exposed.
(Leitch, 1995; Wessely, 1990). It was suggested that these stresses disrupted the body’s internal environment and resulted in the dispersal of nervous forces from critical homeostatic centres (Kim, 1994). Treatments were many and varied, with the rest cure providing the primary therapy (Haller, 1970).

The decline of neurasthenia as a diagnosis began in the early 1900s. The clinical vagueness of neurasthenia meant the diagnosis was non-discriminatory. Neurasthenia therefore, functioned as a depository for diagnostic anomalies as medical scepticism increased. Additionally, it was reported as occurring in lower socioeconomic groups, thus violating one of its major premises. The diagnosis fell out of favour among neurologists and the symptom cluster was gradually incorporated into the new specialty of psychiatry. As psychiatric classification became progressively sophisticated, the view developed that the diagnosis of neurasthenia was blurred with hysteria, depression, neuroses and hypochondriasis. By World War 1 neurasthenia was held in low medical esteem and by the 1920s had almost disappeared as a diagnosis (Kim, 1994; Wessely, 1990). It was retained in the Diagnostic and Statistical Manual of Mental Disorders II until the third edition (published in 1980) and remains in the International Classification of Disease (ICD–10) (Greenberg, 1990; Leitch, 1995). Regardless of the virtual disappearance of neurasthenia as a diagnosis, the symptom complex remained.

Throughout the years following the diagnostic decline of neurasthenia, outbreaks of fatigue-type illnesses involving diverse geographical areas were reported, including the Los Angeles County General Hospital in 1934, Akureyri, Iceland in 1948, the Royal Free Hospital in London in 1955, and Tapanui, New Zealand in 1984 (Bell, 1991; Levine, Snow, Ranum, Paul, & Holmes, 1997). The symptoms most commonly described included physical and mental fatigue, low-grade fevers, headache, sore throat, myalgia, and disturbances of mood and sleep. There were two schools of thought regarding the causes of these outbreaks, one view proposing the role of infectious agents while the alternative suggested epidemic hysteria (Kim, 1994). In addition to reports of outbreaks, individual sporadic cases were also found in the literature (Bell, 1991).
During the 1930s, 1940s and 1950s causal hypotheses for chronic fatigue were reflected in diagnoses that included chronic brucellosis (Straus, 1991), adrenal exhaustion, acidosis (Loblay, 1995), and in the case of cluster outbreaks, epidemic neuromyasthenia or benign myalgic encephalomyelitis (Kim, 1994). Throughout the 1960s to 1980s the symptom cluster was diagnosed as post-viral syndrome, occult coxsackie (Calder, Warnock, McCartney, & Bell, 1987), chronic hypoglycaemia, total allergy syndrome, and chronic candidiasis (Straus, 1991).

In 1985 a cluster of patients in Lake Tahoe (USA) reported the symptoms of fatigue-type illnesses and were found to have elevated levels of Epstein-Barr virus (Bell, 1991). By late 1985, the Division of Viral Diseases of the CDC had received several thousand inquiries about chronic Epstein-Barr virus syndrome (also known as chronic mononucleosis) from physicians and patients (Holmes et al., 1988). An informal working group was organised to formulate a definition and develop a consensus of the primary features of the chronic Epstein-Barr virus syndrome that would provide a basis for future research and evaluation of patients. Research, however, was indicating that the Epstein-Barr virus did not appear to be a causal factor, and in 1988 the CDC working party proposed the name “Chronic Fatigue Syndrome” which described the salient clinical features but did not imply a specific causal agent (Holmes et al., 1988). In the absence of aetiological explanations or diagnostic tests, the definition was based on a distinctive pattern of symptoms and defined as a syndrome. In 1994 the CDC reaffirmed the name.

**Definitions, Classification and Diagnostic Consensus**

The complicated and debated history of CFS is reflected today in the ongoing dialogue among clinicians and researchers regarding definition and diagnostic criteria. The ontological and diagnostic dilemma is centred on whether CFS (or a subset of it) is a distinct disease with a unique pathophysiology found among a homogeneous group. Alternately, CFS may be an arbitrary collection of unrelated and common non-descriptive symptoms with numerous causes that are artificially labeled as a syndrome amongst a heterogeneous population (Fukuda et al., 1994; Loblay, 1995). The diverse and non-definitive symptomatology, the absence of specific diagnostic tests, the lack of effective treatments and the primacy of
neuropsychiatric symptoms that may indicate atypical variations of other psychiatric disorders (such as depression or somatisation disorders) have posed unique difficulties for the formulation of defining criteria.

It has been suggested that many of the problems associated with definition are those found in the early stages of defining any medical condition (Twemlow, Bradshaw, Coyne, & Lerma, 1997). It is also possible that in spite of defining criteria, diagnostic labels may reflect the specialty and beliefs of the practitioner. Consequently, the symptom cluster of CFS may be interpreted as myalgic encephalomyelitis by a neurologist, multiple chemical sensitivity syndrome by a clinical ecologist, immune dysfunction syndrome by an immunologist or atypical depression by a psychiatrist (Loblay, 1995).

CFS is clinically defined and can only be diagnosed when other conditions associated with chronic fatigue have been excluded, particularly neuropsychiatric conditions which are said to be the most important confounding source (Fukuda et al., 1994). Internationally a number of diagnostic criteria are in use. The first definition was provided in 1988 by the CDC and was based on signs and multiple somatic symptoms that required the presence of two major criteria related to fatigue, minor criteria, and the exclusion of other conditions (Holmes et al., 1988). The inclusion of multiple somatic symptoms in the 1988 case definition led to the criticism of inadvertent biases towards selection of patients with high levels of psychiatric morbidity, notably somatisation (Hickie, Lloyd, Hadzi-Pavlovic et al., 1995; Jason et al., 1997). To address these criticisms and to facilitate systematic, standardised and comprehensive research, the 1988 definition was revised under the leadership of the CDC by the International Chronic Fatigue Study Group in 1994 (Fukuda et al., 1994). The revision was not intended to be definitive but open to evolution as new knowledge was gained.

The revised CDC case definition (Fukuda et al., 1994) required the presence of unexplained, persistent or relapsing chronic fatigue of a new or definite onset lasting 6 or more consecutive months. The fatigue was not related to exertion, nor relieved by rest, and resulted in a substantial reduction of activities. Additionally, four or
more minor symptoms were required. These included self-reported short-term memory or concentration impairment severe enough to result in substantial reduction in activities, sore throat, tender cervical or axillary lymph nodes, muscle pain, headaches, sleep disturbances, post-exertional malaise longer than 24 hours, and joint pain without swelling or inflammation. Minor criteria must have been present or recurred during 6 or more consecutive months. The revised case definition eliminated some minor criteria symptoms, in addition to the physical examination criteria. It was recommended that clinical diagnosis include a patient history, physical examination, mental status examination and a minimum battery of laboratory screening tests (Fukuda et al., 1994).

The overlay between CFS and psychiatric disorders, as evidenced by some shared symptoms, has been a stumbling point for the development of a case definition. While the 1988 CDC definition categorised psychiatric disturbances as exclusionary to CFS, other classifications have acknowledged the primacy of these disturbances to the syndrome. The revised (1994) CDC definition does not classify most psychiatric conditions as exclusionary to a diagnosis of CFS (with the exceptions of major depressive disorder, bipolar affective disorders, schizophrenia, delusional disorders, dementias, anorexia nervosa or bulimia nervosa) but acknowledges the possibility of co-existing conditions (Fukuda et al., 1994). It has been suggested by Sharpe (1996) that the revised CDC classification represented a move away from the assumption of a specific disease to “nothing more than a working definition of a clinical problem” that attempted to “straddle the medical-psychiatric divide” (p. 552) while limited by overlap with psychiatric syndromes.

Other case definitions, which predated the CDC revision in 1994 and focused on fewer criteria, have originated from the United Kingdom (Sharpe et al., 1991) and Australia (Lloyd, Hickie, Boughton, Spencer, & Wakefield, 1990). The Australian definition required a history of at least 6 months of disabling, prolonged or relapsing fatigue exacerbated by minor physical exertion that significantly disrupted daily activities and that could not be explained by an alternative diagnosis. Additional criteria included neuropsychiatric dysfunction such as newly acquired memory and concentration difficulties.
The research mostly suggests that the 1994 revised definition is able to differentiate between CFS patients, other illness groups and healthy controls. A community-based investigation found that the symptomatic criteria of the current CDC case definition was able to uniquely discriminate individuals with CFS from the control groups (Jason, Torres-Harding, Carrico, & Taylor, 2002). Similarly, Komaroff, Fagioli, Geiger et al. (1996) in a prospective study concluded that the major criteria of the 1994 CDC case definition distinguished between 369 patients with CFS and depressed patients, patients with multiple sclerosis and healthy participants. However, research further indicates that patients diagnosed with the 1994 revised criteria do not constitute a single homogeneous group. While the 1988 criteria appeared to select individuals with increased severity and prevalence of symptoms and greater functional impairment, the less restrictive 1994 criteria led to increased heterogeneity (de Becker et al., 2001; Jason, Torres-Harding, Taylor, & Carrico, 2001).

While the evidence suggests that the 1994 criteria have the ability to differentiate CFS from other illness groups, there is some research (with some exceptions, such as Komaroff, Fagioli, Geiger et al., 1996) to suggest that overlapping symptoms complicates the diagnosis of psychiatric disorders. There are reports of misdiagnosis and non-diagnosis of psychiatric conditions occurring among CFS patients (Deale & Wessely, 2000). Similarly, it is argued that some CFS patients who meet existing criteria can be given an alternate psychiatric diagnosis (Sharpe, 1996). There is also overlap of the diagnostic criteria with fibromyalgia (Lloyd, 1998), with some suggestions that the diagnostic labels of CFS and fibromyalgia are largely interchangeable (Wilson et al., 2001). These difficulties might arise from the heterogeneity found with the 1994 definition.

The heterogeneous nature of CFS with regards to symptoms, functional disability, mode of onset, duration, and psychosocial factors, suggests the possibility of subtypes, with CFS representing an umbrella term. By identifying subtypes, investigators seek to introduce greater homogeneity into the research context. To date the research has identified numerous CFS subtypes, usually divided into two
groups. These have included gradual onset with co-morbid psychiatric disorder versus sudden onset without psychiatric disorder (DeLuca et al., 1997), the presence or absence of post-infective fatigue syndromes (Lloyd, 1998), and less functional disability and psychiatric morbidity versus features consistent with a somatoform illness (Wilson et al., 2001). Other subtypes have included CFS with primarily nervous, endocrine, musculoskeletal or immune system disorders (Tan, Sugiura, & Gupta, 2002). With refinement subtypes may provide greater homogeneity for future research. Meanwhile, current studies continue to mostly use the revised 1994 CDC case definition and it retains considerable clinical application. The recently published Chronic Fatigue Syndrome Practice Guidelines (Loblay et al., 2002) for use by Australasian medical practitioners have used the revised CDC definition as the basis for diagnosis.

Medical Acceptance of the CFS Diagnosis
The controversy and lack of clarity regarding diagnostic criteria influence the acceptance and use of CFS as a discrete diagnosis. Limited research has revealed inconsistencies among medical practitioners regarding the acceptance of CFS as a legitimate medical condition and varying degrees of willingness to use the diagnosis (Prins, Bleijenberg, Rouweler, van Weel, & van der Meer, 2000; Woodward, Broom, & Legge, 1995). Ho-Yen and McNamara (1991) reported a 71% acceptance rate of CFS as a clinically valid diagnosis among Scottish general practitioners, while Denz-Penhey and Murdoch (1993) found a 90% acceptance rate among New Zealand general practitioners. A substantially lower figure was reported in an Australian study of 1615 randomly sampled general practitioners in which it was reported that 46% believed CFS to be a distinct syndrome (Steven et al., 2000). Among the 31% who did not believe CFS to be a distinct syndrome, the most commonly held beliefs about aetiology (with multiple aetiologies allowed) were depression, post-viral illness, stress, anxiety and personality disorder. The findings of Steven et al. need to be interpreted with some caution. Although the study is a relatively recent publication, the data was surveyed in 1995 and may be no longer representative of the beliefs of Australian general practitioners.
Some reasons for the marked variance and hesitancy in the use of the CFS diagnosis among medical practitioners have been identified. Woodward et al. (1995) reported that reluctance among general practitioners to diagnose CFS was based on concerns about the diagnosis acting as a self-fulfilling prophecy, fears that “normal” symptoms of fatigue and weakness might become unnecessarily pathologised, and scientific uncertainties related to the syndrome. Additionally, the absence of consistent organic pathology or biological markers may predispose practitioners to question the legitimacy of CFS as a diagnosis or interpret the symptoms from a psychiatric or psychological perspective (Richman et al., 2000). Prins et al. (2000) found that 91% of general practitioners that did not diagnose CFS attributed the patient’s complaints to psychological factors. They also reported that the general practitioners considered CFS patients as comparatively more problematic (73%) and time-consuming (89%). 31% rated the co-operation of CFS patients as bad, and 54% reported less empathy for CFS patients. The tendency to somatisation, vague complaints and the attitudes of CFS patients were mentioned as most problematic.

The hesitancy of diagnosing CFS based on scientific grounds has been challenged by Lapp and Hyman (1997) who argued that the CDC criteria are no more difficult to use or any less objective than those used for rheumatic fever or lupus. It remains to be seen whether diagnosis of CFS in Australia becomes less problematic for both medical practitioners and their patients with the (2002) publication of diagnostic guidelines.

**Describing CFS**

**Demographics and Epidemiology**

Epidemiological and prevalence studies have reported varying estimates and mixed findings with difficulties arising from the heterogeneity of CFS, the hesitancy of some medical practitioners to diagnose CFS, and the reliance on physician referrals. Additionally, the various classification criteria identify different people as affected with CFS, resulting in disparate findings, comparative limitations and further heterogeneity. In sum, samples may be subject to selection bias and underestimate prevalence (Jason et al., 1999; Jason et al., 2000; Levine, 1997).
Findings have tended to indicate that the majority of cases occur endemically in the community rather than as localised outbreaks (Lloyd et al., 1988). Female gender appears to be a risk factor and community based studies have indicated that more women than men are affected by CFS (Jason et al., 1999). There is also evidence to suggest that women are more severely affected than men, with poorer physical and emotional role functioning and more pain (Jason et al., 2000). It may be that the higher incidence of autoimmune disease or the heightened antibody response to viral infections found generally amongst women contributes to gender related CFS-vulnerability (Levine, 1997).

CFS is reported to occur across social classes and ethnic groups. Early research (and a minority of more current work) suggesting that CFS affected the middle and upper socioeconomic classes and professional occupations (thus reinforcing the label of “yuppie flu”), has not held up over time and most likely reflected sampling bias. In contrast to the perception that CFS is a condition of white, middle class and professional people, a large community-based study recently reported a higher incidence among middle-to-low socioeconomic groups, with the lowest rates among professionals and the highest rates among skilled workers (Jason et al., 1999). Additionally, ethnic group differences have been suggested with non-Caucasians reported as experiencing more severe symptoms (Jason et al., 2000). CFS occurs across the life-span, peaking during middle age with individuals in the 40 to 49 range displaying the highest rates (Jason et al., 1999). It is also well documented in adolescents and reported in children, although childhood diagnosis is difficult as symptoms are commonly non-typical (Levine, 1997).

Prevalence remains unclear. An early Australian population-based study demonstrated a rate of 37 cases per 100,000 people but cautioned that the figure was to be regarded as the minimum (Lloyd et al., 1990). Indeed, this estimate is substantially lower than most other figures. According to Dutch general practitioners, prevalence was estimated at 112 patients per 100,000 as a minimum (Bazelmans et al., 1999). A population-based study reported higher prevalence rates of 740 per 100,000 (Lawrie, Manders, Geddes, & Pelosi, 1997) and a large community-based randomly sampled and multi-ethnic study in Chicago found an
estimated prevalence of 422 people per 100,000. The predominance of women was reflected in prevalence rates of 522 per 100,000 for women, and 291 men per 100,000 (Jason et al., 1999). Although there is marked variation in prevalence rates it appears that CFS is relatively common.

**Course and Prognosis**

There have been relatively few studies on the natural course and long-term outcomes of CFS, which along with methodological constraints has limited the ability to determine clear trends. The natural course of CFS appears to follow two patterns: relapsing and remitting or continuous. Typically, there is an acute onset following self-report or diagnosis of an infective episode (Shepherd, 1997), although some patients describe a more gradual onset that is not related to a previous illness (Murray, 1992). Symptoms are often described as flu-like, and marked fluctuations in the severity and intensity of individual symptoms are commonly reported. Fluctuations can occur quickly, from one day to the next or within the same day (Dougall et al., 1998).

The natural progression of the syndrome appears to be towards a slow improvement, however, there is substantial variation in the degree of improvement reported. Rates of reported improvement have ranged from 17% (Vercoulen, Swanink et al., 1996) to 64% (Bombardier & Buchwald, 1995) as measured over periods of 18 months. Hill, Tiersky, Scavalla, Lavietes and Natelson (1999), in a quantitative study of people severely affected with CFS, found that the majority showed no symptom improvement over a 4-year period. There are also reports of deterioration during follow-up periods (Joyce, Hotopf, & Wessely, 1997) and some people remain chronically affected with little improvement.

It is difficult to ascertain recovery rates for CFS but the general trend appears to indicate that complete recovery is uncommon. In a review of prognostic research, Joyce et al. (1997) reported that among 5 studies 0-6% of participants returned to premorbid levels of functioning with the majority experiencing significant ongoing impairment. Prognosis worsened as the definition became more stringent. Pheley et al. (1999) found that none of 117 participants reported a complete recovery, with
10% reporting recovery at a level approaching their premorbid state. A 4-year study of people severely affected with CFS reported a recovery rate of 4% (Hill et al., 1999). More optimistic findings have been reported in a longitudinal study by the CDC (Reyes et al., 1999) which found that a period of self-defined recovery could occur at any time but was most likely in the early years. A 31% cumulative probability of recovery was reported in the first 5 years and 48% during the first 10 years of illness. However, it was also found that a return of fatiguing illness was reported by 25% of the recovered cases.

A number of factors have been proposed as associated with prognostic outcomes, for example, greater illness severity with poorer prognosis (Levine, 1997) and a shorter illness duration with improvement (van der Werf, de Vree, Alberts, van der Meer, & Bleijenberg, 2002; Vercoulen, Swanink et al., 1996), although some studies have not found shorter illness duration to be of significance (Hill et al., 1999; Pheley et al., 1999). Similarly, a younger age has been reported as related to better prognosis (Vercoulen, Swanink et al., 1996) while other studies have found no association between age and improvement or recovery (Pheley et al., 1999).

The relationship between psychiatric illness and prognosis is also unclear. It is reported that illness outcomes are not predicted by concurrent or premorbid psychiatric status or psychological well-being (Hill et al., 1999; Vercoulen, Swanink, et al., 1996). Other research has found psychiatric illness to be associated with poorer outcomes (Russo et al., 1998). It has also been reported that people with rigid beliefs of physical causation have a poorer prognosis (Hickie, Lloyd, & Wakefield, 1995) and that a relative absence of physical causal attributions is associated with a better prognosis (Vercoulen, Swanink et al., 1996). These findings, however, are not consistent with other studies that report no association between physical illness attributions and outcomes (Heijmans, 1998).

It is difficult to draw any conclusions about prognosis on the evidence available at this time. In addition to the usual limitations of CFS research related to numerous definitions, use of self-reports and selection bias, are specific issues such as inconsistent definitions of improvement and recovery and the use of single measures.
that do not accommodate a fluctuating condition (Hedrick, 1997; Pheley et al., 1999). Additionally, the length of time between initial measures and follow-up may need to be extended to detect changes. Nevertheless, to date the research suggests that although improvement is likely for most, there is marked variation in the degree and duration of that improvement and recovery to premorbid levels is uncommon.

**Clinical Presentation and Assessment**
CFS typically presents with non-descriptive symptoms, and often, the person does not appear ill. Sometimes onset is gradual with no apparent precipitating condition, however, for most people the onset is abrupt and described in terms of a prior acute infection. This is most commonly described as a viral or flu-like illness that did not go away (Albrecht & Wallace, 1998; Lloyd et al., 1990). Assessment includes a medical history and physical examination that may find minor, non-specific signs of illness but that characteristically detects no marked abnormalities. To account for the overlay of psychiatric symptoms a mental status examination is recommended along with laboratory investigations such as blood screening and liver and thyroid function tests. Diagnosis is made following exclusion of other conditions (Loblay et al., 2002).

**Fatigue and Activity**
Fatigue is a symptom that people with CFS struggle to communicate to others. It is a cardinal symptom of CFS, yet the research is confusing and somewhat contradictory with difficulties arising from the subjective nature of fatigue, in addition to the general methodological limitations of CFS research. People with CFS report that activity leads to symptom deterioration, particularly fatigue, and when compared with healthy and ill controls, they exhibit significantly lower levels of physical activity (Servaes, Prins, Verhagen, & Bleijenberg, 2002; Vercoulen et al., 1997). Nevertheless, there appears to be a continuum of activity, ranging from “pervasively passive” to activity patterns that are close to those of healthy controls (van der Werf, Prins, Vercoulen, van der Meer, & Bleijenberg, 2000, p. 373). In other words, there is marked individual variation in levels of reported fatigue and activity.
There is some evidence to suggest that beliefs held about the consequences of activity are predictors of behavioural avoidance or persistence among people with CFS. Specifically, it has been reported that the commonly held belief that activity produces a worsening of symptoms is associated with an avoidance of activity (Silver et al., 2002; Vercoulen et al., 1997). Such activity avoidance is viewed as problematic. The cognitive behavioural model of CFS disability proposes that the avoidance of activity results in a decreased level of fitness and increased somatisation, so that over time symptoms are perceived as worsening at increasingly lower levels of activity. This pattern establishes a perpetuating circle of decreasing physical fitness and increasing functional impairment. There has been some support for the cognitive behavioural model of disability in CFS (Fischler, Dendale et al., 1997).

Limited work has generally not supported the view held by many people with CFS that activity worsens symptoms. In one study, for example, the objective measures of decreased activity following exertion were found to be consistent with patient self-reports of diminished activity, but the exacerbation of symptoms was not found to be as severe as suggested by the self-reports (Sisto et al., 1998). Studies investigating the hypothesis that poor physical fitness and physical deconditioning operate as perpetuating factors in CFS have yielded inconsistent results. There are reports that physical deconditioning contributed to the maintenance of CFS-related disability (Fulcher & White, 2000). Alternately, it has been reported that there were no differences in fitness between CFS patients and well-matched controls, and that physical deconditioning did not appear to be a perpetuating factor in CFS (Bazelmans, Bleijenberg, van der Meer, & Folgering, 2001). The research findings on fatigue, inactivity and beliefs regarding activity in the possible maintenance of CFS are inconclusive and contribute to the continuing poor understanding of the condition.

Functional Impairments
The extensive symptoms and reports by people with CFS of personal, social and occupational effects related to the syndrome has led investigators to examine functional impairments. The research has demonstrated marked and severe
functional impairments among the CFS population regarding the ability to carry out daily activities when compared with other disease comparison groups (chronic and acute) and the general population (Komaroff, Fagiolo, Doolittle et al., 1996; Wessely, Chalder, Hirsch, Wallace, & Wright, 1997). While there are negative effects to all domains of functioning, those that have been consistently demonstrated as markedly impaired are social, role and physical functions.

Two large, comparative studies conducted independently and simultaneously, and using the same measure of functional impairment (SF-36 comprising of 8 scales) reported very similar results. Komaroff, Fagiolo, Doolittle et al. (1996) found impairments among CFS patients to be severe and affecting overall health, with work and social roles particularly affected. The CFS group was more severely affected on all scales than the comparison groups of hypertension, congestive heart failure, type II diabetes, myocardial infarction, depression and multiple sclerosis. Data were collected over several years and the results remained stable, suggesting that the functional impairment did not change markedly. Additionally, following analysis it was hypothesised that a number of key symptoms (notably fevers, pharyngitis, muscle weakness, post-exertional malaise and difficulty in thinking), or the process that produced them, resulted in much of the functional impairment. Buchwald, Pearlman, Umali, Schmaling and Katon (1996), in comparisons between CFS, chronic fatigue, acute infectious mononucleosis, major depression and healthy controls, found results similar to those reported by Komaroff, Fagiolo, Doolittle et al. (1996). The CFS and chronic fatigued groups were markedly affected in social functioning, role functioning and vitality. Also consistent with the Komaroff, Fagiolo, Doolittle et al. (1996) data was the association between the flu-like symptoms and resultant disability.

In a study using the Sickness Impact Profile (SIP), Schweitzer, Kelly, Foran, Terry and Whiting (1995) examined the effects of CFS in the categories of physical, psychological and social functioning. They found that when compared with healthy controls and people with multiple sclerosis, the CFS group reported considerably higher impairments (within the severe range) across all categories, with areas of social and role functioning being the most affected. The authors noted that only in
studies of terminally ill cancer and stroke patients have the overall SIP scores reached the levels found in this study.

Buchwald et al. (1996) noted that much of the functional variance associated with illness is not explained by specific medical conditions but by variables such as illness duration and severity, treatments, and patient characteristics. Nevertheless, as measured by the SF-36, there is evidence of marked similarities in the CFS-related impairments found within the CFS-population of three countries (USA, United Kingdom and Germany), suggesting an unusual illness profile (Hardt et al., 2001). Similarly Dougall et al. (1998), in a smaller controlled study also using the SF-36, found impairments in physical and social functioning with CFS patients that were clearly distinguishable from the general USA population as well as other disease groups.

The factors related to the functional impairments associated with CFS are not known and the research is limited. There is some evidence that increasing fatigue is associated with increased functional impairment (Buchwald et al., 1996; Fischler, Dendale et al., 1997) and that maintaining activity is associated with less functional impairment (Ray, Jefferies, & Weir, 1995a). It has also been reported that psychological morbidity is related to functional impairment (Wessely et al., 1997), however, Christodoulou et al. (1998) concluded that psychiatric factors did not explain the finding that patients with CFS who performed poorly on neuropsychological testing were also more likely to display greater functional impairments.

The magnitude of functional impairment associated with CFS, particularly to roles, would suggest that the ability to engage in work is compromised and this is consistent with research that indicates that employment status is significantly affected. There is a notable decrease of participation in the workforce following onset and low levels of employment have been recorded ranging from 31% (Vercoulen et al., 1994) to 37% (Bombardier & Buchwald, 1996). Among those employed many move from full-time to part-time employment, and significant differences with respect to the number of hours worked per day have been found.
between people with CFS and healthy controls (Vercoulen, Hommes et al., 1996; Vercoulen et al., 1994). Additionally, the negative effects on work are frequently longstanding. Follow-up (at 1.5 years) on a CFS outcomes study (Bombardier & Buchwald, 1995) found that 34% of participants remained unable to work and 23% reported a decreased working performance. Clinical, psychiatric or demographic variables were not predictive of a return to work and there was a trend of greater unemployment in participants who at the initial examination fulfilled CDC case criteria.

The research on functional impairments is limited by the reliance on self-reports, potential sampling bias towards greater debility, the possibility that CFS patients over-report impairments, and uncertainty regarding the correlation between subjective and objective indices (Buchwald et al., 1996; Komaroff, Fagiolo, Doolittle et al., 1996). Therefore, there may be more variance in function and disability than what is reflected in the research, but it is clear that for many people with CFS the extent and degree of impairment is of concern and associated with considerable suffering.

**Quality of Life**

The effects of the functional impairments are evidenced by the quality of life reported by people with CFS. While the specific research into quality of life is limited and frequently uses the same measures as found in functional impairment studies, the findings consistently report a comparatively poor quality of life. An international comparative study, for example, using the SF-36 concluded that the health-related quality of life reported by CFS-affected participants in the USA, United Kingdom and Germany was poor (Hardt et al., 2001).

In studies using specific quality of life measures it is concluded that quality of life is “particularly and uniquely disrupted” among people with CFS (Anderson & Ferrans, 1997, p. 359; van Heck & de Vries, 2002, p.30). A comparative study using other chronically ill groups and the World Health Organization Quality of Life assessment (WHOQOL-100), reported that 4 of 6 domains were considerably lower for CFS than for other groups, overall quality of life was impaired, and the effects of CFS were
profound (van Heck & de Vries, 2002). Anderson and Ferrans’ study (1997) highlighted the extreme impact of CFS on the lives of 22 participants. The symptoms affected all aspects of functioning and there was general dissatisfaction regarding health. Multiple and extensive losses were reported, and in particular, losses associated with relationships and social support contributed significantly to high dissatisfaction in the psychosocial/spiritual domain. Additionally, marked disruptions in the economic domain were reflected in financial hardships.

Anderson and Ferrans (1997), using a between-methods triangulation design, identified unique aspects of CFS that were found to have a significantly negative effect on quality of life and that included symptom variability, cognitive dysfunction, exertional relapse and impaired social networks. A later quantitative study, consistent with the findings of Anderson and Ferrans, found severity of symptoms to be related to quality of life (Dougall et al., 1998). Further, the importance of illness beliefs to perceptions of quality of life among people with CFS has been suggested. For example, de Ridder, Schreurs and Bensing (1998) in a comparison between people with CFS and Parkinson’s disease, found that the self-evaluation of adaptive tasks was predictive of quality of life among the CFS group, while objective disease characteristics were more important to quality of life among patients with Parkinson’s disease. The authors concluded that quality of life among the CFS group was associated strongly with their illness beliefs and cognitions, and by the resultant actions.

Given the chronic nature of the syndrome, it is likely that functional impairments and poor quality of life are ongoing experiences for people with CFS. They are also likely to contribute to the suffering associated with CFS.

**Neuropsychological Impairments**

People with CFS report neuropsychological symptoms as particularly common and distressing. These reported problems include slowed thinking, difficulty with learning new material, and deficits in memory, attention, concentration and abstraction skills (Cope, Pernet, Kendall, & David, 1995; Marshall et al., 1996).
A substantial body of research using standardised measures and illness groups and healthy controls for comparison has supported some general trends, but definitive anomalies have not emerged and the findings are inconsistent. The most consistent neuropsychological deficit found is slowness and inefficiency in information processing. Other deficits include impaired verbal learning, mild memory deficits (particularly in working memory), and slowness in psychomotor reactions (Crowe & Casey, 1999; Marshall, Forstot, Callies, Peterson, & Schenck, 1997; Michiels & Cluydts, 2001). Research has generally found the neuropsychological impairments to be mild and subtle (Jain & DeLisa, 1998). A minority of studies reports no cognitive impairments. Short, McCabe and Tooley (2002), for example, compared 23 CFS participants with 23 healthy controls using standardised tests of cognitive performance and found no difference between groups on objective measures. As an explanation for the various findings, it has been suggested that a single and/or non-specific deficit or dysfunction (for example, slow information processing) may be responsible for most of the reported cognitive anomalies among CFS patients (Vollmer-Conna et al., 1997). Some results, however, do not support this proposition (for example, Short et al., 2002).

The effects of fatigue and depression on cognitive performance have also been investigated. Most of the evidence has not supported the premise that fatigue leads to a decrease in cognitive performance (Michiels & Cluydts, 2001). Johnson, Lange, DeLuca, Korn and Natelson (1997) compared 3 illness groups in which fatigue was a primary symptom (CFS, multiple sclerosis, and depression) with healthy sedentary controls and concluded that performance on neuropsychological tests was not impaired by fatigue. Nevertheless, Michiels and Cluydts (2001), in their review of the research on neuropsychological functioning in CFS, reported that it would be premature to conclude that cognitive function among CFS patients does not decline with fatigue. There are a few reports of an association between poor cognitive performance and comparatively greater levels of inactivity (Christodoulou et al., 1998). Using a battery of standardised tests and motion-sensing devices (that overcame the limitations of self-reports), Vercoulen et al. (1998) reported that slowed information processing was related to low levels of physical activity.
Depression has been of interest because of its association with neurocognitive deficits and because it is a relatively common experience for people with CFS. In the main, the research has concluded that while there might be some slight similarities in the cognitive profile of CFS and depressed patients, cognitive impairments among the CFS population are not explained by depressive processes (Daly, Komaroff, Bloomingdale, Wilson, & Albert, 2001; Marshall et al., 1996). Vollmer-Conna et al. (1997) measured mood disturbance and both broad and specific cognitive performance using a battery of standardised tests. Four groups (CFS, non-melancholic depression, acute infection and healthy controls) were matched for gender, age, education, and general intelligence. It was found that while the 3 patient groups all showed cognitive impairment (with the infective group showing a better performance than the CFS and depression groups, who did not differ), the correlational data did not support the proposition that depressed mood accounted for cognitive impairment. Daly et al. (2001) measured neuropsychological functioning using a battery of standardised tests and found that the cognitive deficits among CFS and multiple sclerosis participants were mild in comparison with the depressed group. Consistent with Vollmer-Conna et al. (1997), they concluded that the cognitive deficits in CFS could not be explained solely by the presence of depressive symptoms.

The inconsistencies in the findings of neuropsychological studies that attempt to describe cognitive functioning and the tendency towards mild effects have made it difficult to evaluate the cognitive impairments. Additionally, the objective measure of impairments have been found to be inconsistent with the subjective reports of the severity of the complaints, with CFS patients underestimating their cognitive performance and reporting more problems in comparison with other groups (Metzger & Denney, 2002; Short et al., 2002). The inconsistent findings and objective/subjective discrepancies may represent methodological limitations. People with CFS describe marked symptom variability and unpredictability and it is possible that symptomatic fluctuations have particular effects on cognitive performance. This suggests the need for evaluating the symptoms during the period of testing, and for testing cognitive performance at different times of the day. Longitudinal studies to track performance changes and the use of subgroups and stratification techniques to
reduce heterogeneity have been suggested as important to clarifying CFS-related
cognitive deficits. As with all CFS research, the heterogeneity of research samples
remains problematic, and sample sizes have been small with the majority of studies
limited to between 20 and 30 participants (Michiels & Cluydts, 2001).

While it currently appears from the research that neurocognitive changes are subtle
and mild, refinement of cognitive measures may demonstrate definitive and
consistent anomalies. Michiels and Cluydts (2001) suggest the use of tests with high
specificity to examine specific components of neuropsychological performance, and
Vercoulen et al., (1998) recommend the linking of neuroimaging with
neuropsychological testing.

**Relationships**

With the exception of research on functional impairments that have included
relational functions, there has been very limited investigation of relationships with
others among people with CFS. This is of concern given that the research on
functional impairment reports marked relationship disruption. Accounts by people
with CFS commonly include descriptions of lost friendships, disrupted familial
relationships, and disbelief, criticism and lack of understanding from others
(Anderson & Ferrans, 1997; Cooper, 1997). These reports indicate the need for
research that examines the effects of CFS on relationships, the social and personal
consequences of altered relationships, and the determinants and role of social support
in the management of CFS.

There is very limited research investigating the effects of social support among
people with CFS. A pilot study of 12 people with CFS examined the effects of a
buddy/mentor program and reported that over a 4 month period, participants who
received volunteer care reported more optimism and less fatigue than those without a
caregiver (Shlaes & Jason, 1996). In a comparison between CFS patients receiving
primary and tertiary care, it was reported that primary cases were more likely to be
married or cohabitating than hospital cases (Euba, Chalder, Deale, & Wessely,
1996). It is possible that those patients who had partners received greater social
support than those without, and that this provided a buffer against requiring greater medical care. These studies suggest benefits arising from social support.

In contrast, Kelly, Soderlund, Albert and McGarrahan (1999) in a study of 41 CFS participants, 25 of whom had a primary support person and using measures of mood and perceived stress, found that social support from a primary caregiver was not of benefit to psychological health. The study used the Inventory of Socially Supportive Behaviors (ISSB) to assess the degree of support that individuals reported. The ISSB has been widely used among illness groups and is reported to have an acceptable reliability. This allowed Kelly et al. to compare their results with other illness studies, and led them to propose that the lack of positive benefits related to social support may be due to the low levels of support that the CFS participants reported, as compared to other illness groups. In other words, they did not receive enough support in order for any benefit to accrue.

It may be that the benefits of support networks to health outcomes are dependent on the interactions of numerous factors. Schmaling & DiClementi (1995) in a pilot study of 11 female CFS participants found that higher levels of fatigue were moderately correlated with less activity for participants in satisfied relationships, but not among individuals in dissatisfied relationships. It was suggested that supportive partners might inadvertently reinforce disability by maintaining a cycle of inactivity, which then proved detrimental to health outcomes. Alternately, the authors proposed that individuals in dissatisfied relationships might be more active because they receive less support, but with consequent higher levels of stress. Schmaling and DiClementi’s (1995) findings highlight the importance of investigating dimensions of relationships (in this case, satisfaction) in order to expose relational complexities and variables.

CFS represents a major challenge for significant others as they too are confronted with a “strange and suspect illness” (Beaulieu, 1995, p. 15). Kelly et al. (1999) suggested that the nature of CFS symptoms posed difficulties for support givers who often do not know how to respond to the symptomatic effects. There is some evidence that suggests CFS is difficult for significant others to understand.
study of 131 women with CFS and their spouses, Goodwin (1997) found a discrepancy between the perceptions of husbands and wives regarding symptoms. Husbands perceived that their wives experienced fewer and less problematic symptoms than were reported by the wives. This discrepancy does support the contention by people with CFS that the effects of their symptoms are generally misunderstood and underestimated. Among significant others there are different views of CFS. Beaulieu’s (1995) qualitative investigation examined the meanings of CFS to significant others and found that CFS was viewed by significant others as a distressing and disabling illness, as an expression of inappropriate coping, and/or as a burden. The view of CFS as distressing and disabling was mostly associated with a belief by significant others that CFS was a physical and real illness. Alternately, the view that CFS was a form of inappropriate coping was related to a belief by significant others of the illness as psychological and representative of a personal failing. The perception of CFS as inappropriate coping was less common than the view of CFS as distressing.

The scarcity of research on relationships among people with CFS results in an inability to draw any general or major conclusions. It remains an important area for investigation.

**Chapter Summary**

This chapter has reviewed the CFS research related to definition and description. The picture that emerges is somewhat confused and contradictory. As it is currently defined (by a number of criteria) CFS is a heterogeneous condition with regards to onset, symptoms, epidemiology, prognosis, functional disability, and psychosocial correlates. CFS is relatively common, and its benign presentation belies the marked functional impairment and poor quality of life that frequently accompanies the symptoms. Its contested nature is reflected in the varying degrees of medical acceptance regarding the legitimacy of CFS as a diagnosis. Chapter 3 continues the review of the literature by examining the research that attempts to explain the causes and management of CFS.
Chapter 3

Explaining Chronic Fatigue Syndrome

This chapter continues the review of the CFS research by progressing from definition and description to an examination of the literature that explains CFS. Chapter 3 addresses the research that attempts to theorise, understand, and explain the condition. This body of work is concerned with causes, predispositional factors, and societal conventions. It includes explanations of how to treat, manage or live with the symptoms.

Chapter 3 presents the causative explanations for CFS using biomedical, sociological and anthropological, psychological, and multicausal perspectives. The chapter also reviews the research regarding management strategies. These include pharmacological therapies, rest and exercise, cognitive behaviour therapy, CFS programs, complementary approaches, and holistic management. In addition, the tensions and controversies that surround the understandings of CFS are discussed through an examination of CFS discourses. The methodological constraints associated with CFS research that were outlined in the previous chapter remain relevant.

The Causes of CFS
There is a wide and extensive body of research that addresses the aetiological questions surrounding CFS but causative factors remain unknown and ways to understand the condition remain elusive. Biomedical, sociological and psychological explanatory perspectives have provided different approaches to investigating possible dynamics underlying CFS. While each is discussed separately, there is overlap, particularly between the biomedical and psychological perspectives.

Biomedical Perspectives
There has been significant biomedical investigation into CFS involving numerous medical specialties. The findings highlight many inconsistencies, with research
describing a variety of abnormalities found in most, or some, but not all people with CFS. The heterogeneous nature of the population contributes to the lack of resolution regarding pathophysiology (Johnson, DeLuca, & Natelson, 1999) and continues to hamper aetiological research. There have been a number of different lines of research, including central nervous system, neuroendocrine, immunological, infection, neuropsychiatric, sleep, muscle, and allergy studies. Each is discussed separately.

While there are some inconsistencies in the findings there is evidence to support the hypothesis that CFS is mediated by the central nervous system (CNS). Diagnostic imaging has indicated neurological abnormalities among substantial numbers of people with CFS. White matter cerebral lesions of the frontal lobes, often subcortical and sometimes deeper, have been detected via magnetic resonance imaging (MRI) and suggest possible encephalopathy and/or demyelination (Johnson et al., 1999). Research has indicated that these white matter abnormalities are significantly related to the subjective reports of physical functioning, which tentatively demonstrates a relationship between pathology and physical functional status (Cook, Lange, DeLuca, & Natelson, 2001). Additionally, single photon emission computed tomography (SPECT) has demonstrated abnormal decreases in cerebral blood flow and significant brainstem hypoperfusion (Johnson et al., 1999). Abnormalities of the sympathetic and parasympathetic systems, disruptions to noradrenergic and serotonergic pathways, and abnormalities in central and peripheral balance have also been demonstrated. Overall there is substantial physical evidence of CNS pathology (Evengard et al., 1999).

A promising line of neuroendocrine research involves a functional abnormality of the hypothalamic-pituitary system causing a secondary impairment of adrenal function. There is some evidence that CFS may be associated with decreases (that is, a down-regulation) in hypothalamic-pituitary-adrenal (HPA) axis functioning and neurotransmission, an underproduction of corticotrophin-releasing hormone, and consequent low levels of cortisol (Evengard et al., 1999; Friedberg & Jason, 2001; Johnson et al., 1999).
Given the history of a flu or infective-like illness that does not go away, immunological research has been a popular line of investigation. Additionally, many CFS symptoms are similar to the treatment effects observed with high levels of cytokines. This has led to hypotheses of CFS as involving immune activation or dysregulation. A range of abnormalities in the immune system have been reported, including increased interferon activity, cytokine levels and lymphocyte markers, and depressed function of natural killer cells (Craig & Kakumanu, 2002). Findings of immunological dysfunction have been ample but inconsistent and of uncertain importance. It has been noted, for example, that immune disturbances are frequently modest, not specific to CFS, appear to have no relationship to disease severity, and are of uncertain diagnostic or prognostic meaning (Demitrack, 1998; Pizzigallo, Racciatti, & Vecchiet, 1999). Nevertheless, while the results have been inconsistent, Craig & Kakumanu (2002) argue that immunological factors may account for a subset of people with CFS.

CFS does not appear to be contagious but descriptions of acute, infectious type onsets have led to investigations into the possible role of infectious agents, particularly viruses. There is little clinical evidence of persistent viral infections, including Epstein Barr virus, Coxsackie virus, human herpesvirus-6, retrovirus, enterovirus, or cytomegalovirus. CFS can follow an infectious illness such as mononucleosis. This progression of infection to CFS, however, has been considered the exception and research has found that few CFS patients had a definite infection diagnosed at onset (Evengard et al., 1999; Salit, 1997). This finding has recently been challenged by a large retrospective study of onset factors among 1546 people with CFS. De Becker, McGregor and de Meirleir (2002), using cluster and odds ratio analyses, found that almost 60% reported infectious onset events, and thus had a potentially infectious aetiology. Current thought suggests that rather than caused by one specific and novel agent, CFS may be a state of chronic immune activation initiated or maintained by infectious agents (Craig & Kakumanu, 2002).

The overlap of symptoms with psychiatric disorders, the historical link with neurasthenia and the absence of organic aetiology have contributed to the argument that CFS is a psychiatric condition. Additionally, given the finding that significant
numbers of people with CFS have concurrent or pre-existing psychiatric disorders, the question arises as to whether such psychopathology represents a primary feature of CFS or is secondary to the effects of CFS (Johnson et al., 1999). The psychiatric conditions of particular interest are depression and somatisation.

While there is some overlap of symptoms between CFS and depression - and large numbers of people with CFS experience depression - the evidence does not generally support the notion of CFS as a form of atypical depression. A number of CFS symptoms are not found with depression and people with CFS do not experience all the classic depression symptoms, notably anhedonia and decreased motivation. The objective profile is different, with an up-regulation of the HPA axis found with major depression while people with CFS are typified by a down-regulation. Measures of functional status are also different for major depression and CFS (Evengard et al., 1999). Further, when CFS does occur concurrently with major depression, the personality and symptom profiles differ from people with only major depression (Natelson, 2001). Additionally, a significant number of people with CFS do not develop depression (Johnson et al., 1999). Similarly, somatisation disorder is found to differ from CFS. For most people, CFS has a sudden onset that is more likely to occur in adulthood, while somatisation disorder tends to begin in adolescence and reach its full expression by age 25 (Friedberg & Jason, 2001). Evengard et al. (1999) noted that the belief that CFS is a psychiatric disorder is less common than it was a decade ago.

People with CFS commonly report poor and unrefreshing sleep, drowsiness upon awakening, early morning waking, the need for naps and difficulties in getting to sleep or staying awake. Generally, these reports have found some support in the research (Krupp, Jandorf, Coyle, & Mendelson, 1993; Whelton, Salit, & Moldofsky, 1992), although there is little support for the view of CFS as an expression of a primary sleep disorder (Le Bon et al., 2000). In an examination of the sleep literature, Friedberg and Jason (2001) suggest that among some people with CFS there is a reduction of deep sleep that triggers a disturbance in the circadian rhythm and neurohormones, such as melatonin, which help regulate the sleep-wake cycle. The authors also note that abnormal serotonin metabolism may underlie the sleep
disturbances. In sum, while no single sleep disorder has been found to be characteristic of CFS, anomalies in sleep are apparent for at least some people with CFS. Treatment of any underlying sleep disorder is recommended but does not alter the CFS symptoms.

Although people with CFS commonly report muscle and joint pains, research has been generally unable to demonstrate musculoskeletal pathology. Muscle physiology has been found to be normal before and after exercise. It is hypothesised that an abnormal perception of effort may contribute to the symptoms (Craig & Kakumanu, 2002; Evengard et al., 1999), but no link has been established or disproved between CFS and musculoskeletal effects. With respect to the role of allergies, most studies have found people with CFS to be more susceptible to allergic responses. It may be that allergens function as triggering agents, in the same way that infection might operate (Craig & Kakumana, 2002).

While the biomedical perspective has not yet been able to explain CFS, physiological abnormalities of varying strengths have been demonstrated. Nevertheless, not all people who meet the case definition of CFS exhibit the same (or any) biological markers. This might reflect the heterogeneity of the population, the fluctuating nature of CFS, or misdiagnosis (Komaroff, 2000) and research is frequently limited by methodological constraints such as a lack of double-blind, randomised and matched trials among the quantitative studies. It is also important to acknowledge that the reported biological abnormalities do not yet explain CFS. Nevertheless, there has been a growing acceptance that the CNS and neuroendocrine-immunologic network appear to be of influence (Craig & Kakumana, 2002).

Sociocultural Perspectives
Sociocultural perspectives are derived from sociology and anthropology and have examined the contribution of social and cultural paradigms, processes, beliefs and structures to the development and maintenance of CFS. Two main schools of thought regarding explanations for CFS are found within the sociological and anthropological literature. There is the view that CFS is a form of escape from role
conflicts and obligations, and secondly, there is a feminist approach that explains CFS in terms of gendered relations.

Historical comparison provides the basis for Abbey and Garfinkel’s (1991) proposition that CFS and neurasthenia are somatic responses to unwanted sociocultural burdens and conflicts. According to this view, CFS and neurasthenia provide an organic explanation for a wide variety of somatic symptoms that are a response to the paradigms and beliefs of their respective eras. It is argued that CFS and neurasthenia have developed in historical periods characterised by an emphasis on financial success, status and personal effort, and by marked changes to the roles of women and to work practices. Within this context it is postulated that CFS, by providing a legitimate medical reason, also provides a legitimate social reason for individuals (mainly women) to abdicate occupational, personal, social and family obligations and roles. The thrust of this position is that the sick role affords an acceptable method for transgressing cultural norms and that CFS is a culturally sanctioned form of illness behaviour (Abbey & Garfinkel, 1991).

There are difficulties associated with this explanation. There is no indication that people with CFS have any desire to abdicate their obligations and roles. Indeed the evidence, found mainly with the work on functional impairments and quality of life and including the findings of the present study, suggests the contrary – that is, the loss of roles is a primary source of distress that contributes to a poor quality of life. It is also arguable that CFS is an acceptable or culturally sanctioned form of illness behaviour given its contested nature and marginalising effects. In other words, CFS does not bring with it medical legitimacy or a socially appropriate method of escape but instead, leaves the individual open to criticism.

Consistent with the arguments of Abbey and Garfinkel (1991), Ware and Kleinman (1992) used the concept of sociosomatics to explain the social course of CFS and postulated that through a process of somatisation, social problems become embodied as physical symptoms. According to this model, events in the local world interact with social forces to influence symptoms (sociosomatics) and the symptomatic experiences affect the local world by providing an impetus for change. Using
interview data from 50 participants with CFS, Ware and Kleinman (1992) described
the premorbid lifestyles of their participants as an “overinvestment” (p. 552) in the
normative cultural values of hard work and achievement, resulting in social
consequences of competing demands and unremitting pace. Fatigue became a
“metaphor for the overcommitted life” (1992, p. 554) and the symptoms functioned
as a mechanism for legitimately affecting change in the social world towards greater
personal efficacy. As a consequence of CFS, just under half of the participants
described a transformation of lifestyle directed towards meeting the needs of self
rather than others, where “the abandonment of expectations of success produced
feelings of contentment and relief” (1992, p. 555). In contrast, the majority of the
participants experienced loss and grief associated with CFS. This suggests that most
participants did not wish to change their local worlds and that an “overcommitted
life” was the preferred life. Sociosomtics does not adequately account for this
finding.

The feminist approach explains CFS as arising from gendered roles and stereotypes
associated with the predominantly female CFS population and predominantly male
medical establishment. It is argued that as the medical world failed to demonstrate a
biological basis for CFS, psychosocial theories became the more popular
explanations and served to discredit the illness as a biomedical phenomenon with
consequences in the public, legal, academic and medical arenas. Feminists argue that
such explanations are typical of the ways in which the illnesses of women are
socially constructed with a bias towards psychiatric or psychosocial perspectives.
According to the feminist approach, this bias underpins the explanation that CFS
provides an escape from burdensome and conflicting roles by allowing women to
assume the sick role (Richman et al., 2000).

Although there is limited sociological and anthropological research that addresses the
causes of CFS, sociocultural explanations based on the assumption that CFS is an
escape from an overcommitted life have proven to be of influence. This premise has
found its way into mainstream media and provides the basis for the use of “yuppie
flu” and “bored housewife’s syndrome” as synonyms of CFS.
Psychological Perspectives
The psychological research has sought to clarify factors or variables that may precipitate or maintain disability, or enhance vulnerability. Stress and life events, personality and illness beliefs have been the primary foci.

Stress and Life Events
Stress is associated with compromised immune and endocrine functions and with an increased vulnerability to disease, and its role in the development, exacerbation and maintenance of illness has been well documented. People with CFS have reported that stress contributed to their illness onset and, once the condition was established, to the exacerbation of symptoms (Clements, Sharpe, Simkin, Borrill, & Hawton, 1997; Ray, Weir, Cullen, & Phillips, 1992). However, findings regarding stress and CFS are somewhat mixed, and directions of relationships are unclear. Consistent with the self-reports there is evidence to suggest that stress predisposes vulnerable individuals to the development of CFS and worsens its symptoms (Dougall et al., 1998; Lutgendorf et al., 1995; Schmaling & DiClementi, 1995). Other studies have found little association between stress and the development or maintenance of CFS (Bruce-Jones, White, Thomas, & Clare, 1994).

The potential for life events to function as stressors has been well established, however, CFS research has not yielded consistent results. Comparative research has reported some association between onset, presence or exacerbation of CFS and an increased number of life event stressors (Masuda, Nozoe, Matsuyama, & Tanaka, 1994; Salit, 1997). Other studies have not reported this association and found no differences between CFS groups, illness groups and healthy controls in number or severity of life-events (Lewis, Cooper, & Bennett, 1994). The possible role for the sequencing of stressors has been highlighted. Theorell, Blomkvist, Lindh and Evengard (1999) in a study based on the retrospective self-reports of 46 people with CFS, tentatively reported that infection might sensitise the person, while the negative life events then increased vulnerability to CFS.

There is some evidence to suggest differential effects between negative and positive life events. Ray, Jefferies and Weir (1995b), in contrast with much of the research
that has focused on onset, examined the effects of life events on 130 people with established CFS. They found that negative life events were unrelated to the severity of fatigue or functional impairment, whereas positive events were consistently related to lower scores for fatigue and functional impairment. While causal direction could not be determined, it was suggested that the lack of effect found with negative events might be related to the dominance of other constant factors (such as strain imposed by the illness), or to the promotion of active coping precipitated by the event. It was concluded that positive life events might contribute to improvement, or alternately, be facilitated by improvement in symptoms.

Other work has examined the possible role of chronic stress, notably victimisation arising from physical, emotional and sexual abuse. Limited research has reported a comparatively higher incidence of victimisation among people with CFS (Schmaling & DiClementi, 1995; van Houdenhove, Neerinckx, Lysens et al., 2001).

In summary, it is difficult to assess the role of stress and life events in explaining CFS because of inconsistent findings and lack of causal directions.

**Personality Characteristics**

The investigation of personality characteristics as causal contributors to CFS has been based on the hypothesis that personality may act as an antecedent or maintaining factor. While there appears to be some consistencies, interpretation of findings is difficult and a unique personality cluster that either functions as an antecedent or arises as a response to CFS has not emerged. Personality profiles are similar to those found with other chronic conditions such as multiple sclerosis and chronic pain (Christodoulou et al., 1999; Schmaling & Jones, 1996) and may reflect a common experience among the chronically ill rather than a specific characteristic of CFS.

People with CFS typically describe themselves as overcommitted and overextended prior to their illness and there has been tentative support regarding the presence of premorbid hyperactivity. Lewis et al. (1994) found evidence for a self-induced, high-pressured lifestyle prior to illness onset. Furthermore, a decrease in high-
driving behaviour as a response to the illness was reported, consistent with other research (for example, Ware, 1993). It has been suggested that qualities, attitudes and behaviours related to high levels of activity may predispose a person to CFS or interfere with recovery. A study that controlled for idealisation of the premorbid lifestyle and for the need of participants to prove “good citizenship” through an action orientation, found support for the hypothesis that a high level of “action-proneness” may contribute to the predisposition, initiation and/or perpetuation of CFS. It was suggested that this might occur by overburdening the body, adding to life stressors and lowering immunocompetence (van Houdenhove, Neerinckx, Onghena, Lysens, & Vertommen, 2001).

Limited research has addressed the role of perfectionism as a possible contributor. Some research has not supported an association between perfectionism and CFS (Blenkiron, Edwards, & Lynch, 1999; Wood & Wessely, 1999). Additionally, the Type A personality construct, a similar measure to perfectionism, was found to be an irrelevant construct in characterising people with CFS (Lewis et al., 1994). In contrast, other work has reported a maladaptive perfectionist personality style that involves impossibly high standards, self-criticism, dissatisfaction and feelings of inferiority (White & Schweitzer, 2000).

General and dimensional measures of personality have produced conflicting results and the presence or effects of personality traits or disorders among the CFS population has not been clearly demonstrated. Studies using personality measures have reported both differences (Schmaling & Jones, 1996) and no differences between people with CFS and healthy controls (Chubb et al., 1999). Similarly, studies into the role of personality as a predisposing factor have produced conflicting results. Blakely et al. (1991) compared CFS patients, a chronic pain group and healthy controls using the Minnesota Multiphasic Personality Inventory (MMPI). The CFS group displayed a higher emotionality factor, consistent with the hypothesis that emotionality is a predisposing factor for CFS rather than a reaction to the illness. A comparative study (Christodoulou et al., 1999), however, reported similar profiles between the CFS and multiple sclerosis (MS) groups (compared with healthy controls), which did not support the hypothesis that personality traits predispose
individuals to the development of CFS. Both illness groups displayed more negative outlooks than the healthy controls with no evidence to suggest that negativity among the CFS group predisposed them to develop their illness any more so than was the case for the MS group. Consistent with these findings, Johnson, Lange, Tiersky, DeLuca and Natelson (2001) found CFS and MS groups to have similar personality variables. The authors suggested that the differences between the CFS/MS groups and healthy controls were likely to reflect demoralisation among the CFS/MS group associated with a disabling and chronic illness.

There are a number of difficulties in interpreting the findings on personality. The demonstration of differences does not provide a causal explanation. Personality instruments measure difference without explaining the genesis of the difference. Explanations would need to account for individuals who do not develop CFS, despite the same personality profile as (some) people with CFS. Additionally, the instrument used to measure personality variables may influence results. The commonly used MMPI, for example, is overly sensitive to physical symptoms and may inflate scores among physically impaired groups as a consequence of ill health rather than as a consequence of personality traits. Interpretation of the results therefore requires caution, and longitudinal studies to assess stability of personality traits over time are recommended (Blakely et al., 1991; Johnson, DeLuca, & Natelson, 1996). For the moment, the association of personality in CFS remains unclear.

**Illness Attributions, Beliefs and Behaviours**

The role of illness attributions in the initiation or maintenance of CFS has been of particular interest given that, although inconsistent, some research has reported a relationship between beliefs in physical causation and poorer outcomes (Joyce et al., 1997). An attributional perspective of CFS has suggested that beliefs may influence the parameters that people apply to their level of functioning (Petrie, Moss-Morris, & Weinman, 1995), and encourage predictions that perpetuate or maintain illness (Clements et al., 1997). For example, according to this perspective the belief of physical causation leads to a belief that activity will worsen the symptoms. Consequently, it is argued, people with CFS avoid physical activity thereby
producing physical deconditioning, amplification of somatic symptoms, illness maintenance and disability.

The research has generally found evidence for strong disease conviction among people with CFS, with a majority of study participants largely attributing their illness to a biological origin, notably viral infections and immune dysfunction (Ax, Gregg, & Jones, 1998; Butler, Chalder, & Wessely, 2001; Heijmans, 1998), thus locating the illness within the body. The continued use among people with the syndrome of the (medically defunct) label of “ME” (myalgic encephalomyelitis) with its biological connotations, rather than the aetiologically neutral “CFS” (used by medical practitioners and researchers), is consistent with the belief of a biological basis (Heijmans, 1998). Nevertheless, in addition to an organic causal attribution, CFS research participants have attributed an important role to pre-morbid or concurrent psychological factors (Friedberg, Dechene, McKenzie, & Fontanetta, 2000; Neerinckx, van Houdenhove, Lysens, Vertommen, & Onghena, 2000). While psychological factors are unlikely to be viewed as the sole cause, they are perceived to be important contributing agents. People with CFS appear to have a causal understanding of the syndrome that is complex and includes both biological and psychological factors, and although physical causation is a strong attribution it is not perceived as exclusionary to multifactorial explanations (Clements et al., 1997; Heijmans, 1998). The psychological factors identified include those considered internal (for example personality attributes such as ‘busyness’ or emotional confusion) and external, notably stress.

The inclusion of non-physical causative factors is interesting given the reported rejection of psychological explanations and treatments among the CFS population. Clements et al. (1997) suggested that this apparent contradiction highlighted the power of the discourse. Psychological factors might be associated with negative connotations of personal blame and inferior character. Alternately, stress might be perceived as a normal event, something to which everyone is vulnerable and external to the individual. Consistent with this interpretation of the importance of discourse, Ray et al. (1995a) explained their finding of more participants attributing the illness to “physical and other factors” (rather than just “physical”) as partly due to revised
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wording on measuring instruments. That is, when non-physical factors were not equated with psychological determinants their contribution to causation was more readily acknowledged.

In addition to levels of disease conviction other aspects of CFS illness behaviour have been investigated. CFS patients are generally found to demonstrate comparatively high levels of somatic preoccupation and hypochondriasis (Butler et al., 2001; Trigwell, Hatcher, Johnson, Stanley, & House, 1995). While the direction of the effect is not known, such attributions may reflect a vulnerability to CFS.

There has been speculation as to why people with CFS hold stronger disease convictions and demonstrate greater illness behaviour when compared to most other chronically ill groups. It is suggested that the controversies surrounding CFS, which are not attached to most chronic illnesses, are of importance. It is noted that chronic pain patients, who face many of the same controversies as CFS patients, display similar profiles of illness behaviour (Howlett & Lindegger, 1996). In other words, strong disease conviction and abnormal illness behaviours may be associated with contested illnesses rather than with CFS specifically. There are some reports of similar illness behaviours between CFS and non-contested illness (for example, multiple sclerosis) that are explained as arising from common features, with the suggestion that in order to understand illness behaviour it is important to know how people acquired their beliefs (Trigwell et al., 1995). Specifically, Trigwell et al. (1995) noted that although patients with CFS feel markedly unwell and are functionally impaired, medical practitioners typically tell them that there is no identifiable pathology. In order to gain credibility patients may strongly declare their disease as “real” (disease conviction), reject psychological interpretations (somatic versus psychological concern) and focus on physical symptoms (hypochondriasis).

The role of illness beliefs and behaviours in the perpetuation and maintenance of CFS remains unclear and it may be that the comparatively strong disease convictions found in many studies is not as problematic as suggested. A study of treatment outcomes, for example, found that it was not necessary for patients to change their
beliefs about a physical basis for CFS in order to improve (Deale, Chalder, & Wessely, 1998).

**Multifactorial Causation**

The confusion surrounding the syndrome as evidenced by its heterogeneity, difficulties in definition, overlap with psychiatric morbidity and the inability to find definitive organic causal agents has resulted in many researchers from various disciplines proposing that there is no single cause of CFS. There is a growing belief that homogenous subgroups currently comprising the heterogeneous CFS population might have different causal agents. Consequently, current explanations of CFS suggest the need to develop multifactorial and interactional models that take into account its complexities. To date, the explanations for the causes of CFS remain obscure.

Recommendations for how to treat CFS and live with its effects have to a large extent been constrained by the lack of causal understanding. The review of this body of research follows.

**Managing CFS**

CFS is managed rather than treated. The strategies for managing CFS are of limited effectiveness. To find relief, patients commonly access various and numerous health providers from traditional and mainstream and complementary and non-traditional backgrounds. This wide use of health providers and healing practices is typical of people with chronic and incurable illnesses.

There are a number of difficulties in interpreting the effectiveness of management strategies. Methodological constraints include variations in the case definitions used, differences in illness severity, reliance on subjective measures, a lack of double-blind, placebo-controlled and comparative studies in adequately defined patient samples, and a lack of standard outcome measures. Additionally, the evaluation of effectiveness is problematic because there is a tendency towards improvement, and a significant placebo response or nonspecific treatment effects have been found (Whiting et al., 2001; Wilson, Hickie, Lloyd, & Wakefield, 1994). Findings are
sometimes contradictory and therefore the guidance provided by the research to people with CFS and to clinicians is compromised.

Medical management of CFS has proven to be problematic. It is aimed towards the relief of symptoms and disability, and gradual rehabilitation and adaptation. Interventions cited in the literature have included minimising the effects of symptoms, increasing (or maintaining) levels of exercise, treating co-morbid disorders (particularly depression and anxiety) and treating psychological or behavioural correlates that may be perpetuating the syndrome. Medical acknowledgment of the reality of the symptoms and suffering has been postulated as important in providing patients with validation and support. Individualised management plans based on collaboration are recommended (Caplan, 1998; Sharpe, 1996; Loblay et al., 2002). The most commonly discussed interventions include pharmacological therapy, exercise versus rest, cognitive behaviour therapy (CBT), CFS programs, and complementary approaches. Each of these is discussed.

**Pharmacological Therapies**
Pharmacological treatments have included the use of antidepressant, antiviral, immunoregulatory, and corticosteroid medications. Although individuals have reported benefits, the efficacy of pharmacologic treatments has not been established and research results have been mixed. There is some limited evidence that antidepressant therapy is helpful to individuals with significant mood and sleep disturbances (Loblay et al., 2002). Sensitivity to drug side effects is common, so low dosages and a minimum number of drugs are recommended (Caplan, 1998). In short, no agent has been shown to be consistently effective.

**Exercise and Rest**
Extensive rest periods were initially recommended for CFS patients. This strategy fell out of favour because of the adverse physiological and psychological effects associated with extensive bed-rest and the postulated role of activity avoidance in the perpetuation of CFS symptoms (Sharpe & Wessely, 1998; Wessely, 1998). Instead, it is suggested that rest be implemented as part of a planned strategy rather than as an automatic response to the symptoms (Sharpe & Wessely, 1998). It is recommended
that a regular and normalised sleep-wake pattern be maintained by strategies such as avoiding day time naps and waking at a regular time (Loblay et al., 2002).

While there is little measurable evidence to suggest that exercise may be harmful (Coutts, Weatherby, & Davie, 2001), some practitioners suggest care in the use of exercise noting that simplistic implementation of exercise programs may damage the person’s confidence (Sharpe, 1996). Achieving an appropriate balance between activity and rest, that is, an energy management strategy known as pacing, involves accommodating energy limits and avoiding activity to the degree that symptoms are worsened (Bagnall, Whiting, Richardson, & Sowden, 2002). Pacing has not been subject to any research and its benefits (or otherwise) have not been demonstrated. Concerns have been expressed regarding the potential of pacing to maintain the symptoms by encouraging an avoidance of incremental increases in activity based on the fear of symptom exacerbation (Straus, 2002).

A more structured and regulated approach to activity is found with graduated exercise programs. These programs are recommended to increase tolerance of activity, minimise secondary deconditioning effects, maximise functioning, minimise avoidance behaviour and increase self-efficacy. Unlike pacing, graduated exercise programs have been evaluated, with conflicting results. There is evidence to support the benefits of graduated aerobic exercise to some people with CFS as measured by self-report and statistical significance (Coutts et al., 2001). Reports of deterioration following graduated exercise programs, however, suggest the need for caution. It is proposed that individualised activity programs be planned in collaboration with the person, starting at an easily managed level and increasing at a tolerable pace (Sharpe & Wessely, 1998).

**Cognitive Behaviour Therapy**

The rationale for the use of cognitive behaviour therapy (CBT) is based on the hypothesis that cognitive and behavioural patterns perpetuate CFS. CBT is not specific to CFS but is used with a number of chronic illnesses. It is currently a popular (and somewhat fashionable) therapy for behavioural problems and psychological conditions. With reference to CFS, CBT aims to increase mobility,
relaxation and social participation (that is, decrease avoidance and increase activity), restructure negative thought processes, and evaluate possible reinforcers of disability (Wilson et al., 1994).

There are inconsistent results regarding the effectiveness of CBT. A number of studies have reported improvements in fatigue and activity levels, function, and symptoms (Akagi, Klimes, & Bass, 2001; Prins et al., 2001; Whiting et al., 2001). Other studies have not shown CBT to be of benefit (Lloyd et al., 1993). There are methodological limitations such as the intensity and duration of treatment, the suitability of control interventions, and the reliance on participants well enough to attend treatments that contribute to difficulties in evaluating effectiveness or comparing studies. Outcome studies have indicated that CBT can have ongoing benefits for some people with CFS but does not constitute a cure (Deale, Husain, Chalder, & Wessely, 2001). Research is also needed to evaluate the long-term effectiveness of CBT.

CBT has not been a popular therapy among people with CFS and there is anger expressed (including among the participants of the present study) that it is one of the few suggested medical treatments. There are indications that a significant proportion of CFS patients refuse to participate in or drop out of CBT programs (Akagi et al., 2001). This may reflect a belief that a psychological treatment infers a psychological cause, and is therefore considered to be of little benefit when the cause is believed to be physical. It has also been suggested, based on subgroups identified in the personality literature, that patients who were either coping or did not acknowledge emotional distress would be unlikely to accept psychological treatment, while those with substantial distress concerning symptoms might be more amenable to psychological therapies (Schmaling & Jones, 1996). Among people with CFS, the use of CBT programs remains a contentious and divisive issue.

**CFS Programs**

There are a few reports in the literature of specialist facilities or groups implementing CFS programs. Using mainly psychological interventions, these programs aim to provide rehabilitation for people with CFS by teaching strategies to minimise...
symptomatic effects and reduce potential perpetuating factors. These programs have included inpatient treatment to address activity avoidance, exercise intolerance, sleep disorders, psychological disorders and inappropriate beliefs (Cox & Findley, 1998). Similar programs that run on an outpatient basis have also been reported (Pemberton, Hatcher, Stanley, & House, 1994). More specifically, a buddy/mentor program that aimed to reduce stress by providing social support has been described (Shlaes & Jason, 1996). Rehabilitation programs are rare and few people with CFS have the opportunity to participate in supervised and/or structured rehabilitation.

Complementary Approaches
Among chronic, incurable or contested illnesses, where conventional medicine has limited or uncertain success, it is common for patients to seek out complementary (or alternative) therapies (for example, Lipson, 2001; Richardson & Ream, 1997). Patients with CFS have reported using a large number of complementary therapies (Johnson et al., 1999). These have included acupuncture, homeopathy, naturopathy, anti-candidal and anti-yeast treatments, exclusion diets, extraction of dental fillings, herbal remedies, and vitamins, minerals and coenzymes. Alternative methods to detect underlying pathophysiology have included allergy and chemical sensitivity tests, hair analysis, and urine analysis. Evidence to support effectiveness of complementary treatments has mainly been anecdotal and testimonial (Kantrowitz, Farrar, & Locke, 1995). Friedberg and Jason (2001) described CFS patient ratings of helpful complementary treatments. Anti-allergy and anti-yeast diets, biofeedback and stress management were rated among the most helpful, however, the efficacy of complementary treatments has not been proven (Whiting et al., 2001) and there are very few randomised clinical trials.

Holistic Management
The physical and psychological sequela of CFS has led some practitioners to view the syndrome as best accommodated by the integrative, biopsychosocial model that promotes holistic management (Lapp & Hyman, 1997; Wilson et al., 1994). It is argued that a broad model is needed to provide appropriate clinical care, including symptomatic treatment, education on lifestyle management, and support with the secondary effects of chronic illness such as interpersonal conflict and financial
disruption. Empathy and acceptance of symptoms have also been noted as important to the therapeutic relationship. Indeed, it has been suggested that factors such as these may partly account for the placebo response seen in a number of CFS treatment studies (Lloyd, Hickie, & Loblay, 2000; Wilson et al., 1994).

There are reports of integrated and collaborative approaches to CFS. These approaches, such as multi-convergent therapy, treat each patient with individually determined, multiple and simultaneous interventions. The wishes of the patients and the symptoms, rather than laboratory values, provide a basis for choice of treatments. Although the research is limited, significant improvements have been reported by CFS patients using multi-convergent therapy (Sadlier, Evans, Phillips, & Broad, 2000; Teitelbaum et al., 2001).

In practice, the extent to which an individual with CFS has the opportunity to utilise most of these strategies is unknown. There is nothing in the research that indicates, for example, whether CBT or graduated exercise programs are components of standard management. Similarly, CFS programs or multi-convergent therapies are exceptions rather than standard care. The research does not adequately tell us how people with CFS are clinically managed in vivo.

In reviewing the research literature, Chapters 2 and 3 have exposed the uncertainty that surrounds CFS. The following section examines the tensions that arise from its status as a contested illness, and the ways in which being a contested illness affects understandings of CFS.

**The Controversy and Conflict of CFS**

As a contested illness CFS is associated with polarised opinions, mutually exclusive viewpoints, a conflicting and incomplete knowledge base, and often, vested interests. The issues of CFS are structured around points of disagreement such as real versus unreal, medical versus psychiatric, practitioner versus patient, exercise versus rest, and mind versus body. CFS is commonly interpreted from these dichotomous positions, which reduces a complex, interactive condition into simplistic and isolated components. The controversies and conflicts of CFS are widespread and entrenched,
and reflect the outward expression or manifestation of a contested illness. To illustrate the discord associated with CFS, a review of issues related to nomenclature and discourses is provided.

There has been vigorous debate between people affected with CFS, researchers and clinicians regarding the name. The label “Chronic Fatigue Syndrome” is criticised for reducing the condition to a state of being overly tired. Affected individuals and advocacy groups argue that this nomenclature trivialises the suffering and symptoms and contributes to negative attributions (Fitzpatrick, 2002; Stein, 2001). In reaffirming the nomenclature in 1994, the CDC acknowledged that the impairments associated with CFS were not trivial. Nevertheless, it concluded that changing the name without scientific justification would lead to confusion and impede clinical, research and public understanding (Fukuda et al., 1994). The introduction of “CFIDS” (chronic fatigue immune dysfunction syndrome) in the USA appears to have been a response of affected individuals and self-help groups (rather than a medically driven label) aimed at enhancing credibility and distancing the syndrome from psychiatric explanations (Leitch 1995). It has been argued that the term “CFS” provides an operational definition that is constructive for research, whereas “ME” and “CFIDS” represent belief systems (Wessely, 1997).

While the research indicates that many people with CFS want a name change, substantially fewer medical practitioners and researchers are in favour of change. (Jason, Eisele, & Taylor, 2001). The name by which something is known does reflect meaning and social construction. Research has reported that the label “myalgic encephalomyelitis”, in comparison to the label of “chronic fatigue syndrome”, prompted unfounded attributions that the condition was a serious illness with a physiologically based aetiology and poorer prognosis (Jason & Taylor, 2001). These findings support the perceptions of people with CFS that firstly, the name of the syndrome is an important factor in the ways that other people respond to them and their condition, and secondly, that the label “CFS” is associated with a minimisation of the symptom effects. In other words, the name given to their symptom complex has consequences to the everyday lives of people with CFS, quite separate and in addition to the associated illness burden.
There appears to be no immediate resolution to the controversy regarding the name of the syndrome. Internationally, advocacy groups, some medical practitioners, and other interested parties continue to call for a change, but there is little consensus regarding a replacement among the different stakeholders with their often disparate opinions (Jason, Eisele et al., 2001). For researchers the name “CFS” reflects an operational definition that is descriptive and aetiologically neutral. It is these qualities that people with CFS object to most. Wessely (1998), a medical practitioner and researcher working in Britain, has found a workable solution: he uses the terms “ME” with patients and “CFS” for research.

The discourses of CFS are a powerful insight into the controversy, conflict and sometimes the vitriol associated with the condition. Vigorous correspondence is published in medical journals between CFS advocacy groups and medical practitioners commenting on CFS research. Perhaps the most glaring feature is the linguistic discrepancy between the medical community and people with CFS. Within medical and research articles titles such as “Does myalgic encephalomyelitis exist”? (Grossman, 2001), “Sucker-punched again! Physicians meet the disease-of-the-month syndrome” (Shorter, 1995), and “Tough love works best in dealing with CFS, fibromyalgic patients” (“Tough love”, 1998) are found. Alternately, personal accounts of CFS include titles such as “The trouble with ME” (Colman, 1988), “Nobody believed ME” (Holt, 1989), and “It’s not in my head” (Stevenson, 1993).

Among the voices of those with CFS is a plea to be believed and to be granted credibility. There are also expressions of anger, frustration and betrayal. Letters to the editor from CFS groups or individuals affected with CFS include perceptions of abandonment and victimisation. For example, members of the Chronic Fatigue Syndrome Society of Illinois wrote to JAMA,

> . . . individuals who have CFS are actually victims of a medical establishment that has failed them (Gilbert, Kaan, Lipkin, & Lepp, 2000, p. 744).

There are also perceptions of being misrepresented. The director of Action for ME, a British advocacy group, wrote to the British Medical Journal,
What we have a problem with, however, is some medical journals’ overemphasis on psychological factors when they refer to myalgic encephalomyelitis. Provocative features about hysteria and wandering wombs have not helped (Jacobs, 1997, p. 949).

There is defensiveness in the discourses of those with CFS and their advocacy groups.

The apparently objective, neutral and dispassionate voice of medicine sometimes fails in discussions of CFS. Like those affected with CFS, medical practitioners and researchers also display strong convictions. Scattered among the medical and allied literature are responses that are not often afforded to other chronic illnesses. Bohr (1999), a medical practitioner, considers CFS to be a somatoform disorder. He wrote to the editor of a research journal:

Anecdotally, patients with “CFS” idealize their motivation and efforts, fitting themselves with halos . . . I have found that persons with this and similar diagnoses (such as fibromyalgia) can be highly energetic, particularly when it comes to litigation, compensation and disability (Bohr, 1999, p. 256).

Showalter, a professor of English, in her book entitled “Hystories. Hysterical Epidemics and Modern Culture”, also criticised people with CFS as being self-serving. Her book examines a number of recently identified maladies, including alien abduction, Gulf War syndrome, multiple personality syndrome and CFS. In a chapter on CFS she writes,

ME is no more life-threatening or lethal than CFS. The acronym ME also ironically emphasizes the patient’s self-absorption (Showalter, 1997, p. 124).

Shorter, in an editorial for a psychiatric journal, commented on the role of the media and patient advocacy groups in perpetuating the belief of an organic basis for psychosomatic illnesses. He wrote of CFS,

Feeling perpetually weary and unable to concentrate? You’ve got ME, or Chronic Fatigue Syndrome, the result of a mystery virus that seems to affect mainly middle-class females . . . a pseudo-disease that does not exist (Shorter, 1995, p. 115).

The author is sweeping in his disdain, including those affected with CFS, those who write (sympathetically) about it, and those medical practitioners who diagnose it.
There is a strong element in the discourses of CFS that is confrontational and divisive, and debate can become personal. In responding to Showalter’s book, a leading British medical practitioner and advocate for people with CFS was quoted as saying, “I feel angry with prats like her” (McMahon, 1997, p. 21). Like other contested and stigmatised conditions, CFS arouses strong opinions.

People with CFS experience the condition within a climate of controversy and conflict. As a contested illness, all aspects of CFS are debated and there are competing discourses of understanding and explanation that represent the various interest groups. The illness burden is magnified as a result.

**Chapter Summary**

This chapter reviewed the research that attempts to explain, understand or theorise CFS. While there is a substantial body of work arising from the biomedical, psychological, sociological and anthropological disciplines, the causes and underlying processes of CFS remain elusive. The research addressing the central nervous system and neuroendocrine-immunologic network appear to be the most promising at this point in time. Management of CFS is constrained by its unknown aetiology, and the research indicates that symptom relief, alteration of potentially perpetuating factors and improved functional capabilities are the main foci. Lastly, the discourses of CFS were addressed. It is through discourse that understandings and perceptions of CFS are communicated, consolidated, challenged, accepted or rejected. Chapter 4 describes the qualitative approach, method and methodology used to address the aims and research questions.
Chapter 4

The Research Method and Process

In this chapter epistemological premises and methodological foundations underlying the present study are made explicit. A description of the study, including its methodological evolution, is provided. Ethical considerations and issues related to participants, instruments, procedure, data collection and analysis are addressed. This chapter also highlights the design characteristics that needed to be considered when collecting narrative data from people with an unpredictable and debilitating illness.

Epistemological and Methodological Foundations

Constructivism

The theoretical approach underlying this study is one of constructivism. It was chosen because the constructivist paradigm is based on the assumption that people are active agents who construct their social worlds, and that these multiple, intangible, changeable constructions become their reality. It is a paradigm of ontological relativism. That is, multiple realities exist that are socially and experientially based and relative to culture, history and place. While constructions may be held as a consensus, there are also conflicting social realities (Guba & Lincoln, 1994; Holloway, 1997). This approach accommodated the varying experiences and realities that typify illness experience.

Knowledge and truth are not viewed as objective and absolute but as matters of consensus regarding constructions considered to be the best informed and most sophisticated. Epistemologically it is a subjectivist perspective of multiple knowledges, where the knower and the known operate to create understandings (Guba & Lincoln, 1994; Schwandt, 1994). The constructivist approach is interested in the emic viewpoint, and focuses on meanings and the world of lived reality constructed by individuals. Schwandt (1994) argues that interpretation is required in order to understand meaning, while Guba and Lincoln (1994) outline the appropriate method for constructivists as requiring interactions between researchers and
participants in order to elicit constructions. Constructivists do not assume constructs or “truth” (such as man, woman, or self) to be self-evident. Consequently, the constructivist position regarding knowledge as derived from multiple constructions and “complicated discursive practices” (Schwandt, 1994, p. 125) informs the present study and provides the theoretical stance. This approach seemed ideally suited to a work where the individuals’ experiences of a contested illness were the focus of inquiry.

**Qualitative Inquiry**

The methodological approach needed to be compatible with the epistemological assumptions of constructivism, able to address the exploratory nature of the research questions, and make visible the everyday, subjective experience of people with, or recovering from, CFS. Subjective and contextual experiences are essentially interpretative, as individuals attempt to seek or ascribe meaning to their lived experiences and disrupted lives. Therefore, the nature of the research questions leads to the use of the qualitative/interpretative paradigm as the methodological approach best suited to this.

**Evolution of the Method**

The general theoretical territory covered in this study is that of illness experience, specifically the subjective world of CFS. Although the subjective world is important to all ill people, it holds a particular salience for those with CFS because the contested nature of the condition locates affected people within a framework that is predominantly subjective, and it places them in circumstances where their subjectivity itself is called into question. That is, they are confronted with situations where they are ignored and their symptoms treated with scepticism. The illness itself is frequently viewed as subjective, lacking an objective diagnostic basis, without discernible pathogenesis, and fraught with definitional difficulties. It represents the antithesis of the objective, a perspective valued by the (mostly) positivist worlds of medicine and science. In other words, there is no “proof” that it is anything other than a subjective experience, and there are likely to be associated consequences for the lived world of people with CFS that I was interested in investigating.
Specifically, the study facilitated an exploration of the subjective illness experience of CFS by focusing on self.

To address the research questions, a method was required that took account of the complexities associated with illness experience and individual differences, and that captured meanings, contexts, and realities related to experiences of self for people with CFS. Given the lack of previous research, the study was essentially exploratory and best served by an approach that did not impose any predetermined theoretical model.

Rather than imposing a researcher-determined agenda, there may be epistemological strength in undeveloped lines of research directly accessing the source to determine constructs and priorities. Qualitative method allowed for exploration with the participants rather than examination of the participants. The predominance of the positivist focus within CFS research and the quantification of findings have not included the voices of those affected. By focusing directly on the participants’ accounts of their experiences it was intended to create “a space for absent subjects” (Frank, 2000, p. 363), to give voice, foster inclusion, and to learn from those with CFS. Therefore, because most of the research regarding CFS has been quantitative in approach, a design that utilised qualitative method was chosen because it could offer something new to our understanding of CFS. This approach was also likely to highlight lines of inquiry for future studies.

It was my initial intention to conduct a grounded theory study because of its potential to fulfil the methodological requirements of the research aims. That is, it is reported to be useful in the investigation of relatively uncharted phenomena where salient variables have not been identified, provides a method for the construction of theory where no theory exists, and does so without the imposition of theoretical expectations (Goulding, 1998; Holloway, 1997). Grounded theory is concerned with processes rather than with static conditions. Therefore, grounded theory appeared suited to identifying, describing and explaining the experiences of illness and self for people with CFS, and in explicating the relationships and processes involved. Additionally, it has been suggested that investigating experience requires an analysis
of associated conditions in order to reflect how that experience came to be (Olesen, 1994). Grounded theory has the ability to discover conditions associated with experience.

Grounded Theory is typified by simultaneous data generation and analysis, and uses intensive processes that include constant comparison, levels of coding, memoing, and theoretical sampling (Strauss & Corbin, 1998). Constant comparison involves each part of the data being compared with every other part for similarities and differences. Theory is discovered through a systematic process of coding that allows theory to emerge from the ground up. Substantive theory emerges from investigation from within a particular context (as was the case in the present study) and is useful for clinical application.

As the study progressed, I found that I was moving away from an orthodox grounded theory study, while retaining a grounded theory approach. The method of the study was developing in response to the participants and to our interactions. This evolution of method is not uncommon in qualitative inquiry as understanding of the issues under investigation grows. The researcher-as-bricoleur, for example, found within the qualitative paradigm uses, modifies and invents methodological tools as required (Denzin & Lincoln, 1994). Similarly, it is argued that robust research can originate from more than “one variety, ‘paradigm’, ‘moment’ or school within qualitative research” (Seale, 1999, p. 8). The literature also contains warnings of methodolatry, an over-involvement with method and a privileging of methodological concerns that excludes other considerations, such as the freedom of researchers to develop new methods appropriate to their studies or the explication of the assumptions underlying research (Chamberlain, 2000; Janesick, 1994). Therefore, the methodological transitions in the study were a reflection of the flexibility of qualitative inquiry to the emerging needs of the field. Ultimately, there is no one brand of method that encapsulates the study. There were two issues important to the evolution of the method.

First was my observation that the questions in the interview guide were, to varying degrees, redundant. Participants answered my questions but used the interviews as
an opportunity to tell their stories, give voice to their suffering, and attach meaning to their own illness experiences. It appeared that participants had important aspects of the CFS experience that they wished to communicate, sometimes regardless of the question asked. This determination of interviewees to tell their stories has been described by others (for example Collins, 1998). My response was to follow the lead of the participants, following up those areas where they placed emphasis, in addition to continuing to explore issues that were emerging consistently as the interviews progressed.

I began to conceptualise the research as less a grounded theory study and more an illness narrative study. Clark and Mishler (1992, p. 368) describe a patient’s story as “a specific narrative reconstruction of illness constituted within a specific social interaction at a particular time and place”. Narratives are characterised as stories that include a temporal ordering of events, attempt to make sense of those events, and that present the experiences of the person in a personally and culturally coherent context (Garro, 1994; Sandelowski, 1991). They involve plot, emplotment, temporality and retrospection (Good, Munakata, Kobayashi, Mattingly, & Good, 1994). Clearly, I was hearing stories. Participants saw themselves as the possessor of many stories that melded together to form their primary (or life) story. For example, participants used phrases such as *but that’s another story*, *let me tell you a story*, or *so that’s the story of . . .* when describing their experiences. They were aware of what they wanted to say and reworked the questions in order to do so. There were plots, subplots and thematic connections. Their answers involved the temporal dimensions of past, present and future and there were end points, although not an ending. What I was hearing was typical of the narrative.

The nature of what I was hearing strengthened my desire to tap into the subjective world of the participants and to do so I utilised methods not generally emphasised in grounded theory. For example, given my premise that data are co-constructed and intersubjective, the interpretation of narratives and exploration of subjectivity required reflexivity. Although there are exceptions (for example, Hall & Callery, 2001) few grounded theorists have argued for the use of reflexivity. Additionally, subjective understanding and dialogic texts became important criteria for ensuring
the quality of the study, as well as the more traditional grounded theory criteria of validity, reliability and credibility (Strauss & Corbin, 1998).

The second issue was related to the tension within grounded theory of its appropriate paradigm location. There is generally agreement that traditional, classic grounded theory is situated within a postpositivist, realist paradigm (Guba & Lincoln, 1994). Alternately, there is a position that argues that grounded theory is consistent with a constructivist world-view (for example, Annells, 1996; Wuest, 2000). Certainly Strauss and Corbin (1998) deliver mixed messages on such issues as objectivity and the nature of reality. As my reading progressed I became more convinced that grounded theory was located within a postpositivist field. This did not fit comfortably with my epistemological framework or with the needs I saw emerging from the study. For example, the grounded theory premise of the naïve researcher entering the field (and again, there are contradictions regarding this premise to be found within the work of Strauss and Corbin) was problematic. I was not a naïve observer but actively used my knowledge and experiences of CFS in both the design and implementation of the study. Indeed, it appeared to me that there was an imperative to do so, given that I was investigating sensitive and painful issues among a clinical population of vulnerable participants. Based on these ethical considerations it was not possible for me to maintain a position – as a grounded theorist – that ignored existing premises or assumptions about what I was studying.

Moving away from an orthodox grounded theory study and into the realms of illness narrative gave me, as the researcher, a stronger sense of the participants’ voices, and I felt better able to reflect and write about their experiences more authentically.

The Interview as Method
The study utilised the in-depth focused interview (also known as semi-structured), a type of unstructured format of content that uses a list of areas or questions to provide direction and generate discussion. The qualitative paradigm understands interviews to be mutually constructed social events in which both the interviewees and interviewer contribute to and determine interactions and in which their relationship is
perceived as fluid and dynamic. The individual participant’s story emerges from this construction (Collins, 1998).

The interview is a type of communication familiar to most people. Silverman (2000) has argued that interviews assume a central societal role in making sense of people’s lives, and that the popularity of interviews by qualitative social scientists may reflect a link between culture and method. Silverman also introduced a note of caution, in that the popularity of the interview is not sufficient to justify its use. Rather, justification depends on its appropriateness to the purposes of the study and the “robustness and credibility” of the design (2000, p. 90). Therefore, the reasons for the choice of the interview as the method of investigation are examined in addition to addressing criticisms of the interview.

There are generic reasons for the use of interviews as method. Interviews provide flexibility, interactive depth and the potential for scope of inquiry. The data derived is generally rich and complex, and in the case of face-to-face interviews also provides data in the form of observations (LoBiondo-Wood & Haber, 1994; Polit & Hungler, 1999). They are useful to the exploration of new areas (Rice & Ezzy, 1994). More specifically, the in-depth interview was the most appropriate method to address the aims of the study that required a method capable of accessing the phenomena of illness and self. The suitability of the interview was therefore related to a number of factors.

First, the interview process is conducive to explicating the meaning of experience. Clandinin and Connelly (1994) proposed that experiences are the stories people live, that experience is shared in storied form, and as a consequence, stories (as found in interviews) are the closest we can get to experience. Further, the interview allowed experience to be investigated from multiple directions – internally (feelings, hopes, dispositions), externally (environment), and backward and forward (temporality of past, present and future).

Secondly, through dialogue the interview is a venue for the exposure and expression of self. Mead (1934) understood the self to arise from social experience and to be
essentially dialogic. The interviewee may engage in multiple dialogues with not only the interviewer but also with self and absent others (Collins, 1998) while using a past, present and future timeframe, thus providing deeper access to experience and meaning. Further to this notion of the interview as being comprised of multiple dialogues, Collins (1998) suggested that in conversation (interview) it might not be meanings that are primarily shared but multiple selves and identity, where social interactions are characterised by a constant re-negotiation of selves. It is these qualities of self-as-dialogue, multiple dialogues, and sharing of selves and identity that gives the interview a special salience in addressing the subjective meanings, the underlying social processes and the experiences of self associated with CFS. Given the centrality and presence of self (selves) in the interview and through disclosure and dialogue, the effects of CFS on experiences of self are directly and indirectly expressed and exposed, and given meaning through the shared interaction of the interview.

Thirdly, interviews provide a method for hearing and including the voices and stories of people with CFS that to a large extent have been absent from the predominantly quantitative research. From this logicopositivist perspective of the quantitative, scientists are concerned with the “other”, that is, the person as the object of investigation. The “other”, however, lacks a human dimension, is removed from the end product of investigation, and is essentially a mute presence. Within the qualitative method, perceptions regarding “other” have undergone change. The “other” is no longer a distant, aseptic, quantified, sterilized, measured, categorized, and cataloged faceless respondent, but has become a human being, usually a forgotten or oppressed one (Fontana & Frey, 1994, p. 373). The interview has the potential to restore and include the humanity of the “other”. It is essentially a conversation between two people that involves asking questions and listening (Denzin & Lincoln, 1994) and therefore, in quite a literal sense, gives voice to that which has been predominantly silent. Using dialogue as the source of the data enhances the completeness of the knowledge and the understanding of the complexity of human existence by incorporating the “other”.
Criticisms of interviews as method have included its use of retrospective accounts (Polit & Hungler, 1999), which are considered problematic because of the distortion of reality that is presumed to occur with re-telling and the consequent uncertainty regarding the accuracy of the data. This criticism generally assumes there is a single and definitive meaning to an experience that occurs at a point in time, that when later recalled is distorted through the process of social desirability or flaws of memory. However, people are likely to have multiple meanings attached to an experience (that may or may not be expressed) and they change as new experiences cause re-interpretation of lived events. Multiple meanings and their recollections do not indicate a distortion of the experience of “reality”, but rather, represent the complex and contextual “reality” of experience. Additionally, “reality” is experienced by the self, which by definition is situated across past, present and future. The present-self is affected by the past-self and by expectations regarding future-self. That is, the self does not exist in an isolated here-and-now but across temporal dimensions. Therefore, the retrospective account is not necessarily an inferior or distorted account. Indeed, given the constant passing of the present it is difficult to envisage what would not constitute a retrospective account, and perhaps what is really being contested are the degrees of retrospection considered to be methodologically acceptable. Further, Morse (2000) argued that it is frequently impossible to collect data of illness experiences at onset or when the illness is severe, consequently necessitating retrospective accounts. Morse concluded that the ability of the interview to trigger memories and recollections is sufficient to produce trustworthy data.

It has been suggested that the interview is one of the weakest methodologies because of the gap between what people say and what people do (Silverman, 2000). However, the saliency of this criticism is not relevant or applicable to the interview per se, but to the appropriateness of the interview as an effective method to address the research aims of a particular study. The present study was concerned with experiences, perceptions, feelings and beliefs related to CFS and self. These are essentially cognitive and emotional dimensions of interpretation, and are not necessarily, consistently, directly or primarily expressed through action, particularly in a context where fatigue had limited physical expression. Further, the same action
can result from numerous and different perceptions and beliefs. Given that self-constructs are essentially beliefs, words rather than behaviour were more likely to provide insight into how the participants were experiencing the self. For example, when participants reported social rejection, the focus of the study was not to record the presence or frequency of rejection but on the effects of the perceived rejection on perceptions and experiences of self. It was, however, also important to assemble a sound data set of the participants in relation to their status as a clinical population, and the interview, with its ability to seek clarification, was also suitable for such data collection.

**Description of the Research Instruments**

There were two instruments developed for data generation, the Participant Background Questionnaire (the PBQ) and the Interview Guide (see Appendices 1a and 2a). For those participants affected with CFS the PBQ consisted of 14 questions that required ticking a box or writing a brief response. The PBQ collected demographic and baseline information, including the length of time affected with CFS, year of diagnosis, other medical conditions, health practitioners consulted, membership of a CFS support group, employment status, income source, educational level, relationship status, living arrangements and social contacts. The Interview Guide for those affected with CFS consisted of 24 open-ended questions that aimed to gather data regarding experiences of illness, self and CFS. Based on prior knowledge of the literature, six general areas incorporating constructs that appeared important to experiences of illness or self were addressed. These were functional status and embodiment; roles and coping; interactions with others; relationships; beliefs and expectations; and perceptions of stability and balance.

Functional status and embodiment explored bodily experiences, perceptions of control and quality of life. Roles and coping addressed self-care and previous and present role discrepancies. Interactions with others examined social interactions and encounters with health practitioners. Relationships addressed occupational, support and intimate networks. Beliefs and expectations examined expectations and perceptions of past, present and future. Perceptions of stability and balance addressed stability of self and perceptions of losses. The interview questions 1
through to 4 were conceptualised and ordered to facilitate an easy transition into the interviewing environment. From number 4 on, the questions were presented in an order most appropriate to, and largely determined by, each participant. The phrasing of the questions was also modified for individual participants.

The recovered participants received slightly modified versions of the PBQ (the PBQ-R) and Interview Guide (see Appendices 1b and 2b). The PBQ-R questions were related to the participants’ current situation and previous situation when affected with CFS. One additional question addressed year of recovery. The Interview Guide used the same questions (expressed in past tense) as those presented to the CFS-affected participants, and included an additional question related to influences on their improved health. In addition all participants received a Consent Form and Participant Information Sheet that were written in accordance with required ethical guidelines (see Appendices 3 and 4).

The Development of the Interview

The interview was developed primarily from pre-existing knowledge. In addition, potential avenues for investigation were discussed with colleagues at conferences, including people affected by CFS and CFS researchers, at seminars and with work colleagues. During recruitment I discussed the areas for exploration and participants concurred that important aspects of their experiences would be addressed.

In order to explore and understand the meanings of the participants, there is a school of thought that considers it preferable to use a topic or theme list rather than prescribed questions (for example, Rice & Ezzy, 1999). However, there were reasons to support the use of questions in the present study. I was concerned that the broad scope of “self” as a construct and experience, in conjunction with neurocognitive disturbances, might be associated with superficial or general responses. Questions provided starting points and were intended to lessen cognitive demands by providing a framework for the thoughts of the participants, rather than a general topic list that might be overwhelming in its possibilities.
Nevertheless, throughout data generation and consistent with a grounded theory approach, the development of the research “instrument”, that is the interview, was ongoing (Strauss & Corbin, 1998). The Interview Guide remained a primary source of questions, however, as the interviews progressed the questions asked were directed by the narratives, the emerging themes, and the ongoing analysis. Consequently, the questions in each interview varied. The questions from the Guide were at times collapsed and sometimes omitted, while other questions became more specific, and new questions that had been revealed through data analysis were added.

The Characteristics of the Interviews

The total number of interview hours was 31 hours and 15 minutes, ranging from 50 minutes to 4 hours, and with a mean time of 1 hour and 37 minutes per interview. The interview, however, did not represent the total time of the session, as varying periods (ranging from 45 minutes to 1 hour and 45 minutes) were spent with each participant before and after the interview. Following the interviews, 4 participants called me to further discuss their experiences, for a total of 4 hours and 25 minutes. Given that fatigue and pain are cardinal symptoms of CFS, the length of the interviews surprised me and participants made a substantial investment of time and energy.

The interviews generated 168,582 words of transcriptions. Each transcribed interview averaged 8,873 words, with a range of 3,384 to 14,264 words per interview. However, the word count did not necessarily reflect the length of the interview. For example, of the 5 interviews that were 1 hour and 30 minutes in length, the word count varied between 8,174 words and 14,264 words. Similarly, the longest interview of 4 hours generated 11,200 words of transcription, while an interview of 2 hours generated 14,024 words. In other words, the amount of content in the interview (in so far as this can be measured or reflected in words) was not related to the length of the interview. From a practical point of view, this made it difficult to estimate the time needed for the transcription and analysis of individual interviews and there was marked variation in the time required. It also calls into question the practice of including within published reports the number of hours from
which data is derived without including a word count and ranges. This would provide a more complete picture of the data gathering process.

**Methodologically Locating Myself**

Explicating the location of the researcher’s self is crucial to rigour and accountability. Davies and Dodd (2002) conceptualise rigour as “attentiveness to research practice” (p. 288) that requires procedural visibility and analytic reliability. Therefore, in order to provide transparency of process and facilitate an evaluation of the interpretation, I examined my assumptions and their influence on the research process. In other words, I have methodologically located myself. (Other methods used for providing rigour are not addressed separately but incorporated and described throughout the chapter.) Two primary methods were used, theoretical sensitivity and reflexivity, with each assuming a different focus. While theoretical sensitivity introduces self into the research, reflexivity operates to evaluate the appropriateness and influences of self once located in the research.

**Theoretical Sensitivity**

The interpretive approach of qualitative inquiry requires the researcher to be sensitive to the subtleties and issues in the data. Grounded theory refers to this practice of enhancing insight as theoretical sensitivity. As a strategy, theoretical sensitivity operates to locate the researcher within the field of study. The theoretical sensitivity of the present study was derived from a number of sources, including the professional and disciplinary literature, literary accounts of people living with CFS, publications by CFS groups, conversations with people with CFS, conference proceedings, media reports, and personal experiences.

While Strauss and Corbin (1998) stated that disciplinary knowledge could enhance theoretical sensitivity, they also emphasised that grounded theory does not require a prior research review because the salient problems are unknown and the theory yet to emerge. They argued that the researcher does not want to be constrained by the body of pre-existing research. The view that a researcher is able to enter an investigation without knowledge of the field (or that it is methodologically desirable) has been challenged. Morse (1994) argued that a lack of knowledge was likely to restrict
theoretical vision, while Charmaz (1995) proposed that grounded theory researchers use pre-existing knowledge as points of departure.

I commenced the research with significant pre-existing knowledge related to CFS, psychosocial aspects of nursing, and health psychology, and it was (and has remained) my perception that this knowledge base was of benefit to developing theoretical sensitivity. Prior to commencing the study I had routinely kept abreast of the CFS literature, so in effect a review had been conducted over a number of years. The knowledge derived from the research strengthened the theoretical sensitivity particularly in the early planning stages of identifying and conceptualising the area for investigation, demonstrating the value of the study, and deciding on the design. It was not my judgement that the analysis was constrained in any way by this prior knowledge, but rather was deepened by the “points of departure” described by Charmaz (1995, p. 32). Nor did I perceive the research literature to be the most important source of theoretical sensitivity. Ultimately, all sources facilitated understanding through all stages of the study. Theoretical sensitivity, for example, contributed to identifying potential problems in recruitment, to choices regarding theoretical sampling, to the development of the instruments, and to the conduct of the interview sessions. Throughout the analysis the sources of theoretical sensitivity continued to inform and were augmented by method.

Reflexivity
There were a number of reasons for the use of reflexivity. The present study adopted the perspective that the researcher’s self is an inherent component of research, that involvement with the field is potentially positive, and that the subjectivity(ies) of the researcher need to be articulated in order to expose factors that are possibly influencing the research. Chesney (2001) maintained that to ignore the “me” in research is deceitful because it ignores the “fundamental shaper of events” (2001, p. 128). It is because the researchers’ subjective worlds are influential to their involvement that it is important that the position of the researcher with respect to the study be articulated (McWilliam, 2000). The researcher-as-research instrument, the co-constructed nature of the data, and contextual influences require researchers to
critically examine and reflect upon their assumptions, agendas, and location in culture, time and place (Davies & Dodd, 2002).

Reflexivity is an important method for examining the influences of subjectivity and intersubjectivity on the research process and findings. It locates the researcher and provides a context for evaluating the trustworthiness of the interpretation and the validity of the data (Sword, 1999) by making it possible for the reader to inspect the “researcher’s analytic lens” (Chesney, 2001, p. 130). Reflexivity has been defined as “thoughtful, conscious self-awareness” (Finlay, 2002, p. 532), requires that researchers acknowledge their stance (Daly, 1997), and is essential to recognising how knowledge is constructed (Finlay, 2002). Reflexive skills include self-questioning of assumptions, the recognition of beliefs and the ability to account for personal positions within the research context (Holloway, 1997). To varying degrees, reflexivity often requires the researcher to disclose information of a personal nature in addition to epistemological and positional influences, in order to provide transparency and scrutiny of the research process and facilitate evaluation of findings (McWilliam, 2000; Punch, 1994; Sword, 1999). Finlay (2002) has argued the importance of striking a balance between reflexivity and “navel gazing” (p. 541) and proposes that the exploitation of self occurs only while purposeful.

Reflexivity was important to all stages of the present study. While I viewed my history with CFS as a resource, it was also potentially problematic if my subjective world blinded me to the experiences of the participants or created expectations that were based in my past rather than on the data. Throughout the thesis (particularly in the present chapter) I have endeavoured to declare my position within the research. However, it was also crucial that reflexivity did not become an exercise in self-absorption and a never-ending process. Therefore, attention was given to maintaining a dual perspective of reflexivity with a focus on the participants.

**Ethical Considerations**

The CFS population is a vulnerable group. There are a number of reasons for this vulnerability, including chronicity, symptoms, sociocultural and biomedical beliefs and responses, marginalisation, and the effects of living with a contested illness. In
addition, vulnerability is associated with the research experience. Theoretical sensitivity alerted me to beliefs among people with CFS of negative consequences arising from research. Firstly, there is a perception that the CFS research has frequently been used to the detriment of those affected, specifically to exclude people from care or to allocate blame. Secondly, there is a belief that people with CFS are viewed as subjects to study and explain rather than as individuals with knowledge to contribute. Thirdly, some research (primarily psychiatric) is considered to be unnecessary, irrelevant, and damaging. Fourthly, there is a perception that results are explained or interpreted in a way that does not represent the reality of CFS and that is destructive to people with CFS. For example, while researchers explain the avoidance of activity as dysfunctional illness behaviour, people with CFS view it as a necessary response in preventing further deterioration. Participants, most of whom spontaneously shared with me their suspicions and anger regarding the use of CFS research, confirmed these four perceptions. The comments were unsolicited and appeared to be part of their decision-making regarding personal involvement in the study.

This multitude of factors outlined above provided the contextual background to the ethical implementation of the study. Punch (1994) has identified the issues of harm, consent, deception, privacy and confidentiality of data as the primary ethical concerns of research. In designing and conducting the study these concerns were kept to the fore, with particular attention paid to minimising research-related vulnerability. The study received ethical approval from the university ethics committee and the relevant area health service.

Confidentiality and privacy were maintained through the use of identifying codes on all documentation. Participant names and identifying codes were recorded once and stored in a locked cabinet in locked premises separate from the data. A number denoting the order of the interview was used to identify each participant. Generally qualitative research uses a pseudonym as an identifier, however, Punch (1994) introduces a note of caution,
The cloak of anonymity for characters may not work with insiders who can easily locate the individuals concerned or, what is even worse, claim they can recognise them, when in fact they are wrong (p. 92).

Some study participants knew other participants, although they did not necessarily know of that person’s involvement. Therefore, at least some of the participants were “insiders”. Following on from Punch’s point, I concluded that the use of a pseudonym might reinforce an erroneous identification of a person who may or may not have been a participant, and therefore considered it more prudent to use numbers. Potential identifying data were not included on the PBQ and were deleted from the transcriptions. Access to the transcripts was restricted to my supervisor and myself. Consent was reaffirmed throughout the study. For example in addition to the Consent Forms, verbal permission was sought to make notes of points relevant to the study that arose from telephone calls, letters or email.

Some participants believed that the interview operated in a journalistic sense, with the researcher reporting the content. Grounded Theory, however, is an interpretive method in which the researcher does the interpretation and therefore, it was important that participants understood the analytical process. Consequently, prior to the interviews I explained the fundamentals of analysis and interpretation and the way that results are presented. Nevertheless, from the participants’ perspective there was risk in disclosing to an unknown person and I could not guarantee to the participants that they would approve of the end result. Ultimately the interpretation would be my own. Further, in addition to checking data interpretation, there were ethical reasons for sending participants a summary of the findings. Participants had a right to know what had come from their involvement and to evaluate the provisional outcomes of the study. Additionally, during the period of analysis and prior to sending each a summary, a letter was sent that provided an update of the study’s progress to that point. I did not wish the participants to think the study had been abandoned, that their contribution had not been valued or that I had forgotten to send them the findings.

There was the potential that the research protocol might prove harmful to the participants’ well-being. I was mindful of their limited energy and intrusive
symptoms, and it was important that the requirements of the study did not contribute to any deterioration. Therefore, time considerations and limiting the amount of writing were factored into the development of the instruments. Additionally, the Interview Guide and PBQ were distributed prior to the interview session. This allowed time for participants to review what was required and, of particular importance, minimised the symptomatic effects by facilitating opportunities for preparation. Given the speed and degree with which symptoms might worsen and their possible duration, it was important that participants had the opportunity to control the pace of the interview. They were offered the possibility of conducting the interview over a number of sessions, and reminded that the interview could be stopped at any time for a rest, postponement, or to withdraw. Other strategies to minimise potential harmful effects included the participants’ choices of location and times of interview. Additionally, to accommodate the unpredictability of symptoms I offered to call the day of the interview to check whether the time was still appropriate and informed participants that they could reschedule at any time, including the day of the interview. Given the coexistence of allergies with CFS, I did not wear perfume or use scented soap, deodorant or shampoo on the days when I was interviewing.

The interview had the potential to mobilise distressing emotions among the participants, and I was able to provide emotional support during the interview if required. Additionally, the possibility of a follow-up telephone call to discuss any issues or emotions that might have arisen after the interview was suggested to participants. I also checked that participants had the telephone numbers of a CFS support group.

I had concluded that it was not necessary for participants to be aware of my CFS history, however, I did not wish to engage in deception. Therefore, if a participant asked how I became interested in studying CFS, if I had some experience with CFS, or as was the case with one participant, did I have CFS, then I responded truthfully and answered any further questions that might arise. I did not routinely volunteer that information. This differential response was not problematic to the data generation because I was not trying to create identical interview situations but rather,
to foster an atmosphere where each participant felt in control and contributed to the
direction of the dialogue. The primary reason for this general position of non-
disclosure was the problem of assumed understanding which could possibly result in
less dense and prematurely foreclosed discussion.

As Clark and Mishler (1992) state, understanding a story requires knowledge, and
storytellers must either provide the knowledge or assume recipient knowledge. By
definition, tacit knowledge is rarely articulated between group members because a
shared and common understanding is assumed. Participant 9 alluded to this premise
of a shared understanding, and although not stated, there is an implication that
communication is different when involving others with CFS.

Unless someone’s had it, they don’t understand. That’s why I was enjoying
the doctor I was seeing because she had it, so if I described something to her
I knew she knew exactly how I felt.

Participants who knew I had CFS were likely to perceive me as a CFS insider,
familiar with the culture and possessing a level of taken-for-granted knowledge.
Consequently there was the potential for disclosure of my experiences to limit the
responses of the participants. There was some justification for this concern of
explanations becoming limited or abbreviated following disclosure. Among the
participants who were aware of my diagnosis, there were times when the sentiment
of, you know what I mean, I don’t need to explain it to you, was expressed. In those
instances I was able to seek clarification but no doubt there were also instances that
were not announced and where my understanding was simply assumed. It was
important that assumptions of knowledge were minimised because they were likely
to be associated with the generation of incomplete data. Nevertheless, I also
considered the decision to disclose or not disclose to be fluid and provisional, and
was prepared to share my experience, regardless of whether I was asked, if I
considered it to be of help to a participant.

**The Recruitment of the Participants**

A number of decisions were necessary in the recruitment of the participants: first, the
inclusion criteria, secondly, the sampling strategies, thirdly, accessing participants
and lastly, the sample size.
Criteria for Participation

Three criteria were necessary for inclusion in the study: a present or previous diagnosis of CFS by a medical practitioner, the ability to speak and read English, and an age of 18 years and over. Participants identified themselves for the study and thus self-reported their diagnosis of CFS. The Chronic Fatigue Syndrome Clinical Practice Guidelines (Loblay et al., 2002), recently produced by the Royal Australasian College of Physicians for medical practitioners, uses the revised CDC case definition for diagnosis (Fukuda et al., 1994). However, the participants were diagnosed prior to publication of the guidelines and the use of different diagnostic definitions may have been problematic to the selection criteria. In other words, although the participants reported a medical diagnosis of CFS, there was no way of knowing which criterion (if any) their medical practitioners had used in reaching that diagnosis.

To assess diagnostic homogeneity among participants that may have been compromised by varying criteria, I evaluated each participant's diagnosis post-hoc using the revised CDC case definition (Fukuda et al., 1994). The revised CDC case definition (described in Chapter 2) was used because of the CDC’s stated intention to provide a more comprehensive and systematic approach to CFS research through the use of a standard reference. The appropriateness of this case definition to the present study was reaffirmed by its later inclusion in the guidelines for the Australasian population. My evaluation of the diagnosis, according to the CDC definition, occurred after each interview and was based on information derived from the interview and the PBQ. The post-hoc evaluations were relatively straightforward given the detailed descriptions participants provided regarding their medical history. The study was limited to the experiences of adults because childhood and adolescent developmental tasks related to self (such as separation and individuation, and identity formation) suggested that these age groups might have specific and different concerns that would require separate investigation. The ability to speak and read English was necessary for data collection as interpretive resources were not available.
While the study was predominantly concerned with people currently affected with CFS, I was also interested in interviewing people who considered themselves recovered or significantly improved. Examining the full trajectory of the syndrome, which included both chronicity and the potential for significant improvement or recovery, provided a more complete picture. In the absence of any biological markers, there are no agreed definitions of recovery or improvement for CFS. Reyes et al. (1999) in a CDC study of the progression and self-defined recovery from CFS defined recovery as a negative response to the question; “Do you still consider yourself sick with a fatiguing illness”? and a positive response to “Have you felt better for the last 4 weeks or more”? (1999, p. 20). An alternative definition of recovery required that the person no longer met diagnostic criteria for CFS (Lovell, 1999).

In the present study there were no criteria for “recovered” or “significantly improved” and participants self-selected into the “affected with CFS” or “recovered/significantly improved” category. Definitions were not provided in order to reflect the participants' understanding. Additionally, because of the fluctuating nature of CFS and the previously reported difficulties of people with CFS in detecting a consistent improvement or decline (Woodward, 1993), a measure of time as a criterion for improvement or recovery was not used. During the initial telephone calls participants who had identified themselves as recovered or improved were asked: “Do you still consider yourself to be ill with CFS”? “In what year did you begin to consider yourself significantly improved or recovered”? and “Do you still have any symptoms of CFS”? Because I wanted to elicit whether the improvement or recovery was fluctuating or constant, participants were asked if they had experienced any relapse or worsening of symptoms during their period of recovery or significant improvement.

**Sampling Strategies**

The characteristics, conditions or variables associated with experiences of illness or self for people with CFS were not known prior to the study, and therefore, the sample requirements could not be predetermined. The grounded theory method of theoretical sampling provided an appropriate strategy.
Theoretical sampling uses constant comparisons as a guide to the gathering of further data. In other words, data is sought out and collected in order to advance theory (Charmaz, 1995). Sequential and concurrent generation and analysis allow for sampling of previously collected data, in addition to data yet to be collected. Theoretical sampling is therefore dynamic, responsive and evolutionary. Strauss and Corbin (1998) state that theoretical sampling is cumulative with an increasing specificity, and is directed by the aims of the coding procedures. Therefore, different sampling procedures are adopted as coding progresses. The sampling of the present study is discussed with respect to the three procedures used: open sampling, maximum variation sampling, and discriminate sampling.

Open sampling aims to expose the data by providing opportunities to identify concepts. Initially, convenience sampling and snowball sampling were used to open out the data and to provide an initial pool of potential participants. While this initial sampling did not allow for purposeful data generation, Strauss and Corbin (1998) acknowledge that convenience sampling is sometimes more practical and realistic, given that researchers can only sample what is available. Further, the process of analysis remains the same and because of naturally occurring variation, differences are still likely to emerge (Strauss & Corbin, 1998). Indeed, Charmaz (1995) argues against the use of purposive or theoretical sampling at the beginning of a project so as to avoid premature closure of the analysis, and suggests that it occur later in the study once significant data has begun to emerge.

Once the group of potential participants was established the sampling method evolved into theoretical sampling and purposeful data generation. Given the limited research that has addressed the experiences of people with CFS, it was important that the data reflected the scope, nuances and patterns of the phenomena. Maximum variation sampling was used and participants were chosen so as to reflect the variety, range and differences in CFS experiences. Thus, from the pool of participants, I purposefully selected women and men for variance, such as sick/recovered, severely affected/moderately affected, older/younger, short illness duration/long illness duration, living alone/living with others, and from a variety of geographical
locations. Exploring differences through maximum variation allowed properties, dimensions, and conditions of categories and subcategories to emerge.

As analysis progressed, discriminate sampling was used. With discriminate sampling, data selection becomes more specific and seeks to integrate categories to form, refine and support theory, relationships, and themes. Discriminate sampling of confirming and disconfirming (negative) cases was used to validate or negate the interpretations arising from the analysis. Confirmation and disconfirmation enhance trustworthiness and rigour.

The recovered participants were found to provide the study with confirming cases. Careful consideration was given to the scheduling of their interviews. I interviewed one recovered participant towards the beginning of data generation (interview number 5) in order to maximise early variation in the emerging concepts. To enhance discriminate sampling the remaining two recovered participants were interviewed at the end of data collection (interview numbers 17 and 19). Additionally, Participant 5R was sampled again. The data derived from the recovered participants confirmed the narratives, themes and theory emerging from the other interviews.

Disconfirming cases do not fit with the emerging concepts or theory. They are extreme and contrary and are of significance to discriminate sampling because they denote variation in a concept (Strauss & Corbin, 1998). One affected participant was selected as an outlying case. Participant 8 had been ill for 57 years and therefore represented an extreme example of an intransigent case. However, Participant 8 had also continued working until he reached retirement age, so he was a disconfirming case to the majority of participants who had been very ill for many years and were unable to work. Further, throughout the analysis specific negative cases were encountered.

**Accessing the Participants**

In line with maximising the sample variation, recruitment strategies were directed towards women and men currently or previously diagnosed with CFS, across the
adult age span, and with varying lengths of illness and degrees of illness severity. Recruitment was drawn from an advertisement placed in a CFS support group newsletter, from brochures distributed to CFS patients attending a specialist clinic in a large city metropolitan hospital, and from referrals by people who knew of the study. Although the newsletter is a statewide publication, participation was limited to areas where travelling and interviewing could be completed in the same day. The advertisement and the brochure outlined briefly the purpose of the study as an examination of the experiences of people living with CFS and requested participants for an interview of approximately 1 hour and 30 minutes duration. Over a period of approximately 4 months 26 people had responded, the majority in the first 6 weeks, and 25 people agreed to participate. Of the 25 potential participants, one withdrew due to ill health (unrelated to CFS), and one lived interstate. This provided a potential sample pool of 23 participants. As the size of the sample was to be determined by theoretical sampling and the principle of data saturation, the required number of participants was at this point undetermined and may have required further recruitment. In fact, saturation was reached after 19 interviews, and the remaining potential participants were not utilised.

Participants appeared to consider me to be a safe and trustworthy person, who by virtue of my profession(s) understood illness, cared about people, and valued knowledge. Although my study was “psychosocial” in flavour (and therefore possibly suspect), I was perceived as belonging to a benign or neutral professional group that did not have a vested interest in specific outcomes in the way that a psychiatrist or psychologist might. It was my perception that my status as a nurse and teacher was associated with a privileged position that facilitated trust and consequently, recruitment.

Of the 23 potential participants, 14 responded to the newsletter and 4 responded to the brochure. A work colleague referred one potential participant, and another 4 referrals came via participants. Twenty potential participants were currently affected by CFS and 3 potential participants defined themselves as recovered or significantly improved. Two of the recovered potential participants responded to the advertisement and one was referred.
A researcher using qualitative method does not seek to attain representative samples and the study did not intend to represent the CFS population. However, to address the exploratory nature of the research questions, the sample needed to include variance and appropriate sources or venues for recruitment were required. Therefore, the criticisms related to selection bias arising from sampling practices in quantitative CFS studies, such as the choice of recruitment venues, provided guidance for the present study. This use of quantitative findings to highlight the potential for inadvertently limiting participant variation is consistent with the premise of theoretical sensitivity.

Criticisms related to CFS sampling practices of relevance to this study included the use of tertiary referral clinics and the reliance on physician referrals, which might be unrepresentative and introduce bias towards intransigent cases (Wessely et al., 1997). Further, people who have opted out of the health system and who manage their own care or those who do not have access to health care have been reported as under-represented in the CFS research (Jason et al., 1999). It was anticipated that advertising in a CFS support group newsletter would access people with a range of illness severity who may or may not be using the health care system. Within the quantitative CFS research, however, the use of self-help groups has also been cited as a source of selection bias. It was possible that this recruitment source limited the sample variation, as 17 participants were members of CFS support groups. Nonetheless, these participants had varying opinions regarding the role of support groups, different reasons for their membership, and various levels of involvement. Quantitative research has also indicated that people of non-Caucasian origin are rarely included in CFS studies (Jason et al., 1999). The inability to provide interpreters or printed translations necessarily limited the cultural variation.

I envisaged difficulties in accessing people who were immersed in symptomatology and emotional distress, particularly during the early years of the illness. Fears regarding further emotional effects, depletion of energy, and possible deterioration could preclude research involvement. These concerns were to some extent validated by participant comments. Two participants stated that they would not have
considered participation a few years earlier because at that time they were too upset and ill, and it was only after some years of being ill that they felt able to speak about their experiences. Further, three other participants reported they had discussed the study with friends recently affected with CFS. Two of the friends declined involvement because of the associated emotional distress, and the third declined because of concerns related to the energy involved and the possibility of worsening symptoms. These reports suggested that there were particular times or circumstances, notably the early years, when people with CFS were especially vulnerable and participation in research more unlikely. Again, the concern was that maximum variation might be compromised.

These access/recruitment difficulties are not specific to the present study. Qualitative research commonly involves vulnerable people, including those experiencing illness. Cowles (1988), in a paper discussing the investigation of sensitive issues and vulnerable groups, noted the potential difficulties in accessing participants during the initial phase of an experience. Although Cowles was studying survivors of murder victims, the reasons given for the anticipated difficulties in accessing participants (such as emotional overload and depletion of energy) were consistent with my recruitment concerns. However, with respect to illness, it has been argued that limited involvement by people in the early stages, one of my concerns with the present study, may not be problematic (Morse, 2000). An important assumption of qualitative method is the familiarity of participants with their everyday and local worlds. Morse suggested that there are difficulties with data collected at the beginning stages of illness (or when a person is very ill) as participants are experiencing a constantly changing reality and lack familiarity “with their everyday worlds” (2000, p. 539). Morse concluded that in such circumstances participants are best described as “poor informants” (2000, p. 540) who had not yet integrated the changes associated with the illness, and that data collected at this time tended to consist of superficial descriptions possibly lacking in experiential and emotional content. It was suggested that data collection might only be possible after the condition of the participant has improved, that data collection need not occur during the experience because interviews triggered memories and emotions, and that
retrospective interviews produced trustworthy data, with participants appearing to benefit from involvement (Morse 2000).

It was further anticipated that the recruitment of recovered participants was potentially problematic. During discussions with CFS advocates in the early stages of the study, I had been told of the difficulties in finding individuals who had recovered and who were prepared to publicly speak about their experiences with CFS. Although discussion would be confidential, it was possible that reasons such as an unwillingness to return to painful times or a lack of awareness of the study might mitigate against involvement. Despite this concern, and although recruitment occurred from within CFS environments, 3 potential participants who self-reported recovery or significant improvement were recruited.

**The Sample Size**

The sample size was not pre-determined but based on the principle of data saturation. Data are generated until each category or theme is saturated. Saturation has occurred when no new or relevant data emerges regarding a category, no new categories are found, there are no theoretical gaps, and the theory can account for all the data (Chamberlain, 1999; Strauss & Corbin, 1998).

The present study adopted principles suggested by Morse (1995) for assuring saturation that included theoretical sampling, maximum variation, the examination of negative cases, and ensuring that data are rich and complete. Morse also recommended the use of a cohesive sample and while this has been generally problematic to CFS research, the selection criteria in the present study such as the use of the CDC case definition, attempted to provide cohesiveness. The data from 19 participants provided saturation.

**Demographic and Clinical Characteristics of the Participants**

Of the 19 participants, 16 were affected with CFS and 3 reported recovery. While most participants who identified themselves as affected by CFS reported degrees of improvement during the years of their illness, it was not of a sufficient magnitude to allow any meaningful resumption of pre-illness activity and they continued to
experience disabling levels of impairment. One participant had experienced the onset of CFS during adolescence that had progressed into adulthood. This participant was included because she was affected as an adult, met the other criteria, and contributed towards the maximum variation of the sample as she was of a younger age and identified as recovered.

Participants covered an age range across the adult life span with variation in the duration of the illness and functional impairment. Seventeen participants resided within the wider Sydney metropolitan area including the inner west (2), the north west (3), the northern suburbs (4), the southern suburbs (2), the eastern suburbs (2), and western Sydney (4). The remaining 2 participants were from areas situated west and north of Sydney.

**Age, Gender and Ethnicity**

Ages ranged from 20 to 75 years, with a mean age of 48.7 years and a median of 45 years. The greatest number of participants (31%) were in the age range of 40-49 years, consistent with the finding that the 40-49 year-old age range exhibit the highest CFS rates (Jason et al., 1999). Fourteen female (74%) and 5 male participants comprised the sample (Table 1), reflecting the higher incidence of CFS reported among women (Jason et al., 1999).

<table>
<thead>
<tr>
<th>Age Range</th>
<th>n</th>
<th>n Females</th>
<th>n Males</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29 years</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>30-39 years</td>
<td>4</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>40-49 years</td>
<td>6</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>50-59 years</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>60-69 years</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>70-79 years</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>19</td>
<td>14</td>
<td>5</td>
</tr>
</tbody>
</table>

The 3 recovered participants were female and their ages were younger than the group mean (Participant 5R, 20 years; Participant 17R, 38 years; Participant 19R, 34 years).
All participants were of Caucasian background. This does not reflect the CFS population with findings that suggest CFS occurs across ethnic groups (Jason et al., 1999).

**Years Affected by CFS**

CFS had been a long-standing condition for most of the participants (Table 2). Among the affected participants, the number of years ill with CFS ranged from 4 years to 57 years, with a mean of 16 years. After removing the participant affected for 57 years, the mean time affected was 13.8 years. Only 3 of the affected participants were ill for less than 10 years. The recovered participants were affected for a mean of 7.6 years, ranging from 6 to 10 years.

Table 2: Years Affected by CFS

<table>
<thead>
<tr>
<th>Years Affected</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 5</td>
<td>1</td>
</tr>
<tr>
<td>5-9 (including P5R &amp; P19R)</td>
<td>4</td>
</tr>
<tr>
<td>10-14 (including P17R)</td>
<td>6</td>
</tr>
<tr>
<td>15-19</td>
<td>5</td>
</tr>
<tr>
<td>&gt; 20</td>
<td>3</td>
</tr>
</tbody>
</table>

Although some studies have not found illness duration to be associated with recovery (for example, Phelay et al., 1999), the shorter illness duration among the recovered participants was consistent with prognostic findings that suggested recovery to be more likely in the early years (Levine, 1997; Reyes et al., 1999).

**Additional Medical Conditions**

Fourteen participants (including those recovered) identified the presence of additional medical conditions. These included other chronic conditions (e.g. allergies, cardiac disease, irritable bowel syndrome, hypertension, back pain) or degenerative conditions (e.g. macular disease, osteoporosis). Participants viewed CFS as their primary health concern because of its chronicity and capacity to affect functional abilities and quality of life.
Education and Occupation

The participants were well educated with 13 holding post-high school qualifications. Eight (42%) held tertiary qualifications (Table 3).

Table 3: Educational Status

<table>
<thead>
<tr>
<th>Educational Status</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not complete high school</td>
<td>0</td>
</tr>
<tr>
<td>High School</td>
<td>6</td>
</tr>
<tr>
<td>Post-Secondary</td>
<td>5</td>
</tr>
<tr>
<td>Tertiary</td>
<td>8</td>
</tr>
</tbody>
</table>

A range of professional and skilled occupations was represented related to education, health, government, publishing, hospitality, sales, secretarial, small business, the arts, and science. Five participants previously, or at the time of the interview, worked in health and welfare. This may reflect the higher rates of CFS that have been reported among health care workers (Jason et al., 2000). Two participants were students at the time of the interview. Consistent with the educational status of the sample none were unskilled workers.

Relationship Status and Living Arrangements

Most participants were not involved in a significant or intimate couple-relationship (Table 4), a situation that was predominantly attributed to CFS and the difficulties in initiating and sustaining relationships.

Table 4: Relationship Status

<table>
<thead>
<tr>
<th>Relationship Status</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>9</td>
</tr>
<tr>
<td>Coupled</td>
<td>8</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>2</td>
</tr>
</tbody>
</table>

Eleven of the participants were parents, including 9 participants with dependent children or children who had been dependent during their parents’ illness (Table 5).
Table 5: Parental Status

<table>
<thead>
<tr>
<th>Parental Status</th>
<th>n</th>
<th>4 with dependent children</th>
<th>5 with children previously dependent during parents’ illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-parent</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>11</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In other words, the majority of participants who were parents were raising (or had raised) their children while affected with CFS.

Most participants, including the 3 recovered, lived alone (Table 6). However, while affected with CFS, 2 of the recovered participants lived with their parents and the third lived alone and with others.

Table 6: Living Arrangements

<table>
<thead>
<tr>
<th>Living Arrangements</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alone</td>
<td>10</td>
</tr>
<tr>
<td>With spouse/partner</td>
<td>4</td>
</tr>
<tr>
<td>With spouse/partner and children</td>
<td>4</td>
</tr>
<tr>
<td>With brother</td>
<td>1</td>
</tr>
</tbody>
</table>

Given the sampling limitations and classification difficulties associated with CFS research it is arguable whether the majority of CFS studies do generally reflect the “true” CFS population. While not attempting to seek a representative sample, the theoretical sampling of the present study did produce a group of participants who shared many characteristics of the population found in quantitative CFS research (as described in Chapter 2). For example, the present study was not able to access unskilled or less educated individuals or to include cultural variation. Generally, these groups are less well represented in qualitative research.
Reasons for Participation
The majority of participants had a number of reasons for assisting with the study. Nine participants wished to contribute to the CFS knowledge base, 8 stated a desire to help increase understanding about CFS in order to improve its legitimacy and reduce negative attributions, and 6 cited a desire to help others with CFS. These reasons for participation are consistent with those found in other CFS research (for example, Lovell, 1999). Three participants felt they might be able to make unique contributions because of their circumstances or experiences. Two participants cited personal reasons – specifically, one wished to learn more about herself through the interview process, and the other considered her involvement as a cry for help and stated that for her to get well she needed to contribute to the knowledge base. One participant did not know her reasons for participation. There was a perception among participants that questionnaires, surveys and other common quantitative measures had not provided a true and complete representation of CFS and had contributed to negative and incomplete (and from their viewpoint, inaccurate) perceptions of people with CFS. The use of interviews and dialogue appealed to the participants because it was a valued opportunity to give voice to their experiences. They expressed to me their belief that being able to talk about CFS, at length, would communicate its reality and provide a truer representation. This feedback indicated that the participants found the method to be appropriate and have relevance, and provided further justification for the research design.

Data Generation

The Interview Sessions
Data generation commenced with the initial telephone calls as potential participants frequently began to discuss their experiences during these calls. Following agreement to participate, participants were posted the PBQ, the Interview Guide, the Participant Information Sheet and the Consent Form approximately 1 or 2 weeks prior to their interview appointments. Thirteen participants opted to be interviewed in their homes. Additionally, participants' work places (2), coffee shops (2), local library (1), and my work office (1) were used. A number of participants expressed relief at conducting the interview in their home because they had been concerned about the need to travel and the possible consequences to their health. Holding
interviews in a location of the participants’ choice was consistent with qualitative method principles of collecting data in close proximity to a local setting.

Participants were well prepared and had thought through strategies to manage the interview process. Four participants, for example, had prepared written answers to the Interview Guide and a further 7 used the Guide as a memory aid during the session. Five participants made notes during the interview of points they wanted to remember. A total of 11 participants, who were all currently affected by CFS, reported that they used these strategies to compensate for neurocognitive deficits. Participants were informed when the audio-taping had commenced and when it was switched off. During the interview notes were made of participant behaviours, such as tears or unease, that may have provided additional information in the data analysis. After completion of the questions participants were asked if there were any other issues they would like to address. No participant required a postponement of the interview and all completed in one session.

After the interview was completed, debriefing involved 3 steps. First, I asked the participants how they felt about the interview. Secondly, to provide reassurance that I valued and intended to protect their story, I briefly reiterated the measures implemented to ensure confidentiality. Thirdly, time was spent with each participant in social conversation in order to move from the personal arena of disclosure to a social arena. All participants declined the offer of a follow-up telephone call. None of the participants appeared emotionally mobilised at the completion of the session, and the majority offered to help in any way they could in the future. Participants who saw me in their homes were gracious and hospitable, and among those primarily confined to their home, there was a sense that the interview session was also a social occasion. It was my perception that the interview session was, for most, a rare link with the wider world and with someone outside of their restricted social circle.

After each interview notes were made of my thoughts and impressions, including descriptions of what I had observed. For example, I noted the presence and number of pets and their interactions with participants, and any indicators of functional impairment (such as one participant who had the blinds drawn because of her
photophobia). I transcribed the interviews to deepen my sensitivity to the data. The tapes were transcribed verbatim, with pauses, laughter, crying and vocalisations included.

Grounded theory views data as arising from many sources. This encompassing view of data serves to strengthen the analysis and the emergence of the theory. Consistent with this premise, all notes made throughout the study were viewed as data. Additional information relating to 5 participants was also incorporated. This included summaries of medical histories, an assessment report of neurocognitive function, records of compensation applications, diaries, and photographs of participants prior to developing CFS. In the days following their interviews, 4 participants telephoned me to clarify or further discuss aspects of their experiences that they considered important to the study. Following completion of data analysis a summary of the findings was sent to participants to provide feedback and verify that the theory generated had meaning and relevance to them.

The Dynamics of the Interviews
Interactions, multiple roles, and the potential for emotional mobilisation are inherent to the co-constructed nature of interviews. Each contributed to the dynamic interplay and consequently, to the data collected. Therefore, the dynamics of the interviews are discussed to enhance procedural transparency.

People with CFS commonly report situations of dismissal, such as disbelief of symptoms and disinterest in the condition by medical practitioners. There was the potential that a “neutral” researcher might be interpreted as a further instance of the professional disregard that had been a strong and consistent theme among participants from the first interview onwards. It has been argued that the interviewer needs to be “engaged” so as to gain a contextual understanding of experiences (Collins, 1998), a view that is compatible with the constructivist approach. Therefore, to facilitate trust, create a safe environment, reduce the hierarchy inherent to the research process, and gain a contextual understanding, principles of engagement and reciprocity were considered crucial.
Some nurse researchers choose not to identify as a nurse in order to decrease the likelihood of being perceived as the (powerful) expert (for example, Sword, 1999). In contrast, I did disclose my nursing background because I did not wish to function as a gatekeeper of information. I believed, given the community regard for nurses, that my status as a nurse would not function as a hierarchical barrier. As discussed previously with recruitment, I was viewed by the participants as belonging to a “safe” health profession that cared about, and for, sick people. Participants responded by sharing intimate and personal information. Additionally, they used medical abbreviations and jargon without attempts at explanation. There was an implicit understanding that I was fluent in medical language and therefore was an insider, at least in the medical sense. This assumed understanding did not foreclose participant discussion (which was my concern regarding disclosure of my CFS diagnosis) because it involved definitions (such as “neurotransmitter” and “graduated exercise program”) and not experiences. Further, there was an assumption of shared understanding about the culture of medicine. As a nurse, it was assumed that I too had experienced difficult encounters related to the practice of medicine. In sum, it was my judgement that identifying myself as a nurse facilitated engagement and trust.

The co-construction of the interview, the fluidity of interactions, changing needs and personal agendas influence the roles adopted by individuals within the interview. The role of interviewer/interviewee or researcher/participant is only one possibility. Charmaz and Mitchell (1996) suggest that while the researcher may present particular roles, the participants can reassign a preferred role to the researcher. That is, the participant constitutes a role for the researcher that is beyond or different from that of “researcher”. Therefore, my role as “researcher” was only one role and participant needs or expectations, such as those related to information, emotional support or validation, influenced the adoption of other roles. Consequently, the researcher may temporarily suspend the role of researcher or adopt simultaneous roles. Moving away from the agreed upon role of researcher to meet the needs of participants has been associated with conflict regarding obligations (Sword, 1999). Nevertheless, the importance of role flexibility to data generation has been demonstrated (for example, Lawler, 1991) and the evolution of the
participant/researcher relationship within interviews, where roles become less rigid, has been described (Sword, 1999). Therefore, while the researcher role was primary, I approached the interviews with a readiness to temporarily adopt other roles based on the needs of participants. Relationship constructs such as reciprocity and the principles of fair exchange provided guidance and contributed to decisions regarding my roles.

With respect to roles, I presented myself as a PhD student researching CFS and occupationally as a lecturer in nursing. I perceived the participants as experts regarding their CFS experiences. Participants considered “researcher” as my primary role. While reviewing the PBQ prior to the interview, for example, Participant 3 expressed the sentiment you can sort that out, you're the researcher. However, consistent with the discussion in the previous paragraph, participants also perceived my roles (as they did their own) as numerous, fluid and multidimensional, and did not appear to perceive any role as being mutually exclusive to the adoption of other roles.

Consistent with my student role, participants acknowledged their own role as expert and teacher, and provided unsolicited explanations regarding specialised aspects of CFS or their experiences. There were times when my student status was replaced and I was viewed as an expert and asked to express an opinion regarding a treatment or medical or social issue. This was sometimes difficult because I wished to reciprocate without taking on the power of the expert, the role primarily ascribed to the participants. For questions of an informational nature, research findings provided a basis for responding. At other times counselling strategies were used, for example, in situations where I was asked to comment on the appropriateness of an action by a family member. When I expressed my opinion I made it clear that it was only an opinion and not necessarily “truth”. Ultimately I found myself to be in agreement with Davies and Dodd (2002) who argued that when participants asked for comments and opinions, the willingness of the researcher to do so was important to both the ethics and rigour of the study.
By documenting the experiences of CFS and associated with my occupation as a teacher, I was viewed as a stepping stone between people with CFS and those who treat people with CFS. Further, as a conveyer of stories I was seen as a collaborator, given the possibility I could pass on the participants’ stories to people believed to be in positions of power. There was also a sense that I was an ally based on my preparedness to conduct the study. Participants sometimes wanted me to bear witness, to validate their perceptions of having been wronged, having suffered, having tried and fought (a role also described by Collins, 1998). Sometimes in these instances, participants were typically distressed or overtly asking for validation. In response, I adopted the role of counsellor and attempted to provide validation, and it was only when the participants were ready to move on that I resumed the role of the researcher. Participants responded quickly to the counselling role and its use was generally brief.

The roles adopted by myself were enacted contextually with the roles adopted by the participants, each affecting the other. There was richness and diversity in the roles the participants bought to the interviews such as CFS sufferer, CFS survivor, storyteller, research participant, expert, teacher, advocate, collaborator, outsider, and client/patient. Additionally, I observed non-CFS related roles (although undoubtedly influenced by CFS), for example, interactions with children and partners that reflected the parent and spouse roles.

Many of these roles and the difficulties encountered have been described in other studies (for example, Collins, 1998; Sword, 1999), and so my experiences appear consistent with others. Collins (1998) suggested that it is unhelpful to deny the presence of roles, given that the selves of the interviewer/interviewee are a joint negotiation and that the interviewee will evaluate and judge the interviewer regardless. I propose, however, that roles serve a more positive function than that of an unavoidable situation that needs to be accommodated. Multiple roles facilitate trust because they provide the interviewer with a vehicle to demonstrate honesty, reciprocity and empathy. Additionally, given the premise that meaning is mutually negotiated between the interviewee and the interviewer, reflection on the roles contributes to understanding the meaning and experience of the interviewee. For
example, the ease of those participants who had been ill for the longest period in adopting the role of teacher and expert, when compared with participants whose illness duration was shorter, alerted me to properties and dimensions of emerging concepts. In that instance, my role as student assisted me in recognising that ease. Finally, the adoption of multiple roles is important because it facilitates ethical practice. The end result is that the generated data are richer and likely to be trustworthy because they reflect the complexity of everyday interactions.

Participants spontaneously reported positive benefits and therapeutic outcomes arising from the interview process that included the opportunity to talk about CFS and have somebody listen, an increased understanding of personal issues, and the disclosure of previously unexpressed feelings and thoughts. The benefits were derived from the telling of the story. For most, this was the first time they had spoken at length, in depth, and without interruption about CFS, sometimes articulating what had previously been unspoken or unacknowledged. For a few participants, as the interview progressed the expended energy appeared to be associated with an increase in symptoms. I observed deterioration in linguistic expression and fluency and increased forgetfulness. Nevertheless, the desire to tell their story was strong, any effects were considered to be secondary to the benefits, and none wished to stop or postpone the interview. The benefits reported by the participants are consistent with other reports that have found interviews to be valuable to self-understanding by providing the opportunity to be heard and to talk through an issue (Collins, 1998; Rice & Ezzy, 1999).

Throughout the chapter I have addressed the potential for the interview to mobilise distressing emotions among the participants and the efforts made to minimise possible distress, in addition to describing strategies to support participants should this occur. Emotional effects can also arise for the researcher. Morse (2000) has described the difficulties of understanding the world of the ill person without taking on and sharing their pain or distress and has noted that the emotional effects of qualitative research on the researcher have rarely been addressed. With few exceptions (for example, Cowles, 1988), there has been limited discussion of the importance of researchers finding strategies to cope with personal emotional
responses. As is the case for any qualitative researcher listening to the descriptions of painful events, I was susceptible to sharing the suffering, as Morse (2000) described. There was also the additional potential for my personal experiences to be reactivated by the stories of others. Therefore, prior to commencing the interviews I arranged to speak with a colleague (who was also a practising therapist) if any issues arose for me from the interviews. Although the accounts of the participants were moving and often distressing, I was able to experience and respond to the emotions within their context, processing the distress that comes from listening to the pain of others without generalising to my own experiences. Because I was able to process my emotional responses it was not necessary to debrief with my colleague. Reflection and making notes of feelings following the interviews provided an opportunity to consider and integrate responses arising from the sessions and to examine how my emotional responses might have affected the interview.

There were two factors in my prior experience that I believed facilitated the processing of emotions related to the research. While ill I had received periodic counselling and was therefore familiar with my emotional world and its relationship with CFS. Secondly, I had developed experience of coping with mobilised emotions because my teaching area was the psychosocial aspects of illness and at that time, much of what I was teaching was also what I was living. These two factors were important to my ability to enter into the emotional world of the participants without becoming overwhelmed.

Other “insider” researchers have expressed concerns regarding the potential for the mobilisation of painful memories arising from personal experience, for example Brodsky’s (1995) study on testicular cancer. Despite initial concerns, Brodsky did not experience painful memories and reported that the length of time that had passed since his treatment for testicular cancer and the “many hours talking about his experience throughout his illness” (1995, p. 94) may have negated the mobilisation of distressing feelings. This context of the passage of time and “many hours talking” mirrored my own situation and may represent important protective variables for researchers investigating experiences in which they have personal involvement.
Analysis of the Data

Data analysis requires that the researcher interpret the words (and actions) of the participants and turn their individual stories into theory. Daly (1997) used Schutz’s distinction between first- and second-order constructs to support his claim that theories are second-order stories, with theory emerging from the researcher’s self. The challenge lies in protecting and communicating the participants’ meanings (that is, the first-order constructs) while developing theory. Chesney (2001) articulated concerns that I shared of interpreting authentically the words and meanings of the participants.

The possibility of drowning out, silencing, misunderstanding, or misrepresenting particular forms of knowledge creates a frightening responsibility because this knowledge comes from real people with real names, faces, and lives (2001, p. 132).

Preeminently, I did not wish to distort the voices of the participants. This does not imply that one true voice or one single theory was to be found, for any data set can yield multiple and valid (trustworthy) interpretations (Strauss & Corbin, 1998). My concerns did, however, lead me to approach the data analysis under a constant gaze of self-examination and procedural evaluation. I was conscious of attempting to use the analytic tools of grounded theory but also to authentically report the narrative embedded in the data.

The methods of grounded theory kept me close to the data. Constant comparison involving multiple, iterative practices ensured a continuous interchange between data and ideas, and enhanced the grounding of concepts. Theoretical sensitivity facilitated insight into the nuances of the data, thus enhancing conceptual density. Conceptualising, clustering, categorising, comparing and contrasting the data, explicating relationships and patterns, the use of confirmatory and negative cases, and checking the emerging findings with participants throughout the process formed a basis for interpreting data.

Data analysis used three levels of coding derived from Strauss and Corbin (1998). The different levels of open, axial and selective coding serve different analytic functions. Open coding provides a method for conceptualising the data, and aims to
break down the data and open out the concepts. In doing so, processes emerge. Initially data were examined, compared for similarities and differences, coded line by line, and broken into separate ideas or discrete parts known as concepts. From the third interview on, open coding utilised larger units such as a few sentences. Each concept was labeled so that the meaning was embedded in its name. Open coding elicited 41 concepts.

Axial coding pulls data back together by condensing, collapsing, developing, clustering and expanding similar ideas and concepts around a single theme. These groups of concepts are higher-order and more abstract, producing categories. Major categories are then derived by grouping together similar categories or by expanding and developing a category. It is through the emergence of major categories and their properties and dimensions that theory evolves. The open codes of “protective acts” and “renewing acts”, for example, were consolidated during axial coding into the category of “strategies”. As coding continued, the properties of “strategies” began to emerge, in conjunction with their relationships with self. Protection and renewal were found to be properties of strategies that were related to the major categories of the “Guardian Response” and the “Reconstructing Response” respectively. Further, the two response categories partly provided a vehicle in which to report the biographical nature of the participants’ accounts, given that there was a risk in using grounded theory to the extent that it could lead to a fragmentation of narratives.

The coding process progressively built up, developed and refined theory. During open coding, for example, I had identified the concepts of “learning about CFS”, “telling others what I’ve learnt”, and “gaining confidence in knowledge”. These concepts were combined to form the category “knowledge – in and out”. I then focused on exposing the variations within the category by asking questions such as, how and when was the knowledge used? What purposes did the knowledge serve? What conditions were associated with the different purposes? What were the outcomes of becoming knowledgeable? Such questions led me to refine this single category into two, “gaining knowledge” and “sharing knowledge and experience”. These categories were associated with different purposes, different outcomes, and were related to different responses of self.
The third stage, selective coding, occurs at a higher level of generality, linking the categories around a core that represents the essence of the phenomenon. This core category integrates the other categories and provides the story line to the emergent theory. The core category was described in the narrative of the “struggling and diminished self seeking self-renewal”. In addition to integrating a theoretical scheme, selective coding further refines theory. For example, realisation of the chronicity and effects of CFS appeared to be an important condition to the development of the Reconstructing Response, but it was through examining confirming and disconfirming cases that the condition of realisation was refined to cognitive realisation.

While the coding process commenced with open coding followed by axial coding, the process soon evolved from a linear sequence into alternate and simultaneous open and axial coding as data was generated and analysed. The labels given to concepts and categories sought to identify the meaning and definition as precisely as possible. When suitable, in vivo codes (that is, member-identified descriptions that used the words and phrases of the participants) were used, such as “turning points”, “uncertain future”, and “living within limits”. As theory developed, new areas of questioning included the role of experience, asking for help, changes in feelings, stigma, anger, shame, estrangement, being listened to, and disclosure. Additionally, previously coded data was reviewed in light of emerging findings. The category of “turning points”, for example, emerged fortuitously during one session and appeared to have saliency in the following interviews, so I returned to previously coded interviews to see if “turning points” was of relevance.

The process of listening and re-listening to the audio-tapes that was necessary for my (slow) transcription had beneficial effects. The process of transcription in conjunction with multiple readings committed to memory the content, emotions, and subtext of much of the interviews. From my field notes I was able to record aspects of the interview that were not evident from audio-taping and that were likely to become lost to memory. For example, using field notes I compared participants to find if there were particular topics more likely to be associated with tears and found
this most often occurred with discussion of the parenting role. This alerted me to the primacy of this role to the participants’ lives, to the multitude of ways that CFS had affected their parenting role, and to the effects on self associated with the disruption to the parenting role.

Both negative cases and confirming cases were important to the analysis. Negative cases challenged the theory, increased rigour and enhanced theoretical refinement. Therefore, particular attention was paid to data that appeared to be an exception to the emerging categories. As analysis continued comparisons were made involving differences to determine whether the emerging theory could account for these differences. Similarly, confirming cases also served to test the emerging theory. For example, it was found that the affected participants experienced a Violated Self associated with the threats of CFS. If violation was associated with CFS then the recovered participants, who had also described retrospectively a Violation to Self while affected with CFS, would not continue to experience violation to the same extent. This was the case and supported the conclusion that the Violation to Self arose from the threats associated with CFS.

Throughout the coding process member checks were carried out to ensure that my interpretations and developing theory had meaning to the participants. Informal telephone calls with 5 participants, who indicated an ongoing interest in the study, provided progressive clarification in interpretation of data. Once the analysis was (provisionally) completed, participants were sent a 10-page summary and were given the opportunity to provide comments if desired on the relevancy of the analysis to their own experiences. Ten participants contacted me with verbal (8) and written (2) comments. The calls averaged 55 minutes in length, ranging from 30 to 90 minutes. Feedback was positive and the analysis had relevance and meaning to the participants. Comments alerted me to refinements that improved the analysis. Participants expressed gratitude to me for investigating CFS and writing an account that represented their experiences. I was relieved to be told I understood and had insight and that the study had been conducted with integrity.
Elements of the grounded theory method are ubiquitous to qualitative research, and
the present study found it to be an appropriate methodological approach in its ability
to articulate with illness narratives. The study aimed to explore the subjective. I
expected to do so through discrete questions and answers, but was presented instead
with narratives. The purposes of the participants in telling their stories (for example,
making meaning of their illness) were not necessarily the research purposes, but nor
were they mutually exclusive. For the participants, the narrative became the goal,
the product, or the end unto itself, but their narratives were not the findings and were
not a method per se. They required analysis and interpretation, and grounded theory,
with its focus on process rather than product, provided analytical structure.
Grounded theory served as a counterpoint to the romanticism or sentimentality that
sometimes accompanies illness narrative analysis. It mitigated against repetition and
collation, and facilitated interpretation and explanation. Additionally, and of
importance to understanding a contested illness, grounded theory facilitated the
exposition of context and conditions, which are not always apparent in narratives.
Alternatively, the (in my opinion) limitations of grounded theory related to
epistemology and the assumption of the researcher as a naïve instrument, were
accommodated by the incorporation of reflexivity and theoretical sensitivity. These
strategies kept me focused on the narratives without becoming preoccupied by
methodolatry. In sum, the use of illness narratives and a grounded theory approach
helped me to stay true to the voices and subjectivities of the participants while
enhancing trustworthiness and depth of analysis.

The methodology and method used were consistent with meeting the aims of the
research, that is, to explore meanings and experiences of illness and self for people
with CFS. By remaining embedded in the experiences of self-with-CFS through
listening to the voices of those affected and through facilitating the emergence of
theory from the data, this study provided a contextual understanding of CFS that is
uncommon in the CFS research. In that sense, the study reinforced the centrality of
people with CFS to the knowledge of CFS and through the methodology and method,
articulated a different interpretive prism of the CFS experiences. The analysis of the
data is discussed in Chapters 5 through 9, beginning with the narrative of the illness
biographies.
Chapter 5

The Illness Biographies of Chronic Fatigue Syndrome

Introduction

This chapter addresses the symptomatic experiences of the participants described in the narrative of the illness biographies. Two major narratives that defined the illness experience of CFS were generated from the grounded theory analysis - the illness biographies, and the struggling self seeking renewal. The two narratives are intertwined and mutually influential. The core narrative related to struggling self, and it represents the primary finding of the study. It is discussed in detail in Chapters 7 to 9. This chapter does not address the narrative of the struggling self seeking renewal but concentrates on the illness biographies. The narrative of the illness biographies provides a contextual basis for comprehending the struggle of self arising from CFS. The illness biographies represent a “composite” or meta-narrative, and provide a broad overview and insight into the shared world of CFS within which the participants’ experiences of self were felt and enacted. The importance of the illness biographies is not restricted to the contextual function. It provides deeper understanding regarding the symptomatic experiences and trajectory of CFS.

The illness biographies referred to the stories of symptoms – their presentation, form and nature; the explanations given for their presence; their progression; the attempts to ameliorate them; the encounters that ensued; and their contentious milieu. While the illness biographies primarily concerned CFS, they also included the many years of symptoms without the diagnosis of CFS. The illness biographies were a strong narrative. Participants told of becoming ill, looking for explanations, finding none, seeking help, pursuing diagnosis, experiencing functional impairments, being diagnosed, improving slowly, relapsing, seeking further help, and in exceptional cases, recovering. Their individual biographies were chaotic, convoluted, and complex, and participants did not provide linear, chronological accounts of their experiences. Their histories with CFS were generally long and participants moved back and forth between time frames and defining events.
To provide a coherent account of the nature of the symptoms and the subjective experiences of the participants, the chapter presents both a narrative and quantified description. The chapter includes sections of transcripts to illustrate, in the participants’ own words, the way in which they found themselves located experientially with a debilitating, troublesome and unpredictable set of symptoms. Additionally, to augment the narrative description, simple statistical description was incorporated as part of the analysis and the participants’ symptomatic and associated experiences have been summarised quantitatively. The findings presented in this chapter are largely descriptive in the first instance, becoming analytical as insights are incorporated.

The construction of the illness biographies was derived from grounded theory analysis. Open coding began to make sense of the complex and disorderly accounts and generated codes including “symptom intrusiveness”, “pain”, “before diagnosis”, “memory loss”, “unpredictability of symptoms”, and “feeling ill”. During axial coding the codes were reassembled into categories and the conditions (dimensions and properties), actions, context and consequences associated with the categories were generated. Axial coding yielded a description that encompassed a qualitative/subjective and chronological account of the symptomatic experience. Selective coding integrated the categories into the narrative of the illness biographies. The numerical summaries are consistent with the narrative and provided another perspective to the illness biographies.

The illness biographies encompassed the participants’ mutually shared burdens, challenges and experiences related to the symptoms. In constructing the illness biographies, this chapter discusses the findings related to the onset, nature and course of the symptoms. Experiences related to diagnosis and medical/health encounters are examined and functional impairments, with particular attention to work, are discussed. Participants’ opinions and experiences regarding the controversies surrounding CFS are also reviewed. Through the illness biographies, this chapter provides a snapshot of the CFS-related experiences of the participants from the onset of symptoms to the time of the interviews.
In sum, the chapter has adopted a comprehensive approach to describing the illness biographies. Quantitative summaries describe the profile of the participants, the data is examined in relation to the CFS research, and most importantly, a personal view of how people experience and make sense of CFS and its symptoms is presented. This provides a unique and inclusive perspective to understanding CFS. Additionally, the generation of the illness biographies assists the reader in locating the experiences of self and evaluating the findings that are presented in the following chapters.

**Onset of Symptoms**

For most of the participants the initial symptoms were disagreeable but viewed as short-term. There was predominantly a fast onset of flu- or viral-like symptoms that left participants feeling very unwell. They knew these symptoms to be common and mostly benign, had experienced them in the past, and anticipated a fast return to health. In other words, the symptoms were not initially perceived to be significant and there was no expectation that they constituted a chronic condition. As time passed, it was the persistence and exacerbation of the symptoms that was inexplicable and of concern. Participants believed their symptoms arose from physical causes.

The illness biographies began with the onset of symptoms. For the majority of the participants the onset was not considered to be an indication of a serious or ongoing threat to health. Most described a fast onset that did not go away, for example:

*I started off with the flu and it didn't go away and then they told me I had glandular fever.* (Participant 16)

*I got a viral infection in January 1990 that just didn't go away.*

(Participant 14)

A minority of participants, such as Participant 8, experienced a slow onset with gradual effects.

*As Doctor X said, I am, about ten per cent I think he said, of people have a slow onset, and I am one of those.*
Most reported viral-like symptoms that were changeable and persistent. While there was some variation in the degree of debility at onset, participants were markedly affected and experienced the symptoms as a very bad flu that left them feeling sick, unable to meet their daily activities and frequently confined to bed. The sudden onset with the associated flu- or viral-like illness, or the less common gradual onset described by participants, were consistent with the CFS-illness presentations reported in the literature (Clarke, 1999; Hill et al., 1999).

The inability to continue with their everyday life and the aversive nature of the symptoms prompted the participants to adopt illness behaviours. Illness behaviour refers to the activities undertaken by people in response to symptoms and feeling ill, that is, it precedes diagnosis, and aims to determine the state of health and to seek treatments (Brannon & Feist, 1997). In chronic conditions it can also be triggered after diagnosis when symptoms change or the condition requires better management (Lubkin, 1990). Participants interpreted the initial symptom presentation as consistent with their previous experiences of acute illnesses. They quickly then also interpreted their symptoms and embodied state as illness and defined themselves as ill. Consequently, participants initially self-treated the symptoms with rest and analgesia, and waited to see if they spontaneously improved. Some sought out medical opinion. They became concerned when the illness did not follow the expected acute course, nor respond to the usual strategies of rest, medications or time. Medical advice was (again) sought to explain and treat the source of the symptoms.

There are few reports that describe the initial responses of people with CFS to their symptoms but the limited findings are consistent with the present study. Hyden and Sachs (1998) reported a similar “wait and see” approach among people with CFS, followed by the recognition that their suffering was atypical and a subsequent seeking of medical assistance. Sachs (2001) has also described the dimension of (passing) time as important to people seeking medical attention for the symptoms of CFS.
A small minority of participants experienced severe and intransigent symptoms at onset. In addition to flu-like symptoms, these participants reported shooting pains, unrelenting generalised pain, numbness, explosive headaches, loss of balance, and sensory hypersensitivity. Participant 6 described the associated fear and panic.

*Before I was diagnosed, and I didn’t know what was wrong and every attack seemed to be involving more of my body, I was in a panic. I wanted it to stop. I wanted somebody to come along and say “we know what’s causing it . . . it’s not going to happen again” . . . I was in [a] panic with every attack . . .*

For two participants (6 and 10) such an onset lasted three years. Panic subsided when the participants experienced a degree of symptom relief or had received a diagnosis.

From the moment of onset participants believed they had a “physical” illness with a “physical” cause. They based this conclusion on the initial presentation, the presence of physical symptoms and their previous experiences of acute illness. This early explanation of organic causation did not change markedly over time. Throughout their illness participants rejected medical suggestions of psychiatric causation and continued to attribute onset to a biological basis, notably viral infections, immune dysfunction, or in a minority of cases, with a specific trigger such as chemical exposure. In addition to physical causes, stress or personality factors were viewed by a number of participants as likely contributors. Participant 16, for example, agreed with the opinion of his doctor,

*My specialist told me . . . “you’re a workaholic and that’s why you got it”.*

The reasons for the participants’ beliefs that their symptoms were physically based are consistent with sociological and psychological understanding of how people make sense of their symptoms. Sociological perspectives propose that lay representations of health and illness are socially constructed, with emphasis on the immediate social context. Psychological perspectives view illness representations as individual cognitive constructions that involve comparisons of symptoms and representations (Levine & Reicher, 1996). In Western culture illness has been socially constructed into physical/mental and body/mind illnesses. Participants knew themselves to be physically ill because they experienced symptoms that were
physically manifested in the body. They did not hear voices, feel depressed, have wide mood swings, or display unusual behaviours – that is, they did not experience symptoms they saw as indicative of mental illness. Their interpretation of the symptoms as physical was culturally consistent with the mind/body dichotomy. The participants also knew that stress could affect physical functioning, and its potential contribution was acknowledged. Further, in line with psychological perspectives, the participants’ cognitive constructions concluded that this was a physical illness because in the past, these same symptoms had been explained by medical knowledge as physically derived. Consequently, at onset there were no reasons for the participants to view their symptoms as anything but physically derived, and their illness behaviours were directed to determining the physical basis for the symptoms.

The participants’ attributions of the symptoms to a biological basis was consistent with other CFS research (Butler et al., 2001), as was the belief that stress contributed to the onset (Friedberg et al., 2000). Additionally, the findings regarding the participants’ reasons for physical causation have support. The Joint Committee Report on CFS (Royal Colleges of Physicians, Psychiatrists and General Practitioners, 1996, London) concluded that patient beliefs regarding physical causation are derived from the significance of the viral infection within the illness history (Banks & Prior, 2001), as was the case in the present study. Similarly, Clarke (2000) reported rejection of psychiatric labels among people with CFS because psychiatric explanations did not fit with their experiences.

**Symptomatic Experiences**
Participants experienced constant symptoms with fluctuations in the types, intensity, frequency, location, and extent of intrusiveness. Regardless of how long a participant had been affected, unpredictability remained a primary characteristic of the symptomatic experience. Some symptoms returned while others disappeared, disability sometimes fluctuated within brief periods of time, and unexpected and fast deterioration occurred. Participants described this experience of constancy and variability:
The whole variety, you have different ones at different times, different intensities . . . headaches, pain, joint pains . . . All that pain builds up day after day, after day, after day. (Participant 4)

The symptoms themselves, just having constant headaches, constant pains in the glands, muscular aches and pains, just tiredness, just the constant lethargy . . . (Participant 16)

The majority experienced years of symptoms without a diagnosis. This contrasts with most illnesses, which are generally diagnosed relatively soon after onset. There are exceptions such as other diagnoses of exclusion (for example, multiple sclerosis), but CFS is distinguished by long and difficult diagnostic periods. The absence of diagnosis excluded participants from medical (and social) legitimation of their symptoms and left them subject to judgements that they were adopting abnormal illness behaviours. Abnormal illness behaviour is defined as an individual’s self-perception of personal illness in the absence of an organic cause (Niven, 2000). Because their medical tests were essentially normal and their symptoms had no identified organic causes, participants experienced medical practitioners attributing their symptoms to abnormal illness behaviour. Subsequently, medical practitioners changed their focus from physiological to psychological investigation. Partly in response to the attribution by medical practitioners (and others) of abnormal illness behaviour, participants attempted to work through or ignore their symptoms, however, this was unsustainable and worsened their condition. In sum, their illness biographies were atypical to most illnesses, with extended periods when symptoms remained unsanctioned. The implications of their atypical illness biographies on the social and personal standing of the participants are discussed in Chapters 6 and 7.

The large numbers of symptoms, their variance and fluctuations introduced chaos into daily life. Symptom unpredictability complicated the management of the condition and uncertainty generalised to other aspects of the participants’ lives. Other chronic illness research has supported these findings that unpredictability in symptoms is dislocating and overwhelming (for example, Stevens, 1996). What was predictable for the affected participants was that physical or mental over-exertion, or
specific stimuli (such as pollutants or stress), resulted in worsening symptoms and while deterioration was usually rapid, improvement was slow. Participant 7 described the predictable cost of doing too much.

I know if I'm going to get up early and have a busy day, then I'll probably pay for it for two days. That's very predictable.

The findings of this project regarding symptom characteristics corroborate previous CFS research. The large number of symptoms, the variation in type and severity, and the daily fluctuations and unpredictability were consistent with previous research (Clarke, 1999; Dougall et al., 1998).

The onset of intermittent symptoms or a worsening of symptoms was taken as a warning that deterioration was likely if the current levels of activity were maintained. Participant 9 relied on small but annoying symptoms to monitor his condition.

You get roof ulcers on your mouth, your tongue, your lips, and so many little things like that, that annoy you more than anything else. But it gives you a good indication of how your level is and you know as soon as these things start showing up that you've got to stop.

With experience participants progressively learnt the significance of specific symptoms.

Participants tended to find either the physical or cognitive symptoms to be the more distressing. For some this was a constant, while for others it changed, dependent on the task at hand, on the needs of individuals, and on the value placed on physical or mental activities. Participant 15 found that as her life situation changed so did the disruption associated with physical or cognitive symptoms.

When my kids were young, the physical demands of young children just, I was totally exhausted. I was in pain all the time . . . And yet now I would say, 'cause I’m not that physically fatigued, I’m actually able to become aware more of the fact that my mind is gone . . . It depends, it waxes and wanes as to what is the most crippling, but I do find I miss my brain.

Participants were asked to identify their most troublesome symptom. Identification of a single symptom proved to be difficult, with most describing a core of 2 to 6
symptoms (with a mean of 3.4). Both physical and cognitive symptoms were included in the core group. Core symptoms were defined as troublesome because they were persistent and associated with impairment and distress. There was marked agreement that the most troublesome symptoms were pain, neurocognitive disturbances and fatigue. Table 7, below, shows the frequency with which participants listed these symptoms as most troublesome.

Table 7: Most Troublesome Symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>n</th>
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<tbody>
<tr>
<td>Neurocognitive disturbance</td>
<td>13</td>
</tr>
<tr>
<td>Pain</td>
<td>13</td>
</tr>
<tr>
<td>Fatigue</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
</tr>
</tbody>
</table>

All participants reported at least one, and 14 participants cited at least two of these three symptoms as the most troublesome. The symptoms of pain, fatigue and neurocognitive disturbances have been reported in other studies as common and problematic (Clarke, 1999; Friedberg et al., 2000; Tuck & Wallace, 2000). These research studies, including the present study, suggest that this symptomatic triad is of importance and may be diagnostic. Therefore, the core symptoms of pain, neurocognitive disturbances and fatigue are discussed separately.

**Pain**

Pain was both a specific and generalised phenomenon. When specific, pain was most frequently reported as muscle pain, headache, neuralgia, pressure, and localised pain. Muscle pain commonly involved the large muscles of the legs and back, in addition to neck, arm and shoulder. Other pain sites included the jaw and face. Headaches were both localised (for example, frontal region) and generalised, and frequently associated with dizziness and loss of balance. When CFS was most severe, pain was felt in the whole body as a total and consuming experience. Participant 2 outlined the overwhelming nature of generalised pain and the difficulties in finding some relief.
I was in pain all over, all the time. Bones, muscles, joints, very sensitive eyes and ears, even to the point that it took me ages to arrange myself in bed, to get the pillows so that the cartilage wasn't having too much pressure. I had to arrange my legs so my bone wasn't resting on another. It was quite an issue.

Similarly, Participant 9 experienced pain as a total body experience.

*When you have an attack your whole body aches, head, particularly in the face. I don't get a lot of headaches but it's the whole face that aches and your whole body is aching like that. Just an ache from your head to your toe and you just don't know what's wrong with you.*

The phenomenon of pain is inherently difficult to communicate to others (Madjar, 1997), and participants found it near impossible to locate, describe and communicate the pain of CFS. Participants believed that the variability and non-defining nature of the pain and the absence of pain-related pathology contributed to these difficulties by casting doubts on their reports. These findings are consistent with those reported by Rhodes, McPhillips-Tangum, Markham and Klenk (1999) in their study of chronic and unexplained back pain (another contested condition). Like pain, the neurocognitive manifestations of CFS were similarly disabling.

**Neurocognitive Disturbances**

Neurocognitive symptoms were reported by all participants and believed to be a defining symptom of CFS. Of the 13 participants who reported neurocognitive disturbances as most troublesome, 8 described a general and global decrease in cognitive functioning, including Participant 3.

*I can't think. I'm really, really confused, like hugely confused . . .*

Specific cognitive symptoms were also reported (sometimes concurrently with general cognitive symptoms) and included decreased concentration, impaired memory, loss of instant recall, loss of verbal ability, and difficulties in decision-making. For example,

*. . . short-term memory has got so bad, particularly in the names, places. If we left now and I went down to the post office and you rolled up in the street I wouldn't know you from a bar of soap.* (Participant 8)
I have no memory. My concentration level is shot. My ability to learn is severely affected. (Participant 15)

Neurocognitive symptoms were perceived by the participants as arising from physiological changes to the brain and were therefore “physically” derived. They did not consider the neurocognitive disturbances to be psychiatric symptoms.

Fatigue
Fatigue was a pervasive and defining symptom that was experienced physically and mentally. Although there were differences between participants in their definitions of and preferences for labels such as fatigue, tired, lethargy, and exhaustion, there were marked similarities in the descriptions of the experience. Descriptions of fatigue were related to energy depletion that resulted in physical and mental immobilisation. In addition to being a core symptom, fatigue was related to the presence and intrusiveness of other symptoms, as demonstrated by the reported relationships between increased fatigue and deterioration of symptoms.

CFS-fatigue was perceived to be abnormal because of its greater intensity and persistence when compared with the fatigue experienced prior to CFS. Consistent with these differences, the recovered participants described how their post-CFS-fatigue was markedly different from their CFS-fatigue. Participant 17R, in discussing her meaning of fatigue, drew attention to a difference between CFS-fatigue and her recovered-tiredness.

But it's [CFS fatigue] not fatigue like feeling tired. It's fatigue like I feel like lead. It's somewhat different. 'Cause now I'm tired, but that's different.

Further, unlike “normal fatigue” (that is, before CFS), rest did not ameliorate CFS-related fatigue. Consequently, when participants referred to fatigue they meant something qualitatively different to the definitions of most people.

Crippling fatigue to the extent that I can't move my legs, can't sit. I still have to lie for about six hours everyday . . . My legs go totally dead . . . I can't be moved. (Participant 12)

You become that tired, it's an effort to get up and walk from one place to another. It's not [like] the fatigue you get after a heavy physical day . . . It's
an effort to even walk from one leg to another. That's the tiredness you get. People don't understand that . . . you become that tired, your mental state, you become fuzzy in the head and you've just got to get up and go and leave them. (Participant 9)

This difference in definition and meaning of fatigue for people with CFS has been reported in other research (Cooper, 1999). Fatigue seeped into every part of their being and was so overwhelming and pervasive that it defined the participants (always tired). The ability of fatigue to be so life changing that identity is altered has been noted in other research, for example, among women with HIV/AIDS (Stevens, 1996).

While pain, neurocognitive symptoms and fatigue were cited as the most troublesome, participants experienced numerous ongoing or intermittent symptoms. These included pharyngitis, dizziness, arthralgia, muscle spasms, anorexia, nausea, gastrointestinal disturbances, disrupted circadian rhythms and sleep disturbances, photophobia and visual disturbances, numbness, chemical sensitivities, food intolerance, chest pain, loss of balance, and emotional lability. Many of these symptoms (including the core) are found with flu and viral illnesses. Indeed, when participants tried to explain to others what CFS felt like, they most often replied that it was like the worst flu that never goes away. This response was consistent among participants and is an important insight into the symptomatic experiences of CFS.

**Diagnostic Experiences**

Diagnosis was a protracted process, commonly lasting years. Consequently, the illness biographies included reports of long periods when participants were without a diagnosis, during which they had either no label or a variety of provisional and non-specific diagnoses. The absence of a diagnosis was harmful to participants - they inadvertently worsened their symptoms by attempting to resume their normal lives and they were judged to be engaging in abnormal illness behaviour. Diagnosis required many consultations with medical practitioners and a multitude of tests that generally failed to detect abnormalities. There was hesitancy by some medical practitioners to diagnose CFS and obtaining written confirmation was particularly difficult. The diagnosis of CFS involved relief and distress for the participants.
Between the years of 1982 and 2000 participants had received a diagnosis of CFS. Prior to 1988, however, and before the introduction of the name “Chronic Fatigue Syndrome”, diagnoses were made as myalgic encephalomyelitis or post-viral syndrome. Five participants had received one of these labels prior to 1988 and considered that to be their point of diagnosis because the term “CFS” represented a name change and not a change of the diagnosis in itself. Table 8 shows the participants’ reported dates of CFS diagnosis.

Table 8: Year of CFS Diagnosis

<table>
<thead>
<tr>
<th>Year</th>
<th>n</th>
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<tbody>
<tr>
<td>1982</td>
<td>1</td>
</tr>
<tr>
<td>1983-1985</td>
<td>2</td>
</tr>
<tr>
<td>1986-1988</td>
<td>2</td>
</tr>
<tr>
<td>1989-1991</td>
<td>5</td>
</tr>
<tr>
<td>1992-1994</td>
<td>4</td>
</tr>
<tr>
<td>1995-1997</td>
<td>2</td>
</tr>
<tr>
<td>1998-2000</td>
<td>3</td>
</tr>
</tbody>
</table>

Diagnosis was typically a difficult, prolonged and complicated experience. The number of years between onset of symptoms and diagnosis ranged from the same year to 49 years, with a mean of 7.8 years. These data are shown in Table 9.

Table 9: Number of Years between Onset and Diagnosis

<table>
<thead>
<tr>
<th>Number of Years</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same year</td>
<td>5</td>
</tr>
<tr>
<td>1-2 years</td>
<td>5</td>
</tr>
<tr>
<td>3-5 years</td>
<td>3</td>
</tr>
<tr>
<td>6-10 years</td>
<td>2</td>
</tr>
<tr>
<td>11-20 years</td>
<td>2</td>
</tr>
<tr>
<td>&gt; 20 years</td>
<td>2</td>
</tr>
</tbody>
</table>

While 10 participants were diagnosed within 2 years of onset, 9 participants remained undiagnosed with CFS for more than 2 years, despite the development of
classifications. Six of these 9 participants (including 2 of the recovered participants) waited for a diagnosis from 4 to 11 years after publication of the 1988 CDC classification (Holmes et al.), with a mean of 6.5 years. Given that the publication of this classification placed CFS in the medical arena, it is unlikely that ignorance of the diagnosis was the only or primary reason for non-diagnosis. Indeed, a number of participants encountered medical practitioners who knew of CFS but were reluctant to label the symptoms as CFS or to accept the diagnosis of CFS made by other medical practitioners. After a decade, Participant 18 still encountered what could be called diagnostic resistance from her medical practitioner.

One of my old doctors, she still believes I've still got post-viral fatigue. And I said “I've had this for ten years and I've been to chronic fatigue specialists” and she says, “but it's all in your mind. You've got to get over it”.

In a few instances, participants had received a verbal diagnosis but found a written diagnosis difficult to obtain.

I needed a written diagnosis for work to get leave, more sick leave, and then to apply for the super and I had trouble getting a written diagnosis.

(Participant 7)

The failure of medical practitioners to provide written confirmation of the diagnosis excluded participants from social and institutional assistance. Participants were in the invidious position of being diagnosed with a condition that the medical practitioner was not prepared to confirm formally.

During the years when participants were undiagnosed with CFS, they commonly received no other diagnoses or, at separate times, different fatigue-related diagnoses including glandular fever and reoccurring flu.

. . . it didn't have a name then. It was just - this is what I've got now.

(Participant 2)

Garro (1994) found a similar outcome among people with temporomandibular joint dysfunction (TMJ). Like CFS, TMJ is a contested condition. Prior to their difficult and lengthy diagnosis of TMJ, Garro’s participants were also given alternative diagnoses or were told nothing was wrong. Additionally, prior to the diagnosis of CFS participants commonly received medical advice that they, in retrospect, believed
had worsened their condition. Participant 13 followed recommendations, only to find herself more incapacitated.

You have all the doctors say “lose weight, exercise, walk for three miles everyday” and . . . I think in the early stages if I hadn’t pushed myself so hard, I probably wouldn't have fallen as hard either. Because I kept saying to myself “you'll work your way out of this” . . . the more I pushed myself, pushed hard, you'll get through it, till in the end I was bed bound.

The absence of a CFS diagnosis was reported as harmful because participants attempted to resume or continue their usual life. Pressure to do so came from medical practitioners, family, friends, and work colleagues, in addition to being self-generated (partly as a response to the perception of others that the participants were engaging in abnormal illness behaviour). The effects were an exacerbation of symptoms and an inability to manage the practicalities of daily life.

Without a diagnosis participants were left in an explanatory void. The consequences were significant. For example, sick leave from work was perceived as unjustified, and participants found themselves ineligible for welfare assistance. They were also subject to negative labeling, such as *malingering* or *hypochondriac*. Diagnosis remained an important goal and the (sometimes intermittent) pursuit of diagnosis continued. Many participants lived for many years in this diagnostic limbo.

In their pursuit of diagnosis participants experienced misdiagnosis, multiple medical consultations, and numerous and predominantly insignificant test results that were commonly repeated by different medical practitioners. Medical explanations of “you're healthy” or “we can't find anything wrong” typified the pre-diagnostic period, such as that received by Participant 4.

*I'd be sent, all these different specialists and all these different tests and they come back and “Oh, you're healthy, [the tests are] negative” . . .*

There is some evidence to suggest that repeated and numerous normal tests results are not necessarily reassuring to people experiencing symptomatology. Meadows, Lackner and Belic (1997) found that among people with irritable bowel syndrome, normal findings from a multitude of tests were associated with an atmosphere of uncertainty. Mushlin, Mooney, Grow and Phelps (1994), in a study of people with
suspected multiple sclerosis, reported that participants for whom no definitive
diagnosis emerged became anxious rather than reassured by their negative results.
My study found that the predominantly normal tests contributed to the anxiety and
desperation felt by most of the participants in the months after onset, thus
corroborating the findings of Meadows et al. (1997) and Mushlin et al. (1994).

The diagnostic experiences of the participants were typical of that reported in the
CFS research. The long diagnostic delays, numerous medical consultations, mostly
normal tests, and the hesitancy of some medical practitioners in ascribing CFS as a
verbal and/or written diagnosis were consistent with several well established findings
(Cooper, 1997; Prins et al., 2000; Woodward et al., 1995). Studies of other contested
illnesses (Garro, 1994; Meadows et al., 1997) also report the need for participants to
pursue a diagnosis.

There were varying degrees of relief associated with the CFS diagnosis. Diagnosis
reaffirmed the participants’ beliefs that there were reasons for their bodily
experiences, helped legitimise their status as a “patient” (to some extent), relieved
anxiety, and provided a source of validation.

\[\text{When it was confirmed that I had CFS I thought “well, at least I know what I’ve got and there is something the matter with me. I just don’t feel awful for no reason”. (Participant 7)}\]

\[\text{. . . what she did say was I had CFS . . . and that my history plus negative tests adds up to the diagnosis so that gave me something to hold on to and Oh, okay I’ve got a name. (Participant 2)}\]

However, participants also reported diagnosis as a mixed experience, both validating
and threatening. The relief of diagnosis was sometimes short-lived and tempered by
the confirmation of chronicity, the effects of the condition, the limitations of
treatments, and the stigma. Participant 19R found her relief was muted by the
chronic nature of the diagnosis.

\[\text{I finally had an answer to what was wrong, so I had mixed emotions. I was sort of happy, yippee, and then all of a sudden this was something that won’t}\]
go away so it was really. *I mean I was happy, over the moon, that at least there was something wrong. I wasn't crazy.*

Diagnosis for Participant 3 was associated with psychiatric labeling and an absence of treatment.

*I went to the psychiatrist and he diagnosed me with it, did tests of me . . . He basically said, “there's nothing I can do for you really, the only thing I can do for you is put you in the psychiatric ward” and I said, “no thanks very much”.*

Additionally, while CFS did provide the general benefits of a diagnosis, CFS as a specific diagnosis was also felt by participants to be disreputable and disputed, bringing with it further stigma.

The findings of the present study were consistent with previous CFS research that has found non-diagnosis to be harmful and diagnosis to be predominantly legitimating, enabling and a turning point that provided meaning and structure, in spite of the ambiguity surrounding the condition of CFS (Clarke, 2000; Cooper, 1999; Woodward et al., 1995). My study is also supportive, however, of reports that diagnosis with CFS is associated with negative effects such as distress related to the verification of its chronicity, the lack of treatment and the undesirable long term consequences, in addition to positive outcomes (Ax, Gregg, & Jones, 1997; Cooper, 1999; Hyden & Sachs, 1998).

The diagnosis of CFS was an important step in the illness biographies of the participants because it signified entry into a social and personal space characterised as illness. Nevertheless, while participants now had a medically sanctioned label, others, including medical practitioners, viewed that label with suspicion and scepticism. They inhabited a contested social space, compromised in their ability to operate satisfactorily in “normal” social relations as well as continuing to suffer physically with a contested medical condition.

**Becoming Impaired**

The onset of CFS symptoms had impaired the participants. As is the case for most people with a flu-like illness, participants had trouble fulfilling their roles and
responsibilities and did not feel well enough to do so, but expected these functional limitations to be temporary. With time, their illness biographies were typified by impairment, which became a source of grief for the participants.

Although there was functional variation at the time of the interview, at some point most participants had experienced marked impairment that radically limited their lives and necessitated assistance from others (the exceptions being the recovered participants who reported a moderate level of impairment while ill). Most participants continued to experience significant impairment that affected their ability to work, maintain relationships, participate in interests and fulfil their range of roles. Participant 12 described her devastating degree of impairment.

*It [CFS] stopped me doing practically everything, everything physical. It made me slower and less effective most of the time in mental matters and I have been removed from my social milieu. I have been forced to live like a recluse and that's because of disability and fatigue and environmental factors.*

Impairment was felt as a total experience and participants identified cognitive, emotional and behavioural impairments in addition to physical.

The marked functional impairment described by participants was consistent with other research that finds CFS to be associated with considerable impairment when compared to the general population and other illness groups (Anderson & Ferrans, 1997; Hardt et al., 2001). The present study corroborated previous findings (Buchwald et al., 1996; Hardt et al., 2001) that impairment was particularly evident in social and role domains.

The loss of the working role illustrates the evolution of increasing impairment that was a major component of the illness biographies and provides a salient example of how CFS disrupted taken-for-granted activities and abilities. It also demonstrates the struggle of participants against impairment. It is therefore discussed in detail. All participants were engaged in paid work or study at onset. The majority had left employment earlier than expected or had substantially reduced their work or study
commitments as a result of the symptoms. Table 10 shows the participants’ work status at the time of interview.

Table 10: Work Status

<table>
<thead>
<tr>
<th>Work Status</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time employment</td>
<td>P17R; P19R</td>
</tr>
<tr>
<td>Part-time employment</td>
<td>2</td>
</tr>
<tr>
<td>Home duties/Parenting</td>
<td>1</td>
</tr>
<tr>
<td>Full-time student</td>
<td>P5R</td>
</tr>
<tr>
<td>Part-time student</td>
<td>1</td>
</tr>
<tr>
<td>Retired or unemployed due to CFS</td>
<td>9</td>
</tr>
<tr>
<td>Retired due to other reasons</td>
<td>1</td>
</tr>
</tbody>
</table>

Although 13 participants (68%) were under the age of 55 years, only 4 were engaged in full-time employment. Two of these employed participants believed that working full-time was detrimental to their health but they were financially compelled to do so, while the other 2 working participants belonged to the recovered group. The third recovered participant was a full-time student.

Prior to their illness participants had strong work histories, or in the case of onset in early adulthood, expectations and plans for personally fulfilling work. Participants tried many strategies to extend their working life. They utilised sick, annual and long service leave, reduced their hours on site and took work home, switched from full-time to part-time, changed to less responsible positions, and adopted short cuts in order to maintain their employment. Participant 13 used all her leave options until the only course of action left was resignation. She has not been able to return to work.

*Then I took sick leave, and then I took long service leave and once all that was used up I went to four days a week with one day's leave without pay till eventually I had to stop work altogether. That was at the end of 1990 that I stopped working.*

There were also fears of dismissal related to diminished performance, disrupted work patterns, or extended sick leave.
The future of my job had been hanging over my head for some time . . .

(Participant 2)

In some instances employers did exert overt and covert pressure that eventuated in participants leaving work. Participant 16 felt bullied out of his employment.

I was sick for six months and that is why they got rid of me ’cause they said to me “Oh, you haven’t had any sick days in ten years”. I was seventeen and a half years in the bank. And in seventeen and a half years I had twenty sick days and in that last year I had forty and they said, “you’re just pulling us along now so we’re going to give you a redundancy package, see you later”. I didn’t have a choice. I mean I had a choice, I could have fought it but I couldn’t be bothered . . . they would have just found some way to get rid of me.

Participant 15, a cardio-thoracic nurse, left work when she realised she was no longer capable of safe practice.

I stopped working as a nurse ’cause I was cardio-thoracic trained. I’d turn round and couldn’t recognise anything on the monitor. I just couldn’t twig what was going on, and because I realised I was putting people in danger.

Efforts to remain in the workforce were commonly associated with financial need, with some participants extending their working life beyond what they felt to be best for their health. Participant 1, a single woman, continued working in order to keep her home.

When I initially got sick and was off on sick leave for a long time, that freaked me out because of the sole income trying to pay my mortgage. So I guessed what that did was that forced me back to work at a time when I should not have been there and so I was fighting, fighting, fighting . . . that didn’t help me.

Participant 8 had a large family to support and saw no option but to continue working.

But we’ve got four sons and I had no choice. I had to make a living for them. Participants also cited self-fulfilment, job satisfaction and career plans as reasons for their attempts to maintain their working role. Even though participants generally left
work in difficult circumstances, giving up work was initially viewed as temporary and the length of time that participants had been unable to work was unexpected.

Although it was found to be a struggle the recovered participants were able to continue with work and education while affected by CFS.

\[ I \text{ was still getting the job done. It was just hard to do. Like someone would be talking to me and I'd be looking at them and not really seeing them and not really hearing them but still doing my job. (Participant 17R)} \]

Typically the pattern for recovered participants was one of intermittent sick leave, a reduction in hours for a number of months and a return to full-time work or school. The recovered participants restricted all other activities to protect their ability to work (or study).

The work status of participants was reflected in the income source that indicated degrees of financial dependency. Table 11 shows the participants’ primary income source at the time of the interviews (excluding those recovered).

**Table 11: Income Source**

<table>
<thead>
<tr>
<th>Income Source of Affected Participants</th>
<th>n (16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Security</td>
<td>7</td>
</tr>
<tr>
<td>Employment</td>
<td>2</td>
</tr>
<tr>
<td>Superannuation</td>
<td>2</td>
</tr>
<tr>
<td>Family/Spouse/Partner</td>
<td>2</td>
</tr>
<tr>
<td>Savings</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
</tbody>
</table>

Most participants had sustained substantial financial losses (actual and potential). The experiences of Participant 3 reflected the downgrading and loss of lifestyle that was typical, particularly those participants without earning partners.

\[ I \text{ probably went through about 100, 000 dollars in that time that I had saved. I had to sell the house, so I lost the house and downgraded to a unit and lost a lot of money . . .} \]
Some participants had already exhausted their assets and were dependent on social security, spousal support, or a combination of sources. The income source for recovered participants had remained mostly unchanged while affected by CFS.

The considerable difficulties in sustaining a working role was consistent with research reporting that many people affected with CFS are unable to work and that among those still working, there is a marked decrease in participation in full-time work (Friedberg et al., 2000; Tuck & Wallace, 2000). While other studies have quantified the work impairments associated with CFS (for example, Vercoulen et al., 1994), the present study describes the extent of the participants’ efforts to continue working, the multitude of strategies used, and the desperation of participants to retain their employment, in addition to their financial burdens. The stories of the participants’ employment did not support the stereotypes of people with CFS as lazy or malingering, but rather, reflected a strong desire to keep working, a tenacity of effort, and a sense of diminishment when their working roles were relinquished.

Becoming impaired was a significant factor in the chaos associated with CFS and in the illness biographies because it required participants to seek help from individuals and institutions in managing and enduring CFS. Encounters with medical and other health practitioners were crucial to the ways that participants came to manage and endure the symptoms of CFS.

**Medical and Health-Related Encounters**

The illness biographies included substantial (although not ongoing) use of medical and health-related facilities, treatments and services. What was clearly evident from the participants’ accounts was the speculation regarding them as individuals that arose from the scrutiny and surveillance of medicine and medical practitioners. Very little benefit, however, had resulted from this medical gaze. Encounters had not elicited treatments or effective ways to minimise the symptoms, advice received had sometimes been damaging, and participants were left with the impression that they and their condition were of little ongoing interest to the practice of medicine and medical practitioners. The dissatisfaction with medical encounters that was
expressed by the participants in the present study has been reported widely in the research on CFS (Deale & Wessely, 2001; Twemlow et al., 1997).

Consultation with medical practitioners had been intense and widespread during the early stages of the condition, and may or may not have resulted in diagnosis. The use of other health practitioners generally occurred as the use of medical practitioners decreased. While participants recognised that CFS posed clinical difficulties for medical practitioners, unsatisfactory encounters were common and arose from structural and interpersonal factors. Satisfactory encounters were less common. Participants saw themselves as responsible for their health and were desirous of collaborative relationships with their medical practitioners. These points are addressed separately.

Participants consulted a wide range and multiple numbers of health practitioners both medical and allied, in order to find a diagnosis, treatment and care. The mean number of individual medical practitioners consulted by each participant was 4.3, with 3.6 individual allied health practitioners consulted. In other words, each participant had consulted an average of 7.9 different health practitioners regarding CFS. Allied health practitioners consisted of paramedical practitioners (such as physiotherapists and counsellors) and alternative practitioners (for example, acupuncturists and naturopaths). (The term “alternative” is used, rather than “complementary”, because of its use by the participants). Joske defined alternative medicines as those that “reject the factual and intellectual basis upon which orthodox medicine rests, and accept different central dogma or techniques upon which healing is considered to depend” (1987, p. 3). This combination of traditional medicine with alternative therapies is not unusual among people with chronic or life threatening illnesses, or with symptoms that have proven difficult for medical management. Montbriand (1995), for example, reported that 81% of 300 people with cancer were using an alternative therapy in conjunction with orthodox medical treatments.

Slightly more medical practitioners were consulted than allied health practitioners, with the pattern of utilisation altering with time. Various medical specialists were consulted prior to diagnosis, with general practitioners, and to a lesser extent, CFS
specialists providing ongoing management. Over time consultations with medical practitioners decreased. Table 12 shows the number and type of medical practitioners consulted.

Table 12: Type of Medical Specialists Consulted

<table>
<thead>
<tr>
<th>Medical Specialist</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practitioners</td>
<td>18</td>
</tr>
<tr>
<td>CFS specialist (may belong to other categories)</td>
<td>16</td>
</tr>
<tr>
<td>Immunologist</td>
<td>13</td>
</tr>
<tr>
<td>Allergist/ Environmental specialist</td>
<td>11</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>10</td>
</tr>
<tr>
<td>Neurologist</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
</tr>
</tbody>
</table>

The use of alternative practitioners commonly arose as a response to the scepticism and the limitations of orthodox medicine in treating CFS and from the need to find symptomatic strategies. However, while most participants had received therapy from alternative practitioners at some time, few had sustained their usage. A wide variety of therapies and allied health professionals were consulted. Table 13 shows these data.

Table 13: Type of Allied Heath Practitioner Consulted

<table>
<thead>
<tr>
<th>Type</th>
<th>n</th>
<th>Type</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acupuncturist *</td>
<td>11</td>
<td>Dietitian/Nutritionist</td>
<td>4</td>
</tr>
<tr>
<td>Naturopath *</td>
<td>11</td>
<td>Kinesiologist *</td>
<td>2</td>
</tr>
<tr>
<td>Psychologist/Counsellor</td>
<td>9</td>
<td>Chinese Herbalist *</td>
<td>2</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>7</td>
<td>Chiropractor *</td>
<td>2</td>
</tr>
<tr>
<td>Dentist</td>
<td>7</td>
<td>Reflexologist *</td>
<td>2</td>
</tr>
<tr>
<td>Social Worker</td>
<td>5</td>
<td>Osteopath *, Massage *, Optometrist</td>
<td>3</td>
</tr>
<tr>
<td>Homeopath *</td>
<td>5</td>
<td>Key *</td>
<td>alternative</td>
</tr>
</tbody>
</table>

The large numbers of practitioners consulted initially, the gradual withdrawal from medical services, and the use of alternative practitioners to compensate for the lack of perceived medical support was consistent with other research on CFS (Ax et al.,
Similarly, research on contested illnesses have reported consultations with numerous medical practitioners (for example, Garro, 1994). Fahey (1999) proposed that people with ambiguous symptoms seek an explanation to gain validation, and consequently consult with many medical practitioners.

Consultations between participants and medical practitioners had been, or were, associated with participant dissatisfaction and with difficulties arising from encounters, health structures and the biomedical model. Factors that contributed to unsatisfactory medical encounters included specialisation, the need to see multiple medical practitioners, disbelief, medical disinterest, lack of knowledge, barriers to and exclusion from social services, and iatrogenic effects. These factors are consistent with previous reports in the CFS research (Cooper, 1999; Deale & Wessely, 2001; Prins et al., 2000). Each of these factors is discussed.

Participants had felt compelled to consult with multiple specialists regarding diagnosis and with numerous general practitioners regarding ongoing care. Yet dissatisfaction was experienced with the reductionism inherent to this process. Participant 15 spoke of her need to be treated as a whole.

\[\ldots you have one who'll do little bits of you and you can't do bits of you with ME, you've got to do the whole lot. You're not just treating a bit. And that's what I needed.\]

The participants’ experiences of CFS as holistic and their dissatisfaction with the more reductive medical approach has been recently reported in other CFS research (Banks & Prior, 2001; Cohn, 1999). As new practitioners were consulted, the repetition of one's medical history, the uncertainty associated with the responses of the ‘untried/unknown’ medical practitioner to a patient with CFS, and the ongoing tests (sometimes repeats of earlier tests) proved to be frustrating, costly and tiring. Participants felt that general practitioners were unaware of the degree to which visits to specialists drained their personal resources, notably energy and finances. Similar findings regarding multiple tests were reported by Meadows et al. (1997) in a study of 14 participants with irritable bowel syndrome (IBS) who also reported frustration with the plethora of tests. Further to the findings of Meadows et al., while the
participants in the present study were frustrated with the need for ongoing tests, it was the repetition of tests that angered them.

When participants experienced symptoms for extended periods of time that did not respond to treatment and when tests were fundamentally normal, consultations with medical practitioners became strained and participants encountered disbelief on the part of specialists regarding the veracity of their symptoms. Other studies of contested conditions corroborate the participants’ experiences of being disbelieved by their medical practitioners (Peters, Stanley, Rose, & Salmon, 1997; Rhodes et al., 1999). Disbelief was further demonstrated by the shift in medical explanations from a physical to a psychological perspective.

_They did a blood test, everything is clear so it's got to be in your head, that's their attitude . . . I've been going to him for something like fifteen years . . . In the end he said, “Oh, it's in your head” . . ._ (Participant 9)

_His attitude was [that] there is nothing wrong with you._ (Participant 1)

Other research on contested conditions has reported this explanatory shift. Garro (1994) found that prior to the diagnosis of TMJ, when nothing could be identified as physiologically wrong, patients were presented with psychological models as explanations of their symptoms. This shift in explanatory focus appears to be the institutional response of medicine to an absence of pathology. Richman et al. (2000) reported that after the failure of researchers to demonstrate a causal link between Epstein Barr virus and CFS, there was a major paradigm alteration from biomedical to psychiatric/psychological explanatory research. These findings reflect the continuing influence of Cartesian dualism on medicine, and in particular, on the diagnostic process. That is, what cannot be detected in the body must be a manifestation of mind. To a large extent, participants in the present study shared this dualistic tenet of mind/body split, as evidenced by their beliefs that symptoms felt physically were symptoms of the body.

Over time, participants felt that some medical practitioners lost interest in their individual cases. A minority encountered a medico-initiated termination of their relationship. The inability to treat the symptoms was cited as the reason given by
medical practitioners for ceasing clinical care, however, participants believed they had become too boring or frustrating for the clinicians. Participant 3 believed that lack of improvement was the basis for her medical practitioner ending their clinical relationship.

*My first GP, the one that I had for ten years, told me to go away basically when I didn't get better.*

Participants came to the conclusion that many medical practitioners would prefer not to treat CFS patients. Additionally, participants reported consultations with medical practitioners that indicated a lack of knowledge about CFS, minimal interest in learning, or little understanding of the suffering involved.

*He [GP] knows nothing about chronic fatigue. He's made no effort to learn anything.* (Participant 13)

There were difficulties in accessing and negotiating health, social and community services. Difficulties arose from the organisation of services that resulted in barriers to care. Additionally, symptom variability resulted in services (such as *Home Care, Meals on Wheels,* or outpatient clinics) being required intermittently and for different periods of time. Services were not equipped for flexibility and participants felt their needs were lost in the service gaps. Participants were also excluded from financial aid or disability benefits (similarly reported by Cooper, 1997). This exclusion was most evident when the participants were without a written diagnosis, however, a written diagnosis and medical certificate were not necessarily sufficient. For example, prior to illness onset Participant 13 had worked in an environment that exposed her to large doses of glutaraldehyde, which she believed to be the trigger for the onset of CFS. When she applied for financial aid after becoming too ill to work, she found that different bureaucracies interpreted her medical records and documentation in such a way as to forgo a payout.

*I applied for superannuation on a total and permanent payout as well as for worker's comp. And the worker's compensation people knocked me back on the grounds that I had chronic fatigue syndrome, which wasn't work related. The superannuation people knocked me back for total and permanent pay-out on the grounds of glutaraldehyde and if I found another job I'd be right as a bank and I could do anything I like and therefore it wasn't a permanent*
disability... So it suited the superannuation to say I had a work-related injury and it suited worker's comp to say that I didn’t.

In this instance, government bodies used the medical ambiguity of CFS in an exclusionary manner that disadvantaged the participant and resulted in serious financial consequences. Additionally, there were risks and iatrogenic effects associated with medical treatments. Participant 12 received medical advice that she believed was detrimental to her health.

I saw Doctor X and he said, “I know what's wrong with you, but there's no treatment and there's no cure so you might as well get on with life as best you can”. And that was probably the worst advice I could have possibly been given.

Featherstone (1998) reported that people with CFS derived benefits from alternative therapies. These benefits arose from the validation of the symptoms. Generally, the participants of the present study did not report significant benefits associated with alternative therapies. Although there were a few exceptions involving specific therapies or practitioners, alternative treatments were mostly associated with risks. They frequently involved high and ongoing monetary costs, and a few participants reported that alternative practitioners had taken financial advantage of their ill health. Compliance was often demanding, and for the majority of participants there were questionable or no results despite the common predictions of improvement made by the practitioners. Definitive claims of cure from individual practitioners or by the manufacturers of treatments were generally viewed with suspicion.

I started ringing up fruitcakes, going to naturopaths, all these cures, “yes, yes we can cure chronic fatigue” and then they’d have to admit later they can’t cure it. The body actually cures chronic fatigue when it's ready. They can only help the body. (Participant 16)

Nevertheless, despite reservations participants had utilised a wide range of alternative practitioners and treatments for CFS. They perceived this as a function of their desperation.

Some aspects of the participants’ experiences of alternative treatments have been reported elsewhere. While high costs and fraudulent claims have been identified as
risks of alternative therapies (Lubkin, 1990), the general absence of benefit found in the present study is difficult to evaluate because research has reported mixed findings on the effectiveness of alternative therapies (Montbriand, 1995). Participants in the present study were seeking a cure or significant symptom relief. Some had commenced therapies with optimism, others with scepticism – regardless, little benefit was reported by most participants. They were looking for physical healing and it did not eventuate, therefore the alternative therapies were judged as ineffective. Alternately, a qualitative study of people with different chronic illnesses (none of which was a contested illness) reported that, compared with conventional treatments, the greatest relief and healing was derived through alternative therapies because they facilitated an integration of mind, body and spirit (Lindsey, 1997). In contrast, the participants in the present study were seeking something more concrete – physical relief – and the failure of alternative therapies to make a difference limited their continued usage.

In response to difficult medical encounters, most participants ceased to report new symptoms, dropped out of the medical system and limited consultations with practitioners to annual checks or to the treatment of other conditions. This illness behaviour is not consistent with hypochondriasis or somatisation where there are commonly frequent and ongoing consultations with medical practitioners.

While negative medical encounters were common, the majority of the participants also described satisfactory experiences with medical practitioners.

_The experience of medical practitioners was very, very negative. Except when you hit the good ones . . . I've had some good experiences, some very good experiences . . ._ (Participant 15)

Satisfaction with medical interactions was related to the participants’ judgment of medical practitioners as “good”. Actions or attitudes of medical practitioners that generally validated the participants’ perceptions, experiences or values defined the “good” medical practitioner. There was marked agreement of the importance of being believed by their medical practitioners. Being believed was a legitimating experience. Participant 1 felt supported by the belief of her practitioner that she was ill.
the GP was really good ‘cause he said “it's not in you head, something is happening, and we'll get to the bottom of it” [speaking through tears].

There were differences, however, in what constituted “being believed”. For some participants this required an affirmation that CFS was not a psychiatric condition but had a physical cause. For others, being believed meant CFS was considered a unique illness rather than an atypical presentation of something else. For a few, such as Participant 3, the medical practitioner’s belief that the participant was ill, rather than a belief in CFS, was sufficient.

*He didn't believe in CFS I don't think, ever, but he actually realised I was ill.*

. . . whenever I asked him he thought part of the cause was psychosocial . . .

*and I think he always thought I was a bit nuts . . . But he took my symptoms seriously too because he could see I was ill.*

Similarly, Clarke (2000) found that among CFS patients “being believed” was a characteristic of a “good” medical practitioner, although the study did not define what constituted “being believed”. It has also been reported that legitimation of CFS, either through diagnosis or being believed, was considered by 52% of participants to be the most helpful act of their physician (Lehman et al., 2002).

Other characteristics associated with a “good” medical practitioner included a willingness to listen, learn and try different strategies. Respect, support and availability were also considered important. A medical practitioner with personal experience of CFS was seen as an ally with a special understanding. Most participants found it helpful for medical practitioners to acknowledge what is not known about CFS and the treatment limitations. Participant 9 considered himself fortunate to have a doctor willing to address his many symptoms while acknowledging the limits of medicine.

* . . . he's been very, very good . . . he's trying to alleviate the symptoms but he was one of the few doctors who said straight out “look, we haven't got a clue” and these other people won't say it.*

Participants valued practitioners and medical encounters that did not leave them feeling disempowered. Additionally, although participants were referring to characteristics found in the medico/patient relationship, there were comments that suggested these qualities were desirable to any clinical relationship. The
characteristics of a good medical practitioner and satisfying medical encounters reported in the present study are consistent with research, both on CFS (for example, Deale & Wessely, 2001) and other conditions. In their study on back pain, for example, Rhodes et al. (1999) reported a willingness to look for causes and solutions, the ability to work with the patients, and the ability to say, “I don’t know” as characteristics of good practitioners.

Participants believed they had a personal responsibility for their health and were generally desirous of a collaborative relationship with their medical practitioners. Participant 1 considered that greater collaboration could have resulted in her achieving better outcomes sooner.

_We also hold a responsibility ourselves to search and try and find answers and get information, but so what I'm saying is maybe between the GP and I, if he had known a little bit more about CFS and then with my desire to find out about different things, I could've actually reached the point of managing things better, sooner._

Similarly, Meadows et al. (1997) found that participants with IBS also desired collaborative relationships with their medical practitioners in conjunction with assuming personal responsibility. Participants in the present study recognised the workload and skills of medical practitioners and the limits of CFS research. They nevertheless expected medical practitioners to provide respectful care and believed that this expectation was within professional parameters.

_Okay, somebody comes in with sore throats for a period of eight years. Instead of actually trying to find the problem, whether the patient comes in with psychological problems it doesn't really matter, your professional issue is how to deal with this patient._ (Participant 4)

During the interviews, participants recalled many medical (and to a lesser extent, other health-related) encounters that had been fraught with difficulty and conflict. Participants sought out medical practitioners (and later, alternative therapists) to make sense of their symptoms, to sanction and legitimate their illness, and to provide treatment. They frequently found, however, that their symptoms were doubted, their diagnosis was of dubious legitimacy, and there was no treatment. The participants
perceived that medicine and its practitioners were mostly unable or unwilling to care for people with CFS. For those who had found supportive practitioners, their sense of gratitude was large.

**Progression of Symptoms**
The illness biographies were typified by uncertainty and changing expectations regarding outcomes. The anticipated acute duration with recovery did not eventuate. Instead, participants faced a chronic illness of uncertain outcome. During the years when participants lived without a diagnosis, their symptomatic outcome was even more uncertain. It was difficult for participants to recognise that the illness was chronic. The course of the illness was one of slow improvement and stabilisation, and symptom intrusiveness and functional impairments tended to plateau. Fast relapses and slow improvement typified the course. Expectations of recovery varied among the participants.

With the exception of those who experienced a severe onset, participants expected the trajectory of their initial symptoms to involve medical treatment and a reasonably fast return to health. The difficulty experienced by Participant 14 in recognising the chronic nature of the illness was typical.

*Initially, I thought, I'll be better in, after three months, six months. I thought maybe in a year and then I think the first five years, I thought I'll gradually get better. And so I never really thought it would go on for a long time... Then I think I probably did too much and then it went down... I never thought it would go on. I was always thinking I would be better in a few months.*

Diagnosis provided, by definition, verification of its chronic nature. However, given the years without diagnosis that was typical for the majority of the participants, chronicity was also inferred from the continuation of the symptoms and the passing of years.

When compared with the early years, participants reported that improvement or a stabilisation of the condition had occurred. CFS was felt as constant (that is, to varying degrees the symptoms were always present), but typified by remissions and
relapses. Remissions did not infer that there were periods of wellness but referred to some improvement in symptoms. Similarly, stabilisation implied less unpredictability rather than no unpredictability. When improvement occurred it tended to be modest, slow, and difficult for participants to detect given the chronicity, changeable symptoms and daily variability. When a certain level of wellness (or illness) had been present for some time, participants hoped that vigilance and care would maintain that level. Episodes of improvement, however, were also associated with an increase in activity and the (frequently realised) risk of deterioration. Overall, the pattern was one of fluctuations (mostly slow improvement and relapses) and stabilisation to the time of the interview.

Each relapse was associated with disappointment. Participant 6 described the grieving and adjustment that occurred.

... and then you start to come good and come out of it. Next relapse, back to square one. Every relapse it goes back to square one.

With experience participants were better able to tolerate the symptoms and relapses because they were known to pass or at least to change.

Now I know that they'll come to an end... they won't continue. Like if I have bouts of severe illness now, I know that the time is shorter. (Participant 3)

Additionally, participants developed strategies to lessen the impact of the symptoms. However, the ability to manage the condition was affected by the capriciousness of the symptoms and its relapsing nature. Even after many years participants continued to seek out ways for managing the symptoms.

With the exception of Participant 9 who had doubts that anyone recovered from CFS, the CFS-affected participants believed that recovery was possible (if unlikely) and had heard of or known people who had recovered. Nevertheless, there was marked variation in their beliefs regarding the probability of personal recovery. For some participants the belief in recovery did not necessarily include their personal situation, while for others recovery remained an active goal.

The participants’ symptomatic progression reflected the experiences of the CFS population as described in the research. The present study was consistent with
findings that the course of CFS was variable rather than constant (Dougall et al., 1998) and the difficulty described by participants in detecting improvement has been reported in previous work (Woodward, 1993).

**Recovery**

The illness biographies of 3 participants included self-reported recovery. While ill with CFS, the participants who had recovered showed a similar progression to the other participants but were less severely affected. Their perceptions of recovery were based on the resumption of desired activities. The recovery periods were relatively recent, ranging from 12 months to 2 years, and participants held different reasons for their recoveries.

The progression described by these participants suggested that their overall experience of CFS was less severe than for the affected participants who continued to be symptomatic. Additionally, there were differences in the self-reports of severity between the recovered participants. Participant 19R rated her previous CFS condition as *quite severe* while Participants 5R and 17R did not consider themselves to have been severely affected. Regardless, the recovered participants described less symptom intrusiveness and functional impairment when ill than the affected participants. While the recovered participants described a similar pattern of slow improvement and relapses, their improvement was more sustained and the relapses less severe. As with the affected participants, recovered participants had found it difficult to detect improvement.

... it's extremely gradual and extremely subtle ... I don't think there is one point where you know. (Participant 17R)

Eventually these participants considered themselves “recovered” because symptoms no longer precluded their activities, they were able to resume pre-illness activities, or they no longer met CFS criteria. The resumption of activities and cessation of symptoms constituted recovery for Participant 17R.

*I don't feel those things anymore [fatigue] and I can do things, tiring or demanding things, and keep doing them. I don't have to have a lie down ... Actually to go back to how did I know when I got better, all my symptoms
stopped pretty much. Not all of them completely but I very rarely get any of them now.

Only Participant 17R considered herself to be symptom free and no longer monitoring activity. Participants 5R and 19R continued to intermittently experience mild symptoms and to monitor activity levels, although they had essentially resumed pre-illness activities.

_Tonight I'd normally be out jogging. But that's how I say I'm better. I still have to watch it. I can go overboard sometimes like I did last weekend. I was crook._ (Participant 19R)

This self-report of recovery despite some continuation of symptoms suggested a definition that did not require an absence of symptoms or a return to the previous health status. Indeed Participant 17R, who was no longer symptomatic, suggested there was a point so close to recovery that it became recovery.

_I suppose you get to a point where you say, “I'm ninety-five per cent well, then effectively I'm recovered” and I think there was a period during which I would have said that. So to all intents and purposes I'm recovered. I'm five per cent unwell. Well, that's a bit negative. I can deal with that._

Participant 5R and 19R may have reached that point. Consequently, although there were still periods when symptoms returned, the ability to fulfil most activities was sufficient for Participant 5R and Participant 19R to consider themselves recovered.

It should be noted that the duration of the recoveries was fairly brief. Participant 17R had been symptom free for 2 years, with one brief relapse early in her recovery. Participants 5R and 19R considered themselves recovered for periods of 12 months and 18 months respectively, with brief relapses during that time.

The recovered participants varied in their explanations for improvement. Participant 19R believed that diet and exercise were the primary reasons for her improvement, while Participant 5R cited attitudinal change as important to improved health.

_I mentioned about the way I saw myself and that was powerful. And then I changed what I saw and I was determined to be what I saw._

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Participant 17R was less definitive than Participants 5R and 19R in attributing a reason for her improvement and expressed uncertainty as to whether her actions made a difference.

> What I'm inclined to say to people, slightly joking, is “it just got better by itself”. And that's what my doctor always used to say, “it'll just get better” and I haven't done anything to get better for years. I gave up on all that. But I was able, one thing that made it better for me to live with it was acceptance. As to whether acceptance makes you better, well, if acceptance makes you live a happier life, that may reduce your stress, which may help your body recover. That could have been going on. I have no idea. I just got better.

The recovered participants shared a number of factors that some research has suggested are associated with better prognosis. They appeared to have been moderately affected (for example, they had remained working), they had a relatively short illness duration, and they were comparatively young. Although findings are inconsistent, research has proposed that greater severity is associated with poorer prognosis (Levine, 1997), and that younger age and short illness duration are associated with better prognosis (Vercoulen, Swanink et al., 1996).

**A Climate of Contention**

The illness biographies included participants’ positional stances regarding contentious CFS issues. Although CFS is a condition of complexity, its controversies are frequently reduced to simplistic dichotomies such as physical/psychiatric, real/unreal, mind/body, sick/well, and normal/pathological, and generally, participants shared this tendency toward the polemic. The debates surrounding CFS and the opinions about people affected with CFS were familiar to and of importance to the participants. Of particular interest and consequence were the social and medical perceptions of CFS, beliefs regarding causation, and appropriate CFS discourses.

Participants found that social beliefs about CFS were generally negative and included disparaging opinions of people with CFS, as was described by Participant 3.
One guy at work said his brother's got this [CFS] and he thinks it's shirking, says his brother says he's got it, but he just doesn't want to work.

Participants described the stereotypes of people with CFS as individuals who were lazy, unable to cope with modern life and stress, hypochondriacal and given to malingering, and all had been subjected to these stereotypes. These perceptions of the participants were consistent with the findings that people with CFS consider their stereotype to be negative (Weinberg, Louw, & Schomer, 1994) and are the subject of negative attributions (Shlaes, Jason, & Ferrari, 1999). These stereotypes were considered to be untrue and were strongly disputed by the participants. They argued that the people they were prior to their illness, that is, active and busy, was proof that they were not indolent malingerers. They questioned why their fatigue and ill health was judged as a sudden onset of laziness.

The controversy regarding the causes of CFS as physical or psychiatric/psychological (traditionally argued as either/or) was of particular importance to participants. Medical adherence to psychiatric models indicated to participants that they were not believed and were strongly rejected. Participants believed that medical expediency was the basis for allocating CFS into the basket of psychiatry. Participant 14 expressed the view that psychiatrists interpret the behaviour and beliefs of people with CFS in such a way as to support psychiatric explanations.

And the awful thing is psychiatrists say, “Well, the people with CFS who think they have a physical disease, think that there is something physically wrong, well, that shows they have a psychiatric disease”. Catch 22.

Additionally, the ineffectiveness of psychiatry in treating CFS further demonstrated to participants the erroneous nature of psychiatric explanations.

If it was depression, okay, you take antidepressants and you'd be back at work, and it doesn't do that. (Participant 14)

The causal debates found within the medical community and between patients and medical practitioners were interpreted by participants as direct indictments on the character or moral worth of affected individuals and as an affront to their credibility and worthiness.
Just as participants rejected psychiatric and psychological theories from orthodox Western medicine, they similarly rejected those New Age philosophies that psychologised CFS. The recent New Age movement emphasises equilibrium, holism, and personal responsibility. Illness is perceived as a life lesson and an opportunity for growth (Samson, 1999), and healing is derived from practices such as addressing unresolved issues, realigning energies, or dissolving stress. Most participants viewed the New Age philosophy and discourse as a repackaging of ‘blame the victim’, and although the majority had tried alternative therapies, acceptance of the underlying premises were selective.

The importance of names and labels and their effects on the perceptions of others were well understood by participants. As a consequence, participants used or rejected specific labels as a way to establish their position and communicate their experiences. Therefore, the medical/research debates regarding the nomenclature and discourses of CFS were of interest. Consistent with the CFS population, participants expressed dissatisfaction with the nomenclature of “CFS” because it minimised the suffering and failed to represent the seriousness and the effects of the condition (Jason, Taylor, Stepanek, & Plioplys, 2001). Despite this dissatisfaction, however, “CFS” was the term used by the majority in their social and medical encounters. A few participants referred to their condition as “ME” or used non-specific descriptions such as “overactive immune system” when discussing their illness with others. These terms imply a biological basis and their usage is consistent with research that has found a preference among those with CFS for a name that uses biomedical terminology (for example, Jason, Eisele et al., 2001).

In addition to nomenclature there were differences between participants regarding appropriate CFS discourses similar to those debated in the wider social and medical arenas. Terms found in the CFS discourse, including those used by people with CFS, were sources of frustration to some participants. For example, the use of “sufferer” to describe those affected with CFS divided participants. Participant 6 believed the term to be most appropriate and she used it with pride and defiance.

Euphemisms are another thing that cheeses me off. The American journals that keep referring to “PWCs”, “people with CFS”. You bloody suffer. Call
us sufferers. It does not imply victim mentality any more than somebody's who's a victim of a road accident has brought about their condition. And you need to acknowledge it, and I think the people who insist on euphemisms, including government departments, are the ones who have their own coping problems that I don’t think should be pandered to.

Zola (1993) wrote in a discussion on the language of disability that although controversial, terms used publicly and with pride kept social and political issues in view. For Participant 6, the use of “CFS sufferers” was a statement of fact that deserved expression in the public arena. Zola also made the point that people with disabilities are not automatically “suffering”, except “in specific situations where they do indeed ‘hurt’ are in ‘pain’ or ‘feel victimized’” (1993, p. 170). This is indeed the crux of the issue for Participant 6 – people with CFS are experiencing pain and hurt that often goes unacknowledged, and the use of “sufferers” provides acknowledgement. Alternately, Participant 1 used the term “sufferer” and then corrected herself, believing she was transgressing some (perceived) imperative of political correctness.

. . . so if I had a message for anyone, any CFS sufferer or any chronic illness, [pause] I shouldn't use that word, “sufferer” . . .

These differences reflect wider opinion. One viewpoint considers “sufferer” to be appropriate, used by both individuals with CFS and researchers (for example, Ware, 1999). The alternative viewpoint considers the term to be non-scientific, reinforcing of a victim mentality and unnecessarily emotional (for example, Bohr, 1999). Similarly, a minority of participants referred to their condition as “chronic fatigue”, presumably as a form of abbreviation, while most were frustrated by the use of this term given that “chronic fatigue” was medically different to CFS. The use of “chronic fatigue” was perceived to inadvertently reinforce the erroneous social perception of CFS as a form of ongoing tiredness.

CFS is associated with ambiguity and negative perceptions, subject to ongoing debates, and with few points of agreement. These degrees of debate and personal criticism are not found with most illnesses and as a consequence, participants experience CFS in a climate different to the social world inhabited by the majority of people with chronic illnesses.
The Illness Biographies

The illness biographies were “contingent narratives” (Bury, 2001), a type of narrative which addresses beliefs about the origin of illness, the symptoms, the causes, and immediate effects of the illness on everyday life. The illness biographies began with troublesome but seemingly benign symptoms that gave no indication of future difficulties – their elusive, changing, yet persistent nature and associated effects wrought havoc to the lives of the participants. The illness biographies also illustrated the obstacles associated with making sense of and finding legitimation for the symptom complex. There was no neat medical category for the suffering of CFS, and damage to participants resulted from their search for diagnosis and treatment. This damage is explored in Chapter 7. Their illness biographies continued, as new symptoms surfaced, old symptoms changed, and the need to endure remained.

Sachs (2001) addressed how people with CFS first identified and related to their symptoms and physical suffering. This “debut narrative” described how the symptoms of CFS could not be explained within an everyday interpretive framework, suffering became chronic rather than acute, and medical care was sought. This narrative is consistent with the description of onset found within the illness biographies. Sachs’ (2001) narrative is concerned with a small segment of the symptomatic experience. In contrast, the illness biographies provide a more complete description. It begins with the onset of CFS and provides a chronological account of the symptomatic experiences, of its progression, of the associated illness behaviours, and of the resulting health care interactions. It therefore provides a unique view of the trajectory of the CFS illness experience.

Participant Profile Summary

The participant characteristics described in Chapter 4 and the illness biographies described in the present chapter provide a snapshot of the illness context and experience. Participants included female and male, with a female predominance. Ages ranged across the adult life span to include early to late adulthood. Diagnosis was commonly protracted and problematic. Although there was some variation in the length of time affected, for the majority CFS was a long-standing and
intransigent condition. The inclusion of recovered participants provided balance to this intransigence. At the time of interview there was variation in the severity of the illness and disability. Nevertheless, at some point, all participants had experienced marked functional impairment. Most had left employment or substantially reduced work responsibilities as a result of CFS. Participants identified pain, neurocognitive difficulties and fatigue as the most troublesome amongst numerous symptoms, and co-morbid medical conditions were common. A range of medical and allied health practitioners were consulted during the early years of CFS. With time the utilisation of health services had markedly decreased and most participants were managing their care of CFS outside of the medical system for most of the time. Participants were generally well educated and from professional or skilled occupations, however, at the time of the interviews most were (to varying degrees) dependent financially on family and/or governmental agencies or on the use of assets. A variety of living arrangements and family structures typical of the wider society were found. There was a strong interest in the debates and controversies surrounding CFS as they were perceived to have direct effects on the lives of the participants.

The description of the characteristics and illness biographies of the participants provides an overview of the shared CFS context. From this context arose the threats to self that participants experienced and it is within this context that experiences of self were felt and enacted. The following chapters detail the threats associated with CFS and the narrative of self, including the experiences of the struggling and diminished self and the process of self-renewal that emerged from the analysis of the data.
This chapter addresses the threats of disruption and invalidation that underlie the struggle and diminishment, and consequent seeking of renewal, described by participants in the narrative of self. This chapter, therefore, discusses the circumstances, events and perceptions that initiated and maintained the process of self-renewal as described in the following chapters.

The threats operated as a bridge or link between the narrative of the illness biographies and the narrative of self. That is, the illness biographies were accompanied by the threats of CFS, and the threats in turn led to the struggling and diminished self seeking renewal. These threats were derived from the nature of CFS as a chronic illness and from its social construction as a contested illness, and resulted in disruption and invalidation that were fundamental to the illness experience of CFS.

**Threats of CFS**

The data analysis yielded a multitude of things that were clearly “threats”, (that is, they had the capacity to harm the participants), however, categorising these threats proved to be troublesome. The number and range were difficult to collapse into categories that provided definition. For example, almost all constructs of threat could also be categorised as “loss”, but doing so did not provide a distinct or defined category of threat. This particular case example was also problematic because loss was both a threat and effect, and there was a risk of forcing the data by fitting these complex ideas into ill-fitting models to explain participant experiences. Constant comparison eventually resulted in categorising the codes in terms of those arising from chronic illness, and those arising from contested illness. This best encapsulated the number, range, and most importantly, the categorical differences between the threats. It identified what was unique to the CFS illness experience.
Chronic illness disrupts the expected and the known. It infiltrates the “circumscribed world of everyday life” (Kelly & Field, 1997, p. 363) and disturbs taken-for-granted bodily states, explanatory systems, assumptions, social networks, relationships, and behaviour (Bury, 1982). Bury’s construct of biographical disruption proved valuable in theorising these threats. Bury described the experience of chronic illness as biographical disruption, which he defined as a situation “where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (1982, p. 169). His definition included disruptions to social relationships and to the ability to mobilise resources. There are criticisms of such a blanket application of the concept of disruption to chronic illness. Williams (2000) argued that the construct does not take into account other possibilities such as chronic illnesses present since birth and likely to be central to biography rather than disruptive, nor to the biographical continuity or reinforcement that illness may bring. However, the data analysis from my project indicated that CFS dislocated and disrupted all aspects of the participants’ lives. It brought distress, uncertainty, and disappointment into the everyday-world of the participants, disturbing and sometimes breaking the continuity and framework of their lives. Biographical disruption therefore is of relevance to CFS and this category of threat, representative of chronic illness, was called “threats of disruption”.

In addition to the threats of chronic illness there was a body of threats associated with the scepticism surrounding contentious conditions. The data are punctuated with what could be described as a constant barrage of threats directed at the integrity, trustworthiness and value of the participants that arose from the contested nature of the condition. These threats were expressed in words and phrases used by the participants such as being discounted, told I was bludging, being lazy, stigmatising, told I was seeking attention, [I was] dismissed, being silenced, excluded, and being trivialised. These threats were categorised as “threats of invalidation”.

The threats of disruption included body failure and embodied deviance, unpredictability and uncertainty, medical and physical invisibility of the illness, functional impairments, and dependency and loss. The threats of invalidation were
comprised of stigma and interpersonal invalidation. These threats are discussed separately. The effects of the threats are addressed in Chapter 7.

**Threats of Disruption**
Threats of disruption are derived from many sources that are common to chronic illnesses, and consequently, the threats are common to chronic medical conditions. In addition, the particular chronic illness contextually influences the threats of disruption. Therefore, while many of the threats of disruption addressed by the present study are relevant to the majority of chronic conditions, their manifestations are specific to CFS.

**Body**
The body is fundamental for being-in-the-world, the vehicle of personhood and identity, and the source of human emotionality (Williams, 1999). In health the body is mostly unnoticed and embodiment is unselfconscious until illness forces attention to that which is usually unattended (Kelly & Field, 1997; Madjar, 1997). CFS disrupted the taken-for-granted and familiar body and demanded that the participants pay attention to distressing and alienating experiences of body and mind.

*I've got to the stage now where I've got to think before I do something because the symptoms are there all the time.* (Participant 16)

Threats arise because identity is lodged in the body (Williams, 1999). Specifically, CFS compromised the embodied abilities of the participants to perform physical and mental activities that, prior to the illness, were part of their taken-for-granted lives and upon which their identity was based.

Experiences of the body-with-CFS were essentially of failure and embodied deviancy. There was a failure to demonstrate pathology, and the inability of the participants to yield up visible proof of their ailing bodies was one of the first threats faced. This led to the “contest of diagnosis” and the “hunt for an elusive disease” (Hadler, 1996, p. 2398). It was followed by the failure to resume their everyday and expected life, and by the continued failure to recover. Threats arising from this embodied deviancy were wide-ranging, and at different times during their illness
participants attributed these failings to medical limitations, their own personal inadequacies or both.

Among participants there was a sense of the body as strange, foreign, and of not living up to expectations. The body became unpredictable, impaired, and a source of pain and suffering. Participants experienced what Madjar (1997) described as the loss of the habitual and familiar body that resulted in a sense of feeling different. As one participant described it:

*My body shouldn’t be like that. It didn’t feel right.* (Participant 17R)

While the body had not changed externally, the internal experience of body was markedly altered. In its unfamiliarity, the body had become discrepant – it appeared healthy and was evaluated as normal, yet felt poorly. Over time, the unfamiliar became the familiar, and feeling *sick, ill or bad* was the participants’ usual and constant state. This subjective state was a backdrop of affliction and malaise on which the symptoms were superimposed. It was difficult for participants to effectively describe this experience of embodiment to others but it was perceived to be an experience of the whole rather than an accumulation of the symptoms. Participant 12 suggested that feeling bad was a symptom in itself.

*I feel indescribably ill most of the time. Every afternoon, which is when I lie down and this is when everything goes dead, I feel indescribably ill . . . It used to be regarded as a symptom, feeling dreadfully ill, used to be a symptom. And that is one of the most difficult things to deal with because you cannot define it.*

This general feeling of being unwell may be representative of the “whole body” described by Hart and Grace (2000, p. 194) in their discourse analysis of fatigue among women with CFS. The women almost always spoke of the whole body, in which fatigue was complete, aching occurred all over, and collapse was internal and external. Participants in the present study also referred to whole body perceptions, notably with reference to pain and fatigue. In sum, CFS physically and mentally overwhelmed the participants with sensations of illness, threatening their sense of embodied familiarity and integrity.
The stubborn nature of the body is a defining characteristic of the chronic illness experience (Kelly & Field, 1997), and consequently, chronic illness is an exercise in endurance. The resistance of many of the symptoms to palliation, the chronicity and remitting/relapsing progression, impairment, and the slowness of improvement presented participants with a condition to be endured. Participants described the unrelenting symptom presence.

*Do you know what it’s like when you’ve got the flu? You ache, your body aches, your head aches, you’ve got a sore throat, every little muscle, you feel your fingers ache, you can’t see properly, you feel dizzy . . . Imagine living with that flu all the time. And then other symptoms, like bowel problems, sleep problems, fevers, loss of appetite. That’s what it feels like, having those flu symptoms forever that never go away. You feel really bad and run down, that you can’t do anything, you have trouble walking. Just imagine that every day and multiply it . . . It’s a struggle every day. (Participant 18)*

*It’s the no-light-at-the-end-of-the-tunnel that’s hard, because you know that tomorrow you’re going to wake up and feel the same . . .* (Participant 13)

Endurance wore down the participants, requiring personal resources not always available. Participant 1, for example, spoke of surrendering to severe symptoms.

*There are days where, if things are pretty bad, then I just stay in bed, and I just lay low till it passes, because to try and push through that barrier sometimes is not very good. Sometimes you just need to give in.*

Waiting to see what happens and waiting to let it pass were important aspects of the symptomatic experience. However, waiting did not represent respite for the participants; it was a further expression of endurance. Threats arose when the participants’ ability to endure their embodiment was compromised or when the costs were too high.

Symptoms that interfered with the participants’ ability to express, enact or maintain valued self-perceptions were considered most significant and represented a substantial threat. For example, for participants who prized their physical nature, the loss of physicality, physical skills and associated activities were powerful threats.
I like to do physical things. I like to dig gardens. I like to move mounds of earth. I'm that sort of a person, and I find it very, very frustrating.

(Participant 15)

I couldn't be full-on anymore, I couldn't be active and physical and into all my outdoor pursuits . . . (Participant 17R)

The threats to the body and its reliability were intimately entwined with the other threats of disruption. Body was the framework upon which the other threats (including threats of invalidation) were constructed. In other words, threats of uncertainty, invisibility, functional impairments, dependency and loss arose from the manifestations and effects of body dysfunction. Further, threats of invalidation arose from the interpretation (by oneself and others) and lived experience of body as dysfunctional.

**Unpredictability and Uncertainty**

Unpredictability encompassed all aspects of the illness biographies, such as symptoms, outcomes, functional abilities, and responses of others. It was an everyday phenomenon that occurred along a temporal continuum of minutes, hours, months and years. This meant that participants were unable to reliably anticipate their level of wellness, with daily, short and long-term future functional abilities difficult to predict.

You can take all the precautions in the world and people think you’re making a big fuss and nothing happens. And then other times you think, “Oh, it’s fine”. Like the other day . . . I was up in the Dome [sports complex], it was hot. I went out to get some air, and I get these sort of episodes where I can’t speak . . . I’m just sitting amongst all this crowd hoping that [husband] will find me . . . it hadn’t occurred to me it would happen. I hadn’t had one of those for a long time, didn’t take precautions about the fact it was going to be hot and airless . . . I find the unpredictability of it extremely difficult.

(Participant 15)
I still after eleven years, I haven’t worked it out because for me it's not consistent . . . it's not predictable. (Participant 7)

Unpredictability threw life into disarray. Ultimately, unpredictability was an essential feature of CFS and was the basis for the feelings of uncertainty that permeated the lives of the participants.

While uncertainty is a feature of most chronic illnesses (Bury, 1982; Miller, 2000), differences between illnesses lie in the focus and timeframe of the uncertainty. Initially with any illness, onset provokes uncertainty and is a factor in initiating a search for diagnosis, and diagnosis may, or may not, reduce or increase uncertainty. Women with breast cancer, for example, were found to experience a reduction of uncertainty over time, beginning with diagnosis, but were subject to feelings of uncertainty resurfacing intermittently, associated with a fear of cancer recurrence (Nelson, 1996). In contrast, participants in the present study experienced ongoing uncertainty that did not lessen substantially with time. There were long periods of diagnostic uncertainty when participants did not know the basis of their symptoms and consequently, they were unable to ascribe symptomatic or symbolic meaning or to envisage their future. Diagnosis, however, did not lessen uncertainty – daily life and long-term outcomes were still unpredictable and therefore uncertainty remained.

There is fear associated with uncertain illness progression (Vickers, 2000) and participants were threatened by the uncertain clinical outcome of CFS and consequently, by the possibility of increasing disability and dependency, decreasing quality of life, and financial insecurity. Planning or preparing, whether for the next day or further in the future, was always contingent on the vagaries of the symptoms.

Like two weeks ago I was really good, so I was planning, Oh, I’m going to read this book, and I’m going to do this course and I’m going to go and talk to these people . . . And then when I got a cold, and then it just went crash. That makes it hard to adjust. It is actually probably one of the hardest things besides the disability, the uncertainty. (Participant 14)
I never knew when I was at my sickest whether I'd be able to do all the things I wanted to do or whether I'd have the freedom to ever do those things again and that undermines your whole certainty about anything. (Participant 17R)

Uncertainty rendered the participants unreliable, and they were exposed to the continual failure of being unable to participate in, or of cancelling, planned activities. As an alternative, participants sometimes chose exile and isolation.

Additionally, there was uncertainty about how others would respond to CFS, such as when consulting a new practitioner, and in how other people truly felt about CFS. Participants sometimes held doubts as to whether the stated opinions of others were truthful or whether other people believed the participants’ truth.

You just really have the feeling that even good friends, that you thought were good friends, doubt you, even though they say they don’t . . . They don't say it, but you feel that maybe they think that if she got more exercise or something [she would recover]. You just have that feeling that they think that you don't have to be sick. (Participant 7)

As a consequence, participants were uncertain of how others viewed their trustworthiness, and there were threats to perceptions of self-worth and integrity.

Implicit in the unpredictability and uncertainty was a loss of perceived control. There has been much research into the relationships between perceptions of control and chronic illness and the findings indicate these relationships to be complex. For example, individuals vary in the degree of control they desire, and both more control than desired or less control than desired can be stressful and anxiety provoking (Christman, 1990). What was clear in the present study was that participants generally felt a loss of control and, more specifically, did not perceive that they had control over CFS.

I've got no control over this at all. (Participant 6)

I didn’t feel like I was managing my condition. I felt like I just had a big screen up trying to hide my illness and I wasn't keeping anything together. (Participant 5R)
While there were periods when participants were able to manage symptoms and regain a sense of control, the common experience of relapse or symptom deterioration repeatedly threatened perceptions of control. The participants continued to desire greater control, as evidenced by their frustration at being unable to relieve the symptoms, anticipate their day, or plan for their futures. The effects of loss of control are discussed in Chapter 7.

Social value is placed on mastery and control as normal to adult life. The unpredictability, uncertainty and loss of control associated with CFS were of threat because they transgressed social norms. This in turn threatened perceptions of self-determination (present and future), and there was an associated risk of ongoing disappointment, anxiety or despair. CFS begins as an unpredictable and uncertain illness, and remains so.

Invisibility
Chronic illnesses differ in their relative visibility to others, with some that are always visible, others that become visible, and those that remain invisible. CFS is more invisible than most – it is neither visibly evident to others, nor pathologically or physiologically evident to medical practitioners. The invisibility associated with the mostly normal diagnostic tests is discussed with threats of invalidation, while the following content addresses the visual picture of CFS that is observed by others.

For the participants, there was a constant contradiction between appearance and embodiment. Visibility of symptoms is important to the legitimation of illness (Bury, 1991), and CFS does not meet the implicit cultural criteria of sickness as visible (Beaulieu, 1995). The participants looked mostly well, and the severity of the illness was frequently not evident in their appearance. Participants experienced joint pain, yet there was no inflammation. They were unbearably fatigued, but did not look tired. Consequently, they were subject to “the fallacy of ‘wellness’ . . . if one looks well one must, necessarily, be well” (Vickers, 2000, p. 5). The participants believed that the discrepancy between outward appearance and embodiment contributed to the symptom minimisation by others.
. . . my being so physically ill was not obvious to people and I was imposed on and also treated very badly . . . (Participant 12).

It's just hard, like you can’t explain it to people. You're constantly ill. You don't look ill, you look great . . . even friends and family, they don’t understand, they see you as a young person who should be fit and healthy. (Participant 16)

The hidden nature of CFS was particularly onerous because it further eroded medical and social legitimation. The absence of visible external markers of illness cast extra doubt on the “reality” of symptoms, added to the scepticism of others, and acted as a barrier to support and care. The frustration that the participants felt over their discrepant external appearance and subjective experiences has similarly been reported in other research on CFS (Asbring & Narvanen, 2002; Ware, 1992).

Invisibility meant that the only way that participants could let other people know about their symptoms and impairments was to tell them. This was problematic because the sense of altered embodiment was difficult to describe. The many, varied and changing symptoms and bodily sensations, when verbalised, sometimes had a sense of the fantastic about them. Nor were their commonplace symptoms easily described. For example, Madjar (1997) discusses the invisibility of pain, the resistance of pain to objectification by language, and its consequent “unshareability” (1997, p. 64) that contributes to the associated threats. In addition to the universal difficulty in communicating the pain experience as Madjar described, participants were further limited by the unexplained basis of their pain (and other symptoms). When participants did attempt to verbalise their embodied experience, they left themselves open to accusations such as dwelling on their illness and of being self-absorbed. Consequently, most participants had stopped speaking of their symptoms, further reinforcing (their) invisibility.

While not common, there were occasional instances when symptoms manifested externally and became visible to others. Their visibility came from the effects of these symptoms on the participants, that is, others were able to see the functional impairment. For example, mobility limitations, spatial disorientation and extreme
neurocognitive symptoms were sometimes apparent to other people. However, although visible, participants believed that their bizarre (unexplained) symptoms only confused others, and did not contribute to their credibility as an ill person. For example,

\[\text{I can’t imagine what it [her confusion] must have looked like on the outside, to other people, because they looked at me very strangely . . . (Participant 3)}\]

\[\text{I’d be running the words back in my brain trying to make sense, trying to comprehend what they just said to me. And conscious at the same time that it looked like petulance ’cause I’m just standing there with my mouth shut, and that I looked like a petulant child. (Participant 10)}\]

Bizarre symptoms tended to be infrequent and more likely to occur when participants were very ill, but they were particularly threatening because of the risk that they might be perceived as providing (further) evidence for the psychological frailty of the participants.

Regardless of whether symptoms were invisible or visible, participants were aware that others commonly perceived their symptoms and behaviours as strange or nonsensical (a perception sometimes shared by participants). The threats arising from invisibility (and from the visibly bizarre) were an absence of support, the attribution of negative judgements, social isolation, and damaged perceptions of self-worth. Additionally, the invisibility of symptoms contributed to the difficulties that other people experienced in accepting the presence of impairment among the participants.

**Functional Impairment**

The everyday-world consists of familiar routines and social experiences (Kelly & Field, 1997), and the functional impairments of CFS described in the illness biographies were substantial barriers to participation in the everyday-world. Consequent disruption and diminishment of roles and relationships were of marked threat.

\[\text{Your roles and responsibilities are diminished in a sense that you are limited in relationships, in career, in a financial income . . . So that affects your self-}\]
Participants described relationships and roles as enmeshed and mutually dependent. In both relationships and roles “doing” was perceived as important to fulfilling expectations, meeting responsibilities and deriving satisfaction. In that sense, participants reflected the cultural norm of valuing performance, action and achievement. When participants were no longer able to engage in the “doing” of their relationships and roles, threats ensued.

Kelly & Field (1997) argue that functional capacity and the ability of the body are essential to inhabiting the social world. Participants reported that as a result of the symptoms their bodies became less able, their functional capacity decreased, they were effectively prohibited from social participation, and consequently, were unable to inhabit their social world. Fatigue, muscle pain, headaches, and feeling *indescribably ill* conspired to restrict social engagement. For some, allergic reactions were problematic.

\[
I \text{ couldn’t be with anybody who’d washed their hair in shampoo or wore deodorant. I was sitting on the beach in the middle of a strong wind and suddenly I started choking my lungs out. And there was somebody twenty-five metres behind me smoking a cigarette. And I was so sensitive I couldn’t go out in the world.} \quad \text{(Participant 1)}
\]

Cognitive symptoms also limited social engagement.

\[
\text{If your cognitive thinking is not the best like, you’re not just going to make a phone call. } \quad \text{With CFS sometimes you're vulnerable too 'cause of your own [poor] memory.} \quad \text{(Participant 4)}
\]

The inability to inhabit the social world excluded the participants from work, social activities and relationships. Symptoms interfered with participants being the person they wanted to be, privately and in their wider social sphere.
Relationships form the basis for social support, and there has been substantial work on the associations between social support, health and stress. Conclusions have been limited by different definitions of social support and by the variety of measures used (Bishop, 1994). There are findings that demonstrate social support to be of positive benefit to health status. For example, among women with rheumatoid arthritis social support was reported to have a significant positive effect on stress and adaptation (Spitzer, Bar-Tal, & Golander, 1995). In contrast, other research has reported negative effects to health and increased stress associated with social support (Bishop, 1994). Schmaling and DiClementi (1995), for example, suggested that supportive partners of the CFS participants in their study might be inadvertently reinforcing disability. What was evident from the present study was that relationships, and consequently social support, were diminished. This was of threat to the participants because effective social support requires sufficient resources (Niven, 2000) and the decline in relationships significantly reduced the social support available. Simply put, participants ran out of people to provide support. This in turn increased the threats associated with isolation.

As Bury (1982) observed, symptoms and functional impairments threaten existing relationships among the chronically ill because they alter the dynamics, expectations, and long-established patterns of the taken-for-granted world, and consequently, bring the character of relationships into sharp relief. Participants reported that existing relationships came under pressure. They were too ill and lacked the energy to engage in the activities necessary to sustain relationships. Participant 15 described the destructive effect of fatigue on relationships.

*I think a lot of the time with ME, especially in the beginning stages, that you're too bloody tired. I was talking to someone who lost her fiancée over it and she said, “I think I was too tired”. And I think that's often the case. You're too tired to have friends, too tired to do what it takes.*

Doing *what it takes* was recognition that relationships involve obligations and reciprocity, which symptoms rendered difficult. The inability to *do what it takes* was distressing and is discussed in Chapter 7. Threats to relationships also arose from the loss of social skills.
When you're mentally switched on you can have interesting conversations with people, but when you're often in that fog brain thing you can't have an intelligent conversation with people. That was a disability. (Participant 17R)

Further, symptoms such as memory loss, aphasia, fatigue and pain limited effective and satisfying verbal and non-verbal communication. Sexual expression was limited by loss of libido, pain and fatigue. Participant 5R described the relationship difficulties arising from the effects of CFS on her sexuality.

I've only had one [boyfriend] that I've told [about CFS] and he still never got it, why I didn’t want to be touched sometimes or I was a bit [sexually distant], always took it the wrong way when I was a bit down or not feeling very well. He never could understand.

As functional impairment increased, other people gradually withdrew and relationships based on shared activities were lost.

All the so-called friends you had, they'd just disappeared. Because they'd say “you can't come out with us, so we're not interested”. (Participant 16)

Further, there were painful instances when relationships were ended abruptly, without explanation.

My oldest friend of twenty years . . . just went into shutdown mode when I got sick, thinking I was acting like a prima donna, and absolutely refused to listen to me anytime I tried to explain . . . (Participant 10)

Additionally and consistent with reports of withdrawal from social relationships among people with chronic illnesses (for example, Bury, 1982), when symptoms created difficulties with interactions, participants withdrew.

I had visitors and I'd say, “can you go away? I really can't cope with this”. And I think that's what pushes people away because you can’t cope with it. (Participant 16)

I quite literally hung up on people and slammed doors in their faces. “Don't call me, I'll call you when I'm better”. And I wouldn’t call them for months and they didn’t know what to do so it really affected friendships. (Participant 18)
Participants recognised the contradictions in their responses – they were hurt by the rejection of others, and yet, acknowledged there were instances when they had instigated the rejection. This contradiction was representative of the complexity that CFS had brought into the worlds of the participants – taken-for-granted relationships were no longer familiar, and the responses of others, and sometimes their own responses, were confusing and threatening. Participants described lives that became progressively distant and more isolated from their existing relationships and social support.

There was difficulty in establishing new relationships because participants were unable to engage in activities where they would normally meet new people. For the single participants there was recognition that forming an intimate relationship would be difficult because, in addition to problems with meeting people, there were the difficulties of finding someone able to cope with CFS.

It’s very difficult with CFS being able to start relationships and to maintain it unless the person is a very understanding person. Very basically together themselves. It’s very hard to find that. (Participant 4)

CFS placed fledging relationships under undue stress. There were only rare instances of single participants beginning an intimate relationship while affected with CFS and none had endured, as was the case for Participant 1.

I was relying on him more for my social stimulus, and I think that uh, placed undue pressure and more stress on the relationship. I think I was asking for too much, from that I would’ve ordinarily have done.

Not surprisingly, the single participants considered it most unlikely that they would be able to establish an intimate relationship while they remained ill.

Prior to CFS, the participants had enacted and identified with a large number of roles. The ability of the participants to establish or fulfil roles related to family, friendship, occupation, social and community domains was affected by the symptoms. Role restriction, that is, an increasing and ongoing inability to fulfil a variety of roles (Ware, 1999), was marked and participants experienced grief over discontinued roles and dissatisfaction with their inability to discharge continuing
roles. The parenting role, in particular, was compromised and participants described the sense of inadequacy.

*You feel as if you're just not doing it [parenting] the way you want to do it.*  
(Participant 15)

*I found it difficult because I couldn't play with the kids like other people, like other fathers, couldn't play football with them or cricket with them . . . I never did anything much.* (Participant 8)

Even when children were no longer dependent, participants continued to perceive their parenting as second-rate or deficient in some way.

While some roles continued, albeit in a reduced form, other roles disappeared. Work was the role most commonly lost and its absence was keenly felt. Chapter 5 has described the process of leaving the work force, including the “resistance strategies” (Ware, 1998, p. 305) used by participants to extend their working life. There were a number of reasons why participants found leaving the workforce difficult, including financial need, sense of identity, and the loss of social relationships and access to social activities. Participants had also absorbed what Vickers (2000, p. 14) called the “ideological baggage associated with capitalism [and] economic rationalism”. They had a strong sense of social duty and a perception that they ought to be working and maintaining a high level of productivity and quality. They would rather push too far than give in prematurely.

*I got really ill to the point where I was almost collapsing, people saying “if you don't stop working you'll be in hospital by the end of the week”.*  
(Participant 18)

Additionally, as noted by Bury (1982, p. 177) the working role was a way to “normalise” and maintain appropriate behaviour. Consequently, by continuing to work participants lessened the threats of being perceived as engaging in abnormal illness behaviour. The social and personal investment that the participants had in their work was not only evident in the extraordinary efforts to keep working but in the efforts made to reenter the workforce.

*It [work] was possible just for a few months here and there, and I've had some high points and I've done some part-time work. So apart from that it's*
impossible . . . and that's probably one of the hardest things to come to terms with . . . (Participant 14).

Participants recognised that significant others experienced difficulties in dealing with changes to relationships and to roles. They perceived that their illness was an inconvenience and burden to those around them. Participant 5R experienced anger from her mother when she was no longer able to provide after-school care for her younger siblings.

She didn't seem to cope with a sick daughter . . . she didn't like the fact that I was sick and incapable when she relied on me for so many things in being a mother with my younger brothers.

They were also cognisant of the emotional distress that their illness caused others. Participant 16 described the pain (for all his family) of his inability to fulfill his parental role.

. . . you can’t explain it to your kids either. Like my oldest child he says to me, “Come on, do this”, and my wife turns around and says, “Dad's sick” and he says, “When is he going to get better?” And I say, “I'll try to do a little bit” . . .

The difficulties of others in accommodating changes led to relationships becoming strained and threatened, and to roles becoming a source of contention and stress.

In sum, social networks were mostly restricted to a few family members as illness led participants to leave the workforce, discontinue activities and decline social invitations. Social marginalisation and isolation increased and a lack of social support resulted. For Participant 12, support of any kind was absent.

I actually don't find I've ever had any advocacy really.

Given the responses of others to their illness, participants questioned the quality of their relationships and the importance or worthiness of their roles. Additionally, the inability to continue in well-established roles or to take on desired roles were significant threats. The guilt and grief derived from these relationship- and role-related disruptions and their effects on participants are discussed in Chapter 7.
Dependency and Loss

Implicit in the preceding threats of disruption are threats of dependency and loss. Social value is attached to self-sufficiency, self-determination, and independence (Longo & Williams, 1986) and CFS interfered with the expected autonomous state of the adult. The participants’ dependency threatened perceptions of control and autonomy and the established patterns of relationships.

*I used to do things like that without thinking twice . . . Without having to consult other peoples’ availability and willingness.* (Participant 2)

It meant participants were reliant on the availability of services and other people, and is of particular importance given that the participants in this study and in other CFS research (for example, Cooper, 1999) have reported barriers to and exclusion from social services, as described in Chapter 5. There has also been limited work to suggest comparatively low levels of social support among CFS study participants (Kelly et al., 1999). In sum, there was the threat of insufficient or unavailable resources.

Few studies have addressed the losses of CFS and the present study found that loss was a significant threat. Participants experienced the losses commonly associated with chronic illness as identified by Miller (2000) among 81 chronically ill adults. With the exception of one category (loss of body parts), each was relevant to the present study. These losses included health status; roles (breadwinner, future); self-esteem and dignity; certainty and day-to-day predictability; sexual performance (intimacy); relationships; independence; and finances. In addition to the presence of these losses, participants were threatened by the range, accumulation, significance and intensity of the losses they had experienced, and were at risk of becoming emotionally overwhelmed and despairing. In one of the few CFS studies to incorporate loss Anderson and Ferrans (1997) also reported the profound and multiple losses found in the present study.

The threats of disruption are a function of CFS as a chronic illness. The threats of invalidation arise from the contested nature of the condition and compound those associated with chronicity. This does not imply that non-contested chronic illnesses do not experience episodes of invalidation (for example, all chronic illness is
somewhat stigmatised), but it is not the crucial, defining and consistent feature that it is among contested conditions.

**Threats of Invalidation**

Invalidation and being devalued included the social and interpersonal, was widespread, and was seen as an automatic consequence of CFS. Threats of invalidation arose from the social process of stigma. Participants were stigmatised prior to and following diagnosis, and the stigma of CFS was compounded with other stigmatising sources, such as chronic illness and psychiatric illness. Participants experienced both felt and enacted stigma. Additionally, threats of invalidation were derived from interpersonal sources, and included disbelief, turning the abnormal into the normal, commandeering of symptoms, the attribution of negative qualities and responsibility, and dismissal. Threats of invalidation were particularly distressing to participants because they jeopardised well-being, trivialised the pain and suffering that were part of everyday life, questioned the reality and perceptions of the participants, and relegated participants to an inferior status.

Invalidation was one of the strongest themes running through the participants’ narratives. People with contested illnesses such as chronic back pain (Rhodes et al., 1999), multiple chemical sensitivity (Lipson, 2001), and chronic facial pain (Marbach, Lennon, Link, & Dohrenwend, 1990), commonly report personal invalidation, stigmatising opinions, and a lack of medical and social legitimation for their condition. Among the CFS research, perhaps the most consistent and frequently reported experience of people with CFS is that of invalidation. It is the defining response of other people to the condition. Experiences of being discounted and invalidated arose from a wide range of interactions involving family, friends, acquaintances, strangers, work colleagues, medical practitioners and other health practitioners. It was of enormous threat because invalidation questioned the reality and truth of the participants and was evidence of the doubts that other people had about their mental health, personal qualities or worth.

There are a few different terms in the literature that partly encompass what I have called the threats of invalidation. Ware (1999, p. 312), for example, refers to
“delegitimation” and the “systematic disconfirmation of the experience of being ill”, while Cooper (1997, p. 186) refers to CFS as an “illegitimate illness” or “non-disease”. In the present study the threats of invalidation referred to social interactions and beliefs that discredited, disconfirmed, demeaned, disregarded and marginalised the perceptions, subjectivities and experiences of people with CFS. “Invalidation” was chosen as the label for this category because it communicated the perception of CFS (and those affected) as unsound, indefensible, ungrounded, and unacceptable.

The threats of invalidation were essentially of two interrelated types, firstly those arising from social processes and secondly, from interpersonal processes. Threats of invalidation associated with social processes were threats of stigma. The interpersonal threats of invalidation occurred at a personal level. Each is addressed separately.

**Stigma**

The sociological concept of stigma was relevant to the societal and structural invalidation reported by the participants in the present study. Stigma is a complex social process where a discrediting, powerful label is applied to individuals that changes their self-perceptions and the way they are viewed by others (Alonzo & Reynolds, 1995; Goffman, 1963; Marbach et al., 1990). It is based on deviation from culturally prescribed norms, ideals or expectations in which individuals who do not meet normative expectations are considered by normal persons to be “marked”, with their identity defined as spoiled, flawed, or incomplete. Furthermore, the mark provides the basis for assuming other imperfections and thus becomes a global attribution, with devaluation becoming generalised to all aspects of the person (Goffman, 1963). Stigma is common among contested illnesses because of the perceived psychological causes, the high rate of treatment failure, and the use of health services that is considered to be excessive (Marbach et al., 1990). Participants were aware that there was something about CFS that provoked strong responses and opinions in others that was not the case for most other illnesses.
If I said I had cancer not everyone would react. Some people still have appalling reactions to cancer but on the majority, it's a lot different. (Participant 15)

They considered this “something” to be stigma and it was familiar to all the participants. Stigma has also been reported in other CFS studies (Asbring & Narvanen, 2002; Cooper, 1999; Green, Romei, & Natelson, 1999).

Participants described four aspects of stigma as important to their perceptions of threat. Firstly, they experienced CFS-specific stigma, related to the stereotype of CFS and to non-normative behaviour. Secondly, stigma arose from other sources, notably chronic and psychiatric illness. Further, participants experienced a generalised discreditation that resulted in negative consequences, and lastly, stigma was both enacted and felt. Each of these aspects is addressed separately.

Participants discovered that while being without a diagnosis was stigmatising and associated with accusations of malingering and laziness, the diagnosis of “CFS” did not necessarily alter these specific attributions.

I was trying for my invalid pension and the bloke who interviewed me, a doctor for the government, he said, “I'm going to make an example of you, you're the fourth person who's come in here with chronic fatigue”. He said, “you're the biggest bludgers I've ever met”. (Participant 16)

In other words, following their diagnosis participants were subject to CFS stereotypes, and as a consequence, continued to be judged as unbalanced, lazy, hypochondriacal and responsible for their condition. Specifically, the diagnosis of CFS had stigmatised the participants with ongoing attributions of malingering, with derogatory descriptions such as “yuppie flu” or “bored housewives syndrome”, and with perceptions that they were individuals unable to cope in a busy and pressured world. This continuation of stigma before and after diagnosis of CFS has been reported by Asbring & Narvanen (2002), although it was found that stigma was greater before diagnosis. Participants in the present study did not make this distinction.

As a result of the absence of pathology and the ambiguity of their illness status, the
inability of participants to engage in normative behaviour became a source of deviation and spoiled identity. Other people frequently held strong expectations of normative behaviour from the participants (as did the participants in the early years), particularly when it was believed that they ought to have recovered. Expectations of normative behaviour were notably evident with regards to work. Participant 14 described the compounding of work-related expectations.

*I think the expectations of others are very strong on that [working], and particularly when people don't understand that you are really sick . . . I think I felt a lot of internal pressure to work but it was also reinforced by what other people say and expect . . .*

Theories of normalisation propose that failure to meet social “norms” leads to blame and the attribution of “abnormal” characteristics. Although people with chronic illness may be subject to a different set of norms than the healthy (Wellard, 1998), the participants were aware that the contested nature of CFS mitigated against them being ascribed the status of “chronically ill” and its subsequent exemption from meeting social norms. When expectations were not met, participants were blamed and judged, and there were social consequences. Participant 16 described the isolation and marginalisation associated with the stigma of transgressing work-related expectations.

*I don’t keep in contact with anyone from work anymore because the first thing they said to me is “what are you doing?” And I say . . . “I’m on a pension” and boom, they just ignore you, you don’t see them again.*

To meet societal expectations, and consequently minimise the stigma, participants had attempted to maintain normal activities such as the work role. Efforts to maintain normality, however, were counterproductive in that physical deterioration and an inability to fulfil expectations resulted. This left participants with further stigma related to dependency and failure.

Stigma encountered specifically from CFS was compounded by that associated with chronic illness and psychiatric illness. Chronic illness and its dependency are stigmatising because they mark the person as different in a way that is perceived as inferior in comparison with unaffected others (Ablon, 1995; Alonzo & Reynolds, 1995). Furthermore, psychiatric illnesses have significant levels of stigma attached
and stigmatising opinions about people with psychiatric illnesses are common and widespread (Crisp, Gelder, Rix, Meltzer, & Rolwands, 2000). Of particular importance to the participants was the stigma underlying the common social perception that physical disease is valid and “real”, deserving of sympathy, while a psychiatric or psychological disorder is in some way imagined or representative of a character flaw (Deale & Wessely, 2001). Participants had repeatedly been told from numerous sources that their illness was all in the mind and that their symptoms were psychiatric. Consequently, given the belief that CFS was a mental illness, participants had experienced the stigma associated with psychiatric conditions. Participants described the ostracism and stigma associated with the presumption of mental illness.

_ I know that people are looking at me as if I'm completely demented because they move away from you._ (Participant 15)

_ They [her friends] probably thought I was going mad [laughter] and they didn't want to get involved._ (Participant 3)

_ It [variable symptoms] made it hard to deal with doctors 'cause they think you're a bloody looney._ (Participant 8)

It is likely that the stigma associated with mental illness contributed to the rejection by participants of psychiatry and psychology in their management of CFS.

In addition to the stigma associated with chronic and psychiatric illnesses, other sources were encountered. Participant 15 described the effects of her body weight on how others perceived her.

_ I'm also talking about it as an overweight individual. An overweight individual is a society no-no at the moment, and I found that crept into the way people treated me as presenting with CFS. I've had doctors say to me “you can't possibly be nauseous, look at the size of you”._

Other research has noted that the predominance of women also serves to increase the stigma of the condition (for example, Asbring & Narvanen, 2002), and the majority of female participants in the present study spoke of instances where they believed
their gender had been disadvantageous and stigmatising. In sum, participants were subject to multiple stigmata that compounded and increased the invalidation.

Consistent with stigma research, the stigmatising marks (that is, CFS, chronic illness and psychiatric illness) became the basis for generalising imperfections and participants were discredited in a general sense. This was particularly the case for mood, behaviour, decisions, and non-CFS related symptoms and pathology, which were interpreted by others from the basis of CFS and were accordingly discounted. In other words, just as the diagnosis of CFS lacked credibility, participants found themselves to be also lacking in credibility. Participant 12, for example, described two instances of misdiagnosis when new symptoms that were not part of the CFS complex were automatically attributed to CFS or to hypochondriasis.

I'm either being fobbed off by being put in the “too hard” basket or patronised and it's still going on. The ophthalmologist patronised me until he looked in my eyes and gave me a little lecture about a whole lot of things before he actually checked whether I did have macular disease.

Nobody should have missed this gall [gallbladder] thing. I had liver function tests with bizarre . . . they went up to thirty-three times the normal. I showed them to three different doctors and they all said “typical CFS”. In other words, he didn't look at it . . . once you get in the CFS basket that doctor’s judgment switches off.

This participant believed that the new symptoms were not adequately investigated and were disregarded because she had CFS. Eventually she was diagnosed with macular degeneration and inflammation of the gallbladder. Participant 12’s experiences can be understood in light of Schulze & Angermeyer’s (2003) study finding that knowledge of a history of psychiatric treatment resulted in medical practitioners taking patients’ physical symptoms less seriously. The medical practitioners investigating Participant 12’s symptoms might have interpreted them as psychiatric because they considered CFS to be indicative of her propensity to somatise.
A generalised discreditation was also involved in the interpretation of the participants’ emotions. Specifically, participants found that their troubling or distressing emotional responses arising from any situation, including those unrelated to CFS, were interpreted as symptoms. This served to invalidate emotions and the situations that gave rise to those emotions, and limited the opportunity for authentic emotional exchanges with others. Eventually, participants felt themselves to be social outcasts with their place in the social structure invalidated by CFS.

*Because people respond very badly, you see a lot of people back away, because they think [gasp of horror] . . . it’s a, not an overt open stigma, they’re not pointing at you but it does make them back away. Very much so.*

( Participant 15)

For participants, stigma was sufficiently adverse to be of threat before it had occurred. Within the stigma research, this is referred to as felt stigma. Felt stigma is distinguished from enacted stigma, which refers to stigma that has occurred and that originates from others. Alternately, felt stigma is maintained by self and originates from the fear of experiencing enacted stigma (Scambler & Hopkins, 1986). It has been suggested that felt stigma may prove the more disruptive, and there has been support for this distinction (for example, Adams, Pill, & Jones, 1997). In addition to enacted stigma, participants in the present study described frequent episodes of felt stigma. Participant 17R, for example, feared the potential stigmatising responses of others.

*I moved into a share house . . . I remember feeling “Oh, what will they think? Will they want to share a house with me if I tell them that”? . . . I remember thinking if I was to meet someone romantically I would have to tell them something.*

Indeed, for Participant 5R the felt stigma was so great that even though recovered, she still did not disclose her past diagnosis for fear of further discreditation. Stigma remained a significant threat to the participants, even after recovery.

Stigma was the invalidation that arose from social processes and as such was general to all people with CFS, however, it also contributed to the personal invalidation experienced by individual participants. To a large extent, stigma provided the social
climate that sanctioned interpersonal invalidation. The interpersonal sources of threats of invalidation included disbelief, turning the abnormal into the normal, commandeering of symptoms, the attribution of negative qualities and responsibility, and dismissal. Each is addressed.

**Interpersonal**

The research literature shows a widespread and common pattern in which accounts of people with CFS are disbelieved (Asbring & Narvanen, 2002; Cooper, 1997; Woodward, 1993), and consistent with these findings the participants in the present study encountered both overt and subtle disbelief regarding their convictions, perceptions and experiences. Disbelief involved aspects such as the existence, presence, severity and functional impairments of CFS. Indeed, any aspect was subject to disbelief by others. As an example, disbelief among medical practitioners is highlighted. This does not suggest that disbelief among family and others was not of threat. It was felt as a deeply personal rejection (its effects are discussed throughout Chapter 7) and regardless of the source of the disbelief, participants were (or had been) desperate to be believed.

> But I've also had some really bad experiences, like family saying, “why aren’t you working” and “you really should be working”. And I have to get bad for them to see, “well, we were totally wrong”. (Participant 14)

> You felt so dreadful and you didn’t have anyone saying there was something wrong with you. So the first choice was maybe people would believe you if you were dead because that’s how dreadful you felt. (Participant 19R)

Encountering medical disbelief regarding the existence of CFS and its legitimacy as a diagnosis was a common and damaging source of invalidation for the participants. They believed that the institution of medicine invalidated CFS as an illness or diagnosis, as evidenced by the dissent surrounding its existence and causation. Participants then faced an enactment of this institutional invalidation during consultations with individual medical practitioners.

> His attitude was “there is nothing wrong with you, it will pass, I'm sure you'll find it will pass”. Every time that I went for this sort of consultation, you
come away and you'd think, “well, this is happening to me”. [begins to cry] (Participant 1)

I might have to go and get the medication, a prescription done and they'll say, “what have you got it for”? “I've got chronic fatigue”. And I've had doctors react in these medical centres that I go to, “Oh, that doesn't exist”. So even doctors are treating me like that. (Participant 19R)

All participants had at some point experienced blatant medical disbelief regarding the legitimacy of CFS. They experienced threats of disbelief both without diagnosis and with diagnosis.

In addition to disbelief surrounding the existence or reality of CFS, participants found their causative presumption of a physical basis questioned. The belief that CFS was a mental illness indicated to participants that they were not believed. The illness was experienced as a physical condition and consisted of symptoms that when encountered previously had been medically explained as physically based. It did not make sense to the participants that medical practitioners (and others) interpreted symptoms felt within the physical and embodied domain as arising from mental processes. This indicated to the participants that they were not considered able to interpret accurately their bodily cues and sensations and invalidated their connections of body and self. Body became a foreign object to self, as others claimed to know better.

The ground used to jump up and down when I tried to walk and everything moved . . . and I didn't know where anything was . . . When I was trying to describe this to my GP, he thought I was talking about depersonalisation [laughs] and was about to ship me off to a psychiatrist. (Participant 3)

I had this little shit of a GP sit me down and patronisingly explain to me that there is such a thing as somatisation, that illness can bypass the brain and basically “it's all in your head and you need a psychiatrist”. And in the end I did and it wasn't for the bloody reasons he thought [laughs]. (Participant 10)
As is the case for other contested conditions, the absence of observable signs of disease left participants open to the diagnosis of psychosomatic illness. Ware (1992) suggests that popular culture understands psychosomatic illness as “imagined” (p. 352) and that as a consequence people with CFS are viewed as either not sick or imagining their illness. Participants shared this social understanding of “psychosomatic” and interpreted that diagnosis as being told that their illness was imaginary. Furthermore, in addition to “psychosomatic”, the participants viewed any psychiatric label as suggesting imaginary illness. This was not because participants believed psychiatric illnesses to be imaginary, but because their symptoms were of body rather than mind. They believed that their physical symptoms were evidence of a physical basis (a finding also reported by Ware, 1992), and therefore, to be told that their illness was from the mind was tantamount to being told that they imagined their physical symptoms and their illness was not real. This was a fundamental challenge to their self-perceptions. And by others invalidating their self-perceptions, participants felt themselves to be invalidated.

Participants were invalidated when others described the abnormal symptomatic experiences of CFS as normal bodily responses. This was most common with fatigue. Participants were told that fatigue is an expected part of modern life and that everybod
ey gets tired. As a consequence, a good night’s sleep was considered adequate in alleviating the fatigue.

Even my Dad didn't believe it. He just said, “Oh, you need to get some sleep”, so he wasn't supportive. (Participant 19R)

Medical practitioners downplayed the abnormality of the fatigue by citing its symptomatic prevalence. Cooper (1997) also reported this tendency of medical practitioners to minimise the significance of fatigue as a symptom of CFS. Participant 8 experienced this medical normalisation.

Doctor X, who's been our family doctor for twenty years or more, he said, and he was sarcastic about it, he said, “two thirds of the people who come into the surgery complain about being tired. So what”? By perceiving CFS as primarily a state of tiredness, other people dismissed the symptom range and the quality of the fatigue experienced by participants, and as a consequence invalidated the totality of CFS. To a lesser extent, others also defined
the neurocognitive symptoms as normal, with the range of neurocognitive disturbances consolidated and explained by other people as forgetfulness and attributed to getting older. Ware (1992) similarly reported a downgrading of symptoms by others and suggested that it arose from the apparent insignificance of the symptoms, a belief shared by the participants in the present study.

It is so easy to be dismissive of a person and particularly when you've got really vague symptoms. (Participant 13)

Minimising and trivialising the symptoms effectively told the participants that they were not sick.

Participants were also invalidated when others commandeered the syndrome by assuming ownership of the symptoms. In these instances healthy individuals expressed the sentiment “I must have what you have, I'm always . . . tired/forgetting things/feeling sick”. Again, this was most common with fatigue. Commandeering of the syndrome is evident in the experiences of the following participants.

The worse thing that people have said to me, “Oh yes, but we all forget things”, to trivialise it to such extent, or, “we all have bad days” or whatever. So they trivialise it and they make it seem terribly unimportant. (Participant 13)

People who have met you for the first time, “Oh, I think I've got chronic fatigue, I'm tired all the time”. (Participant 18)

Suddenly everyone started to get the symptoms of it at work. They all thought they had it as well and that was really annoying when I thought, “well, you're out doing all these things and you get tired because you've burnt the candle at both ends”. And so I was really getting annoyed with them because it was like making a mockery of it and it's more than that. So they were just thinking it was a little bit of tiredness. (Participant 19R)

These encounters were of particular threat because they reflected the gap between the reality of the participants’ existence and the understanding of others, and the degree to which the extent and severity of their symptoms were disregarded. Trivialisation invalidated their suffering.
A particularly harsh form of invalidation associated with stigma involved the attribution of negative qualities and consequent blaming of the participants. This occurred with accusations of serious character flaws or with judgments such as lazy, needy, unbalanced, selfish or malingering. Participants believed that negative judgments were an expedient method for discounting the symptoms, the mostly normal diagnostic tests, the failure to recover, and in the case of medical practitioners, in providing justification for their lack of curative or management success. In other words, attributing negative qualities provided a basis for judging the participants as responsible for their condition.

*It was put down to me not wanting to work and being lazy.* (Participant 18)

*I got told I was doing it to get attention. I was faking . . . to get attention from my parents or because there was no love in my life.* (Participant 19R)

*Dad . . . said to me “look you're just a bludger” and I said, “how can you say that, I worked seventeen and a half years of my life Dad, I was a workaholic and now I can’t even get out of bed”. “Doesn’t matter”, he said, “what you need is a swift kick in the back-side and get out there, don't go bludging off the system”.* (Participant 16)

*It was very, very painful when people would ring up and say, “aren't you better yet”? I got that a few times, and then people would talk about my nerves, “Oh yes, she's suffering, your nerves are on edge”. And so discounting my experience and the seriousness of what was wrong with me.* (Participant 3)

Participants believed that for other people attributions of flawed personalities, psychological damage, or moral deficiencies became the causes of the illness. There is some evidence to support the belief of the participants that negative judgements by others was a mechanism for attributing blame for the condition onto the participants. Shlaes et al. (1999) in their development of an attitudes test of CFS, reported that the belief that people with CFS are responsible for their condition is related to the belief that people with CFS have negative personality characteristics.
It has been argued that chronic illness occurs within a culture of victim blaming. Galvin (2002) proposed that the chronically incapacitated person violates the notion of the “good citizen” who is self-reliant, makes rational choices and is responsible. Health is viewed as the result of appropriate choices and behaviours and consequently, according to Galvin, chronic illness becomes culpable behaviour, an “instance of moral failure” (2002, p. 108) with widespread ramifications for the self-perceptions of individuals and for institutional expectations regarding individuals. Furthermore, Sontag (1999) argued that psychological theories provide the means to blame ill people for their illnesses. Similarly, Samson (1999) proposed that a psychosomatic approach implied that the ill person bears responsibility for their illness, commonly as a result of personality. Taking these arguments as points of departure, the attribution of moral failure and blame is likely to be compounded in the case of contested chronic illnesses like CFS, where psychological and psychiatric explanations are commonly invoked. Consequently, people with CFS may be held doubly responsible, firstly because they are chronically ill and secondly, because it is a contested illness.

The participants certainly felt that they were blamed for their condition and the longer the illness, the guiltier they believed they became in the views of others. The perception that they were being held accountable was of significant threat, particularly given the powerlessness and loss of control participants mostly experienced in relation to the condition. The attribution of blame was invalidating because it questioned their moral character and indicated to participants the low esteem in which others held them. As Sontag (1999) has postulated, ill people who are told that they have, in some way, caused their disease are left with the feeling that they deserved it.

Dismissive experiences were a common and important source of invalidation. Ignorance and disinterest, being silenced, and exclusion were used by others to dismiss the participants’ experiences of CFS. While other studies have reported the contribution of medical ignorance to delegitimation (Green et al. 1999), the present study found the presence and threat of ignorance to be more widespread. Ignorance,
in the form of a lack of knowledge and understanding by others (including medical practitioners, as described in Chapter 5), contributed to dismissal by trivialising the symptoms and minimising the effects. All participants experienced ignorance from others.

_A lot of people don't know. A lot of people say things like, the normal thing is “Oh, you feel tired a lot”. And then you say, “no, it's not just that”._

(Participant 7)

Participants did not view ignorance among individuals who had no experience with CFS as dismissive. It became dismissive with individuals whom they believed ought to have a knowledge base (such as medical practitioners) or with people of significance to the participants who refused to learn about CFS. Ignorance and disinterest frequently occurred together, as was the case for Participant 3.

_People used to ring me up and say, “how are you feeling”? And I'd say, “terrible, really sick”. And they'd say, “Oh well, ring me when you get better and we'll go out to dinner” . . . And I knew that this was terribly serious and wouldn't go away in a hurry and other people act as though I had the flu and it would go away and then I could go out to dinner . . . I felt very socially isolated, like very isolated from normal life. Because no one really understood what was happening._

The actions of her friends indicated to Participant 3 that they did not understand CFS, nor were they particularly interested in learning. Disinterest was more likely with the passing of time, even among CFS specialists.

_I liked Doctor X, he was very good to me to start off with, but he's not interested . . . in the ongoing crap of ME._ (Participant 15)

The disinterest experienced by Participant 16 was related to the perceived lack of seriousness of CFS, as if it was too benign to elicit any concern.

_You haven't got cancer. You haven't got some disease that's catching, so straight away they don't want to talk to you. They don't want to give you the time of day because its not something they can see outwardly, it's an inwardly thing._

Sometimes individuals who were interested nevertheless demonstrated ignorance. For example, advice was given (such as joining a gym) that indicated that the person
did not understand the nature of CFS. Ignorance and disinterest were of threat because they resulted in a dismissal of suffering and needs.

Dismissals through being silenced occurred when participants felt they did not have permission to talk about CFS or were actively discouraged from doing so. Fennell (1995) has also identified this censoring among people with CFS who were pressured to avoid discussion of their illness, particularly of any negative aspects. Participants were silenced by a number of strategies, such as ridicule, humour, or paternalism. For example,

’Cause I was told I had neuralgia, and they said, “Oh, you mean neuroses”. And then when I was told it was brachial reticulitis, they said, “ridiculitis [ridiculous], that's even better”. I couldn't win. (Participant 6)

A psychiatrist I went to see said, “you're just doing marvelous, Oh, if I was in your position”. And I'm saying, “I am not doing well. I am falling apart at the seams. I am not doing well”. “Oh yes you are, marvelously”. That is no help to me at all. (Participant 13)

Being silenced also resulted when participants were fearful of criticism or abandonment. For example, non-disclosure in order to avoid negative outcomes was a form of being silenced and is discussed further in following chapters. Being silenced was of marked threat to participants. Participant 6 described her devastation at being silenced while a work colleague with the flu was allowed to express her feelings.

I thought, “I'm not allowed to complain but she is about the same sort of symptoms, as if they're the worst in the world and yet mine do not exist”? And the sense of being totally unvalued was quite devastating, and not being able to talk to anybody . . .

Being silenced rendered the participants voiceless and without the capacity to communicate their experiences. They were not worthy of being listened to.

Exclusion from health care and social support was a tangible form of dismissal and was a consequence of policies, lack of resources, beliefs of practitioners, and medical and social abandonment.
I tried to get help and I was told “for God’s sake don’t waste our time, somebody who is really sick needs us”. And these were from agencies or professionals who were meant to know. (Participant 15)

At the end he [acupuncturist] said there wasn’t much point in me going any more ’cause he’d turned himself inside out, read all his books again and he couldn’t find what’s wrong with me. (Participant 12)

Exclusion generally was first evident prior to diagnosis. For example, as described in Chapter 5 the absence of a diagnosis excluded participants from disability and other social services and as was also reported by Featherstone (1998), participants found that family and friends used the ongoing absence of a diagnosis as a reason for excluding support. However, lack of credibility regarding the CFS diagnosis meant that exclusion continued following diagnosis.

While exclusion mostly resulted from the responses of others, there were instances when it was self-generated. In these instances the invalidation previously encountered had been sufficiently traumatic that participants avoided placing themselves in a position of further invalidation. Thus, invalidation that resulted from the pursuit of a diagnosis was associated with a cessation in Participant 18 trying to find a diagnosis.

I went in and asked about chronic fatigue and this doctor just basically lectured me so I just left if for years.

Participant 10, who had avoided an initial medical consultation because she did not want to encounter a gendered interpretation of her symptoms, demonstrated similar self-exclusion.

When I first got sick it never ever occurred to me to go to anyone for help because I didn’t want to be branded as just another woman turning up at a GP complaining of headaches and leg pain and dismissed for that. And I was.

Her self-exclusion was not related to previous invalidation of the CFS symptoms, but with the invalidation associated with being a woman seeking health care for nondescript symptoms. Exclusion threatened the participants’ physical well-being, sense of belonging, engagement and entitlement, in particular threatening self-worth.
As Asbring and Narvanen have noted, “a person expends a great deal of energy to be regarded as a valid person” (2002, p.158). The participants, by virtue of their symptoms or diagnosis, were judged to be taking on an invalid illness, and the consequent invalidation was of significant threat. It denied their illness reality and suffering and communicated to participants, to varying degrees, that they were not worthy of care, not worthy of support, not worth listening to, and not worth knowing.

**The Unique Constellation of the Threats: A Conclusion**

Dewar and Morse (1995) identified aspects of illness found to be unbearable, including uncertainty of diagnosis and prognosis, confronting reality, loss of control, loss of function with dependency, not being believed, not being listened to, being treated as an object, caregiver ignorance and insensitivity, disregard from significant others and feelings of being a burden. Each of these aspects was reported in the present study and highlights the threats associated with CFS and the suffering involved.

As a chronic illness, CFS was associated with the threats common to chronicity. The medical controversies, however, and the beliefs, encounters, situations, delegitimation and premises associated with the invalidation and stigma of CFS are not shared with most other chronic illnesses. That is, CFS was associated with unique threats related to its historical, sociocultural, medical and temporal contexts. CFS belongs to that small group of questionable and disputed illnesses where the “reality” of the experience is strongly debated and the people affected are marginalised by disagreements within the medical system. As a consequence, the participants were exposed to an additional dimension of threat not found with most chronic illnesses. The effects of the disruptive and invalidating threats and the responses of the participants were articulated in the narrative of the struggling and diminished self seeking renewal. The next chapter begins the examination of the narrative of self by addressing the effects of the threats, that is, the experience of the Violated Self.
Chapter 7

The Violation of Self

This chapter begins to articulate the narrative of self as it changes among people with CFS. The major focus here is the negative effects to self, that is, the Violation of Self, which necessitated the process of self-renewal. The analysis generated a primary narrative about the process of the struggling self seeking renewal that arose in response to the threats of CFS. The narrative describes the negative effects of the threats on self, which I named the Violation of Self, and the consequent efforts made by the participants to alleviate the struggle and feelings of violation. The efforts are called the Guardian Response and the Reconstructing Response, and they are considered in detail in Chapters 8 and 9. These responses served different purposes and employed different strategies. The threats of CFS fluctuated but were always present, therefore violation, to varying degrees, was ongoing. Under different conditions, the relative strengths of violation, guardianship or reconstruction fluctuated, and it was these fluctuations that presented the participants with the ongoing struggle and uncertainty of CFS.

In this chapter the effects of the threats on experiences of self are articulated. The participants’ understanding and meanings of self are discussed. The features of self-discrepancies, self-doubt and self-blame important to the development of the Violated Self are addressed. The impact of CFS on the known-self, with particular attention to the foci of the violation (that is, identity, place and time, agency and connections), is also examined. Lastly, the lived experience of the effects of the threats, the Violated Self, is described.

The Participants’ Understanding and Meanings of Self

The narrative of self indicated that participants shared an understanding of the abstract construct of “self”. While there were individuals differences, views were markedly similar suggesting that participants reflected culturally endorsed norms or perceptions of self. They perceived self to be an agreed-upon, self-evident, and
taken-for-granted experience. Participants considered self to be the measure and manifestation of existence, that which constituted the unique person, a singular entity representing an integrated whole. There was a perception of a core, real and authentic self, however, there was also an understanding of multiple selves that represented different facets of the person. Additionally, self was viewed as dimensional. That is, self was embodied and physical (physical-self); it was mental and used thought processes (self-as-thinker); it was active and sought to control (self-agency); it existed in relation to other people (relational-self); and it included self-perceptions of value (self-worth).

These meanings are consistent with premises generally found among theories of self. For example, the singular, multiple and dimensional nature of self are longstanding premises (see for example, James, 1999; originally published 1890). More specifically, Baumeister (1999) identified three apparently universal human experiences that form the basis of selfhood. Firstly, the self demonstrates reflexive consciousness, operating with self-awareness of body, feelings and thought. Secondly, self is an interpersonal being interacting in relationships and as a group member. Thirdly, self involves an executive function by making choices, taking action, and exerting control over self and environment. The participants’ understanding of the dimensions of self was consistent with the three defining experiences described by Baumeister (1999).

Participants viewed identity as different from self, however, to some extent the defining difference remained unclear. As Shoemaker (1963) observed, identity and self are not defined and clear constructs, and the nature of persons, self and identity has challenged philosophers in a way that the identity of other things has not. In that sense the participants were reflecting these broader philosophical concerns, in addition to the ambiguity found in the self/identity research where the distinctions between the two constructs are not always articulated or the relationships explained (for example, Goffman, 1963), resulting in a certain conceptual fuzziness. Although some researchers have used identity as the organising presiding construct in which self is a component (for example, Dimond & Jones, 1983) most researchers appear to view self as the primary construct, with identity representing a more specific
experience of self. This was in line with the perceptions of the participants. While self was the encompassing construct, identity more specifically encapsulated the participants’ notion of “who I am” and “what makes me who I am”. The participants’ perception of identity was consistent with that proposed by Erikson (1968) in that identity was viewed as a relatively clear and stable sense of who one is and what one stands for. Similarly to self, participants perceived that they had a singular identity in conjunction with multiple identities that were primarily related to roles and interests, and included both public (social) and private (personal) dimensions. Participants attributed a familiarity to their identity(ies), consistent with Shoemaker’s premise (1963) that identity implies persistence. Nevertheless, despite participants viewing self and identity as separate, there were instances when the terms were used as interchangeable, and from an experiential perspective they were interwoven. The participants’ understanding and meanings of self provide the basis for discussing the Violated Self in this thesis.

The Development of the Violated Self

The Violated Self was the result of cascading situations and effects. Violation began with the threats and as was described in Chapter 6, the threats had direct effects on experiences of self, such as isolation and loss of self-worth. Additionally, the threats gave rise to the participants experiencing self-discrepancies, self-doubt, and self-blame. It was these three experiential features of CFS, in conjunction with the threats, which violated the known-self and led to the development of the Violated Self. Self-discrepancies, self-doubt, and self-blame contributed to violation because they indicated to the participants that the known-self was disappearing and an unfamiliar self was moving to the fore. Participants found that comparisons of life-before-CFS and life-with-CFS demonstrated an impoverished and diminished existence. They questioned their perceptions, beliefs, rationality and sometimes sanity, and experienced various degrees of responsibility for their illness. These three experiential features of CFS compounded the threats, and in conjunction with the threats provided a powerful climate for the development of the Violated Self. Each is discussed below.
Self-Discrepancies

Self-discrepancies were of influence to the development of the Violated Self because they made apparent the undesirable changes that CFS brought to the lives of the participants. Self-discrepancies arose from comparisons that indicated erosion in the quality of their lives. The participants’ descriptions of their lives and themselves prior to CFS tended to reflect activity, valued attributes and positive expectations.

*I raised four boys. I had a vegetable garden. I used to play hoola hoop with them out the front. I sewed. I knitted. I made all their clothes and I went back to part-time work when the youngest was four and I had a busy life.* (Participant 2)

*I was pretty goal oriented . . . I had a lot of things going on, working part-time, studying full-time, had a family. I was just full on with everything.* (Participant 14)

Alternately, following CFS, descriptions involved limitations, negative appraisals and the loss of valued attributes.

*I have less confidence in myself. I am more reliant on my partner than I probably would like to be. Less able to think things through and make a decision . . . less confident in my own ability to mount an intellectual argument.* (Participant 15)

*That was my old life . . . I was the life of the party, completely different. I used to go out all the time. My friends were over all the time. I was very motivated, very disciplined, always happy, always had a smile on my face. Very outgoing, always doing a lot of things . . . that was me. Not now.* (Participant 18)

In particular the threats of disruption, such as those related to body and functional impairments, distanced participants from their pre-CFS lives. Their comparisons demonstrated large discrepancies between past and present, expected and actual, or self and others. For example,

*My expectations of myself before were very high [begins to cry], whereas now as you can see I sometimes even lose track of what I'm talking about.* (Participant 1)
In the present study self-discrepancies were an important measure of change and
difference. Self-discrepancy theory proposes that the greater the magnitude and
likelihood of a self-discrepancy held by a person, the more that person will suffer
associated distress (Higgins, 1999). This general hypothesis is consistent with
illness-related findings. Among cancer patients, for example, higher self-
discrepancy was associated with lower levels of psychological well-being (Heidrich,
Forsthoff, & Ward, 1994). Although self-discrepancies among people with CFS
have been reported (Woodward, 1993), they have remained largely unexamined.
The present study indicates discrepancies to be significant and associated with
marked violation. The discrepancies between life before and life after CFS reflected
the dislocation to the biographies of the participants.

Self-Doubt
As was described in Chapter 6, participants experienced disbelief and doubts from
others regarding their realities. Over time, the doubts of others became, for most,
doubts regarding self. While self-doubt associated with delegitimation has been
reported in a few CFS studies (for example, Fennell, 1995; Ware, 1992), examination
has been limited to mention of its occurrence. Research into other contested
conditions have similarly reported the presence of self-doubt arising from the lack of
legitimacy but have provided little detail (Garro, 1994; Rhodes et al., 1999).

Self-doubt arose from invalidation, specifically the disbelief and scepticism of
medical practitioners and significant others, and the absence of direct and objective
clinical findings. Participants had been subjected to constant and wide-ranging
episodes of invalidation in which other people claimed to know the participants
better than they knew themselves. Additionally, normal test results and the absence
of a legitimate biomedical explanation transgressed medicine’s doctrine of
aetiological specificity (Dubos, 1959) and reaffirmed to participants their
questionable reality, further contributing to self-doubt. For most, self-doubt was
episodic, fluctuating with the threats. A minority of participants found there was always a presence of self-doubt regarding the authenticity of their interpretations.

*Even the self-doubt never really goes away . . . I think what happens is you sort of sometimes say, “am I really tired or am I just being lazy? Do I really feel awful or am I just being lazy”? And then something happens that confirms that you really are sick. But there is this constant questioning.*

(Participant 7)

Generally, the self-doubts of the participants were the same as those held by others, that is, doubts about the “reality” of CFS, the legitimacy of their impairments, and their responsibility for the illness.

*For a while I was wondering if I was malingering . . .* (Participant 17R)

[It was] . . . even in doubt that I had CFS, because there's no blood test that says you have CFS. How did I know it wasn't depression or anxiety or something else that was causing it? (Participant 5R)

Self-doubt regarding psychological health was reported, with some participants experiencing a sense of *losing my mind* or *going crazy.* While this tended to be a short-term phenomenon that was reported by only a few participants, questioning and doubting of one’s sanity was associated with fear and distress. It is possible that participants under-reported this extreme manifestation of self-doubt. A participant who telephoned me a couple of weeks after her interview alerted me to this possibility. She had not acknowledged self-doubts about her mental health during the interview because repressing them and not giving them voice was how she coped with the fear of *losing my mind.* There are numerous other potential reasons why CFS research participants would not report doubts regarding their mental status (such as protection from further invalidation or social desirability), particularly given the psychiatric/psychological labeling to which they are already exposed. It may be that doubts regarding psychological health are more widespread than is currently suggested in the limited amount of research that has reported fears of “going crazy” among people with CFS (for example, Fennell, 1995; Ware, 1992).
For some, self-doubt became a loss of trust. It was difficult to consistently maintain trust in oneself when that involved rejecting the beliefs of many others, including medical experts.

\[
\ldots \text{you don't know, or whether you really do feel, whether that's real. So you've got to keep going through other people's reality checks all the time, 'cause you cannot do it yourself.} \ldots \text{(Participant 10)}
\]

\[
\text{I don't trust anything. I've lost a lot of trust and I can't even trust myself. I don't know what's right. I don't know how I feel. I had so many people telling me I was depressed and I don't know whether I am or whether I'm not. I really don't.} \text{(Participant 13)}
\]

Loss of trust tended to generalise and was corrosive to positive perceptions of self.

Self-doubt contributed to the development of violation by throwing into disarray the participants perceptions of themselves as experts in and of their own lives. Their certainty about their knowledge and understanding of themselves, which had previously been taken for granted, was disrupted. Participants felt alienated from who they believed themselves to be and from what they believed to be true.

**Self-Blame**

Self-doubt and self-blame were commonly entwined. As participants began to doubt their perceptions and became more susceptible to the opinions of others, there was an increased self-questioning regarding their contribution to the illness.

\[
\text{There's also a constant feeling of maybe there is something I can do myself to make it better. Maybe the headaches are my fault 'cause I'm feeling tense or stressed, or my fault because I'm not taking the right vitamins or the wrong vitamins. Maybe there's something I can do. And then you try it and no, that wasn't it.} \text{(Participant 7)}
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\[
\text{[I questioned] whether I'd thought them [symptoms] into existence . . . I blamed myself . . . that it was anxiety or something . . . I thought it was in the mind. I thought I had given up on things because that's what people were telling me at that time.} \text{(Participant 5R)}
\]
Time goes by, months go by, and you're no better. And then a year goes by and you're no better. And why am I no better? I must be doing this.

(Participant 13)

Self-blame was problematic because unlike other medical conditions where there are established links between lifestyle and disease, no such link has been demonstrated for CFS. Participants felt responsible and blamed themselves but did not know why. They hypothesised many possible reasons (such as diet, failure to find the ‘right’ therapy, personality attributes) but essentially, participants were left with free-floating blame. Therefore, through what was potentially an infinite process of exclusion participants searched (for a time) to find the trigger, stimulus, behaviour, missing vitamin or unresolved conflict that was causing or contributing to their illness. This search was commonly used against participants with accusations of hypochondriasis or invalidism.

Self-blame contributed to the development of the Violated Self because it was associated with participants questioning the role of their personal qualities, abilities, perceptions and actions in the genesis and maintenance of their illness. Self-blame resulted in perceptions of self-deficits, inadequacies, moral flaws, and powerlessness.

The Impact of CFS on the Known-Self
The combination of these three features and the threats resulted in the violation of the participants’ understanding and experiences of self. Prior to CFS, the participants’ constructs and concepts of “self” were taken for granted. They knew themselves to be individuals with personalities, roles, responsibilities, hopes, expectations and morals. They had histories, futures and ways-of-being in the world that were familiar. There were connections to people, their environment and communities, and to ideas. This knowledge of self was experienced by the participants as their known-self. It was this aspect of self, that is, the participants’ understanding and experiences of self built up over their lifetimes, that was violated by the onset and continuing presence of CFS. That is, CFS violated the known-self, the taken-for-granted and everyday understanding and experience of self. What was once the familiar had become foreign.
Participants described the violation of the known-self as encompassing different domains: identity; place and time; agency; and connection. The relevance of these domains have been partly identified by others, for example Freund and McGuire (1991) who, similar to the present study, describe illness as an assault on identity, on the ability to control one’s life, and on connectedness. The effects of violation to each of the domains of the known-self, as identified by the participants, are addressed below.

Violation of Identity
Lowen (1967) observed that under normal circumstances people do not ask themselves, “who am I” because identity is taken for granted. For the participants, the nature of their identity prior to CFS had been known. It encompassed past, present and future, was biographically continuous, comprised of core qualities and roles that were enacted within their daily lives, and derived from numerous sources. CFS and its threats presented the participants with abnormal circumstances which compromised the participants’ ability to be “who I am” and violated their understanding and experiences of their known identity. Specifically, identity was violated by the diminishment of valued core qualities, future identities and identity sources, and by the inability to enact or express identity.

Core qualities encompassed unique and valued attributes that were defined by participants as fundamental to their identity. They contributed to positive self-perceptions and through their enduring nature provided continuity and predictability that was part of the known-identity. Consequently, the diminishment or loss of core qualities violated the experience of persistence, which as noted by Shoemaker (1963) was crucial to identity, resulting in biographical disruption. Further, identity was a fundamental dimension of self, and the loss of core qualities important to identity was felt as a loss of self, which is consistent with Charmaz’s (1983) findings of a loss of self among chronically ill people.
If you said to me what was the hardest part about it I'd have to say... it took away my core personality and so to feel even a fraction of myself is a major battle. (Participant 12)

I don’t feel like me that I can’t sing. (Participant 11, who prior to CFS had been a professional singer)

Other research has also reported that CFS deprived people of the self-attributes they most valued (Woodward, 1993).

CFS violated future identities. These were related to age and personal goals, and were both culturally and personally generated. The participants’ future identities were similar to the construct of possible selves (Markus & Nurius, 1986), and the inability of participants to enact their intentions or meet their expectations resulted in an inability to actualise desired possible selves.

My life is completely different. I think that people who knew me before - I met one recently and she was gob-smacked that I was a housewife because that’s not what I’d planned, it's not what I'd envisaged, and it's probably not what I would have done. (Participant 15)

Participants who became ill during early adulthood experienced a greater loss of possible selves because fewer age-related expectations and goals had been accomplished and more of their future had been violated. Participant 4, for example, became ill in early adulthood and consequently, had no opportunity to establish a career or working history. The possible selves he had envisaged in his youth remained unfulfilled.

... so for me, a young person being agile with dreams and aspirations, it's basically cutting into your future.

In addition to the loss of desirable future identities, violation also encompassed possible selves that were conceptualised as undesirable.

I'd be half asleep and I'd be having flashes into the future of being sick and my partner being there and trying to do things for me, and children missing out. I didn't want that. (Participant 5R)

The violation of the future identities was in practice, a violation of the global future.

I didn’t believe I had a future. (Participant 19R)
CFS limited identity sources and the ability to express or enact identity. Identity was largely derived from doing and thinking, and participants questioned what was left of their identity when doing and thinking were limited by functional impairments.

*I spent most of the day . . . watching my friends climbing and thinking, “who am I? I'm not climbing with them anymore . . . What sort of person was I if I wasn't able to climb anymore . . . what am I if I'm not one of these physical people”?* (Participant 17R)

*Because if you're not working and all you're doing, which is all I was doing for a time, is looking after yourself . . . you just question all the things about purpose of life. What is the purpose of your life and everything? Just looking after yourself is not, doesn't seem like a very purposeful way to live.*

( Participant 7)

Participants were unable to define identity by occupation, roles, interests, or relationships and consequently, were left without an identity framework. Participant 3 described the extent to which her identity sources had been compromised.

*But a lot of what I could've [done], maybe I could have, while I was still young enough. Build up some kind of a permanent relationship with somebody, which I haven't done so I missed out on that. I feel like I've missed the boat in a lot of ways and my career as well. I was earning a lot of money at that stage, so I lost a lot of money. I lost maybe a permanent relationship. I don't think I'm going to have one now . . . I think I'm too old. [laughter]*

The diminished roles related to work and family were particularly significant to identity as they represent the two main sources of the adult's productive and emotional enterprises (Whitbourne, 1986). Occupation is frequently the primary means through which a person expresses their identity as a competent agent, so that limitations in performance have identity implications (Christiansen, 1999). Further, Whitbourne, (1986) found that an overwhelming majority of adults considered involvement in their families as their first and foremost area of identity. Clearly, the diminishment of relationships and roles and the functional impairments reported in the present study curtailed the participants' identity sources and precluded the enactment of identity.
Identity was fundamental to experiences of self, and to a large extent violation of identity was a direct violation of self. CFS and its threats attacked the essence of identity by compromising valued and defining attributes, disrupting biographical continuity, and reducing perceptions of a positive future.

Violation of Place and Time
Prior to CFS participants perceived themselves as having a temporal location in the “scheme of things” that provided an everyday, taken-for-granted groundedness and predictability. CFS and its threats resulted in participants experiencing violation of their place in the world and in time. They became displaced in a wide and general sense, separate from humanity. Place and time were experientially connected. For the purposes of discussion, however, each is addressed separately below.

Violation of place was most commonly experienced as a break in their connection with the world that left participants dislocated and apart from other people and the environment. It was also expressed as an altered or detached reality. Participants described an alienation from their known world and the loss of their place within society. In sum, the violation of place resulted in estrangement.

I realised a few months ago, I was walking down the street, I do feel, I recognised that I felt estranged from society . . . (Participant 14)

[With CFS] you're not part of the world. (Participant 16)

It [CFS] does make you feel like you're a person from Mars. (Participant 3)

For Participant 3, estrangement had generalised to perceptions of self as alien. Her loss of relational-self and social location was sufficiently strong that she expressed disconnection from her species. While a minority identified estrangement as confined to the early stages, most participants experienced estrangement as intermittent but ongoing.

Estrangement was associated with threats of invalidation, notably stigma, and threats of disruption related to symptoms. Stigma was associated with estrangement
because it signified to participants that they occupied an inferior social location. Indeed, Participant 3 was so stigmatised that a friend intimated soul possession as an explanation for her symptoms.

*One friend rang up and said that she'd read an article about people being taken over by people from outer space, people's souls being taken over. It must have seemed like that to her, like I'd been taken over by a, being like I was a zombie.*

Additionally, there was social distancing and isolation arising directly from the neurocognitive disturbances.

*With my memory loss I forget tracks of my life. I forget people. I forget conversations I've had . . . you are slightly removed from reality . . . And that's where I think you get this sense of [being] removed from reality because your memory is playing such tricks on you and your concentration, that you do actually feel slightly removed from reality.* (Participant 15)

Estrangement as an outcome of stigma has been documented elsewhere (Marbach et al., 1990). Partly consistent with the present study, Green et al. (1999) found that 95% of participants reported stigma and estrangement resulting from the severity of their CFS symptoms. The direct effect of neurocognitive symptoms on estrangement was not reported. Woodward (1993), however, consistent with the present study, reported estrangement related to loss of cognitive functioning. Given the prevalence and intrusiveness of neurocognitive symptoms, these direct effects are worth exploring.

Diagnosis somewhat lessened perceptions of displacement and estrangement because it signified that others shared the social location of the participants. As Participant 10 described, there was relief with diagnosis because of the ability to say to people, *this is why I have been so seemingly estranged.* Woodward (1993) similarly noted the importance of explanation for reducing estrangement among people with CFS. Nevertheless, while diagnosis assisted in modifying the degree, the symptoms and stigma continued to fuel episodes of estrangement.

The participants’ understanding of “having a place in the world” was not a static construct but involved perceptions of life as progressive. Consequently, violation of
place was also described as a state of inertia, with perceptions of living in limbo, marking time and existing in a state of suspended animation while waiting for a return to health.

. . . it's like the earth has stopped, but all of a sudden something is going past you. That's what it's like . . . I'm existing, the whole world out there is living. So when you exist you're staying still. You're not moving, so that's what it's like. You can see . . . everyone moving and you just can't. (Participant 18)

The life trajectory of others was continuing while their own had stalled. That is, they had lost their place in the progression of life.

A sense of time is crucial to human existence and chronic illness damages taken-for-granted assumptions about and towards time (Crossley, 2000). The violation of time disrupted the expected temporal flow of the participants’ lives and changed their lived experience of time into something unfamiliar, involving temporal elongation, lost time and discrepancy.

Temporal disruption manifested as an elongation where the passage of time and experiences were lengthened. For example, symptoms were experienced over an extended time frame, diagnosis and realisation of chronicity were usually lengthy, the effects of over-exertion commonly lasted months, and waking up and starting the day was slow and protracted.

I'm still catching up from overdoing it in February, March, April, May. I keep thinking I've had a good rest today, I'll be able to start earlier tomorrow. (Participant 2)

Additionally, there was a temporal elongation associated with the social domain, and the time between visits or calls from friends became longer. Elongation of time was felt as an imposed slowing down. Violation of time also included the perception of lost time that could not be reclaimed. Indeed, participants measured their losses and the costs of CFS in terms of years.

What I feel like I lost was ten years out of my life from this illness. (Participant 3)

I felt like there was five years of my life that I lost. (Participant 19R)
Lost years were equated with lost life. With CFS the congruence between time and biography was violated.

Prior to CFS participants had experienced congruence between time and biography, that is, between their chronological age (a measure of passing time), embodiment and age-related expectations. Temporal discrepancies were commonly experienced as a mismatch between the participants’ age and the age they felt themselves to be. Participants felt old before their time, a young person trapped in an older body.

They described it like this:

I said, “Dad I'm telling you, you're seventy-six years of age. I'm only forty. There's a big difference. How do you think I feel when you're telling me I can do this and I can do that and I should be doing this and I should be doing that?” . . . [I am] a person who is virtually living in an eighty year old body. (Participant 16)

What is hard and especially being a young person and somebody who just loves life and wants to be alive, is holding back, and having to think of yourself as a ninety-five year woman in a forty-year old body. That's really hard. (Participant 10)

In addition, certain events or milestones are generally associated with particular times in life, and CFS had violated the expected temporal biography resulting in discrepancies of what was expected and what eventuated. For example, participants retired earlier than expected, dependency replaced the expected independence of the adult, or the opportunity for parenthood passed.

I had been working and I had to give up work at that stage. That was when I was forty and there was no easing in. (Participant 12)

We are so often described as what we do rather than who we are, so that it becomes when we lose that, like when somebody retires, you lose that identity. But you've attained an age so that it's your right to do this, whereas I hadn't attained any of the things to make it my right to not be at work. (Participant 13)
The discrepancy between time and biography described by the participants mimics Bury’s (1982) account of chronic illness as resulting in a biographical shift from the expected normal trajectory of predictable chronological steps, to one that is fundamentally abnormal and inwardly damaging. Similarly, Boughton (1997, p. 4) described a “temporal pathway disruption” associated with premature menopause. Unlike the present study that found temporal elongation, Boughton’s participants reported a “sense of time flying” (p. 4). Nevertheless, while the lived time was different, the temporal disruptions similarly arose from discrepancies between the expected and the actual. In sum, CFS had violated the taken-for-granted nature of time, and lived time was changed and disrupted.

**Violation of Agency**

Participants had known themselves to be the presiding agents over their own lives. Their lived experiences, until CFS, had been of autonomy and independence. Participants had exercised control over decision-making and felt competent in their everyday lives. They had both the physical and mental capabilities necessary to operate as free agents. CFS violated this self-agency.

Many of the threats of CFS contributed to the violation of self-agency. Invalidation communicated to participants that others perceived them as incapable or incomplete, fostering self-doubt. For example, being disbelieved violated agency because it signalled to participants that their perceptions, decisions and interpretations were untrustworthy. Functional impairments precluded the enactment of roles and consequently, an important source of agency was diminished. Physical impairments, for example, left participants limited in their ability to meet self-care needs or responsibilities.

*And then you're living off social security, which comes with some difficulty . . . you're not making it [money]. Somebody is just handing it out to you so there's that feeling of failure that you're not achieving.* (Participant 13)

*I get upset sometimes when it takes me three hours to mow the lawn. I can’t do it in one go . . . I got to wear a mask . . . gloves . . . eye goggles. By the time I dress myself up every one thinks I'm a nut case.* (Participant 16)
Cognitive impairments and emotionality compromised decision-making and positive perceptions of self as intellectually capable.

*I know I can't do what I could do before and sometimes I get very frustrated if I can't understand something difficult that I know that I could've understood before, especially if it's abstract, conceptual. That really bothers me because that's what I used to be really good at. And now if I read a paragraph and I can't make head or tail of it, that really makes me feel bad . . . *(Participant 7)

Further, agency was violated for those participants who perceived CFS as an entity that could overtake or colonise their identity.

*It [CFS] has a life of its own and it's going to get you when it wants to . . . it became clear to me that it was going to do what it wanted to do and it wasn't my fault.* (Participant 17R)

*CFS became like a monster wanting to take over my identity. [I was] trying to outrun it all the time.* (Participant 5R)

In other words, CFS was felt to have its own agency and life that participants either struggled against or accepted.

Violation of agency meant that the taken-for-granted nature of self-agency had been transgressed. Participants continually experienced failure where they once demonstrated competency - work, family responsibilities, self-care, recovery. Failing became part of everyday life, resulting in a loss of self-worth. Other CFS research has also reported a loss of agency related to the condition, with consequent undermining of volition and self-esteem (Cohn, 1999; Pemberton et al., 1994).

**Violation of Connections**

As a consequence of CFS, participants were unable to socialise and engage in activities, relationship sources disappeared, existing relationships were frequently strained and questions arose about relationships that had been or were part of their lives. That is, the relational connections that participants had experienced prior to CFS were violated.
The violation of connections removed participants from the protective aspects of relationships, contributed to feelings of rejection and loneliness, and compounded losses. Their consequent isolation was of concern, given the persuasive research findings on the detrimental effects of isolation on health (Freund & McGuire, 1991). Disconnection was experienced across the temporal continuum. That is, in addition to past and present, future connections were felt to be lost. The relational-self was weakened and became an uncertain judge or a disappointed observer of others and self. There were two interrelated aspects of connection that were violated by CFS: entitlement to relationships and beliefs about value to others. That is, participants believed themselves to be no longer entitled to some relationships and that the relationships they did offer were qualitatively inferior. Each aspect is addressed below.

Disconnection left participants with the belief that they were not entitled to specific relationships or had limited rights within a relationship. Lack of entitlement arose from perceptions of relationship inequality and imbalance. Bury (1982) noted that reciprocity is a central relationship norm and, as was discussed in Chapter 6, functional impairments left participants unable to do what it takes to sustain and nurture relationships. Symptoms and dependency left participants unable to reciprocate, perceptions of equity were violated and they felt they had lost the right to maintain that relationship.

*I can't keep in contact with people. You can't respond to them so you feel as though you can't keep in touch with them if you can't respond to them. It's got to be a two-way thing, getting them to come all the time and then you can't respond.* (Participant 9)

In response, participants withdrew from relationships or lived with failure within the relationship, further increasing their disconnection.

CFS also violated the participants’ perceptions of the quality of the relationship they offered others. As their functional impairments, disrupted relationships and roles, and invalidation continued, and as they observed the effects their illness had on others, participants developed a belief that they were only able to offer a relationship
that fell short of what was expected, desired or owed. In particular, participants spoke of their distress regarding their parenting relationships.

That's what is so hard, you're losing that time with your children when they're growing up and that's what upsets me the most because you think it's not fair . . . I should be out there playing with them and I can't. (Participant 16)

I know that I'm a fight person, not a flight person. So when I got really fatigued I'd be blowing up all over the place to get this energy to keep me going, to do what I physically had to do. But that was an emotional disaster for young children. (Participant 15)

CFS left the participants with beliefs that relationships with them were second-rate, or worse, damaging to others. Their confidence in being able to offer a valuable and valued relationship was violated.

Concerns regarding inferior relationships included not only present but also future relationships. Participant 1, for example, expressed doubts about her worthiness as a potential partner.

I haven't gone out with anyone in a serious way because although I can probably cope better with it now from the physical point of view, I feel like my life is too limiting and it wouldn't be fair on the other person. They couldn't say, “how about we go get a curry tonight?” Or “how about we go and climb Sydney Harbour Bridge?” I'm kinda just holding that sort of relationship at arms length until I feel like I'm in a better position to offer someone a more fuller life.

The self-sacrifice implicit in her decision reflected her perceptions of relational inferiority and loss of self-worth. In addition to relationships being avoided, relationships ended because of the self-perception that participants could not measure up to rightful expectations. Participant 4 ended a relationship because of his inability to provide his partner with an income and “normal” life.

As a lived experience there was mutuality and interaction among the domains of self and no clear demarcations between identity, place and time, agency and connections. While these domains of self have been separated for purposes of identifying aspects
of violation, in practice violation was an integrated and encompassing experience. Violation of identity, place and time, agency and connections prompted existential questions, such as “Who am I”? “What is my purpose”? “Where do I belong”? In sum, what was violated was the participants’ understanding and experiences of the known-self, and the known-self became a Violated Self.

The Experience of the Violated Self
The effects of the threats, self-discrepancies, self-doubt and self-blame, and of the violated domains of self were encapsulated in the experience of the Violated Self. The Violated Self referred to the participants’ negative perceptions, beliefs and feelings regarding self that resulted from CFS. Essentially, it involved experiences of self that were diminished, disturbing and traumatised. The following content describes the lived experience of the Violated Self.

As compared to the known-self, participants experienced the Violated Self as changed and inferior.

*I feel like I'm the ugly twin that has nothing to offer . . . I think probably the foremost thing would be that I just feel like I'm so different.* (Participant 1)

Change and feelings of inferiority were evident in the distinction made by the participants of a “real” versus “unreal” self. The before-CFS self (that is, the known-self) was viewed as the “real” and preferred self capable of living a normal life, while the “unreal” self was a consequence of CFS. Participants felt that their real self was not evident to others.

*I've made a lot of new friends but even when I talk to them . . . I'm still not that person that I was. I notice that and I feel that.* (Participant 18)

The desire to reflect to others the authentic self remained strong and the inability to do so contributed to the Violation of Self.

*Somehow I want people to know that this 'new person' is not who I really am . . . The real me is not slow or stupid.* (Participant 7)

Further, CFS was considered to be sufficiently traumatic to elicit or necessitate undesirable behaviours or qualities that would otherwise have remained unexpressed. Participant 6 described a newly acquired self-absorption.
But sometimes you can become very self-centred with this disease when in fact it's not necessarily the way you normally would have gone.

In sum, CFS changed self by diminishing valued qualities and promoting undesirable qualities of self.

The perception of becoming a different person as a result of illness has been reported with many chronic conditions (Crossley, 2000; Fife, 1994), and although limited, other CFS research has found perceptions of an undesirable changed self (Woodward, 1993). Weinberg et al. (1994) reported that negative changes in self-concept among their participants had occurred since contacting CFS, and that admiration for the self had declined. Changes to the personality and functioning of the person with CFS have also been observed by their significant others (Beaulieu, 1995).

While the Violated Self was essentially a changed self, the majority of participants also described, to varying degrees, an unchanged quality. 

You don't suddenly become a loose cannon, you're still essentially yourself, and within yourself you're sitting there untouched and watching with horror at what is happening to you. (Participant 10)

That is, the Violated Self was experienced as a duality between change and stability where some core qualities were altered or lost while a few remained constant. Unchanged qualities, however, were not necessarily active or able to be expressed. For example, while dependability might remain, the ability to act consistently with that quality was compromised by the unpredictability of the symptoms. The duality of the changed/unchanged self provided some biographical constancy. Nevertheless, within the Violated Self the biographical links were often tenuous, the perception of a changed self was pervasive and the relationship between changed and unchanged self vacillated, depending on the degree of threat. In other words, when threats were salient and enduring, participants perceived the changes to self as undesirable and greater in magnitude. By distinguishing between two apparently contradictory aspects of self, participants were reflecting an important premise described in most comprehensive theories that recognise the stability and endurance of the self, in conjunction with its ability to change and present different selves (Marcus & Kunda,
1986). Other research into chronically ill groups has reported this contradiction of being the same and yet a different person (Garro, 1994).

The Violated Self was typified by distressing emotions and emotional turmoil. There has been limited research regarding the emotional impact of CFS. What has been reported is that recently diagnosed CFS patients are overwhelmed by emotional distress (van Houdenhove et al., 2002) and specific emotions, such as anxiety, depression (Tuck & Wallace, 2000) and shame (Ware, 1992) are associated with CFS. This project found emotional overload to be a marked effect. Distressing and intense emotions were often experienced concurrently and were associated with concern regarding the release of pent-up emotions.

*I think then, people have all this emotion just built up inside of them. And it's like, if I start up, I cry a river* [crying]. (Participant 1)

The compounding of emotions, loss of emotional control, lack of opportunities to express emotions and the fear of doing so resulted in emotional overload. Further, there were instances of free-floating emotions and emotional unfamiliarity that contributed to fear and the sense of an unfamiliar self. The discrepancy between the known-self and the self-with-CFS was exacerbated by the emotionality. Anger, guilt, shame, depression, anxiety, fear and loneliness were entrenched in the illness experience of CFS and central to the affect of the Violated Self. Loneliness arose from the significant violation of connections experienced by the participants, while guilt and shame were to a large extent the result of the contested nature of CFS. These three emotions are discussed below.

Participants felt guilt about their failure to recover, the burden their illness posed to others, and their inability to live independently, accomplish goals, meet expectations, and fulfil roles and responsibilities.

*Guilt of not being able to do certain things, to feel normal and able to accomplish things.* (Participant 4)

*Everybody says this zero to five [years of age] is so important. I had that drummed into me and yet I know they had a shithouse time from zero to five and they didn't have this happy idyllic little toddler-hood. I was just too sick*
to give it to them . . . I would loved to have given my children a happier start to life [begins to cry]. That's what I feel most guilty about. (Participant 15)

Additionally, guilt was heightened by the attributions of responsibility imposed by others, that is, that the participants were guilty of inadequate coping, laziness, or instability.

. . . before you're diagnosed you feel guilty because you're going around to all these doctors and you get the label of “malingering”, and “hypochondriac” and “paranoid”, and “time waster”. (Participant 13)

The transgression of social norms and expectations was commonly the basis for guilt, and as a result guilt engendered a loss of self-worth, self-agency and control. Further, a relationship between blaming self for the condition and guilt was found among the participants. Fennell (1995, p. 162) used the construct of the “just world” to explain this relationship by suggesting that perceptions among people with CFS that they caused their illness led to a belief that illness was their deserved punishment, and consequently, to guilt. While participants did not speak of their illness as deserved, most at different times did blame themselves, and consequently, carried a burden of guilt. For the majority, guilt remained a troubling and destructive emotional accompaniment to CFS, as did shame.

Participants described an emotional response that was best encapsulated as shame but that also included feelings or elements of humiliation, embarrassment, disgrace and mortification. It was difficult to find a label that adequately encompassed the range, depth and extent of this emotional response. “Shame”, however, was the descriptor most often used by the participants and was therefore chosen for use in the analysis. Most participants felt shame associated with functional impairment, invalidation, and unmet expectations.

I'm not stupid by any stretch but I feel really silly. I can read a sentence and it makes no sense at all. (Participant 13)

Shame was also related to the participants’ perception that significant others found them to be shameful or embarrassing.

They rang up to say why wasn't I at my appointment and my husband said, “she's gone out”. He couldn't bring himself to say she's passed out on the bed . . . I felt then it had to be something that I should be hiding . . . I feel that
in many ways when people around me and close to me deny it, then I feel shame. (Participant 15)

Shame was particularly violating because participants perceived it as a reflection of personal failure, inferiority and deficits in oneself. Consequently, it was associated with a loss of self-worth and identity, further isolation and estrangement.

In addition to shame, participants described a related, but different experience that was not readily identified or labeled. It was not shame because it did not arise from within oneself and its presence was not viewed as contingent on personal failing. Instead, this experience was related to society and social impositions of the generalised other.

Shame before you get the diagnosis because you don’t know what it is . . . shame in the sense of public embarrassment, not about having it but about what people will think because they don't understand it. But not shame at having got it . . . It's not personally owned shame. It's just I don't want people to know this. (Participant 17R)

I think you've been shamed by society automatically. I don't think it's a personal shame in the sense of I'm ashamed that I've got it. I think you're shamed in the sense that the whole society has gone against you . . . It's not us, it's society in general. They don't know how to cope with it. (Participant 16)

While two participants described it as a social shame this emotional experience was more akin to something being imposed rather than something coming from within, as is the case with shame. There is little in the literature that helps identify the experience described by the participants and it needs further investigation.

The Violated Self was essentially lonely. Abandonment, rejection and diminished relationships indicated to participants that they had lost their social value. Their loneliness was deeply felt, sometimes leaving participants feeling unloved.

. . . people won't say, “I really want to spare half an hour and come and talk
to you”. . . It really, really makes you cry sometimes when you think, gee, no one really gives a damn. (Participant 16)

It doesn’t occur to any of them [her neighbours] anymore to just have a cup of tea, that I just might want to talk or just have some kind of human company. I mean both of them have said often enough, “don’t know how you get on over there by yourself”, but they’ve long since stopped saying “come and have a cup of tea”. (Participant 13)

I don’t feel loved. I’ve been through too much with rejection with people I know. (Participant 3)

When loneliness was great, participants perceived themselves as invisible. Social marginalisation had become social disappearance.

I feel disliked. I feel nobody sees me clearly because I'm basically never seen . . . seeing I have to be on the sidelines all the time, it puts you in an artificial relationship with people . . . I was a non-person. (Participant 12)

The relational diminishment and disconnection, and the consequent hurt and isolation among people with CFS has been reported by others (Anderson & Ferrans, 1997; Pemberton et al., 1994). The present study extends these findings to articulate loneliness as a fundamental experience of the Violated Self.

To summarise, the overwhelming nature of CFS resulted in emotional turmoil and sometimes chaos. This emotionally charged state was central to the Violated Self, and eroded the positive perceptions associated with the known-self while compromising the ability of participants to form new positive perceptions of self.

At times the burden of physical symptoms and emotional responses were so overwhelming that they were associated with feelings of entrapment. It was essentially an experience of helplessness. Physical entrapment was related to the threats of disruption, notably symptoms and functional impairments. The incapacity of body was so marked that participants reported their sense of embodiment as characterised by restriction or imprisonment.
You're a prisoner [in her body] . . . you're living through incredible agony, the helplessness is absolute. There is nothing you can do to help yourself. You can't go for a walk . . . you can't read so you can't even escape in books . . . You can't do any of the “feel good” things. (Participant 10)

Psychological entrapment arose from both threats of disruption and invalidation, and involved stress and emotional overload.

. . . it's like living in a narrow tunnel with no exits. You're trapped . . . I don’t ever seem to find my way through . . . I always, always fail . . . I don't have the stamina. (Participant 12)

In this situation [having CFS] you are trapped so you can't release. You've got to deal with it mentally and mentally you're stressed in the first place. This is why it's like an entrapment. I felt entrapped. (Participant 4)

While other research on CFS (for example, Hart & Grace, 2000) and chronic illness (for example, Boeije, Duijnstee, Grypdonck, & Pool, 2002) has reported perceptions of physical entrapment, they have not generally described psychological entrapment. Entrapment has tended to focus on that arising from body. In the present study, the inability to escape physical or psychological entrapment was associated with perceptions of failure and inadequacy, and compromised perceptions of agency and control.

The Violated Self was felt as unworthy. Feelings of shame and guilt, as well as experiences of being doubted and invalidated, the sense of being damaged or spoiled, rejection by others, conditional social acceptance, and dependency were common occurrences for the participants and were typically associated with a loss of self-worth. Participants expressed a generalised loss of worth arising from the global or cumulative effects of CFS. That is, the participants’ perceptions that they had lost value to self and others flowed from and into all aspects of their lives.

If I can’t do these things [her activities prior to CFS] what sort of person am I? In that sense it [CFS] had an effect on self-esteem. (Participant 17R)

In many instances participants were surprised by the extent of their diminished worth, the ease with which it occurred, or its continuing presence.
I had no idea until it happened to me just how much, how easy it is to dehumanise and humiliate a person. (Participant 13)

The perception of self as unworthy indicates that participants experienced a loss of self-esteem. Chronic illness is reported to undermine self-esteem (Swanson & Chenitz, 1993; Vilhjalmsson, 1998), and high levels of self-esteem have been found to be associated with perceptions of better health (Paxton & Phythian, 1999). Studies of self-esteem and CFS are few and although some have found unimpaired levels, recent studies using healthy and chronically ill comparison groups have reported lower levels of self-esteem among people with CFS (Creswell & Chalder, 2002; White & Schweitzer, 2000). Given the significant violation experienced by participants and their descriptions of lost self-worth, the present study supports these findings of diminished self-esteem among people with CFS.

The Violated Self demonstrated the widespread and negative effects of the threats associated with CFS. There was, however, an unexpected and disturbing finding that indicated the magnitude of the violation. During the interviews 5 participants spontaneously discussed their thoughts on suicide. Of these 5, one had attempted suicide a number of years prior to the interview following years of severe symptoms, marked impairment and social isolation, for which she had received psychiatric treatment. Two participants had considered suicide as a solution to the ongoing suffering.

... if someone had given me a gun I would have shot myself. I suppose I would never have pulled the trigger but I felt that way. (Participant 16)

I've been pretty black at times and I've thought about suicide more than once. Well, a lot more times than once, and the only reason I've never done it, 'cause I've never come up with a guaranteed way to succeed because I wouldn't do it just to make a statement. I'd do it to do it. (Participant 13)

Participant 6 recognised an instant when she appeared sufficiently depressed to be considered suicidal, and had attempted to allay the fears of her GP. Whether she felt suicidal, in addition to appearing suicidal, was unclear. Participant 4 expressed a new understanding of why people perceived suicide as a possible solution to CFS. In
addition to these direct references, one recovered participant (19R) expressed a previous desire to be dead while she had been ill.

It is beyond the scope of the study to address the complex issue of suicide ideation and suicide among the CFS population, and there is little specific research within which to place these findings. An exception (Pemberton et al., 1994) reported that 3 of 64 CFS patients attending a fatigue clinic had attempted suicide. Participants in the present study implied or stated that thoughts of suicide (by self or others) arose from the havoc of CFS and its attendant suffering. The suffering of CFS is discussed in Chapter 10. In sum, the issue of suicide does provide insight into the potential depth and severity of the Violated Self and it is an obvious area worthy of further research.

**Concluding Thoughts**

The narrative of self-with-CFS was a story of struggle, and that struggle was most clearly evident in the Violated Self. CFS, its threats and experiential features violated identity, place and time, agency and connections, and in doing so, violated the participants’ known-self. Consequently, the participants’ experience of self became that of violation, where the lived experience was fundamentally one of suffering. Violation had resulted in a changed, inauthentic, inferior and traumatised self.

The Violated Self served to initiate and maintain a process of reclamation, reconstruction and self-renewal by prompting the responses of guardianship and reconstruction. These responses were the tools for the process of self-renewal. The following chapter continues the examination of the process of self-renewal associated with CFS by addressing the Guardian Response.
This chapter continues to examine the narrative of self. It addresses the Guardian Response, the primary response to the Violation of Self that provided care and served to protect and defend participants against CFS-related threats and their effects on self. CFS, with its unpredictability and variation, was a constant presence in the lives of the participants and as a consequence, the Violation of Self was potentially ongoing. Therefore, the Guardian Response was a constant response, sometimes functioning at a subliminal or background level and at other times highly vigilant. The strength of the Guardian Response was largely determined by the dominance of the Violation of Self. When threats increased or became more salient or when participants became overwhelmed by the Violation of Self, the Guardian Response operated as the primary (and sometimes exclusive) response. In sum, the caring, protective and defensive position of the Guardian Response reduced the threats and struggle, and in doing so facilitated a move away from the Violated Self, towards the retrieval and reclaiming of self.

The discussion and analysis in this chapter examines the Guardian Response. The purposes and characteristics of the Guardian Response are described. The strategies for care, defense and protection against the Violation of Self are discussed, and include living with limits, seeking and accepting help, gaining knowledge, evaluating health-related encounters and treatment, establishing safe relationships, and containing emotions and emotional threats. The effects of these strategies on the Violation of Self and on the participants’ experiences of self also are discussed.

**Purposes of the Guardian Response**

The primary purposes of the Guardian Response were to provide physical and psychological self-care, and protect and defend self from the threats associated with the Violation of Self. The Guardian Response sought out diagnosis and treatments in order to reduce the participants’ vulnerability to threats and maximise the possibility of recovery or improvement. Specific strategies, which were located in the present
and future, were implemented to achieve the purposes and reflected both actuality
and possibility. The Guardian Response, for example, used protective strategies pre-
emptively to limit potential episodes of invalidation, in addition to whenever
invalidation occurred.

By providing care, protection and defense the Guardian Response sought to recover
and retrieve dimensions of self. The Guardian Response did not seek new sources of
self-fulfilment or self-definition but rather attempted to reclaim aspects of the
known-self. Consequently, the Guardian Response was primarily concerned with
rescuing and re-establishing dimensions of the known-self that were still available to
(or desired by) participants within the boundaries of the participants’ changed lives.
As such, the response instigated a process of self-reclamation. Despite the
protective, defensive, and caring intentions of the Guardian Response, the outcomes
were sometimes paradoxical, with both positive and negative effects to self. This
paradoxical aspect of the Guardian Response is addressed throughout the chapter.

**Characteristics of the Guardian Response**

The Guardian Response was typified by a number of characteristics that defined the
response, provided the basis for self-care and protection, and were evidenced in the
strategies. The characteristics of the Guardian Response were firstly a focus on self-
defense that was directed towards threats of disruption and invalidation. Secondly,
vigilance was maintained and incorporated self, environment and interactions. The
third characteristic, cost/benefit analysis, provided a basis for decision-making.
Lastly, the burden of proof served to counter disbelief and invalidation. Each
characteristic is discussed.

Participants experienced a strong need to defend themselves against the Violation of
Self. Therefore, the focus and stance of the Guardian Response was essentially
defensive. It was the primary and defining characteristic of the Guardian Response.

\[ I \text{ went into top defense mode which is top aggro mode, and that's sort of what}
\text{happens when you lose yourself. I had never needed to be aggressive and}
\text{then I lost the plot. I lost myself.} \text{ (Participant 12)} \]
They [people with CFS] try to defend and they become so defensive that they
don't have a psychiatric illness . . . it's a sense of them fighting for credibility.
(Participant 10)

I'm still not sure who to tell and who not to tell 'cause I realise I've got to be
defensive. (Participant 14)

Defensiveness encompassed all aspects of living with CFS and sought to provide
physical, psychological and social protection and to re-establish a sense of control
within the lives of the participants. The defense of self was directed at both threats
of disruption and invalidation, and was provided by the strategies of the Guardian
Response.

Protection against the threats of disruption was essentially protection of physical
well-being that involved actions aimed at minimising the symptoms, improving the
condition, and finding recovery. Monitoring for over-exertion and seeking help, for
example, were defensive efforts against the symptoms. Defensive lifestyle changes
were made that altered social interactions.

[Prior to CFS] People would just ring me in the middle of the night and say,
"I'm stuck somewhere. You're the closest. I'm getting a cab, had a fight with
my boyfriend". That was great but I had to tell all of those people, “give me a
break” so I wasn't their refuge or haven anymore . . . (Participant 18)

Defense against disruption was also evident in a “just-in-case” mindset that involved
pre-emptive action to accommodate unexpected deterioration or events. Participant
13 lived alone with few people available to provide help. She defended herself by
ensuring her home was well stocked with essential items. When she could shop, she
shopped for extra.

I make sure I have spares. I have spares of everything . . . because you're
never sure if you'll get to the shop.

As with any effective defense, the Guardian Response frequently had contingency
plans in place.

In addition to the need for physical defense, invalidation and stigma were powerful
threats to psychological and social aspects of self and were therefore the foci for a
strong defensive stance. Consistent with this finding, other research of a contested condition has noted a defensive stance in response to disbelief and discreditation (Rhodes et al., 1999). In the present study, the extensive invalidation that participants had experienced heightened their sensitivity to situations of potential invalidation and as with physical well-being, there was pre-emptive defense. Participant 10, for example, recognised that in order to defend herself from having a psychiatric diagnosis (and the associated stigma) imposed on her, she had limited the information she shared with medical practitioners.

*What that guy [previous GP] instilled in me was that anything that looked like I might be branded as a psychiatric patient, I protected against exposing.*

Defense was necessary for reclaiming control and commonly required learning new behaviours, skills and ways of being that were often difficult for participants. The nature of the symptoms hindered learning and sometimes (further) transgressions of the known-self were necessary.

*Another hard lesson to learn was “do it when you can and don't worry about it when you can't”. It was a hard lesson for me because if I see something that needs to be done, then I like to do it... I've actually had to do little exercises with myself to sit there and watch something that really needs to be done and not get out of the chair and do it.* (Participant 13)

One of the most important self-defense behaviours that participants felt the need to develop was the ability to argue for the legitimacy or validity of CFS. By doing so, the Guardian Response was arguing for the validity of the participants' experiences and consequently, defending against self-doubt. Arguments for the validity of CFS commonly centred on presenting evidence for its physical basis and required participants to seek out information and become informed. Additionally, participants perceived self-assertion to be an important skill for defending self, particularly in medical encounters. The degree of success to which participants were able to incorporate new information and adopt new behaviours influenced perceptions of self-agency and self-worth, and facilitated the reclamation of personal control.

While the defensive stance of the Guardian Response did provide protection against threats and violation, there were also negative outcomes for participants. The
defensive position was associated with isolation and social distance that arose from the focus on self and from perceptions of “self against others” or of “being on guard”. Defensiveness tended to separate participants from their external worlds through withdrawal, containment, restriction and limitation with effects to relational-self, worth, agency and identity. Pre-emptive defensiveness, while facilitating a sense of control, affected relationships and interactions. Additionally, defending self required effort and attention, which added a further burden.

Being defensive required a vigilant sensitivity of self, the environment, for example, avoiding cigarette smoke or scanning public venues for rest spots, and interactions, such as evaluating the likelihood for the acceptance or rejection of CFS by others.

*It requires constant vigilance. You are living around it all the time. You're compensating for it. You're trying to avert the compensation from being too huge and horrific. You're just tippy toeing around this bastard thing all the time.* (Participant 10)

*If I don't overdo things too much I'll probably stay at this level and I'll have to be really vigilant and keep going to the doctor and try to find out what I'm allergic to this time . . .* (Participant 3)

In line with the present study, research into multiple chemical sensitivity (MCS) has also noted vigilance of the physical and social environment (Lipson, 2001). This is not surprising given that many of my study’s participants were susceptible to environmental allergens and that both CFS and MCS are contested illnesses subject to similar social stereotypes. It is possible that contested illnesses require social and interactional vigilance because of the threats of invalidation, in addition to those arising from the symptoms. By vigilant attending and monitoring of self, environment and interactions, the Guardian Response sought to increase the participants' perceptions of control through anticipating problems and minimising threats.

A cost/benefit analysis is a common strategy among people with chronic illnesses (see, for example, Lipson, 2001), and similarly, the Guardian Response used a cost/benefit analyses as a basis for decision-making. Costs were commonly defined
in terms of over-exertion and the resultant deterioration of symptoms. Therefore, the
cost/benefit analysis tended towards decisions and actions that protected against
over-exertion. Nevertheless, when the outcome outweighed the costs, participants
were prepared to pay the price, and in doing so, nurtured a specific aspect of self. In
addition to energy expenditure, costs were measured in terms of psychological
consequences, social/familial effects and embodiment. Participant 1, for example,
evaluated the use of antidepressants.

... he [medical practitioner] was going to give me antidepressant tablets and
I took them for a couple of days but I didn't want to go down that path
because I didn't want to live in an unreal world because then how would I
know if I'm getting better with that false, false feeling? So that wasn't going
to work for me.

In addition to the use of cost/benefit analyses in decision-making, the Guardian
Response monitored and evaluated the resources available for protecting the
participants against threats. This included resources related to personal attributes,
circumstances and external resources.

The Guardian Response attempted to counter the scepticism and disbelief of others
and the associated threats to self by taking on the burden of proof for the illness.

[When] you meet with any scepticism, your focus then becomes to prove that
you're not malingering. (Participant 6)

All the way through I've fought to make other people see what this is like with
CFS. (Participant 3)

Initially the Guardian Response, in seeking diagnosis, attempted to prove illness via
demonstrable pathology. However, pathological evidence of a physical illness was
not forthcoming, medical tests were predominantly normal, and most participants
subsequently pushed themselves to resume their usual activities, a finding also
reported in other CFS research (Woodward, 1993). In other words, at this stage they
were attempting to prove wellness, but this was counterproductive as attempts to
prove wellness were met with the continuation or worsening of symptoms.

My responses were to push myself, to prove I'm okay, and that's detrimental
'cause if you push yourself with this, you get sicker. (Participant 14)

At first . . . I was doing all the wrong things and denying that I had it. I'd go out and force myself, and go down again. It wasn't until probably two years ago I started to see a bit of sense . . . (Participant 19R)

Consequently, the Guardian Response relinquished proving wellness and shifted back to assuming the burden of proving illness.

Proving and justifying their condition (even with a diagnosis) was a burden for the participants because of the level of resistance displayed by others, the amount of energy used, and the recognition that proving illness was not generally required of people with other diagnosed chronic conditions.

One of the hardest things is to [find someone to] talk about it with, somebody who actually knows, that you're not feeling as if you've got to vindicate yourself for everything, explain yourself away. And the more people that you [the researcher] get telling you these sorts of things, the more people you're going to tell. So the more that I don't have to explain myself away, and try and prove that I am not a malingerer or psychotic or whatever else I might be. (Participant 13)

Additionally, when participants assumed the burden of proof their focus was placed on disability rather than ability or even possibilities.

. . . and to have to prove that you're sick at a time when you should be focusing on “what can I still do”? (Participant 6)

In that sense the proving of illness constituted a threat to self-agency, self-worth and coping. Nevertheless, by assuming the burden of proof the Guardian Response was defending self against disbelief, ignorance and invalidation.

In order to protect and defend self and to minimise the violation, the Guardian Response implemented a number of strategies.

**Strategies of the Guardian Response**

The strategies of the Guardian Response were essentially concerned with reduction, limitation, restriction and containment. As Woodward (1993) has noted, people with
CFS learn to reduce activity rather than pursue an active rehabilitation.

*CFS is an illness about undoing, not doing.* (Participant 10)

Guardianship strategies were more dominant during the early years, when relapses were experienced, or when the threats became overwhelming during the course of the condition. For a minority of participants who sustained high levels of ongoing violation the strategies of the Guardian Response remained dominant.

During the early years of the syndrome, the Guardian Response sought out curative treatments. When a return to health did not eventuate, attention was directed to symptom-specific strategies and the Guardian Response became more discriminating about trying new treatments. This protected participants from experiences of repeated failure. Other CFS research has also reported a decreased use of treatments over time (see, for example, Woodward, 1993). Prior to diagnosis, the strategies were generally adopted in the absence of (or counter to) medical guidance. These strategies were essentially the same as those adopted after diagnosis and were aimed at symptom relief. In other words, strategies were a response to the symptoms rather than the diagnosis. Following diagnosis, participants felt relieved that the strategies used had been appropriate. This recognition was associated with positive effects on self-agency and self-trust, and partly constituted the benefits associated with diagnosis.

The strategies implemented by the Guardian Response included living within limits, seeking and accepting help, gaining knowledge, evaluating health-related encounters and treatments, establishing safe relationships, and containing emotions and emotional threats. While these strategies were associated with positive experiences of self, there were paradoxical effects that contributed to the Violation of Self.

**Living within Limits**

Living within limits was both an effect of CFS and a strategy for its management. As an effect, participants led lives restricted by the symptoms and the need to rest. This is a finding that is commonly reported in the research (Asbring & Narvanen, 2002). As a strategy, living within limits referred to a downgrading of physical and
mental activity and was expressed in restricted, reduced, altered and monitored activities. Its role as a management strategy has also been widely reported in the literature (Ware, 1999). Living within limits required planning and evaluation, but nevertheless remained difficult to implement. Limits were transgressed, both unintentionally and intentionally.

While limits protected participants from the deterioration of symptoms associated with too much activity, the restrictions were not welcomed. In the early months/years participants struggled to maintain, rather than restrict, valued activities. As has been reported in other CFS studies (Ware, 1992; Woodward, 1993), participants in my study reported that they tried to *push through* their symptoms. That is, they attempted to “pass” as healthy, but this response was ultimately unsustainable. This pattern of responding to, and attempting to overcome the effects of the condition, has been widely reported in the CFS literature (Fennell, 1995; Ware, 1992). Participant 2 described her unsuccessful efforts to push through and continue her university studies.

*I thought I needed a six-month break and go back the next semester. That's what I kept on doing, not finishing a semester and going back next time and she [the lecturer] said, “I think you need a two-year break”. And I found that distressing at first but then I found it was [pause], I'd been hitting my head against a brick wall. But I have never been back.*

Throughout their illness, participants continued to reflect a desire to do more. So although limitations became routine, associated distress remained.

Symptoms and deterioration, rather than diagnosis, were the important considerations in the initial limitation of activity. Diagnosis had generally taken years, and was not necessarily associated with instructions to rest or limit activity. However, regardless of when diagnosis occurred, and despite sometimes prolonged efforts at maintaining activities, participants found that the symptoms necessitated living within limits. Because limits had been imposed by the condition, participants initially perceived living within limits to be a consequence rather than an intentional strategy.

*In a lot of ways it’s a self-limiting disease and you can’t go into marathons or*
whatever. (Participant 8)

*I feel so awful if I don't do that* [limit activity], *that life is not worth living* [laughs]. *So I don't have any choice.* (Participant 3)

This restriction was not about choice but was more akin to an imposed surrender to the symptoms and their effects. It was with the recognition of the benefits of restriction, (that is, protection from over-activity and consequent symptom deterioration) that the Guardian Response intentionally adopted and manipulated limits.

The Guardian Response perceived rest as fundamental to self-care. In its most essential form living within limits was expressed as the need to rest, lie low, and give in when the symptoms were bad. Rest was also used to prepare for activity, aiming to compensate for the energy output and minimise the symptomatic consequences. Resting was associated with a sense of doing what was needed.

Implementing limits required monitoring and pacing of activity, and involved cognitive planning, behavioural preparation, and evaluation of resources, costs, and benefits.

*I can't stay up late anymore. I can't drink anymore. If I eat too much I throw up* [laughs]. *I need lots of sleep. I can't work very hard. I can't get too over-excited. I have to really watch the level of my stimulation otherwise I get exhausted. I just have to generally tone down everything.* (Participant 3)

*I have to plan everything. And I've got to plan a recovery period . . . At the start of the week I usually sit down and write down the things I have to do during the week, and I spread them out over the days with five-hour breaks in between each activity . . . the tiniest things.* (Participant 10)

Interaction skills, such as learning to say “no”, were developed in order to maintain personal limits. Life, as described by Participant 1, had become *planned, controlled, and strategic.* Establishing limits involved trial, error and modification. Symptom unpredictability made living within limits difficult because the baseline shifted with
symptom fluctuation. It was also problematic to balance activity with rest, as fatigue was the constant state. Knowing when to stop was an issue.

*Some days I can garden for two hours and other days I can't go for half an hour, so you just don't know. You can't say, “stop” before you get tired because you don't feel it straight away, and you can't say “well, yesterday I could do two hours so today I'll keep it under two hours”. You might feel totally wiped in half an hour. One day you could only do half an hour and the next day you could do two hours.* (Participant 7)

*I find it terribly hard to know that exact spot where you should stop. That's a major problem.* (Participant 12)

Even after many years participants continued to struggle with the unpredictability of their activity threshold.

Limits were both unintentionally and intentionally transgressed.

*I'm a mess today because I did something on Sunday and I did something on Monday.* (Participant 10)

When limits had been crossed participants described a *price to be paid* and the need to *catch-up* or *payback*. These phrases or words used to describe the consequences of transgressing limits have become a part of the CFS vernacular, commonly used by people with CFS, medical practitioners and researchers (for example, Ware, 1999).

Unintentional transgression of limits occurred more commonly during the early years when participants were determining boundaries. There continued to be, however, episodes of unintentional over-extension related to difficulties in determining how much activity constituted too much, and sometimes from the insidiously gradual deterioration that was less likely to be noticed.

*I won't recognise when I've gone too far until it's too late.* (Participant 10)

Additionally, relief from symptoms was associated with a premature relinquishment of limitations and a tendency to try and make up for lost time.

*When you feel good you forget about being sick and you try to do guitar, and catch up for lost time, and that can bring you down very quickly.* (Participant 4)
These transgressions were unintentional because participants did not perceive themselves to be violating a limit or did not consciously consider the issue of limits.

Similarly to a finding reported by Ware (1999), the participants in this study in unique circumstances intentionally transgressed limits to achieve a desired outcome, and chose to pay the price of catch-up or payback.

\[ \ldots \text{sometimes I don't moderate things. I'll go out dancing and be immoderate for a little while and then I'll pay for it.} \] (Participant 3)

\[ \text{Sometimes you think “I'm really tired of being tired all the time” . . . and you just go on adrenaline and feel great and then you pay for two days but you have one really good day.} \] (Participant 7)

In the present study intentional over-extensions of limitations functioned as breakouts or tests.

Breakouts were single events or instances that aimed to meet the emotional needs of the participants or to re-establish links with the known-self.

\[ \text{[Her sister] asked if I'd have them [her nieces] over here and I will even if it takes all of next year to recover. She said, “it won't wear you out”. I said, “it will wear me out, you know it will wear me out but it's beside the point”.} \]
\[ \text{If you did everything right so they weren't going to wear you out, you'd never do anything at all.} \] (Participant 13)

\[ \text{Somehow in your own madness, in your own little bloody cocoon you're living in, you've got to break out or you go mad.} \] (Participant 10)

Breakouts were infrequent but their positive effects were highly valued. Alternately, tests of limitation were actions undertaken to identify or measure changes. For example,

\[ \text{I went and did a university entrance course just to prove I wasn’t completely brain dead. It did prove to me that I wasn’t brain dead but it also proved to me there was no way in the world I could manage a university course.} \] (Participant 15)
It felt really good to be able to take control. I was abusing caffeine but I could still stay awake longer than my body wanted to and it was really nice to be able to do that. That there were things higher than CFS that could keep me awake and could beat it. (Participant 5R)

Tests of limitation involved proving something to oneself about capabilities and attributes.

Paradoxically, although limits were intended to provide self-care and protection, there were negative effects to perceptions of self. Limits involved self-discrepancies, the shrinkage of choices and the loss of desired roles, activities and interactions. Self-agency, worth and relational-self were compromised by the reduced possibilities for engagement and by altered role dynamics. Unintentional violation of limits reinforced the uncertainty of living with CFS, further threatening positive perceptions of self. Intentional transgression of limits included the risk of failure, represented by a deterioration of symptoms and by the inability to achieve the desired outcome, with attendant negative effects to self.

There were also positive effects to self. By reducing activities the Guardian Response was enacting a strategy congruent with bodily cues. Limiting activities increased the likelihood of participants fulfilling some aspects of their responsibilities. This strengthened their perceptions of control and trust. Downgrading and restricting activity reduced the cognitive demands, which assisted in the management of cognitive symptoms and protected participants against threats to self-agency. Because living within limits was often associated with solitude, it also provided time for self-reflection. By intentionally over-extending limitations, even infrequently, the Guardian Response provided opportunities for a regained sense of control, enhanced self-agency, and countered depression.

**Seeking and Accepting Help**

Functional impairments left participants unable to meet their own needs, and consequently, seeking and accepting help was important to guardianship. The need for assistance was associated with the dependency and vulnerability of the Violated Self, and served to diminish identity and agency. Therefore, participants attempted
to restrict their requests or need for help. Accessing help was often problematic, and barriers included a lack of sources, inappropriate help, the participants’ self-perceptions, the effects of symptoms, and the transgression of expected relationship norms. Help was requested and offered, accepted or refused. Further, among a minority of participants and in some instances help was not sought.

There were numerous barriers associated with seeking and accepting help. As Participant 3 said, *people get sick of helping*, and offers of help became less frequent the longer that help was required.

*When I first got sick people around here offered help and support but it quickly dwindled because they've got their own lives and things to do.*  
(Participant 13)

The help available was not always the help that was needed.

*She* [social worker] *used to come and basically just talk to me and it was quite good . . . but what I needed was really practical help, someone to take to the physical bloody labour.*  
(Participant 15)

This mismatch between the help required and the help available was also evident in the skills or attributes participants perceived as necessary for a situation. Participant 4 found his brother’s reticence to be a disadvantage during an (unsuccessful) attempt to obtain test results from the medical practitioner.

*My brother's not like that, he's very quiet, so that was it. We kind of got pushed out the door . . .*

Most participants were more comfortable asking for physical help than emotional support.

*What I didn't ask for and should have, was all those years when I had troubles, I would spend a lot of my time in the bedroom. And the boys were out watching television and I was lonely in there, and I didn't see as much of them as I would've liked.*  
(Participant 2)

Additionally, it was more difficult for participants to ask for or to accept help when the need for help compromised valued and defining self-perceptions such as independence or mastery.
I didn't want things that would make me different from other people. I found it very difficult to ask for help. Asking for help was like a cop out.

(Participant 5R)

Further, the severity and type of symptoms, notably cognitive symptoms, interfered with the ability to seek out help.

The nature of the relationship with others was of influence. Seeking and accepting help was less difficult when the participants felt that doing so did not transgress the expected roles and obligations of a particular relationship.

I felt that when I asked I was entitled, because I looked after other people when they were sick and that's how it works. (Participant 2)

Although deeply regretting the need to burden others, participants were more likely to accept and ask for help from their significant others. It was difficult to accept help from their children, particularly dependent children, because this violated the expected division of roles.

I was a carer and a mother before I got sick and then I couldn't look after my son anymore, and he had to look after me. Luckily he was twenty-one when I got ill but still, a very big role reversal . . . (Participant 3)

Alternately, help from spouses/partners was less threatening because mutuality was seen as a characteristic of that relationship. While there were strong concerns expressed about the imbalance that resulted, particularly when the participants were limited in their ability to reciprocate, the right to seek and be offered help by one's partner was seen as appropriate to that relationship.

For participants living alone, asking for and accepting help was even more complicated. Participants living with significant others received help within the context of a daily and ongoing relationship where support was viewed as part of the relationship. Additionally, asking for help was not always necessary when others saw the effects of CFS and provided unsolicited assistance. This pre-emptive help was uncommon for participants living alone. The general lack of understanding by others, in conjunction with the isolation that rendered their suffering invisible, left participants who lived alone with fewer human resources for when help was
required. Therefore, instead of seeking help from individuals, there was a reliance on self and institutional services, or needs remained unmet.

The strategy of seeking and accepting help was enacted via a number of responses, including asking for and receiving help from others, and asking for and being refused help from others.

*My parents said to me, “Oh, if you need anything done, your washing done, make dinners or you need some money, just let us know”. I didn't want them there. But when it came to, “Hi Mum, Hi Dad, sorry, I've run out of money”. “Oh well, you better go back to work full-time”. So I went.* (Participant 18)

Additionally, participants accepted help offered by others, and rejected help offered by others.

*I was also a very independent person, so at first that was hard because when people did offer to help, I'd never really wanted anyone's help to do anything anyway, but secondly, I didn't know what they could do. I found myself saying “No, it's okay, it's all right. I can cope. I can deal with this” when in actual fact I probably should've just said, “maybe you could come and perhaps do some of my housework or do this or that”. But I kept saying “no” to everyone.* (Participant 1)

There was also the option of not asking for help.

*I told them [her friends] the position I was in and if they didn't offer help then I wasn't going to ask for things, because you can't really be ringing people up asking for things.* (Participant 3)

Different consequences were associated with each of the responses. Even when participants received the help that was required it was at a cost, including guilt, embarrassment, shame, regret over the perceived burden on others, and the indebtedness that arose from the inability to reciprocate. For most of the participants, seeking and accepting help remained an onerous necessity.

**Gaining Knowledge**

Gaining and sharing knowledge about CFS facilitated care and understanding from others. The strategy was a response to the lack of medical and community knowledge about the condition and its effects. By becoming informed and
subsequently sharing the information, participants attempted to protect themselves from medical ignorance, misguided advice, stigma and scepticism. Knowledge, for example, facilitated the evaluation of health encounters and recommendations, and assisted participants in meeting self-care needs and in pursuing treatment and management options. Consistent with the present analysis, self-education about CFS by people with the condition has been reported (Clarke, 2000) and research has indicated that people with CFS disseminate information as protection against stigma (Asbring & Narvanen, 2002; Green et al., 1999). Knowledge was sought from many sources, and shared with medical practitioners and lay people. The type of knowledge sought changed pre- and post-diagnosis. Symptoms were a barrier to knowledge acquisition and interfered with the participants’ ability to access and learn information.

Knowledge was gained from as wide a variety of sources as possible and included research, the internet, the media, and CFS advocacy groups. Other people with CFS were considered to be valuable knowledge sources, and stories, poems and case studies provided points of comparison and assisted participants in the interpretation of personal experiences.

At my worst stages I had this little chronic fatigue file and I'd read the case studies . . . to find out what other people were going through and also to help myself understand that I did have it, which was a very difficult process.

(Participant 5R)

They're some of the reasons I became a telephone counsellor, so I could listen to other people and maybe get some idea of where I fitted in the framework at that stage. (Participant 6)

The acquisition of knowledge began with symptom onset and was aimed towards finding a diagnosis. As time passed without a diagnosis, gaining knowledge was directed towards managing the symptoms. With diagnosis, participants were able to concentrate their learning specifically on CFS. For many participants, usually years into the syndrome, there came a point when they no longer actively sought out information.
I'd probably been studying eight years and read as much as I possibly could, talked to a million people ... and then I'd had enough [laughs]. I thought I knew as much as I needed to know about this now ... (Participant 3)

With the establishment of a CFS knowledge base looking for new information became spasmodic.

Many of the medical practitioners consulted were seen as having inadequate or outdated knowledge regarding CFS or as having an inflexible mind-set that precluded them from seeking information. By sharing knowledge with their medical practitioners participants hoped to receive better care. In many instances, however, there was little apparent willingness by medical practitioners to learn about CFS from their patients.

I'd give him [GP] information but I don't know if he took much notice.

( Participant 3)

Knowledge was also shared with family, friends, acquaintances and strangers to increase the understanding about the impairments associated with CFS and modify negative and stigmatising perceptions (such as judgments of participants as lazy or overly sensitive).

Cognitive symptoms and the chronicity of CFS complicated the acquisition of knowledge, and consequently, compromised the protection of self. The presence of cognitive symptoms was associated with self-reported learning difficulties and participants were aware that learning was more difficult than prior to CFS. As a result of the cognitive difficulties, for example, the inaccurate or alarmist information found in the discourse of CFS was initially difficult to evaluate and threatened hopeful perceptions of the future.

Gaining knowledge provided protection and defense but there were negative effects to self. The learning difficulties associated with the cognitive disturbances were a source of frustration and shame for participants and positive perceptions of self-worth and self-agency were compromised. Additionally, the subject matter was itself threatening. For example, the chronicity of the syndrome that was evident in the literature presented participants with a picture of the future that was far removed
from their expectations, and that increased self-doubt and concern about the longer-term outcome.

Nevertheless, knowledge was found to be crucial to the care and protection of self and gaining knowledge proved to be beneficial in a number of ways. Self-worth was enhanced by the knowledge acquisition that occurred in spite of the cognitive symptoms, and the associated mastery and competence contributed to positive perceptions of self-agency. By minimising exposure to or defending self against stigma and episodes of invalidation, sharing of knowledge contributed to protecting and augmenting identity and self-worth.

**Evaluating Health-Related Encounters and Treatments**

The Guardian Response evaluated health-related encounters and treatments for costs and benefits, and in doing so facilitated decision-making and defended participants against potential negative effects to self. The encounters evaluated included medical and alternative health practitioners as well as the wider community. Specifically, beliefs and explanations, advice and treatments were evaluated. Chapters 5 and 6 describes the unsatisfactory, invalidating and shaming health-related encounters that contributed to the Violation of Self, and that was the focus of evaluation.

The evaluation of health-related encounters with medical practitioners was multifaceted and included aspects such as the practitioners’ CFS knowledge base, beliefs, and explanations (as described in Chapter 5). From the perspective of most participants, when medical practitioners rejected the reality of CFS they rejected the participant. By evaluating the belief and explanatory systems of medical practitioners, the Guardian Response was able to defend against threats of invalidation and rejection. Proposed treatments or management were also evaluated.

In contrast to experiences with medical practitioners, participants did not experience disbelief regarding the existence of CFS from alternative practitioners. Rather, they received definitive explanations and treatments for CFS. While traditional medicine was typified by uncertainty, alternative medicine proffered solutions. Perhaps for this reason health-related encounters with alternative practitioners were evaluated as
(or more) rigorously as the encounters with medical practitioners, particularly with regard to outcome claims, financial costs, and effects on lifestyle. Even though participants frequently rejected the explanations of alternative practitioners, there was comfort in being believed, and in some instances support was gained from the relationships.

_Naturopaths all think they know what to do for you. They all believe in it, so they're good in that sense._ (Participant 17R)

Nevertheless, few reported benefits and participants had modest expectations of the ability of alternative therapies to cure CFS. By adopting a cautious attitude towards the likelihood of success of alternative therapies the Guardian Response defended against disappointment and self-perceptions of failure.

In addition, participants received health-related advice from others.

_A lot of the people I knew also thought that the answer was alternative medicine._ (Participant 3)

My Aunty . . . keeps on going to the paper and pulling out articles on cures for chronic fatigue and I said to her “that's all well and good, half those things I'm already doing anyway”. And I said, “all it does is help you along, it doesn't cure it” . . . (Participant 16)

Advice was mostly unsolicited and initially evaluated in terms of the credibility of the person offering the advice. With the exception of advice from others with CFS, evaluation often indicated to participants a lack of understanding about the nature of CFS. Suggestions to increase exercise or to try a new diet, for example, were discounted because they indicated ignorance of the effects of CFS or had been found previously to be futile. When participants either did not follow advice, or did not continue with a treatment, or indeed failed to respond to a treatment, they were subject to criticisms from others of “not trying” or “not wanting to get well”.

_After about two years I gave up on that because it actually made me worse . . . I stopped, and so a lot of the people that I knew thought that I wasn't trying. I wasn't helping myself._ . . . (Participant 3)
As a consequence, the Guardian Response, while defending against threats to self by evaluating the costs and benefits of health-related encounters, also opened up additional avenues of invalidation and the possibility of further violation.

Contradictory advice and the absence of demonstrably effective treatments or supportive strategies left participants without a definitive protocol.

>You've got one side telling you, “you got to go off and exercise” and the other side saying “you can’t do too many exercises ’cause you'll kill yourself”, so what do you do? If you don’t do the exercises your body seizes up, if you do the exercise you suffer for it. (Participant 16)

Among the alternative therapies there was a plethora of potential treatments, and evaluation was therefore important in guiding decisions of what to try and for how long. Evaluation, however, was complicated by stories of recovery. The wide range of treatments cited in the reports of recoveries left participants uncertain as to what to try.

>All these people who said they were cured by claws of an owl on a full moon . . . I tried the cold baths. And then you see something and it's very expensive and you think, “should I spend the money”? And I still don't know. I know that there's nothing that's been proven to work even the majority of cases in a study. Still, if it helps twenty per cent, well, maybe you'll be one of the twenty per cent. (Participant 7)

Evaluation of treatments remained problematic for participants, and it was the evaluative difficulties in conjunction with the lack of success that prompted the Reconstructing Response to relinquish the search for a cure.

By evaluating health-related encounters and treatments, the Guardian Response attempted to maximise the possibility of improvement or recovery while defending self against threats associated with invalidation. Additionally, evaluation helped to protect participants against the failure and disappointment that was associated with repeated unsuccessful treatments. To varying extents, evaluation limited the perception of failure by limiting exposure to failure, and in that sense protected against threats to self-agency. By assessing and evaluating treatments, the Guardian Response empowered participants through enhancing perceptions of control and
choice. A trust in self-perceptions was renewed. However, by rejecting the advice of health practitioners and others, participants were exposed to criticisms regarding their desire to get well, their psychological state, or their moral character.

First of all you're not believed, then people get sick of it, and then they think you're not doing anything to [get well], or that you want to stay ill because you're not trying anything new. (Participant 3)

Invalidation was further compounded. Identity, self-worth and relational-self were threatened, and when the criticism was sufficiently powerful, the positive benefits to self-agency were compromised.

Establishing Safe Relationships
Participants defined safe relationships as those that acknowledged the reality of CFS and its deleterious effects or those that accepted the participants regardless of their illness. Finding safe relationships was necessary for protection against invalidation and rejection. Additionally, self-care involved dependency on others, therefore, it was necessary to seek out relationships that could provide the needed assistance. Establishing safe relationships involved identifying relationships that supported participants and discarding or limiting those that threatened well-being and positive self-perceptions. This relational selectivity has also been reported with other chronic conditions (Brodsky, 1995). In addition to complete or partial avoidance, disclosure was used to ensure safe relationships. Safe relationships were found with individuals, support groups, spirituality and pets.

To protect the integrity of existing relationships, there were initial attempts by participants to explain to family and friends the nature of their symptoms, the impact of CFS, and the need for social withdrawal. Nevertheless, criticism and invalidation remained common and persistent responses, and explanations were mostly ineffectual in ensuring safe relationships. Complete or partial avoidance of people found to be unsympathetic protected self from rejection and from the reactions of others, and minimised negative effects to self. This involved intentional decisions to no longer maintain or to markedly reduce contact.

. . . if after ten years and I've tried and they [his family] haven't, won't listen. With them I've got to the point where I've given up trying to explain . . .
because it's hard to handle rejection I sort of stay away from it. That's how I've handled it . . . I don't like that at all 'cause I don't like losing touch with them and I feel very sad about that but I've come to see that's about all I can do. (Participant 14)

A woman that I call on where we live, she almost snubbed me yesterday and if that's how she feels, cheerio, goodbye. I'm not going to waste my time. (Participant 11)

I'm not going to be hurt like this by these people so I avoided them. I didn't ring, see them. (Participant 3)

Participants generally regretted the need for avoidance, and when close family were involved guilt and distress were common. In the case of significant relationships, avoidance was perceived as a last resort and required a substantial period of time to reach that point. However, the threats to self that participants had sustained from personal criticism, delegitimation and derogatory social comments were extensive and avoidance was seen as preferable to continued exposure to the threats found with unsafe relationships. Consistent with these findings are reports of people with CFS avoiding others who in the past have reacted negatively, so as to evade exposure to enacted stigma (Asbring & Narvanen, 2002).

Participants were not always able to judge the responses of others or had learnt from previous experience that reactions were not always as expected. Therefore, issues associated with disclosure were important to establishing safe relationships.

I've talked to people about it that I've expected to react in a certain way and they've reacted the opposite. (Participant 5R)

The decision to disclose or not disclose the presence of CFS has been widely reported among the literature (Asbring & Narvanen, 2002), with secrecy seen as an important protective strategy (Green et al., 1999; Ware, 1999). Disclosure versus secrecy was important to guardianship and participants thought carefully about the costs and benefits. Among participants there were diametrically opposed positions regarding the basis for disclosure decisions. One position saw disclosure as risky because of the negative judgments commonly attributed to people with CFS, and
consequently protected self from the criticism or ridicule of others by limiting disclosure.

A friend . . . said to me that I was faking it or I was looking for attention or something, which was quite upsetting . . . She hadn't actually seen me when I was very sick, the year before, so that was quite upsetting. And I didn't tell many people after that. (Participant 5R)

I also try to avoid getting into situations like that, and being put down for having this illness, so if I know someone is not sympathetic I won't mention it and I haven't told a lot of people. (Participant 3)

The alternate position saw disclosure as necessary to establishing safe relationships because regardless of the judgments of others, protection required others to be aware of symptoms and impairments.

I find you're much better off saying you can't do it . . . (Participant 9)

The way I deal with it is also to tell people, nothing happens if you don't say something . . . they can't read your mind, they don't know what's going on in your life so if you want something to happen to help you, you have to tell them. (Participant 1)

Both these positions, even though the disclosure outcomes were different, aimed to maximise the safety of relationships. Most participants moved between these positions, learning when to disclose or not disclose.

You choose who you open up to and that's a skill I'm still learning. You've got to know when to open up and when to say to yourself, “well, this is only going to be a damaging situation”. (Participant 14)

Additionally, disclosure involved decisions regarding the amount and type of information shared with others, a finding also reported by Asbring and Narvanen, (2002). Participants sometimes chose to censor and control the information. Therefore, when participants perceived there was a risk arising from the responses of others who knew of the diagnosis, limited information was provided or information was withheld.
A one word or two word answer was all they'd get from me. "How are you today"? "Crap". "Oh, how are you today"? "Oh, not too bad. Bit better". But I wouldn't elaborate. (Participant 6)

I do not tell my parents anything about my illness 'cause they freak and they don't know how to deal with it . . . I don't tell them anything. (Participant 18)

Limiting or withholding information rather than discarding the relationship was more likely with familial relationships or close friendships that remained important to participants. There is some support for this finding. Anderson and Ferrans (1997) reported that 19% of their participants maintained valued friendships by pretending they were well or by not discussing CFS, that is, by withholding information. In the present study, information was also limited or withheld from work colleagues as a way to protect employment. Additionally, the Guardian Response limited the time spent with significant others when there were continued or potential threats of invalidation and rejection. Participants, for example, reported reducing their visits with family members who criticised their management or beliefs related to CFS.

There was recognition of the need to talk with someone about CFS and this was possible with the use of support groups. For many participants CFS groups were perceived as a venue for safe relationships. Woodward (1993) also reported this in her study. One of my participants put it like this:

I went to the CFS support group where I met people in a similar position and we would give each other advice, emotional support . . . it was much easier to relate to other people with this illness, where you could be honest with each other . . . You could just say “look I’m tired, I can’t talk anymore, I need to go” and the people understood what you were going through. (Participant 3)

While there was variation in the ability of participants to attend and in the availability of support groups, these groups were seen as opportunities to meet 'with similar', to lessen isolation, to exchange knowledge, to engage in honest relationships and to receive emotional support and advice.

Not all participants desired or were able to initiate or sustain contact with CFS groups. Some did not feel that group work was of personal benefit.
I actually don’t want to go anywhere near the support groups. That wouldn’t work for me. For some people it does. (Participant 1)

For a small minority, CFS groups were not safe venues when they consisted of members more severely affected than the participants. Confrontation with people experiencing greater impairment presented these participants with a frightening possibility that threatened future-self. Sometimes impairments were so great that participants who were less affected did not feel a sense of shared experience or identification.

I used to walk out of there depressed . . . I went there a few times and you had these young people in their wheelchairs and they were people who just couldn’t budge, get out of bed. And here I was on the drive up, I'm going, “hang on, I shouldn't be here” . . . and that's what's so hard because you sort of sit there together as a group and you're comparing notes virtually. “How can you do this and how come you can’t do that”? And you're not there to do that. You're supposed to build up actually, not sort of put each other down, so it wasn't one of the things that was my cup of tea. (Participant 16)

Asbring and Narvanen (2002) also reported this difference among people with CFS regarding the perception of support groups as beneficial or threatening. Nevertheless, regardless of whether support groups provided the venue, the present study found that being able to talk to someone else with CFS was in many ways considered the safest of relationships and of considerable benefit.

For religious or spiritual participants safe relationships were sought with God or a Higher Being. These relationships were not subject to the judgments and criticisms of earthly relationships and provided direction, connection and protection. Participants who were members of religious groups continued to attend church or other services as much as possible as part of their relationship with God. However, the relationships that participants shared with fellow church members were not necessarily any more accepting or supportive than with other friends.

There’s the people at church who say, “We prayed for you, you stubbornly refuse to get well, obviously you are possessed by the devil and I'm not going to have anything more to do with you”. Great. I'd rather give you a wide berth if you think that way anyway. (Participant 6)
Another participant described how her failure to get well was interpreted by some members of her church as spiritual damage.

Another important source of safe relationships was found with pets. They provided company and a source of validation not received elsewhere. This was particularly the case for participants living alone where pets provided daily contact and affection. The relationships with pets were highly valued and participants were mindful of their responsibilities. For example, Participant 1 gave priority to walking her dog regardless of how she was feeling, and Participant 13 chose the breed of her dog based on her ability to manage with CFS. Relationships with pets were not viewed by participants as inferior substitutes for human relationships but valued as a unique and separate bond.

Establishing safe relationships contributed to shrinkage in the social networks as unsafe relationships were avoided or shed. This led to an increase in relational disconnection and social isolation and a decreased ability to enact roles, with associated negative effects to self-worth, agency and identity. The protection of self from the responses of others that was at the basis of establishing safe relationships also involved elements of deception.

*I don’t tell them anything. I could be in agony and say, “Oh, I’m okay”. So they ask, “how are you”? “Oh, I'm good”. We'll be having conversations and they'll talk about whatever they want to talk about, but we don't talk.* (Participant 18)

In these instances, although the relationship was safe in terms of negative judgments, it required participants to compromise or deny their own reality and experiences. While participants found deception to be undesirable in relationships, it was considered preferable to the further exposure to threats. The secrecy implicit in non-disclosure was also problematic because it alienated participants from the support of others, a finding similarly reported by Ware (1992). Additionally, participants were not always able to gauge which relationships were likely to be safe, or were compelled to remain in relationships felt to be unsafe, with attendant threats to self. For example, most participants had experienced a break in confidentiality regarding their illness. Further, consistent with the participants in this study, Asbring &
Narvanen (2002, p. 154) noted that people with CFS could develop a “situation consciousness” that arises from their pre-emptive assessments of the responses of others.

In terms of positive outcomes, by increasing control through exercising choice and implementing decisions regarding their relationships, participants also decreased threats to self-worth, agency and identity. Safe relationships reduced the threats that arose from judgmental responses or inadequate relationships and were valued by participants.

**Containing Emotions and Emotional Threats**

The range, intensity, concurrency and nature of distressing emotions (that is, the emotional load) found with the Violation of Self were contained or controlled by the Guardian Response, with containment distancing participants from the overwhelming nature of their emotions. Common emotion-focused coping strategies such as distraction, cognitive restructuring and self-talk, and the defense mechanisms of denial and repression were used. For example,

*If I think to myself, “Jesus, look I’m forty-four this year, if I kind of come out of this at fifty, what the hell am I going to do? How do you start your life at fifty”? So I just don’t think about it.* (Participant 10)

*I might go out on the train just to see things. I do try to not just mope.* (Participant 14)

Two further methods of containment, voluntary withdrawal and the normalisation of emotional responses, were of particular importance to the participants.

Voluntary withdrawal as a response to chronic illness has been well documented (Charmaz, 1983), and the CFS research similarly reports the use of withdrawal as a protective strategy against emotionally aversive situations (Asbring & Narvanen, 2002; Ware, 1999). Participants used physical and psychological withdrawal from others to avoid and contain distressing emotions. It provided respite from emotional overload, limited the exposure of participants to the negative responses of others, and at times, provided protection from the pain arising from losses.
It's very depressing and quite often you're quite happy to shut it [the world] out because if you don't see it then you might not think about it so much.

(Participant 2)

Withdrawal removed (temporarily or permanently) a source of emotional output and input, and therefore, as similarly reported by Ware (1999), it also compounded the social marginalisation and relational disconnection.

Additionally, the Guardian Response attempted to contain emotions and defend self through normalising those emotions considered by participants to be undesirable, negative or stigmatised. Normalising involved making a favourable comparison of the participants’ emotional responses with the likely response of a “normal” person (that is, someone without CFS).

Even a healthy person, you put them in that situation [ill with CFS], it will wear them out [emotionally] . . . (Participant 4)

I'm not as bitter as other people might be. (Participant 1)

By placing the emotions of the participants within the realms of “normal”, the Guardian Response attempted to contain the aversiveness (and perceived deviancy) of emotional experiences, reduce the stigma and decrease self/other discrepancies.

The containment of emotions was an important strategy of the Guardian Response because it reduced the threats and negative effects associated with emotional intensity and unpredictability. It provided participants with emotional time-out. Containment, however, was not sustainable and provided respite rather than long-term relief. Despite efforts, emotional overload broke through and participants were compelled to gain an understanding of their emotional worlds. Indeed, it was this failure to contain emotions and their ongoing nature that provided a stimulus for grief work, a precursor to the development of the Reconstructing Response.

**Overview of the Effects on Self Associated with the Guardian Response**

The primary purposes of the Guardian Response were to reduce the threats of disruption and invalidation, protect and defend participants against the Violation of Self and provide physical and psychological care. However, the effectiveness of the
Guardian Response in fulfilling these purposes resulted in both positive and negative outcomes for experiences of self.

The Guardian Response was oriented towards reduction, limitation, censorship, shrinkage, introspection and isolation. This orientation distanced participants from the external world and tended to perpetuate the symptom-imposed social withdrawal and relational disconnection that was found within the Violated Self, subsequently increasing isolation and loneliness.

*You become very internalised and that can help out to a certain degree to cope, but you can keep on going inwardly . . . becoming diminishing, the spiral downward and then you become like a tornado which goes down.* (Participant 4)

Further, strategies of the Guardian Response required rest and introspection rather than social engagement, thus compounding social withdrawal and attendant negative effects to self. Additionally, the Guardian Response sometimes reflected qualities that were antithetical to the preferred or known-self.

*I was quite spontaneous. I'd say, “let's go for a drive” . . . and we'd pack a car. Everything is planned, very much so. And even then if you plan something you might have to ring and cancel.* (Participant 18)

Participants were generally aware of the negative effects to self arising from the Guardian Response. Asking for help threatened feelings of efficacy, living within limits threatened identity, and establishing safe relationships involved deception. Dimensions of self, such as agency and worth, were protected but sometimes also diminished. Nevertheless, the need to provide care, protection and defense and the resulting positive effects to self made the Guardian Response crucial to reducing the struggles of self.

In terms of positive outcomes, the Guardian Response provided relief for the struggling self by reducing violation, reclaiming self, and promoting positive self-perceptions. The Guardian Response sought to solve problems, and when effective, was associated with perceptions of mastery and empowerment. The reclamation of previous skills and the development of new skills augmented positive self-perceptions and helped to compensate for the negative perceptions of the Violated
Self. When the Guardian Response was effective in solving problems, the physical-self was protected and positive perceptions of agency and worth were experienced. While control of the symptoms came to be viewed as unrealistic by the majority of participants, perceptions of self-efficacy were nevertheless enhanced as control was gained over aspects of symptoms, daily life or the overall condition. Participant 12, for example, had some sense of control regained with her medical encounters.

*I had such a surge of power because in one week I told him off. I told off Dr X and I told off the physician . . . I had such a state of power when I told them all off within a week* [laughs].

The Guardian Response not only defended against invalidation, but also provided opportunities for participants to be validated. For example, establishing safe relationships and seeking and accepting help constituted situations in which others could demonstrate their concern for participants.

*I've been so overwhelmed with gratitude. When I was the sickest I couldn't speak and I couldn't tell him [her GP] anything I was going through. But what he gave me, it was the only place I had to go in the world, the only safe haven, where I could go and not have to qualify, justify, explain.*

(Participant 10)

Validation also occurred with the recognition that other people with CFS had similar problems. This recognition was developed from strategies such as gaining knowledge and establishing safe relationships. The sense of shared experience and identification decreased perceptions of deviancy. Validation demonstrated to participants their importance to others, reduced self-doubt, and was some compensation for the invalidation so prevalent with the Violation of Self. The balancing effects of validation contributed to stronger perceptions of a stable self, and there was a reclaiming of positive perceptions as participants' self-worth was enhanced.

The Guardian Response worked to recover the identity losses associated with the Violation of Self by defending against further loss and by reclaiming elements of the known identity. To achieve this, the Guardian Response used positive comparisons
of the known-self and knowledge of previous capabilities (for example, self as competent or powerful) as protection against feelings of inferiority.

The interesting thing was that when I was able I did more than they [her neighbours] did anyway because I remember one of them used to talk about having finished her work at nine o'clock in the morning whereas I would never think that I was finished. If I'd done the usual things I'd often go and pull the curtains down and do them, or sew. (Participant 2)

I know a lot of people came up against me and I know I can defeat them, skills with sports or whatever. You know when it comes to the clash you can win [if not for CFS]. (Participant 4)

By reaffirming their known self-perceptions regarding previously capable lives, participants were able to view their current limitations as a consequence of CFS, an external force rather than a deficit arising from self, and thus defend themselves against judgments by others of fault or inadequacy. Favourable comparisons also reaffirmed the presence of qualities important to self-definition and consequently facilitated reclamation of self. Additionally, reclaiming identity and reducing self-discrepancies helped to re-establish biographical continuity. Participant 10 exemplified this process of reclamation in her statement, Recently, I have a sense of being me again.

**Concluding Thoughts**

The Guardian Response provided the necessary basis for participants to develop the more positive response of reconstruction. The reclamation, retrieval, recovery and re-establishment of self that were outcomes of the Guardian Response were the precursors to the renewal and redefinition of self found with the Reconstructing Response.

The following chapter addresses the second response to the Violation of Self, the Reconstructing Response. The Guardian Response was not replaced by the Reconstructing Response, but worked in tandem, with one response stronger and more dominant than the other at different points in time.
Chapter 9

The Reconstructing Response

This chapter presents the second response of participants to the violation that was described in the narrative of self. The Reconstructing Response facilitated the movement of the struggling self away from diminishment and reclamation towards a redefined and renewed self. While the Guardian Response, discussed in the previous chapter, focused directly on CFS in order to reduce threats to self, the Reconstructing Response further ameliorated the threats by building upon the experience of living with CFS and thus, moved beyond damage control. That is, the Reconstructing Response extended or reinterpreted the boundaries of self-definition and adopted a wider perspective than the CFS-defined focus of the Guardian Response. The Reconstructing Response was motivated by intentions of improving quality of life in a more encompassing sense, rather than responding to specific threats as was typical with the Guardian Response. And while the Guardian Response was implemented quickly and was at its most basic almost an automatic response, the Reconstructing Response needed time and specific conditions for its development. Participants had to learn from their experiences and to incorporate this knowledge into adaptive strategies, attitudes and self-perceptions.

The chapter explores the nature, purposes, characteristics and effects of the Reconstructing Response. Conditions associated with the development of the Reconstructing Response, that is grief work, cognitive realisation, diminishing of defensiveness, psychological and physical space, and turning points are addressed. Strategies related to downgrading and shifting of self-perceptions and expectations, and rebuilding and renewing sources of self-fulfilment, are also discussed. The effects on self associated with the Reconstructing Response are explored. Finally, the recovered participants’ redefinition of a post-CFS and well-self is examined.
**Purposes of the Reconstructing Response**

The primary purposes of the Reconstructing Response were to redefine and renew positive experiences of self and to improve quality of life. This was achieved through strategies of firstly, altering expectations and secondly, seeking out new sources of fulfilment that provided participants with opportunities for positive experiences of self. Additionally, by focusing on rebuilding and healing, in addition to the management and treatment focus of the Guardian Response, and by re-establishing balance between meeting CFS-related needs and the fulfilment of other desires, the Reconstructing Response further improved quality of life and provided opportunities for the renewal of self. Finally, in conjunction with the Guardian Response, the Reconstructing Response functioned as an additional source of protection against the effects of CFS and threats to self. Consistent with the present study, the need for renewal and redefinition among people with CFS has been reported elsewhere. Anderson and Ferrans (1997) found that the changes and losses of CFS were so extensive that a redefining of self was required.

**Conditions for the Development of the Reconstructing Response**

The effects of the Guardian Response, both positive and negative, were instrumental in facilitating the conditions necessary for the development of the Reconstructing Response. While the Guardian Response was at least initially almost an automatic response, the Reconstructing Response required more time and specific conditions. The conditions were progress in grief work, cognitive realisation, diminishing of defensiveness, and availability of psychological and physical space. Any of these conditions was sufficient for initiating the Reconstructing Response, however, the conditions were interrelated and frequently concurrent. There was one further condition, turning points, which had a direct and indirect effect. Turning points led to a shift in thinking that acted directly as a catalyst for the Reconstructing Response or indirectly by strengthening the other conditions. These elements are considered below.
Progress in Grief Work

The Reconstructing Response required participants to have partly grieved their losses and to have addressed the salient emotions associated with what had been lost, perhaps permanently.

The hardest lesson I think was to give up that [former] life and it wasn't just the work part of it, it was all the rest of it as well. And it was like a death. You had to grieve for that and you have to allow yourself to grieve for that and it was a long time before I allowed that. (Participant 13)

And the grieving process is important too, because when you first get hit with this illness suddenly you change. What you are, who you are, is gone, and some people want to mark time and go back to where they were. You can't do that. You changed and you're not what you were and you go through a grieving process for that . . . (Participant 6)

The positive and negative effects of the Guardian Response provided both opportunity and need for grief work. The internal focus, the strategies and the threat reduction of the Guardian Response fostered a more benign and supportive climate for the processing of grief than was the case with the Violation of Self. Alternately, the Guardian Response also facilitated grief work because of an inability to contain emotional threats. As grief work progressed, it facilitated development of the characteristics and strategies associated with the Reconstructing Response. The Reconstructing Response did not require the resolution of grief (which was experienced as ongoing) but needed a degree of progress and re-development of one’s life that was individually different. Grieving for losses was fundamental to the healing of self, the reconstruction of identity and biographical continuity. Grief work served to facilitate the relinquishment of perceptions of the known-self that were detrimental to positive experiences of self.

Cognitive Realisation

An important condition to the Reconstructing Response was the participants’ cognitive realisation of the impact of CFS on their lives.

It's simply accepting what is, and seeing what you can do with what you've got. (Participant 6)
Although participants did not overtly make the distinction, the realisation demonstrated was specifically cognitive and a coming to understand intellectually that much had changed, while emotional realisation was more elusive, visceral, experiential and embodied and therefore, more difficult to attain.

You can go through it [living with CFS] intellectually but emotionally it’s still huuuumff [mimics a hit in the stomach]. It’s very much there.

(Participant 15)

Given the lack of medical knowledge and acceptance of this condition, the uncertain prognosis, stories of recovery, and ambiguous research findings regarding causes and treatments, it was difficult despite years of illness for participants to realise emotionally the possible permanency and consequences of CFS. For all participants, emotional realisation was an ongoing struggle. Nor was cognitive realisation readily acquired. Two key features of CFS required cognitive realisation, first, the symptoms and their effects, and second, its chronicity.

Symptom Effects

Cognitive realisation required acknowledging the unpredictability and intrusiveness of the symptoms and the effects and changes associated with CFS.

I don't know how you can be effective in dealing with it [the symptoms] other than to accept them for what they are and to rest . . . You've got to accept it [laughs]. When it comes you realise you can't do things you'd like to do, and there's no good getting frustrated or uptight or anything else, you've just got to accept it and get on with life. (Participant 9)

My spiritual side is one hundred per cent healthy and my physical self I feel miserable. But I can’t help that, and that's what it is. I had to realise I can't deal with my physical side . . . everybody is sick with something and you've just got to cope as best you can with it. (Participant 16)

The continuation of the symptoms and the lack of success in significantly ameliorating them prompted the realisation by participants that they were limited in their ability to control the symptoms or resume their previous lives. However, participants desired quality of life and consequently, they began to turn their focus from eradicating the symptoms to enhancing their daily lives and experiences of self...
despite the symptoms. In sum, cognitive realisation of the nature of the symptoms allowed participants to make this shift in focus.

**Chronicity**
The other feature of CFS that required cognitive realisation was its chronicity and the uncertainty of recovery.

*It's only probably changed in the last couple of years. It's finally got through to me . . . it sort of got better, and then it got worse, and then another two years, and then, well, this is really a long term problem . . . And whether I've really come to terms with it yet that's another question . . . It is difficult to accept that I might not have a very good level of functioning for a long time but I think I found I have accepted that.* (Participant 14)

*What happened for me for the first eight years, or six years maybe, was that what you really lived and breathed was the thought that they'd come up with a cure and they'd cure you and you'd be all right and go back to normal life. And what I realised was they weren't going to come up with a cure in a hurry.* (Participant 3)

The acute presentation, expectations of recovery (held by both the participants and others), and difficulties in obtaining a diagnosis extended the length of time required for realising the chronicity of CFS. Subsequent to the cognitive realisation of chronicity was the realisation that recovery may not eventuate. Recognising an uncertain recovery, however, did not necessarily mean that participants relinquished hopes for improvement or a return to health.

There is some further support for these findings in the work of other researchers. Dewar and Morse (1995) reported on the many difficult events that are encountered in bearing serious illness or injury. They included, similar to the cognitive realisation of the present study, “learning to bear it” (1995, p. 962), defined by Dewar and Morse as an acceptance of the ongoing nature of illness or injury. More specifically to CFS, although a distinction was not made between cognitive and emotional acceptance, de Ridder et al. (1998) reported that among participants with CFS, acceptance of being ill was considered the most important task imposed by the
illness. Acceptance included “learning not to fight the disease at all moments”, “admitting that you are an ill person”, and “accepting you cannot do the things you used to” (1998, p. 94), all of which are consistent with the features of cognitive realisation found in my research. In sum, cognitive realisation facilitated the development of the Reconstructing Response by providing a climate for adopting a more realistic and discriminatory perspective, and enabling the implementation of achievable goals, thus reducing the likelihood of failure. Cognitive realisation also facilitated grieving.

**Diminishing the Defensive Stance**

When threats decreased or participants were better able to protect themselves from threats, the need to maintain the defensive position typical of the Guardian Response was lessened. Conversely, when a defensive position was ineffective alternative methods for self-protection were sought. That is, both the effectiveness and ineffectiveness of the defensive stance contributed to its diminished use.

*It took me a long time to understand how deeply I'd been affected by that GP but I'd become unconsciously very, very defensive and I have to check myself in Dr X's presence and realise that this guy is my ally. I don't have to be protective.* (Participant 10)

*If there's a conflict and they're like “Here, prove it to me”, well, that's terribly hard. I can't do that. I just don't have the energy to prove anything to you . . . You don’t get anywhere usually because people don’t like losing arguments [laughs].* (Participant 14)

By decreasing defensiveness participants were able to expand personal perspectives from protection and treatment to include rebuilding and healing. It created possibilities that emphasised other aspects of life in addition to (or instead of) CFS. As defensiveness diminished there were flow-on effects, and re-engagement became more likely with potential benefits to relational-self and self-worth.

*And what has helped their [her family] acceptance is not my continually trying to prove it to them or continually focusing on illness but finding another focus so then I can point to my writing and say, “Look, I've done this, look, I've done that”.* (Participant 6)
Psychological and Physical Space
As participants gained more experience at self-care and protection or experienced a period of comparative wellness or improvement, psychological and physical space became available for reflection on how best to live in spite of CFS.

Physical space resulted from symptom improvement, either spontaneous or as a result of the management strategies. As symptom intrusiveness decreased, participants shifted their attention from monitoring physical experiences to the self-reflection necessary for the renewal of self. For example,

*At the moment I’m having great difficulties because I think I’ve become well enough to open my eyes and think “Excuse me, I’m not really happy [laughs] with the surrounding things”.* (Participant 15)

Management strategies also directly affected physical space by curtailing activities, thus providing time for self-reflection.

*I never really spent much time being so introspective . . . I was always so busy, it wasn’t really part of life, whereas I have more time now.*

(Participant 1)

Psychological space resulted from progress in grief work. As distressing emotions were processed, psychological energy was freed and made available for augmenting positive or healing experiences of self. The provision of psychological space was further facilitated by the withdrawal and self-focus of the Guardian Response as these characteristics prompted introspection. Additionally, strategies of the Guardian Response limited the exposure of participants to invalidating encounters, creating psychological space.

Relinquishing the burden of proof also created psychological space. Relinquishment did not reflect a change in the participants’ beliefs regarding their illness but a shift away from constantly trying to prove to others that their illness was “real”.

*If someone came up and said, “Oh, you got that CFS thing, isn’t that that yuppie flu”? How do you know that? I wouldn’t try and prove that. I’d*
asked, “Why do you say that? What evidence did you have for that”? (Participant 14)

My son refuses to admit that I’m ill . . . I never lost my love for him but I was always trying to prove to him that I was really ill. And now I just listen to his problems. (Participant 12)

As participants became better able to manage the condition, less defensive and more realistic, and with the recognition of ongoing resistance by others, proving their illness became more selective. To varying degrees participants retained a sense of responsibility for the burden of proof but it was intermittent rather than a constant activity as with the Guardian Response. For those participants active in CFS advocacy the burden of proof remained an issue, but it was directed towards proving the existence of the condition rather than proving the existence of their personal illness. Relinquishing a need to establish proof of their CFS gave participants space to look for healing rather than cure, and for concentrating on ability rather than disability.

Hadler (1996) argued that in the absence of demonstrable pathology people generally are not prepared to believe a person is ill, but challenge the person to prove illness. This in turn maintains illness because “to get well is to abandon veracity” (1996, p. 2399). By relinquishing the burden of proving illness, the participants in the present study were able to find the space to foster the renewal of self, and while not able to “get well”, they were able to improve quality of life.

Psychological and physical space therefore provided participants with opportunities to place CFS within a wider context and as threats were decreased, participants sought out strategies to enhance their lives and renew positive self-perceptions.

Any of these conditions were capable of providing sufficient impetus for the development of the Reconstructing Response. Underlying these conditions was the passage of time. It may be that the losses associated with CFS were so substantial and the threats to self so great that participants clung to the expectations of the
known-self and only with time, some symptom relief and emotional work, were they modified or relinquished.

*Early on you're so ill you don't know what is going on . . . It's when you're getting to a point where you're starting to get a little bit better . . . You start to question what is actually happening to you, and what's your role within your life. You know how people keep saying, “that was my old life, this is my new life”? I think it’s the transition, the realisation of, well, that didn’t happen, that's not happening any more, this has happened, and this is all going on out there and I'm just here, and I'm not doing anything. So I think it's more that process.* (Participant 18)

In addition to these conditions, for some participants the emergence of the Reconstructing Response was not exclusively a gradual process but involved a turning point.

**Turning Points**

The construct termed “turning point” is experienced as a pivotal and single moment, interaction or event (positive or negative) that resulted in a sudden clarity, recognition or understanding by the participants about some aspect of their lives. This meaning is consistent with other research, such as King et al. (2003) who defined turning points as emotionally compelling realisations that involve the acquisition of meaning. Similarly, Shih, Chu, Yu, Hu and Huang (1997) defined turning points as something that suddenly affects a preceding condition and that lead to a more positive or negative health outcome.

For those participants who experienced a turning point, most reported a single and independent episode. The turning points which the study participants noted included: the inability to continue working; becoming a pet owner; diagnosis following many years of illness; finding a sympathetic doctor; and finalising workers’ compensation. The understanding and sometimes relief that resulted were different for each participant.

*That's how I ended up with a dog. And that was the start of the turning point in the change in my thinking. I think she [the dog] was a catalyst for a lot of things . . . I'm really convinced that she was the one that started me off in the*
right track of thinking, well, I need a different focus, this has happened to me, I cannot wallow in it . . . I'll continue my quest to get better but I need a balance. (Participant 1)

Getting that worker's comp pay sorted, satisfactorily or otherwise, gave me a chance to turn around and start focusing on wellness instead of illness. (Participant 6)

In addition to independent events or moments, two participants described turning points related to the passage of time.

. . . that thirty-year mark . . . I'd been sick seven or eight years. By that time the CFS would [should] have decreased and you'd have a career to aim towards, things would flow on. So that was a very major turning point when that didn’t really come to fruition, a reality-check, hitting a brick wall. (Participant 4)

Similarly, Participant 6 described a turning point that arose from recognising the losses and deterioration that had accumulated over years. In these instances the turning points were moments of sudden recognition but there had been a growing saliency over time.

Turning points acted as a direct catalyst for the Reconstructing Response. The sudden and clear awareness resulted in a cognitive change in the participants’ understanding of their circumstances. This served to modify the aversive into something less threatening and strengthen positive perceptions of self-agency about issues of choice and quality of life. In addition, turning points strengthened indirectly the conditions associated with the Reconstructing Response. For example, for two participants relinquishing the working role was associated with the recognition that CFS was chronic, severe and disabling, which in turn facilitated cognitive realisation. Regardless of whether the turning point was desired or undesired by the participant, its occurrence led to a new understanding and was recognised as important to physical and psychological healing. Turning points helped also to reinstate a sense of balance, provided opportunities for healing, and augmented positive perceptions of self.
Characteristics of the Reconstructing Response

The main characteristic of the Reconstructing Response was its largely cognitive nature and related recognition of a new reality about what life is now like. By a conscious modification to thoughts, the Reconstructing Response provided different perspectives and new interpretations, and these cognitive shifts provided a basis for a redefinition of self and how one lived one’s life. The restructuring of thoughts was associated with re-prioritising activities and seeking alternative sources of identity and self-fulfilment. In this way, cognitive modifications were operationalised and enacted, and a renewal of self was facilitated. The cognitive characteristics of the Reconstructing Response included reflection; external, positive and realistic perspectives; and expertise. Each is discussed below.

The Reconstructing Response was reflective and self-evaluative rather than defensive and self-absorbed. Participants developed greater insights regarding their experiences, personalities and responses. These insights assisted participants in pre-empting problems, determining priorities, and discriminating between aspects of CFS that could be controlled and aspects that could not, thereby facilitating perceptions of mastery and self-determination.

Now . . . I can look at something and say, “is that really urgent? I don't think so. Yep, that is”. So it does make me stop and think about priorities.

(Participant 1)

With the symptoms I probably have very little control . . . With CFS altogether I feel I got it pretty much in hand. (Participant 7)

This increased self-knowledge of the participants has been widely reported among people who are chronically ill (Frank, 1997; Lindsey, 1996).

The Reconstructing Response adopted an external and exploratory perspective that altered the participants’ CFS-focus to include their wider existence, of which CFS was one part.

It's looking at the whole spectrum and focusing on life generally instead of
“What is my latest symptom? Is it a sign of something worse”? (Participant 6)

What I'm finding now is, I'm actually beginning to be able to see this in the big picture... to put it into place. (Participant 10)

This external and expanded perspective provided participants with an encompassing context within which to understand their experiences. Consequently, CFS and its effects were considered to be one instance of broader social phenomena such as prejudice. Similarly, CFS was viewed as one of many chronic illnesses that caused suffering and marginalisation.

People were getting on with stuff that I couldn’t get on with, but at the same time I knew there were other people who were also not able to get on with things so I was just one of that group. So I wasn't on my own, or in another world. I was just in a sub-world that had other people in it like me. (Participant 17R)

It doesn't matter what sickness you have, you're not the only one. When you start identifying with other people the thing is you can see the bigger picture. (Participant 4)

I took the focus off me and I put it on other people... I was able to see other people who were probably in a worse state than I was, so it can bring some perspective... (Participant 1)

This external perspective helped to reduce self-perceptions of deviancy, estrangement and relational disconnection.

The external and broader context assisted participants to reduce threats and violation by fostering explanations for the behaviour of others that did not imply self-blame or personal responsibility.

It shows a problem in them, that they have to try to deal with illness, disability, infirmity, anything that's less than perfect in that way. (Participant 6)
A lot of relationships just don't exist anymore . . . because of other people's resistance or ignorance or refusal to listen, or their own screw-ups basically. It stings a little bit when it happens but it actually doesn't matter. If these people didn't survive this experience so be it, it's not my problem. It's like shedding dead wood. You're just moving forward. (Participant 10)

In other words, threats were lessened because participants interpreted the behaviour of other people as determined by those people. Nevertheless, the adoption of an external focus was not associated with a relinquishment of the internal focus found within the Guardian Response. Rather, the internal/external operated together to provide balance.

The Reconstructing Response adopted a positive perspective instead of the negative perceptions that typified violation and the defensive perspective of guardianship (this positive perspective is discussed at a later stage). A positive focus, however, was not perceived as a source sufficient in itself to ensure improvements in the condition. If you say “Oh I'm sorry, I can't do that”, they say, “have a positive attitude”. Positive attitude ain't gonna help. I've got a positive attitude but it ain't gonna help me get down that cliff . . . (Participant 15)

Rather, the Reconstructing Response provided realistic appraisals. The appraisals were not necessarily consistent with medical opinion or the CFS self-help literature. The appraisals of the participants reflected a developing “objective” perspective regarding their subjective realities, based on evaluations of their illness experiences and personal circumstances. CFS, for example, was viewed as one important life influence that co-existed with other sources of change.

I don't know if it's CFS or age . . . but I'd say at the moment I'm more accepting of myself. But I think that has a lot to do with being a parent, being, having CFS, whatever. I'm more “this is what I am”. (Participant 15)

Even if I get completely better it's still a past life because after having been out . . . of the system for ten years I couldn’t walk into a job as a radiographer because everything is so different. (Participant 13)
The realistic appraisal was notably evident in the participants’ ceasing to search for a cure.

*I'd follow the news really, really closely and we'd all ring each other up being excited about some new development, and I stopped doing all that because it's ridiculous. It's not going to happen. I don't think it's going to happen. Not in my lifetime.* (Participant 3)

This decreasing search for and use of treatments has been previously reported (Woodward, 1993). Although participants were criticised by others for not trying treatments (and therefore, for wanting to remain ill), there is some evidence to suggest that searching for cures is not an adaptive coping behaviour. A study on cancer patients reported that searching for a cure among alternative therapies exacerbated stress (Montbriand, 1995), a finding that is consistent with the views of the people who participated in my study.

*I'd think, “maybe I should try that” and I got very stressed about all these things that were out there, that people were trying and getting cured . . . I still don't know what to make of these.* (Participant 7)

Similarly, participants acknowledged their (and medicine's) lack of success regarding recovery.

*But I don't think you're ever cured. The damage is done and then it depends on your level of physical work or stress or whatever, that takes you down again.* (Participant 9)

*I more or less assume that I'll probably always have it to some degree anyway. It will probably pretty much stay as it is now . . .* (Participant 7)

By relinquishing the search for a cure and acknowledging the lack of success regarding recovery, participants were able to focus on aspects that were under personal control (such as expectations of outcomes) and to pursue alternative (and more achievable) goals, no matter how modest.

*And with everything, I don't go thinking, “Oh, this is going to instantly cure me”. I use them as a management tool.* (Participant 15)

Further, because the Reconstructing Response was based in their reality, unpleasant situations were not denied or minimised but placed within an external framework.
that facilitated a reinterpretation that was of benefit to participants. Additionally, there was an empowerment that came from being realistic and practical.

The Reconstructing Response considered self to be an expert in CFS. This confidence in personal expertise was exemplified by participants who believed they were better equipped to diagnose CFS than many medical practitioners.  

*I can diagnosis CFS much better than ninety-nine per cent of the doctors. It's so simple. It's a core of problems. Arthralgia, myalgia, sore throat, headache, fatigue and that's about it. They've got those, there's a ninety per cent chance I reckon they've got CFS.* (Participant 8)

The perception by people with CFS that they are experts has been noted by other CFS research (Clarke, 2000). Self-as-expert signified the trust participants placed in their own perceptions rather than in the perceptions of expert-others, as was often the case with the Violated Self. It also reflected the self-agency and self-reliance that developed as consequences of the inadequate health care that participants had received.

The characteristics of the Reconstructing Response were evidenced in its strategies which in conjunction, operated to enhance positive perceptions, provide opportunities for rebuilding and renewing self, and facilitate a focus on wellness instead of illness. Participant 6 summarised succinctly by saying, *I've needed to go further and reinvent myself.*

**Strategies of the Reconstructing Response**
The Reconstructing Response was associated with two categories of strategies: firstly, downgrading or shifting the focus of perceptions, expectations and beliefs regarding self, and secondly, seeking sources of self-fulfilment. Downgrading or shifting expectations were cognitive strategies and included the reduction and modification of expectations, the relinquishment of counterproductive expectations, the re-framing of negative perceptions into positive perceptions, and the adoption of new and more realistic expectations. Seeking sources of self-fulfilment were behavioural and enacted strategies, and included sharing knowledge, social re-engagement, and seeking positive outcomes. There is some further support for the
effectiveness of the strategies of the Reconstructing Response in enhancing quality of life. De Ridder et al. (1998) reported that quality of life among people with CFS was associated strongly with their cognitions and resultant actions, consistent with the altered expectations and seeking out of sources of self-fulfilment that was found by the present study. The strategies are discussed below.

**Downgrading and Shifting of Self-Perceptions and Expectations**

Downgrading expectations involved an evaluation by participants of their lives and expectations in light of personal resources, abilities and responses of others, with the aim of fostering positive self-perceptions. Other CFS research has also found downgraded and shifting expectations. Blenkiron et al. (1999) showed that some participants set lower standards for themselves and others as a coping mechanism, while Ware (1999) reported a re-definition of performance expectations and a relinquishing of perfectionism. Similarly, Woodward (1993) noted a change in expectations from an active to a less active life. However, as a strategy downgrading and shifting of expectations has remained relatively unexamined by the research.

Adopting favourable comparative measures positively altered self-perceptions. Expectations of the known-self were relinquished and replaced with expectations that were realistic and achievable.

> *Expectations about CFS and myself. They are a lot less so that's partly good. I can't do [some things], so you have to change your expectations.*
> (Participant 14)

> *I've learned to cope with what I can do and that's the hardest part, instead of saying, “Well gee, I should be able to do x, y and z”. No, I can't do that anymore, I can only do whatever.* (Participant 16)

Rather than comparison with the known-self or with healthy-others, the Reconstructing Response used the participants’ history with CFS, current condition and temporal experiences as a basis for evaluation.

> *I'm much better now. I can stand for five minutes instead of half a minute.*
> (Participant 2)
Self-comparisons evaluated present health with CFS at its worst, rather than with previously healthy states. Comparisons with others decreased, and when they did occur were interpreted from a perspective favourable to participants.

*I can walk. I am not dying. There are people worse off than me. So I always remember I’m very lucky. I have my life.* (Participant 18)

This evaluative position used downgraded expectations that provided a more realistic basis for comparison. By doing so participants were able to focus on improvement, even when the degree was minimal, and reduce self-discrepancies.

The passage of time and recognition of aging were important to the modification of expectations regarding tasks, occupational aspirations, and the likelihood of recovery.

*You know you’ve got a bit old in the tooth so you got to learn to let go.*

(Participant 4)

There was a sense that too much time had passed, too much had been missed and that one had become too old for most expectations of the known-self to be maintained. Advancing age and life stage were important mediators of downgraded expectations.

Downgrading or shifting of expectations, beliefs or self-perceptions involved four methods: reduction and modification of expectations to fit with current capabilities; relinquishment of counterproductive expectations; re-framing of negative perceptions into positive perceptions; and adoption of new and more realistic expectations. These cognitive modifications were directed at self, others and illness-related perceptions, expectations and beliefs, and were reframed or shifted within the context of present and immediate and distant future. The expectations of the distant future were less limited than the immediate, and for some continued to include the hope of recovery. Future plans were replaced, however, with future possibilities, and hopes became modest and tentative.

**Reduction and Modification of Expectations to Fit with Current Capabilities**

Participants were no longer able to meet their expectations of the known-self, and expectations were reduced or modified to fit with current capabilities.
I have only half a day expectations [laughs]. My day stops at midday, anything achieved after that, it's a bonus. (Participant 15)

I don't expect myself to conquer the world anymore. I don't place undue pressure on me anymore . . . (Participant 1)

The downgrading of expectations was evidenced by a focus on simple, taken-for-granted aspects of life. Expectations were modified to accommodate a sense of achievement and self-worth within the personal context of the illness. Participants' future expectations were also reconstructed to be congruent with present capabilities or circumstances and involved compromise.

Reduction and modification allowed participants to retain what they could from previous expectations, to redefine expectations, and to enact or express expectations in different ways. This helped sustain a sense of biographical continuity, identity and self-worth. For example, prior to his illness Participant 4 had expected (and worked towards) a career in music. Many years of illness with CFS had rendered that expectation unrealistic. He reduced his expectation to one of gaining pleasure from music and had sought out ways to continue to express himself musically.

Listening to music . . . We do karaoke from time to time. With my brother we would probably have done music on stage, we were at that high level, but now, karaoke where you have the lyrics in front of you so you don't have to remember things.

Relinquishment of Counterproductive Expectations
As it became apparent to participants that expectations of the known-self were no longer viable, valued and long-standing expectations that were counterproductive to their current situations were relinquished.

I was talking to one of my friends the other week and he said, “Oh, sounds good, you have plans” and I said, “Well no, I don’t have plans anymore, I just have hopes that I might be able to do that”. I don’t have plans. I have possibilities that might happen. (Participant 14)
Relinquishment was generally difficult for participants as it involved letting go of expectations that were important to the sense of self. Personal expectations such as perfectionism and values such as a strong work ethic were gradually relinquished in light of their incompatibility with the participants’ new realities. By relinquishing counterproductive expectations the Reconstructing Response sought to minimise failing experiences.

In addition to expectations regarding self, and consistent with Blenkiron et al. (1999), counterproductive expectations regarding others (and their capabilities) were relinquished.

“I would like to have a relationship with a GP who could help me manage it on an equal basis and not just say, “this is what you need to do”, but listen to what I’m saying and help me manage it and work it out. But I don’t have that sort of relationship and I’ve given up trying.” (Participant 15)

By relinquishing expectations regarding others, participants attempted to modify loss, rejection, abandonment and unfulfilled needs.

**Re-framing of Negative Perceptions into Positive Perceptions**

Re-framing of negative perceptions and expectations to reflect a positive perspective was another strategy used by the Reconstructing Response.

“Why have I got it”? I don’t say that anymore. I say, “I’ve got it, what am I going to do with it”? (Participant 16)

Re-framing shifted threatening expectations into expectations supportive of positive self-perceptions and an improved quality of life. The focus was changed from what had been lost to what had been gained. For example, with the Violation of Self, the loss of the participants’ extended social network was associated with rejection, loneliness, and questioning regarding perceived value to others. By re-framing the negative perceptions that arose into perceptions that supported a positive sense of self, such as the relationships that remained were strong and true, the Reconstructing Response was able to temper threats to self associated with this loss. Rather than
accept rejection and its effects on self, the Reconstructing Response was able to ameliorate the threats associated with lost relationships by adopting a positive viewpoint.

**Adoption of New and More Realistic Expectations**
The Reconstructing Response also adopted new and more realistic expectations that were considered to be achievable. While realistic, the adoption of new expectations challenged participants. Participant 1, for example, described a new expectation of herself that she would walk the dog daily. The participant considered the long-term benefits to be greater than the discomfort associated with physical activity, and despite days when she was too ill to leave the house, the participant was pleased that she mostly continued to meet this expectation. Sometimes adopting new expectations involved expectations that were previously considered undesirable. This flexibility typified the Reconstructing Response.

The downgrading and shifting of expectations, beliefs and self-perceptions was substantial for all participants. This strategy was perceived as a fundamental necessity while affected with CFS. A few beliefs and expectations, however, were not contingent on the continuation of CFS but were sufficiently important to be incorporated into the participants’ values. Additionally, when pre-illness expectations were still considered to be realistic, they remained unchanged by CFS. The downgrading and shifting of self-perceptions, expectations and beliefs contributed to positive perceptions of self and quality of life in a number of ways. As expectations shifted and acceptance developed, the associated distress became less constant and acute. Self-discrepancies were reduced, and the achievement of goals became more likely which provided opportunities for enhancing self-worth and self-agency. The incorporation of new perceptions and expectations provided opportunities for finding new identity sources.

**Rebuilding and Renewing Sources of Self-Fulfilment**
New sources of fulfilment and identity that rebuilt and renewed positive perceptions of self were adopted by the Reconstructing Response. The continuation of the symptoms, the effectiveness of the Guardian Response in defending against threats
and the reflective, evaluative and realistic perspectives of the Reconstructing Response facilitated the recognition that new sources of self-fulfilment were necessary. Finding a new sense of self involved exploration, flexibility and taking risks. Rebuilding and renewing sources of self-fulfilment involved three methods: sharing knowledge and experience; social re-engagement; and seeking positive outcomes.

**Sharing Knowledge and Experience**

The Guardian Response sought out and shared knowledge to protect participants. Alternately, the Reconstructing Response shared knowledge and expertise so as to meet altruistic needs. Participants considered sharing knowledge to be a way to help people with CFS, improve the acceptance of CFS as a legitimate illness and enhance medical and social understanding.

> It's really important that we learn as much as we possibly can about this illness, all aspects of it, and also just to make it more, seen as a more valid area of study. (Participant 3)

Sharing of knowledge has been reported among chronically ill people and as in the present study, this was based on a desire to help others (Lindsey, 1997). In contrast, however, Woodward (1993) found that among her CFS participants becoming an “expert” did not translate into the sharing of that knowledge, and instead, participants reported a reluctance because of experiences of pejorative associations. That is, expertise was gained and kept secret for the protection of self. Woodward’s findings are more consistent with the gaining of knowledge described by the present study in the Guardian Response, even though expertise was a characteristic of the Reconstructing Response.

The information shared with health practitioners and the public encompassed clinical manifestations, causation, diagnosis, management, and invalidation, and aimed to enhance the understandings of unaffected others and improve the quality of experiences for other people with CFS.

> Because I've carried myself through the experience . . . pretty much alone, then maybe this [participating in the study] can help someone else who is
diagnosed in the future (Participant 1)

I'm putting back into helping other people, and maybe lessen their load or give them shortcuts, or help in some way that yourself didn't have.

(Participant 4)

Participants believed that they had something unique to offer and were able to appreciate the value of their personal experiences as a basis for helping other people understand CFS.

Knowledge and experience were also shared directly with other people with CFS. All participants knew or had known others with CFS and the sharing of information was enacted through a variety of roles such as fellow-sufferer, teacher, mentor, advocate, or friend. The knowledge shared was wide-ranging and included practicalities and aspects of protection.

I tell them . . . “don't push yourself it's fine, you need to rest”. That's something . . . especially in the early stages, people need to be told. That's something they need to be told often 'cause they're always going to feel that they want to get out and do things. (Participant 14)

I have a contribution to make by telling people it's definitely not only all right to give up when your body says give up, it's critical, 'cause you don't want to end up like me. (Participant 12)

In addition to management issues, knowledge was shared regarding attributes, qualities and goals found to be helpful.

If I had a message for anyone, any CFS sufferer or any chronic illness . . . it would be to somehow try and find a purpose and hopefully purposes. You've got to have something to get out of bed for. And if you don't feel like you have it, then you have to find it yourself, and make it up, create it.

(Participant 1)

Sharing knowledge sometimes required disclosure that was not necessarily the preferred option but was perceived as the “right” action by the participants. While disclosure in the Guardian Response was defensive and focused on the protection of
self, disclosure in the Reconstructing Response focused on contributions and responsibilities to others and the fulfilment of altruistic goals.

*I feel that I have to be* [open in disclosing her condition] . . . *that's part of my responsibility as someone who has ME for other people who have ME.*

(Participant 15)

Sharing information was sometimes a burden. Nevertheless, expertise opened up opportunities to contribute to society, adopt new roles and meet altruistic needs. Contributing to the well-being of others and to the social legitimation of the condition through the sharing of knowledge and experience fostered self-worth. Additionally, roles associated with the sharing of information (such as membership of support groups) provided new identity sources.

**Social Re-Engagement**

The Reconstructing Response replaced withdrawal with re-engagement and established ways to reconnect participants with others and with their surroundings. The Reconstructing Response recognised the importance of social re-engagement as a source of self-fulfilment and in contrast with relationships of the Guardian Response, which were centred on the provision of safety, the Reconstructing Response focused on other relational needs, seeking to expand social contact and expression. Nevertheless, re-engagement remained markedly limited by the symptoms and impairments and participants continued to use a cost/benefit analysis, in addition to the skills of the Reconstructing Response, in decisions regarding re-engagement.

The Reconstructing Response understood the effects of CFS on relationships and interactions and used these insights to facilitate re-engagement. For example, the Reconstructing Response was better equipped to assess the possible responses of others and was able to modify the interaction accordingly.

*I've probably got to a point where I wait for people to ask* [about his well-being] *and not even to tell, and also learning not telling people more than they ask 'cause they probably can't handle it. If they don't ask, they can't handle it.* (Participant 14)
Additionally, experience with CFS and the development of communication skills assisted in the transition between withdrawal and re-engagement.

*After the first couple of years I was better in dealing with the social aspect, telling people what I could do and not do . . .* (Participant 17R)

By re-engaging with the external world (to varying degrees), participants believed they demonstrated to others their desire to be well, isolation was ameliorated, identities expanded, and new interests and friendships were developed.

*It's rather nice being part of this writing group and hearing the wonderful literature now I've lost my [singing] voice.* (Participant 11)

*By doing a thing like this [working with a support group] . . . [I'm] developing another circle of friends through CFS . . . it's budding, it's opening up again.* (Participant 4)

*I'm really fulfilled by being able to be a good friend to some of these young people . . . not that I can do that a lot, but I do feel that's what I really enjoy.* (Participant 14)

Social re-engagement was a significant step for the participants. Lindsey (1996) found that “seeking and connecting with others” (p. 465) was important to feeling healthy while living with a chronic illness. By re-engaging the participants of the present study sought to return to the wider world, one beyond CFS. Positive effects for self included a renewed sense of relational-self and benefits to self-agency and self-worth.

**Seeking Positive Outcomes and New Meanings**

While not denying the costs of CFS, the Reconstructing Response sought out experiences beneficial to self and actively interpreted outcomes as positive. By looking for the positive and constructing valued meanings for experiences, the Reconstructing Response provided sources for affirming self-perceptions.

Positive outcomes were associated with cognitive re-interpretation or with satisfaction regarding activities. Achievements were measured with new criteria,
abilities were no longer taken for granted, and activities not related to CFS were valued.

I had to learn bit by bit, and it took a number of years, to readjust my successes and failures. And what I started to do fairly early on, and I do it now to this day, is at some point I say to myself or Daisy [her dog], “we did good today. Now what did we do today”? . . . It’s the little things now that are as important as the bigger things . . . you’ve got to be able to make that leap otherwise you spend so much time with the “what ifs” that you forget to be living in the here and now and you don’t accept or even recognise the little achievements. (Participant 13)

I drove to Newcastle to look after Mum a few months ago which was lovely. Everyone was worried ’cause it had been so long but I said, “No, don't worry”. It was a great achievement. (Participant 2)

Downgrading of expectations was associated with participants finding new pleasures in simple things and this ability was seen as a positive difference between the known-self and the self-with-CFS. As expectations were evaluated and modified, participants were able to recognise and take pride in their strengths.

Seeking positive outcomes was also reflected into the future. Participants hoped that future goals and improvements in quality of life were possible.

There's a lot of the world I want to see . . . (Participant 2)

Despite what everyone says, definitely I'm getting better every day, slowly . . . Slowly get there and I know I will. (Participant 18)

They attempted to prepare for their futures and recognised the need for holistic rehabilitation. Skills that developed as a response to CFS were examined for their potential contribution to positive outcomes in the future.

I'm at a level now where actually I do some counselling . . . I'm hoping that this is a stepping stone . . . (Participant 4)

An important aspect to the search for positive outcomes related to the construction of meaning. The impact of chronic illness is often so profound that the meanings
people hold regarding their lives are lost, damaged or diminished. The need to seek new meanings and the ability of chronically ill people to do so has been well documented (for example, Fife, 1994; Lindsey, 1997), including among people with CFS (Ware, 1999; Woodward, 1993). In the present study, reflection, altering expectations and seeking positive outcomes helped participants to find new meanings for their lives, different from those held by the known-self. New meanings provided future directions, protection against living in the past, and sources for self-renewal.

*I had a direction I thought God wanted me to pursue, and so one of the biggest struggles I had when I was bed bound was “How can I do this? What are you doing to me”? And I became aware after all that my ministry was to the sick, so I discovered the meaning.* (Participant 2)

The strategy of seeking positive outcomes and new meanings facilitated the renewal of self by providing new and additional sources of self-fulfilment. What was being renewed was not necessarily aspects of the previous self, but the sense of “who I am”. Seeking positive outcomes and new meanings was beneficial to all dimensions of self. In particular, identity was strengthened and self-agency and self-worth were enhanced.

The strategies of downgrading and shifting self-perceptions, expectations and beliefs and seeking self-fulfilment facilitated the redefinition and reconstruction of self and contributed to an improved quality of life. In this way the Reconstructing Response compensated for the losses and disruptions found with the Violation of Self, and moved beyond the reclamation of the Guardian Response to a renewal of self.

**Overview of the Effects on Self Associated with the Reconstructing Response**

Participants described themselves as changed by CFS, but unlike the Violation of Self where changes were undesired and distressing, the Reconstructing Response viewed the changes from a positive perspective, which provided participants with a redefined and renewed self.

*You've just got to change. It's like starting a new life and just thinking, “Okay, this is what I can do now”, not “what I could've done”.*

(Participant 16)
In other words, the Reconstructing Response viewed CFS as a catalyst for positive self-change rather than resulting exclusively in a Violated Self. The comparisons used to measure change were structured so that the outcome was positive, for example,

*I'm not as hard on myself now when I make mistakes and I'm not as hard on myself when I forget things.* (Participant 1)

*I'm probably less achievement oriented and more people oriented now and that's a good thing.* (Participant 14)

These kinder comparisons reduced the self-discrepancies experienced with the Violated Self and fostered desirable perceptions of self that contributed to identity. Recognition of the positive changes did not imply that participants desired to remain ill, but reflected the belief that it was important to make the best of the situation and to live a fulfilling life.

The shift toward viewing change as positive (while not denying its negative impact) also arose from viewing CFS as a potentially beneficial force. The Reconstructing Response perceived CFS as a teacher and a source of life lessons, that although unwanted and damaging, was also of value.

*It's concentrated me, having CFS, it's helped me work out what I need from life, keeps me on track.* (Participant 5R)

*I can look at the CFS experience and just see the importance. It's sort of given me a real focus and a real centre, to actually train my mind from negativity and to cultivate my mind.* (Participant 10)

*It's [CFS] given me a direction in my life. If I hadn’t had chronic fatigue I would never be doing what I do now. I wouldn’t have dreamed of it because there was no need for it. I would have been materialistic, going my own way. I would have had no caring attitude. I would have had no empathy. And I think having chronic fatigue and coming back to reality and saying “well okay, this is how people feel like when they're sick, and money isn’t all there is to it, you still survive”. It's amazing.* (Participant 16)
Consistent with other CFS research (Ware, 1999), the participants spoke of personal growth, lessons learnt, and evolution. Pettie and Triolo (1999) note that illness as evolution includes a sense of gratitude, and the participants, although not thankful for becoming unwell, were grateful that they were able to learn new ways of being. Adopting a positive perspective and looking for the lessons of CFS helped participants construct meaning for their illness experiences and enhanced personal perceptions, particularly self-worth. Similarly, in a study examining meaning among people with chronic illness, Fife (1994) reported the beneficial effects to self-esteem associated with using a positive perspective.

The development of a feeling of inner strength resulted from the ongoing experience of living with CFS. That is, the Reconstructing Response exhibited a resilience of self (rather than defensiveness) that was reflected in the endurance of the participants. This endurance or strength was perceived as essentially psychological or spiritual, and was seen as independent of health or physical capability.

Many times you did feel you took one step forward to be knocked down again and again and it's very hard to, when you feel weak to actually get back up. So you rely on some sort of inner strength to, not actually physically get up and do it, but internally, to actually come to terms with things. (Participant 4)

I'm no better than I was physically. I'm probably worse, but mentally I'm a lot better, emotionally I'm a lot better. I still get down. I still get black depressions. I still get “Why me? This is a bitch”, but because I've come through it so many times I'll know I'll come through it again. (Participant 6)

The development of personal strength not only contributed to the participants’ confidence about their ability to cope with an uncertain future but also enhanced their perceptions of self-agency and self-worth.

The Reconstructing Response sought out avenues for the expression of identity from within the restricted roles available and by placing greater emphasis on these remaining identity sources. Additionally, although limited by impairment, the Reconstructing Response sought out new sources of identity that provided achievable
goals and experiences of success. The ability to transfer previously valued attributes to other avenues enhanced identity.

I'd lost my sense of identity as a welfare worker. . . . So now I help run the support group. I did telephone counselling. I've got to the point now where I'm on subcommittees, fund raising, which is not where I expected to be . . . I'm discovering skills I never expected to develop. (Participant 2)

In particular, participants who had been able to resume some degree of part-time work (paid or unpaid) experienced positive effects on their identity.

It's being part of some sort of system or work ethic. Becomes again a part of who you are. (Participant 4)

For most of the participants, however, work remained impossible and a painful reminder of their identity losses.

Redefining and reconstructing a sense of identity was a difficult task and required reflection about the nature of self. CFS and the marked changes to self associated with violation led to questions of “who am I and what is my purpose”? An acceptance of “it's not what you do, but who you are” was a challenge for the majority of participants and for a few, this remained a struggle. Nor was the identity of the known-self entirely relinquished, but rather, was tucked aside as a future possibility, hope or memory. As Participant 18 described it:

. . . that was my old life, this is my new life and I have those qualities, [they] are lying dormant at the moment.

There was a renewed sense of trust in self-perceptions. As participants experienced success related to lowered expectations and achievable goals, there was a developing self-confidence in decision-making and abilities, and participants gave priority to the validity of their own judgments.

[You] do what you think is best and if you don't you're in trouble.

(Participant 9)

The self-trust found within the Reconstructing Response was also evident in the participants’ views about the uncertainty of their futures. Although fears remained, there was (some) confidence among most participants in their ability to cope with the future.
In the future I am concerned if anything happened to my husband, who the heck would even show concern, so I just say the philosophy of the Lord’s prayer. I've managed today and I hope tomorrow. (Participant 11)

It's just a case of being prepared to cope with life on the edge, coping with uncertainty. (Participant 6)

Given the impact of uncertainty on the Violation of Self, minimising self-doubt and regaining self-trust were important to positive perceptions of self and was associated with a strengthening of self-agency. Nevertheless, despite the participants’ trust in their ability to cope with the future and its uncertainty, plans, goals or expectations remained mostly vague and non-definitive without clear statements of intent. There was a sense of having to wait to see what eventuated and the perceptions of future possible selves were tentative and conditional. The future was conceptualised in the short and medium term, with the long(er) term difficult to envisage.

I hope I might be able to spend a day or two at the CFS society, maybe doing some PR or something like that. That's something I'd like to do in the next year if I'm up to it, that's sort of the level of my planning. (Participant 14)

I don't know what I'll be actually doing . . . There are plenty of things that I could do, so which one of those things I'll do I don't really know. (Participant 7)

The realistic goals of the Reconstructing Response increased the likelihood of success. Participants experienced achievement with taken-for-granted activities and from simple acts that the known-self considered ordinary and unworthy of attention.

Things that I can do, I can do and that impresses me. And when I achieve, it doesn’t matter whether it's doing the chores or washing the dog, I've achieved and that's how you have to try and keep up your self-esteem . . . in the past I wouldn't even consider those worth noting, so you have to completely re-prioritise everything. It's not easy . . . but if you get to that point, then you can be really pleased with what you did. (Participant 13)

The development of new skills or the adaptation of previous skills to the limited circumstances of CFS also provided benefits to perceptions of self.
I won a major [writing] award, and I thought, “Oh, I’ve got value again”, and it's needing to be valued and needing to be of use. (Participant 6)

Experiences of success or satisfaction enhanced perceptions of efficacy and agency. A sense of achievement was also associated with perceptions of being valued and having value, and strengthened self-worth and relational self.

Despite the continued perception of life-before-CFS and life-with-CFS, there was a renewed biographical continuity and an enhanced congruence of self that resulted from the reduction in the discrepancies between the preferred (known) self and the self-with-CFS. Leidy and Haase (1999, p. 67) concluded that among ill people personal integrity (that is, the sense of individuality and wholeness) required “being able” (effectiveness) and “being with” (connectedness). The Reconstructing Response sought to maximise ability (“being able”) and connection (“being with”), and consequently strengthened integrity and identity. In short, a sense of holism and self-integration was expressed in the Reconstructing Response.

The Recovered Participants

For the recovered participants, the Reconstructing Response had a further task. Redefinition and renewal of the ill-self was followed by a reconstruction of a well-self.

I got out of being a CFS person, and a person with this crappy thing and that was good, starting to look forward . . . doing what I want to do. Back on track. (Participant 17R)

I'm not a sick person anymore. Because you start to think in a certain way when you've been sick for a while and I'm not thinking that way anymore.

(Participant 5R)

For Participant 17R, recovery meant relegating CFS to her past, as she said, she had the desire to put all of that [CFS] behind. In contrast, although they had resumed many aspects of their pre-illness lives, for Participants’ 5R and 19R CFS was still a presence.
The continuing presence of CFS was evident in the participants’ experiences of residual threats and of new threats that arose as a result of improvement. The importance of threats emerged early in the data analysis and by the time of the interview with the first recovered participant I was interested in exploring the threats that remained post-CFS and their effects to self. These were not research questions originally formulated and although involving only three participants, the findings of the present study highlight areas for future research. Again, Participant 17R was the exception, stating that she was no longer willing to think of anything as a threat.

Participants 5R and 19R feared relapse. The threat of relapse was realistic because all recovered participants had episodes of deterioration during their recovery. The fear of relapse was essentially a fear of returning to an inferior, undesirable existence that involved violation and suffering.

*I don't want to be in a family situation where the other person regards me as sick. I hate this sick stereotype and the way I'm expected to behave and . . . [the] judgments would start all over again.* (Participant 5R)

There was a sense of urgency related to the fear of relapse, and consequently, participants wanted to maximise their lives while healthy. This urgency was heightened by the need to make up for lost time, of trying to catch up with the life that had been forestalled by CFS.

*I have to make up for lost time. I'll always feel like I have to make up for lost time. I didn't actually lose that much time out of my life but I feel like I have to work twice as hard now to satisfy myself.* (Participant 5R)

*I'm trying to squeeze in as much now in case it should come back . . . I want to do everything now . . . in case I get sick again tomorrow.* (Participant 19R)

The fear associated with relapse influenced these two participants in different ways. Participant 19R exercised caution while Participant 5R took risks. Participant 19R, for example, felt herself to be trapped in her present job.

*I didn't have confidence before but it's [CFS] made it worse . . . going for a new job, I just can't do it . . . I found one about six months ago and they offered me a job. I was sitting around in tears. I was just so scared to leave*
the job I'm in because what happens if I get in that job and I get sick again? And there is that possibility. [CFS] It's sort of controlling that part of my life at the moment still, even though I've tried to get over it and I know I'm over it, I still [remember] how bad that was and I don't want to go there again. And getting into a new job you have to prove yourself . . .

This quote illustrated a number of threats and perceived effects to self in addition to the fear of relapse, such as a loss of confidence, emotionality and powerlessness. Alternately, the concerns of Participant 5R that CFS might return were channeled into overcoming CFS.

Everything I do in my life now is beating it and getting over it . . . I took last year off, and I went to outback NSW and I was going to a station out there and I was going knowing nobody and I had a completely CFS free year and that's how I want things to be in the future.

While the responses of Participants 5R and 19R were markedly different, both demonstrated the significance that CFS continued to exert in their lives. What distinguished their responses was the degree of control they experienced. While Participant 19R perceived (the fear of) CFS as controlling her life, Participant 5R perceived herself as controlling CFS.

Threats of stigma also remained for Participants 5R and 19R who were concerned that their past diagnosis of CFS may result in present or future stigma. That is, they experienced felt stigma.

It would be very hurtful if you're very close to someone and you found out they thought what you had gone through is a bit of joke. (Participant 5R)

Similarly, there was fear that the invalidation experienced in past encounters would be part of their present and future encounters. Indeed, there was some basis for these fears.

She [Mother] never did cope with it and even now I don’t bring it [CFS] up 'cause there’s always a look. (Participant 5R)

The participants (including, to a lesser extent, Participant 17R) were uncomfortable with disclosing their past CFS history with people they have met since their recovery. The fear of relapse supported a decision for disclosure while the fear of stigma and invalidation supported a decision for non-disclosure. Even with recovery,
decisions regarding disclosure continued to be an issue. Additionally, Participant 5R retained some self-doubt associated with the invalidation and disbelief she encountered from others while ill. That is, although she knew it to be untrue, Participant 5R continued to have instances of self-doubt that she had been ill with CFS.

The markedly different experiences of threats post-recovery between Participant 17R and Participants 5R and 19R appeared to be related to a number factors. Participant 17R considered herself virtually symptom-free while Participants 5R and 19R continued to experience some symptoms and to monitor their activity. This suggests that while threats are markedly diminished with significant improvement, continuation of the symptoms may be associated with ongoing (and new) threats. The threat of relapse, for example, was salient while the symptoms remained noticeable. In contrast, the ongoing threat of stigma appeared to be related to the shame felt by participants during their illness, rather than to the symptoms. That is, Participant 17R did not experience shame related to stigma during her illness and therefore was not subject to its retrospective effects. Participants 5R and 19R, for example, had experienced shame, and stigma remained a powerful threat despite their recovery. There was also a significant individual difference between Participant 17R and the other participants. Participant 17R was a clinical psychologist skilled in helping others manage change, and she used her therapeutic skills, in particular cognitive restructuring, to enhance her own coping and quality of life throughout her illness experience.

**Concluding Thoughts**

The Reconstructing Response redefined and renewed positive experiences of self. This was possible because the Guardian Response facilitated the conditions necessary for the development of the Reconstructing Response. The Reconstructing Response included characteristics of reflection, expertise, and external, positive and realistic perspectives. These characteristics were evident in the strategies of downgrading expectations and seeking sources of self-fulfilment.
The positive perceptions of self associated with the Reconstructing Response were expressed in a number of ways. CFS was viewed as a catalyst for constructive change, and consequently, while self was perceived as changed, those changes were interpreted in a positive light. Additionally, participants reported the development of an inner strength. The life lessons learnt from CFS and their positive perspective helped participants to construct meaning. Nevertheless, reconstructing identity was a difficult task involving reflection on the nature of self, and this remained, to varying degrees, a struggle for most. Perceptions of the future were vague and ill-defined, with participants adopting a wait-and-see approach and possible selves remaining contingent on symptoms. For the recovered participants, reconstruction of the self-with-CFS was followed by reconstruction of a well-self, although CFS continued to exert influence over their lives.

The Reconstructing Response was not an end point, and did not ameliorate all negative self-perceptions. Nor was it a constant state. Experiences of violation continued or resurfaced, and subsequently, the strengths of guardianship and reconstruction fluctuated, with one response to the fore and other response in the background. Thus, the narrative of the struggling self seeking renewal was perceived as an ongoing endeavour, as participants continued to meet the challenges of responding to CFS.

The final chapter discusses the data analysis, that is, the illness experience of CFS, in the context of extant research.
Chapter 10

Self and the Illness Experience of Chronic Fatigue Syndrome

This chapter discusses the fundamental illness experience of CFS, that is, the struggling self seeking renewal. The limitations of the study in conjunction with future directions, and the contributions of the study are also discussed. Specifically, the data analysis of the present study is located and compared with theoretical and research perspectives on self and CFS. Further, the narrative of self is discussed with reference to extant narrative research. Specific attention is given to the suffering of people with CFS and the moral status of CFS. In conclusion, the ongoing struggle of the CFS illness experience is described.

Overview of the Illness Experience

The participants described their past and present subjective, qualitative, and everyday-existence of living with CFS and the struggle that entailed. Two narratives operated concurrently to articulate the illness experience of CFS, that is, the illness biographies and the narrative of self. The illness biographies encompassed the stories of symptoms and the course of the condition, while the primary narrative was the one of self that included the effects of the threats associated with CFS and the responses. The effects of these threats on the participants manifested in the Violated Self, with diminished identity, lost self and social disappearance. Participants responded with the Guardian and the Reconstructing Responses.

The narratives were bridged by the threats to self. That is, the illness biographies were accompanied by threats of disruption related to chronic illness and by threats of invalidation that arose from CFS as a contested condition. In turn, these threats provided the basis and impetus to the struggling self seeking renewal described in the narrative of self. It was the need to decrease the struggle and violation, and reclaim and renew aspects of self that prompted first the Guardian Response and later the Reconstructing Response. Unlike violation and guardianship, which were constant, the Reconstructing Response was not always present. It was both more difficult to
implement and, when threats increased, to maintain. There was fluidity to the struggling self, with the strengths of the Violated Self, the Guardian Response and the Reconstructing Response varying according to circumstances. At any point in time, there was a dominant presence, that is, the violation or either of the responses was strongest, with the other(s) operating to lesser degrees.

In sum, the illness biographies gave rise to the threats, and the threats gave rise to the struggling self seeking renewal described in the narrative of self. It was these three components: the illness biographies; the threats; and the narrative of self that constituted the key theoretical/structural characteristics of the illness experience of CFS.

Before examining the data analysis with reference to other research, the limits and future directions, and contributions of the study are described.

**Limitations of the Study and Future Directions**
Interpretation of the analysis and conclusions is best served in this project by understanding the limitations of the study. Firstly, participants were culturally and ethnically homogenous. The construct of self, the values attached to self, and dimensions and perceptions of self are embedded within ethnic and cultural expectations and constraints. Western cultures, for example, emphasise the value of the individual within society, stress the importance of personal responsibility and independence, and promote the rights of the individual. Other cultures variously emphasise the value of the group, stress the importance of collective responsibility and mutuality, and seek to maintain group order. Such different perspectives influence understandings of self, and consequently, are likely to affect experiences of self within the illness context. Further, this cultural distinction is broad and general, and within each are to be found many and various ethnic and cultural backgrounds. The participants of the present study were of Caucasian origin and Western culture, and thus, their experiences of self are located within that ethnic and cultural background. A more ethnically and culturally diverse group may have generated different outcomes.
Most of the participants had been ill for many years, with only one participant affected for less than five years. That is, the participants represented that group within the CFS population whose condition is intransigent. Consequently, the struggling self seeking renewal may, or may not, be relevant to people with CFS whose condition improves more rapidly or for those in the early stages of the condition. It is therefore unclear if the Reconstructing Response occurs when people improve relatively quickly or if it is more likely among individuals affected for many years. Violation may be qualitatively different for people who improve relatively quickly. The inclusion in the present study of the recovered participants (who were less affected) suggests that the process of the struggling self seeking renewal is of relevance across the spectrum of severity. Nevertheless, there are likely to be experiential differences and nuances among people with CFS, particularly given the likelihood that CFS consists of subgroups. Further, participants were formally interviewed only once, and so their recollections were restricted to a single point in time. An additional interview might have elicited a different perspective, more information, or further support to previous recollections. The chronicity of the condition and the fluctuating nature of violation, guardianship and reconstruction would be ideally investigated with longitudinal studies that have the ability to track changes over time.

The extensive invalidation and consequent suffering reported by the participants requires a specific research focus, including factors that mediate invalidation and structural or institutional strategies that protect individuals against invalidation. Given that invalidation arises from other people, research into the perceptions of others about CFS and about people who are ill with CFS would be beneficial. Specifically, research addressing the perceptions of invalidating others is needed, such as the sources of their invalidating perceptions, their awareness of the effects of invalidation, and the aspects of CFS that foster invalidation. Potential differential effects of invalidation arising from various relationships, such as medical practitioners, family, and generalised others, are worthy of exploration. Additionally, the findings related to the recovered participants suggest the need for further investigation, notably aspects that may have contributed to their recovery and the ongoing impact of CFS in their lives. Finally, the thoughts of suicide (and in one
case, an attempt) reported by the participants is of significant concern and requires investigation, particularly given the absence of research into suicide and CFS.

**Contributions of the Study**

Despite the limitations, the study has contributed to the CFS research base with both original and corroborative findings. The study addresses a number of neglected areas of CFS research, that is, the subjective world of CFS, the insider perspective, and the experiences of self-with-CFS. There has been comparatively little qualitative work among the predominance of quantitative studies, and that which had been done has frequently focused on specific aspects, such as diagnosis. In contrast, the present study took into account the participants’ entire CFS experience, from onset of symptoms until recovery. Given the many years of participant illness this provided a long term-trajectory of CFS, its effects, and the responses of those affected. Further, apart from epidemiology studies, experiences of recovery have not previously been addressed.

The illness biographies provide a new perspective and understanding of the symptomatic experiences of CFS, and the multitude and complexity of threats identified and described in the study have only been partially addressed by previous research. Experiences of self have not been a research focus, and the theory of the **process of the struggling self seeking renewal** is a fresh contribution to the CFS research. By addressing the struggles, violation, suffering, responses, and positive outcomes, the analysis reflects the complexity and multifaceted nature of the CFS illness experience, with specific reference to self. With a few exceptions (for example, Morse, 1997), most studies of the chronically ill do not identify the strategies used to maintain the integrity of self. Nor has there been extensive exploration into how people with CFS respond to or cope with the condition. The present study, in articulating the Guardian and Reconstructing Responses and addressing these gaps, makes a unique contribution to the CFS research.

The delineation and articulation of experiences of self and of the subjective worlds associated with CFS provides insight into the particular and potentially unique effects of CFS on the person. Furthermore, CFS is experienced within the self, it is
the embodied phenomena where effects and consequences of CFS are manifested and felt, and where ways of coping originate. Therefore, knowledge regarding experiences of self associated with CFS provide a contextual basis for understanding and interpreting other CFS research. As a consequence, the present study articulates new knowledge while providing a different prism for interpreting other related CFS findings.

This study does not present the only possible account of the CFS illness experience, and the process of data analysis is not one of extracting “the truth”. Rather, a grounded theory approach builds a construction of accumulated and collective experience, in conjunction with maintaining the essence of individual experience. As such, this study is a contribution to the “continuing research conversation” (Schou & Hewison, 1998, p. 302). Finally, to conclude this study and place the data analysis within the context of the “research conversation”, the findings and their relationships with extant research is discussed.

**Theoretical and Research Perspectives on Self and CFS**

Theoretical and research exploration of self and its constructs is longstanding and crosses numerous disciplines. To better understand and evaluate the data analysis of the present study, the findings are located within and compared to the extant knowledge base on self. Firstly, the process of renewal described in the present study is consistent with the general trend of adaptation and regeneration of self reported in the literature on chronic illness. While there has been little work on CFS and self, aspects of the Violated Self, and to a lesser extent some strategies of the Guardian and Reconstructing Responses, have been supported by previous research. Secondly, the participants held a complex understanding of self that they perceived as both singular and plural in nature. That is, they experienced a core self and multiple selves. Additionally, CFS was associated with changes to self and movement between violation, guardianship (retrieval of self) and reconstruction (renewal of self). Thirdly, comparison and interpretation were important for self-definition, and different constructs of reality between participants and others that functioned to invalidate participants was associated with conflict. These points are addressed separately.
In the present study, the theory of the struggling self seeking renewal essentially describes a process of ongoing adaptation to the effects of CFS, and there is a substantial body of work that, in various ways, describes this process of damage, repair and regeneration. For example, chronically ill people have been described as “transcending the self” (Lindsey, 1996, p. 465) or as “regaining a valued self” (Swanson & Chenitz, 1993, p.270), and as developing a “reformulated self” (Morse & Carter 1996, p. 43), or a “redefinition of self” (Anderson, 1991, p. 712). Common to these studies are the findings that chronic illness has negative effects on perceptions of self and that in response, the self adapts to the changes and develops different and positive qualities. Additionally, although some of these studies are presented as stage theories, none found an exclusively linear progression but reported movement between stages or themes depending on changed circumstances. The data in the present project are consistent with, and add weight to, these common findings of the wider research.

There is limited research on experiences of illness and self among people with CFS, and therefore little extant knowledge within which to locate the present study. The CFS research has not focused on the subjective picture, such as the illness experience, or on exploring the macro and micro effects and responses from the insider and personal perspective. Therefore, comparison of similarities and differences with other CFS research involves components of findings rather than broad theoretical propositions or constructs. For example, Ware (1993) described the social course of CFS as a process of marginalisation and resistance strategies. Marginalisation included role constriction, delegitimation, impoverishment and social isolation, and reflected some of the threats of disruption and invalidation identified in the present study. In other words, while some aspects of the struggling self seeking renewal have been articulated in the CFS research, other aspects and the process, complexity and integration of that experience have not been previously described.

In particular, there was support for the Violation of Self. Van Houdenhove et al. (2002), in a comparative study, found that people recently diagnosed with CFS were
overwhelmed by daily problems and emotional distress, and focused on dissatisfaction with themselves, feelings of insecurity and lack of social recognition. These characteristics were similarly described in the Violated Self. Tuck and Human (1998, p. 16) described the experience of living with CFS as “being in the illness”, “life’s contrast before and after CFS”, and “living with symptoms of CFS”. These categories were consistent with aspects of the illness biographies and the Violated Self. Specifically, “life’s contrast” with its distinction between “life-before-CFS” and “life-with-CFS” mirrored the self-discrepancies and temporal disruptions found by the present study. Consistent with the experiences of the Violated Self, Weinberg et al. (1994) reported that participants regarded the public stereotype of CFS as negative, identified themselves in accordance with their negative perceptions, and believed they had acquired characteristics that they disliked in other people. Weinberg et al. (1994) also found, in accordance with the self-discrepancies of the Violated Self, that participants attached importance to their pre-diagnostic state and ideal state, and little to their present state. Furthermore, the research on functional impairment and quality of life described in Chapter 2 supported the findings of violation.

The research on the responses of people to the effects of CFS is limited and articulation of the Guardian Response and Reconstructing Response is not found in the CFS literature. However, there were consistencies between the Reconstructing Response and, to a lesser extent, the Guardian Response with specific and individual characteristics and strategies reported in the literature (and discussed in Chapters 8 and 9). For example, the resistance strategies described by Ware (1999, p. 305) of “preserving the lifeworld” (“cutting corners and “passing”) and “re-making the lifeworld” (“downshifting”) were consistent with the strategies of living with limits (Guardian Response) and downgrading expectations (Reconstructing Response). Further, Ware reported that while a significant proportion of participants had experienced positive outcomes and found new meanings and ways of living, another group had not experienced a positive transformation but reported distress and profound losses. In terms of the present theory, the two positions reported by Ware reflect the Reconstructing Response and the Violated Response, with participants evidencing different points in the struggle for self-renewal.
Theoretically, conceptually, and as a lived experience, there is complexity to the construct of self. Theorists have distinguished types of self-representations, for example, core and central versus peripheral self; past, present or future self; or actual versus possible selves (Markus & Wurf, 1987). Participants in the present study also used complex self-representations. The construct of the core self found in the participants’ descriptions of the illness experience was crucial to their perceptions of self and was related to, and reflected, the process of adaptation. Prior to CFS the core self had been experienced as stable and largely predictable. CFS transgressed that stability of self and consequently adaptation was required. That is, the Violated Self perceived the core self as unpredictable with negative changes, while the more adaptive Reconstructing Response viewed the core as more stable and including changes that were positive. Further, consistent with the complexity of self and in addition to the singular nature of the core, the participants perceived self as encompassing plurality. The constructs of a core self, known-self, self-with-CFS and self in the past, present and future inferred that participants held multiple constructs of self. Based on clinical practice with CFS patients, Berger (1993) similarly used the multiple constructs of the nuclear (core) and peripheral selves to explain the experiences of people with CFS. Berger proposed that the functional impairment of CFS limited the ability to move among peripheral selves, so that the sick peripheral self became the stable subjectivity while the nuclear self was denied sustenance. The participants in the present study, within the illness biographies and Violation of Self, articulated the existence of a peripheral sick self that was a stable (and sometimes dominant) experience. While the Guardian Response, and more notably the Reconstructing Response, rendered the sick-self further into the background, there nevertheless, to varying degrees, remained a strong presence.

There are arguments against the notion of multiple selves based on the premise that acceptance of multiple selves would require a regress of selves to a presiding and overarching self (for example, Bandura 1997). Certainly participants spoke of a core, real, authentic, or true self but there was little to indicate that this primacy represented a presiding or master self. Rather, the multiple selves described by the participants co-existed with the core self to comprise the construct of self. The
numerous distinctions between real self and not real, past present and future, possible selves, lost selves and dormant selves were reflections of the complex constructs held by the participants. Ultimately, participants described an experience of self and selves.

Perceptions of the participants regarding core and multiple selves reflected both the stability and fluidity of self, which is essentially an emergent structure (Charmaz, 1987), arising from reflexivity, social interactions, and evaluations (Mead, 1934). The malleability of self was also reflected in the changing self and by the effects of altered conditions. This fluidity is consistent with a premise of symbolic interactionism, that is, that the self is a temporal process of evolving and becoming rather than static and fixed (Bowers, 1988). Specifically, the process of the struggling self seeking renewal was not a linear progression but one of flux and change, with violation, guardianship or reconstruction coming to the fore or fading to the background. The Reconstructing Response, for example, was not experienced as an end point or as a sustained response but required ongoing intention and attention. However, when participants were able to predominantly enact the Reconstructing Response, they experienced a greater stability of self. In practice, participants found different elements of the Reconstructing Response more sustainable than others (such as maintaining a cognitive shift or a positive focus), thus contributing to the changing perceptions of self and to the struggle.

The analysis indicated that the process of comparison and the beliefs of the participants about how others perceived them were crucial to the experiences of self and illness. The role of comparison and interpretation and the importance of the “other” to perceptions of self have long been recognised and are major tenets of symbolic interactionism. Mead (1934), a major theorist of symbolic interactionism, considered the self to be essentially a social structure arising from social experience, and proposed that internalised interactions function as standards for evaluating personal behaviour regardless of the presence or absence of others. The “other” was both individual and general, with the “generalized other” signifying the attitudes of the sociocultural environment. Further, a main premise of symbolic interactionism is that actions are interpreted, and these interpretations provide a means for acting.
towards one another (Blumer, 1978). As the theoretical perspective has developed, symbolic interactionism has stressed the interrelationship between the person’s self-concept, the person’s perceptions of others’ attitudes and responses, the actual attitudes and responses of others, and the person’s behaviour (Kinch, 1963).

The relationships between self-perceptions, comparisons, interpretations and interactions are of particular concern given the wide-ranging threats of invalidation by others that participants experienced. Consistent with a symbolic interactionist approach, invalidation arose from interactions between participants, individuals and generalised others, occurred within a social context and involved discordant interpretations regarding the participants, their needs, behaviour and beliefs. The images that other people had of the participants (or the participants’ perceptions of the images) had changed in response to CFS and these images did not initially match the self-representations of the participants. For example, participants did not believe themselves to be lazy or neurotic despite the overt or covert criticisms of others. However, with continuing and extensive invalidation, participants, to varying extents, assumed the doubts and critical judgements of others as evidenced in the Violated Self (and as similarly reported in Weinberg et al., 1994). That is, the interpretations of others became the interpretations of self and as Charmaz (1999) has noted, internalised negative definitions of self are difficult to change because they are assumed into self. (It should be noted that the rejection of the negative interpretations of others found in the Reconstructing Response is also consistent with symbolic interactionism because the crucial role of social experience to perceptions of self, although interpreted differently, remained. That is, the interpretations of others were rejected rather than accepted, but in being actively rejected were still exerting influence).

One example of the strength of the interpretations of others on the self-perceptions of the participants was found in the experience of stigma. Research indicates that some individuals or groups exposed to stigma reject its negative impact and maintain feelings of acceptability despite the stigmatising perceptions of others. Essentially, they are protected by a strong sense of identity. An alternative response is for stigmatised individuals to assume the negative perceptions of others and evaluate
their attributes as undesirable (Lubkin, 1990). In the present study, the second response of assuming undesirable attributes was found to occur within the Violated Self (and similarly reported in Weinberg et al., 1994). It was only in the Reconstructing Response, when identity became stronger, that the stigmatising perceptions of others were rejected, and for most, that rejection was partial and intermittent rather than continuous. Further, while research suggests that a person can experience stigma without being stigmatised (that is, felt stigma does not require enacted stigma, for example, Scambler & Hopkins, 1986) the present study found both enacted and felt stigma to be of significance. Participants reported extensive episodes of enacted stigma (as was also reported by Asbring & Narvanen, 2002), both before and after diagnosis, in addition to felt stigma. Importantly, felt stigma remained despite recovery, suggesting the powerful and ongoing effects of CFS.

Different interpretations are the basis for different reality constructs. Just as the interpretations of participants and others (as interpreted/perceived by the participants) were often discordant, so were there differences in constructs of reality. According to symbolic interactionism, when people hold different constructions of reality about a situation, conflicts and barriers result (Blumer, 1978). Again, this was clearly evidenced in the threats of invalidation, where the constructs that participants and others each brought to their encounters were commonly at odds. For example, the medical practitioners’ construct of organic disease did not necessarily accommodate the non-descriptive symptoms, the causal void or the absence of a diagnostic test or clinical findings, thus prompting psychiatric interpretation. In contrast, the participants’ experience of the symptoms was congruent with their personal construct of organic disease and the absence of a cause or diagnostic test was interpreted as a function of medical limitation. Consequently, different constructs were brought to the medical encounter, with (some) medical practitioners constructing a psychiatric reality and participants constructing a physical reality for the symptoms. In these instances the possibility for a shared reality was remote. Similarly, the participants’ construct of fatigue was markedly different than that held by others. The reality of the participants’ fatigue was of much greater consequence to quality of life than the reality of fatigue for others, when a few early nights were
sufficient to make a difference. In sum, interactions of invalidation were typified by a clash of realities.

A theoretical approach to self provides one perspective for discussing the struggle of self seeking renewal reported in the present study. Additionally, because the participants’ experiences of illness and self were presented as stories, the analysis is also discussed from the perspective of the narrative.

The Narrative of Self
The narrative of self was a story of struggle that involved suffering. The suffering of CFS was longstanding and at various times, intense and existential in nature. The responses of guardianship and reconstruction lessened suffering but did not eliminate it, and its presence both diminished and developed self. The contested nature of CFS left participants with unacknowledged and unsanctioned suffering. Further, participants believed that their moral standing was disputed and that they lacked legitimate moral status. This lack of moral credibility was demonstrated to the participants by the disbelief of others regarding the participants’ reality, including their experiences of suffering. It was difficult for participants to make sense of their struggle and suffering, and the narrative of self was also a narrative of reconstruction. Each of these aspects is discussed below.

The narrative of self was a story of struggle that encompassed past, present and future, and that changed in intensity and focus. The struggle and the damage to self was most keenly felt in the Violated Self, and while all the participants still experienced degrees of violation, it was hoped that the Violated Self as the dominant and primary experience of being-in-the-world was past. Participants had responded to the violation with guardianship and reconstruction, and the struggle became one of reclaiming and renewing self. In a general sense, the struggle of self was experienced as suffering. Consequently, struggle and suffering were unifying threads to the experience of CFS, and as with struggle, suffering was ongoing and constant.
Suffering was a strong theme in the participants’ narratives. Participants rarely referred to suffering directly and yet their stories were replete with episodes of pain, distress and anguish. For most of the participants suffering had been a part of their lives for many years. They could no longer remember the feeling of embodied health, just as they could no longer remember a time when they were not crippled by fatigue. It is at this point of enmeshment according to Charmaz (1999), where memories fail, that the story of suffering becomes the story of self. Suffering at its worse was existential, with participants questioning their purpose, value, identity, integrity and existence. Charmaz (1999) has similarly noted the existential problems associated with suffering, notably problems of identity and continuity of self. Indeed, the depth of the participants’ past suffering was reflected in the findings related to suicide. It may be that when physical and psychological suffering was overwhelming and when that suffering was dismissed as inconsequential or self-generated, then participants were at risk for thoughts of suicide.

Suffering was at its worse when the Violation of Self was dominant, and was progressively lessened by the responses of guardianship and reconstruction. Nevertheless, while the participants were better able to minimise and live with suffering, sources such as pain, fatigue, losses, and invalidation continued to exert influence. Additionally, only a minority of participants operated predominantly out of the Reconstructing Response, and therefore most still experienced, at times, significant suffering related to the Violated Self and to the paradoxical effects of the Guardian Response. The experience of suffering as a pervasive dimension of CFS has been reported in the research and in personal accounts of living with the syndrome (Fennell, 1995; Hyden & Sachs 1998; Ware 1992). It is also reflected in the consistent reports of a poor quality of life among people with CFS (Hardt et al., 2001; van Heck & de Vries, 2002).

Nevertheless, despite its ongoing presence the experience of suffering was altered by the responses. Suffering became a focus for reflection, examination and reinterpretation. Its meaning was transformed to evoke life lessons and wisdom. In other words, within the Reconstructing Response, the relationship between suffering and self transformed into something different. Suffering remained suffering –
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painful, unwanted, distressing - but its effects on self now included enrichment as well as damage. Consistent with the Reconstructing Response, Charmaz (1999) similarly described the changed relationship between self and suffering that followed from altered definitions of illness. In sum, suffering was a painful constant within the Violated Self, somewhat controlled by the Guardian Response, and transformed by the Reconstructing Response. Thus, at different times and to different degrees, suffering led to either the development or diminishment of self.

Suffering was intrapsychic, embodied, social and spiritual. There were many aspects of the participants’ lives that contributed to their suffering. The symptoms and perceptions of embodiment, the unpredictability of their everyday lives, uncertain futures, diagnostic difficulties, the absence of explanations and treatments, functional impairments, and losses all contributed to suffering. However, it was the experiences of invalidation that provided the most powerful and overwhelming source of suffering. Participants suffered because they were doubted, shamed, isolated, stigmatised, ridiculed, and blamed.

Invalidation signified to participants that their suffering was not worthy of intervention or support. As a contested illness, a diagnosis of CFS did not confer a consensus of medical (or social) legitimacy to the symptoms, and consequently, nor was the suffering of CFS legitimated. Participants described complexity in the ways that other people responded to their unsanctioned, ill-defined or discredited suffering. Sometimes it was simply not noticed because of the invisibility of CFS, but more commonly the suffering of CFS was dismissed, disbelieved, minimised, rationalised or mocked. Invalidation of suffering took many forms. For example, the participants did not suffer but were malingering; or they suffered but it was their own fault; or they exaggerated their suffering from normal aches and tiredness; or they were crazy and their suffering was psychiatric. Ultimately, dismissal of suffering was felt as the dismissal of self.

Hyden and Sachs (1998) described the difficulties facing their study participants in making the suffering of CFS legitimate. They reported that following CFS diagnosis and treatment, a relationship with the illness was established and the life world of the
participants was kept intact, and consequently, suffering was no longer an unknown and foreign experience but had become socially and personally legitimate. In contrast, and while not disputing that diagnosis provided some measure of social legitimation, the present study did not find suffering to be diminished by diagnosis. Invalidation was much more than discreditation associated with undiagnosed and unsanctioned symptoms, and many other sources of suffering remained, such as perceptions of causation, attributions of blame, and disbelief. In other words, the label of “CFS” brought its own invalidating experiences. Consistent with the role of invalidation and its wide-ranging sources as explicated in this project, Ware (1992) also found the delegitimation associated with CFS to be crucial to the suffering of CFS, particularly the perception that CFS is not “real”, the humiliation of being trivialised, and the psychosomatic dismissal. In conjunction, the findings suggest that if the suffering of invalidation is to be reduced, the multitude of invalidating sources needs targeting.

The contested nature of CFS produced stories of justification. There was an adversarial theme underlying many of the participants’ illness experiences where participants had to take positions in opposition to medical practitioners, family, work colleagues, friends, or social institutions. Participants had experienced many episodes when others had sought to undermine or disprove their accounts of CFS and the interviews became an opportunity for presenting their “side of the story”, thus the narratives were constructed to justify the perceptions, actions and beliefs of the participants. Essentially, through their narratives the participants sought to justify their moral status, and in doing so, defend self.

The role of narratives in providing a venue for moral tales has been described in the research. Hyden (1995, p. 67) identified the “moral quest” of people with disruptive illness, as they question their way of life and its moral meaning. The moral status desired by the participants in the present study encompassed two related aspects of living with CFS, firstly, that their truth be believed and secondly, that their suffering be acknowledged. These two aspects are addressed below. Without acceptance by others of their truth and suffering participants believed that their moral standing was disputed, their moral claims were rejected and their moral worth was decreased.
The importance of being believed was a consistent and significant thread running through the narratives of the participants. Disbelief was interpreted by participants as a moral judgement of their honesty in which they were rendered untrustworthy and viewed in a way that was in direct opposition to their self-perceptions. Wessely (1997) suggested that the stories told by people with CFS are, in part, moral tales to distinguish themselves from malingerers, and that their explanations are metaphors rather than literal truth, with the centrality of the immune system providing a narrative device and a cultural explanation that preserves self-esteem. Wessely rejected the literal truth of the CFS narrative as told by people with CFS, and in contrast, interpreted CFS as a vehicle for the expression of social concerns and problems. In the present study the participants attributed a causative role to the immune system and stressed their differences from malingerers. In other words, they articulated a CFS narrative, including its literal truth, consistent with that observed by Wessely. They had also experienced disbelief of their “literal truth”, which they believed was interpreted in such a way as to promote explanations of personal inadequacy or psychiatric pathology, as was suggested by Wessely’s conclusion. However, as interpreted by the participants, it was not psychiatric pathology but disbelief (that is, the rejection of their literal truth) and the need to establish moral status that necessitated their telling of a moral tale that distinguished them from malingerers. Typically, it was different interpretations of reality that frequently underpinned the disbelief and the lack of moral status experienced by the participants.

In addition to being believed, the acceptance of their suffering by others was also an important aspect of the participants’ moral claims. Part of the suffering associated with invalidation was its denial of the participants’ moral status. Nor did their suffering elevate the participants’ moral status. Charmaz (1999, p. 368) contextualises suffering as a moral status that confers rights and entitlements, such as “deserving” or “in need”. When suffering is defined as legitimate, status is elevated and worth is ascribed to the person. Charmaz also suggests that suffering presents an opportunity for living the heroic, of emerging victorious from the unbeatable. Participants in the present study imbued their stories with a moral imperative and
were angered or saddened by, or resigned to, the lack of moral status afforded to their suffering. They believed that like other people with (more acceptable) chronic illnesses, they deserved to have their struggle acknowledged and moral status affirmed. Furthermore, in addition to an absence of moral affirmation, the moral status of the participants was actively denigrated. They were subjected to moral judgement, and when others attributed suffering to malingering, psychological dysfunction, or personal failing, the participants’ moral status was decreased. In short, the diagnosis of a contested illness meant they were viewed as morally inferior. And while there was some personal sense of victory, their heroics were unnoticed.

The relationship between moral status and suffering was exemplified by the lack of medical and social care available to participants. This absence of care signified to the participants that they did not possess a moral status that defined them as “deserved” or “in need”. The participants believed they had attempted to fulfil societal expectations by seeking diagnosis and treatment, and in particular by their initial responses of pushing through and trying to live their normal life. That is, they perceived themselves as both “deserved” and “in need”. However, the length of time without a diagnosis and the subsequent labeling with a contested diagnosis left participants in a position of moral ambiguity where their suffering was not sanctioned and their need was not confirmed. They were not located within the medical framework in any meaningful way, and over time, their right to care was disputed. Tang & Anderson (1999) noted that chronic illness is associated with a definition of self-as-patient that is situated in the culture of patienthood. The narratives of the participants did not contain perceptions of themselves as patients, and they lacked a position or status with the culture of medicine. Rather, they described instances and encounters when they were patients, but there was little sense of ongoing care – no course of treatments, rehabilitation, physiotherapy, or occupational therapy, and eventually for most, withdrawal from the medical culture. The intense medical gaze on CFS included little in the way of care for the participants. Experience had indicated to the participants that people with CFS were neither deserving of care or sufficiently in need, and consequently, their suffering was increased and moral status was denied.
The narrative of self was a way for the participants to make sense of their largely unacknowledged suffering and of the turmoil that it had brought to their lives. CFS led to disruption and trauma in which meanings, expectations and personal coherence were lost. Participants had struggled to adapt to its effects, to reestablish a sense of biographical continuity, and to find meaning and a way of life that reflected life values and goals. Adapting to loss and making sense of suffering had entailed changing expected life stories and had required the use of the Guardian Response and the Reconstructing Response. In other words, participants had lost the known-self, and consequently, the process of the struggling self seeking renewal was also a narrative of reconstruction. The importance of narrative reconstruction has been highlighted in the literature. It has been argued that personal narrative facilitates a reconfiguration of identity and meaning (Crossley, 2000), locates illness within the context of a life (Robinson, 1990), and provides an opportunity for reevaluation of life (Charmaz, 1999). Williams (1984) proposes that among ill people, narrative reconstruction is necessary for realigning past- and present-self with society and to reaffirm a sense of purpose.

The narratives told by the participants were complex stories of suffering, loss, adaptation, searching, healing, uncertainty and perseverance. According to the narrative typology proposed by Frank (1998) the participants told stories of chaos and quest. They did not tell a restitution story, the culturally preferred story of becoming ill, receiving treatment, and returning to health. The participants’ illness experiences of CFS had begun as a restitution story, but with the passing of time and the development of cognitive realisation regarding the chronic nature of the condition, the restitution story was relinquished. This relinquishment was sometimes at odds with other people, who maintained belief in the restitution story for the participants and who then interpreted their relinquishment as invalidism or abnormal illness behaviour.

In terms of the present study, the chaos story was consistent with the Violated Self. Frank (1998) describes the chaos story as encompassing the deepest illness, where medical problems proliferate into social problems. Participants in the present study
described a chaotic spiraling and compounding of problems as their physical complaints gave rise to a multitude of undesirable consequences. Frank found that the chaos story lacked a logical ordering of beginning, middle and end, with the story perpetually moving into “and then” contingencies. In the present study, the “and then” contingency was particularly prevalent when participants were discussing medical encounters. There was urgency among participants to share their experiences of medical practice, and it was evident that the contentious nature of the condition and the medical ethos surrounding contested conditions was damaging to participants, contributed to their chaos, and functioned as a barrier to care and legitimation. The chaos story, however, was not restricted to medical encounters but included all aspects of the Violated Self. By its nature the Violated Self was chaos, because this was when the participants were immersed in illness and overwhelmed by its physical, emotional, social, cognitive and spiritual effects. Frank (1998) observed that the chaos story is troubling for western culture and that both professional and lay people pathologise its presence and effects. Frank used the example of depression that is a response to living with chaos, but which is labeled by medicine as clinical pathology. Certainly the participants of the present study stated that their depression, much of which they defined as a response to their losses, had been labeled as psychiatric and subsequently used to support the view that they were mentally ill.

The quest story was consistent with the Reconstructing Response. Illness becomes a quest, where lessons can be learnt and shared and new qualities of self developed. Within the quest story the existence of chaos is still recognised and there is understanding that improvement is always provisional. The quest story reflected a relinquishing of “what I am not and never will be” comparisons. Each of these characteristics was found within the Reconstructing Response. Further, Frank (1998) proposed that the three narratives of restitution, chaos and quest intertwine, with one to the fore and the others as background. These shifts in foreground and background are consistent with the illness experience described in the narrative of self in the present study. Violation, guardianship, and reconstruction were present in different degrees at different times as the conditions and resources of the participants fluctuated.
Within the narrative of self it is the Guardian Response that is of particular interest. With the exception of some of its strategies, it has not emerged in previous studies. Its articulation is a significant finding of the present study. The Guardian Response provided participants with protection at times of vulnerability and risk. Guardianship facilitated the ability of the participants to counter the negative effects of CFS sufficiently enough for the renewal of self via the Reconstructing Response. Further, the Guardian Response indicated that the process of struggling self seeking renewal was multifaceted, and that the damage to self arising from CFS was associated with complex, interactive, and fluctuating responses.

**The Ongoing Struggle of the CFS Illness Experience**

The ability of the participants to reclaim their lives and renew the lost and violated aspects of self does not imply that the struggles of CFS were over. The Reconstructing Response restored quality of life but did not constitute a “happy ending” to the narrative of self. The strength of the Reconstructing Response fluctuated, and participants varied markedly in their ability to access the strategies of reconstruction. The study’s findings of ongoing struggle and complex trajectories are somewhat at odds with recent chronic illness research that has frequently drawn more optimistic conclusions regarding illness experiences. Thorne and Paterson (1998) conducted a meta-study of the qualitative research on chronic illness experiences reported in the last twenty years. They found that from the early 1980s there was a research shift away from the more traditional perspective that focused on suffering and loss towards an examination of the transforming and positive aspects of chronic illness. The authors suggested that researchers have stressed the beneficial and transforming features to the detriment of the “mundane and ordinary features such as pain and despondency” (1998, p. 176). It was further suggested that this focus denied the multifaceted nature of chronic illness and misrepresented its complexity. The present study highlighted the threatening, the mundane, the chaotic, the protective and the transforming aspects of CFS, and thus addressed the complexity of the illness experience.
The illness experience of CFS was multidimensional. The particular temporal and
deci and clear relationships, conditional findings and questions regarding its existence and nature as an autonomous and homogeneous condition place CFS as a uniquely
threatening condition, where the pervasiveness, extent and severity of threats to self are attenuated. Many of these threats are peculiar to the experience of CFS, bound by its emerging nature where medical practitioners and society constantly question its reality, while profoundly real for the people who live with it everyday within an environment tainted by stigma and scepticism. The resulting Violation of Self was largely unacknowledged by others, and consequently, participants yearned for recognition of their subjective experiences. There was isolation at many different levels. Certainly the participants shared the social and relational isolation that is common among those living with chronic illness, but there was an added and significant dimension that remained even after the social re-engagement of the Reconstructing Response, that is, the isolation derived from invalidation. Specifically, they were profoundly isolated from structural, sanctioned medical and sociocultural support. The participants knew they would remain at odds with the medical world until some objective indicator of their illness was found, and they knew that as a consequence, institutional support would be limited. That is, they were isolated from care, support and acknowledgement of their suffering by the contentious nature of CFS.

Participants were left with unique and difficult challenges. How does a person counter self-doubt when medical expertise contradicts embodied experience and personal explanations, when the behaviours that society expects in response to chronic illness worsens the condition, and the behaviours that provide some relief are judged unhealthy, indulgent, hypochondriacal, or as malingering? The responses of guardianship and reconstruction that enabled the participants to reduce their suffering and struggle, and to reclaim and renew self, were crucial. The responses were evidence of adaptation, evolution and ultimately, healing, and they were, along with threats and violation, part of the ongoing and everyday illness experience of CFS. In sum, the present study contributes to the subjective understanding of CFS by examining the illness experience.
As with the recovered participants, I also think of CFS as something that, apart from a few recalcitrant symptoms, is in my past. Yet, I wonder if it is possible to ever fully move beyond the threats of invalidation associated with CFS, even when recovered. A number of months ago, after moving to a new area, I consulted a medical practitioner for a cough that persisted after the upper respiratory tract infection had disappeared. While ill, I had experienced stigma associated with CFS, and therefore, I did not initially disclose my previous history of the syndrome to the medical practitioner. It was during the second visit that I told her of my history. I had re-evaluated my position and decided that sharing only partial information was potentially detrimental to my health. However, upon my disclosure, the medical practitioner stopped discussing possible diagnostic tests and presented to me, without explanation, a prescription for anti-depressants. I was uncertain how the prescribed medication would alleviate the cough, nor was I depressed, and I concluded that somehow, my history of CFS had influenced the prescribed treatment. With feelings of resignation and frustration, I refused the prescription, and it was some weeks before I sought out another medical practitioner. This time I did not draw attention to CFS. The medical practitioner quickly determined the reason for the cough, prescribed a short course of medication, and the cough disappeared. Of course, I cannot be sure that it was my history of CFS that prompted the first medical practitioner to prescribe anti-depressants. But I was left with the recognition that “CFS” is an enduring label that continues to define an individual and influence the ways that other people respond, even when the illness is no longer present.


Hadler, N. M. (1996). If you have to prove you are ill, you can’t get well: The object lesson of fibromyalgia. *Spine, 21*, 2397-2400.


PARTICIPANT BACKGROUND QUESTIONNAIRE

The purpose of this questionnaire is to gather background and demographic information about your experiences of living with Chronic Fatigue Syndrome. Please complete the questionnaire prior to your scheduled interview, or if you prefer, at the time of your interview if you would like assistance.

Please tick the appropriate box (●) and write your answers in the space provided. There are no “right” or “wrong” answers. Some questions may have more than one answer so please tick as many boxes as is appropriate for you. Throughout the questionnaire Chronic Fatigue Syndrome is referred to as CFS.

To ensure anonymity please do not write your name on the questionnaire.

1. What is your age?  ____ yrs ____months

2. What is your sex?  
   • female  
   • male

3. How long do you believe you have had CFS?  ____ yrs ____ months

4. In what year did your doctor diagnose your condition as CFS?
   199__  198__  197__

5. Do you have any other medical conditions?
   • No
   • Yes: Please list ______________________________
6. Which of the following health care workers have you consulted at any time about CFS? (Please include those seen prior to diagnosis. Tick as many boxes as required).

**Doctors:**
- General practitioner
- Immunologist
- Neurologist
- Psychiatrist
- Allergy/Environmental specialist
- CFS specialist (may also belong to one of the above)

**Others:**
- Social worker
- Psychologist or counsellor
- Community nurse
- Physiotherapist
- Dentist
- Dietitian or nutritionist
- Naturopath
- Homoeopath
- Acupuncture practitioner
- Other: ______________________________________

7. Are you a member of a CFS (ME) Society or support group?
- Yes
- No

8. What is (or was most previously) your occupation?

9. What is your current work situation?
- Full-time work
- Part-time work
- Home/parenting duties
- Full-time student
- Part-time student
- Unemployed
- On leave from employment - eg: sick, annual, long-service
- Retired for reasons other than CFS
- Retired due to CFS
10. What is your main source of income?
   - Employment
   - Savings
   - Family/spouse/partner support
   - Welfare/Social security payments
   - Superannuation
   - Other

11. What is your level of completed education?
   - Did not complete high school
   - High school
   - Post-Secondary - College, TAFE
   - Tertiary – University

12. What is your marital status?
   - Single/Never married
   - Married/ De Facto
   - Divorced/Separated

13. Do you live?
   - Alone
   - With your parents
   - With flatmates/friends
   - With your spouse/partner
   - With your spouse/partner and children (child)
   - With your children (child)
   - Other: Please describe: ______________________________

14. Which of the following do you use to maintain contact and social relationships with people who do not live with you?
   - Visit others in their home
   - Participate in social clubs - eg: sport, book
   - Participate in courses/classes - eg: language, craft
   - Participate in social activities with work colleagues
   - Join friends for social activities
   - Friends visit my home
   - Work provides social contact
   - Telephone
   - Fax
   - Internet/Email
   - CFS Support Group

Thank you very much for your time, effort and energy in answering the questionnaire.
Appendix 1b: **Participant Background Questionnaire - Recovered**

Dept. Professional Nursing Studies Faculty of Nursing University of Sydney

**Recollections of Experiences of Self for Adults Recovered from Chronic Fatigue Syndrome**

**PARTICIPANT BACKGROUND QUESTIONNAIRE**

The purpose of this questionnaire is to gather background and demographic information about your recollections and experiences of living with Chronic Fatigue Syndrome. Please complete the questionnaire prior to your scheduled interview, or if you prefer, at the time of your interview if you would like assistance.

Please tick the appropriate box (●) and write your answers in the space provided. There are no “right” or “wrong” answers. Some questions may have more than one answer so please tick as many boxes as is appropriate for you. Throughout the questionnaire Chronic Fatigue Syndrome is referred to as CFS.

To ensure anonymity, please do not write your name on the questionnaire.

---

1. **What is your age ?**
   
   ____ yrs ____ months

2. **What is your sex ?**
   
   • female  • male

3. **For what length of time do you believe you had CFS**
   
   ____ yrs ____ months

4. **In what year did your doctor diagnose your condition as CFS ?**

   199__  198__  197__

   **In what year did you consider yourself mostly recovered?**

   199__  198__  197__

5. **Did you have any other medical conditions at the same time as CFS?**

   • No

   • Yes : Please list __________________________________________

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6. Which of the following health care workers did you consult at any time about CFS? (Please include those seen prior to diagnosis. Tick as many boxes as required).

Doctors:
- General practitioner
- Immunologist
- Neurologist
- Psychiatrist
- Allergy/Environmental specialist
- CFS specialist (may also belong to one of the above)

Others:
- Social worker
- Psychologist or counsellor
- Community nurse
- Physiotherapist
- Dentist
- Dietitian or nutritionist
- Naturopath
- Homoeopath
- Acupuncture practitioner
- Other: ______________________

7. Were (or are) you a member of a CFS (ME) Society or support group?
- Yes
- No

8. What is your occupation? ______________________

9. For most the time you had CFS what was your employment situation?
- Full-time work
- Part-time work
- Home/parenting duties
- Full-time student
- Part-time student
- Unemployed
- On leave from employment - eg: sick, annual, long-service
- Retired for reasons other than CFS
- Retired due to CFS

What is your current work situation?
- Full-time work
- Part-time work
- Home/parenting duties
- Full-time student
- Part-time student
- Unemployed
- On leave from employment - eg: sick, annual, long-service
- Retired for reasons other than CFS
- Retired due to CFS
10. What is your main source of income?

- Employment
- Savings
- Family/spouse/partner support
- Welfare/Social security payments
- Superannuation
- Other

For most of the time you had CFS what was your main source of income?

- Employment
- Savings
- Family/spouse/partner support
- Welfare/Social security payments
- Superannuation
- Other

11. What is your level of completed education?

- Did not complete high school
- High school
- Post-Secondary - College, TAFE
- Tertiary - University

12. What is your marital status?

- Single/Never married
- Married/ De Facto
- Divorced/Separated

13. Do you currently live?

- Alone
- With your parents
- With flatmates/friends
- With your spouse/partner
- With your spouse/partner and children (child)
- With your children (child)
- Other: Please describe: ______________________________

For most of the time you had CFS did you live?

- Alone
- With your parents
- With flatmates/friends
- With your spouse/partner
- With your spouse/partner and children (child)
- With your children (child)
- Other: Please describe: ______________________________
14. Which of the following do you use to maintain contact and social relationships with people who do not live with you?

- Visit others in their home
- Participate in social clubs - eg: sport, book
- Participate in courses/classes - eg: language, craft
- Participate in social activities with work colleagues
- Join friends for social activities
- Friends visit my home
- Work provides social contact
- Telephone
- Fax
- Internet/Email
- CFS Support Group

When you had CFS which of the following did you use of maintain contact and social relationships with people who did not live with you?

- Visit others in their home
- Participate in social clubs - eg: sport, book
- Participate in courses/classes - eg: language, craft
- Participate in social activities with work colleagues
- Join friends for social activities
- Friends visit my home
- Work provides social contact
- Telephone
- Fax
- Internet/Email
- CFS Support Group

Thank you very much for your time, effort and energy in answering the questionnaire.
Appendix 2a: Interview Guide - Affected

Dept. Professional Nursing Studies Faculty of Nursing University of Sydney

The Experiences of Self for Adults Living with Chronic Fatigue Syndrome

INTERVIEW GUIDE

These are the questions you will be asked during your interview session.

1. How did you find out about this study?

2. What are your reasons for joining the study?

3. Before we begin, do you have any concerns you’d like to address?

4. Which symptoms or aspects of CFS have been the most troublesome for you?

5. Please describe how the symptoms of CFS have altered the things you do?

6. How effective do you think you are in dealing with the symptoms of CFS?

7. How does it feel to be in your body now that you have CFS?

8. Would you describe what you were like before you developed CFS?

9. How would you describe yourself at this point in time?

10. Would you describe what it is like living with CFS?

11. Has CFS affected the different roles and responsibilities that you have?
    11.1 Would you please describe these effects?

12. Generally, how well do you think you manage living with CFS?

13. Are you presently able to manage the condition well enough to satisfy yourself?
    13.1 How has this changed since you were first diagnosed?

14. Has CFS affected your interactions or relationships with people generally?
    14.1 How has CFS affected your interactions or relationships?
15. Would you describe your overall experiences with health practitioners?
   15.1 Could you give an example of a positive, helpful experience?
   15.2 Could you give an example of an unpleasant, unhelpful experience?

16. Has CFS altered your relationships with work colleagues?
   16.1 How has CFS altered your working relationships?

17. Have your friendships with others altered since you developed CFS?
   17.1 Would you please describe what you mean?

18. Has CFS affected your relationships with the people closest to you?
   18.1 Could you describe the nature of these relationships, for example, parents, partner, siblings?
   18.2 How has CFS affected your closest and most important relationships?

19. How has CFS changed your life?

20. Are there aspects about your life before CFS that you now miss?
   20.1 Would you please describe these aspects?

21. Have your expectations of yourself changed since you developed CFS?
   21.1 Would you please describe these changes?

22. Has CFS changed the way you feel about yourself?
   22.1 Would you please describe these changes?

23. When you think of the future, what do you see and how do you see yourself?

24. Is there anything else that you consider important and would like to discuss?
Appendix 2b: Interview Guide - Recovered

Dept. Professional Nursing Studies Faculty of Nursing University of Sydney

Reollections of Experiences of Self for Adults Recovered from Chronic Fatigue Syndrome

INTERVIEW GUIDE

These are the questions you will be asked during the interview.

1. How did you find out about this study?

2. What are your reasons for joining the study?

3. Before we begin, do you have any concerns you’d like to address?

4. Which symptoms or aspects of CFS were the most troublesome for you?

5. Please describe how the symptoms of CFS altered the things you did?

6. How effective do you think you were in dealing with the symptoms of CFS?

7. How did it feel to be in your body when you had CFS?

8. Would you describe what you were like before you developed CFS?

9. How would you describe yourself at this point in time?

10. Would you describe what it was like living with CFS?

11. Did CFS affect your different roles and responsibilities?
   11.1 Would you please describe these effects?

12. Generally, how well do you think you managed living with CFS?

13. Were you able to manage the condition well enough to satisfy yourself?
   13.1 Did this change from the time you were first diagnosed?

14. Did CFS affect your interactions or relationships with people generally?
   14.1 How did CFS affect your interactions or relationships?
15. Would you describe your overall experiences with health practitioners?
   15.1 Could you give an example of a positive, helpful experience?
   15.2 Could you give an example of an unpleasant, unhelpful experience?

16. Did CFS alter your relationships with work colleagues?
   16.1 How did CFS alter your working relationships?

17. Did your friendships with others alter when you developed CFS?
   17.1 Would you please describe what you mean?

18. Did CFS affect your relationships with the people closest to you?
   18.1 Could you describe the nature of these relationships, for example, parents, partner, siblings?
   18.2 How did CFS affect your closest and most important relationships?

19. How did CFS change your life?

20. Were there aspects about your life before CFS that you missed while ill?
   20.1 Would you please describe these aspects?

21. Did your expectations of yourself change when you developed CFS?
   21.1 Would you please describe these changes?

22. Has CFS changed the way you feel about yourself now?
   22.1 Would you please describe these changes?

23. What do you consider to be the most important influences for your improved health?

24. When you think of the future, what do you see and how do you see yourself?

25. Is there anything else that you consider important and would like to discuss?
Appendix 3: Consent Form

The University of Sydney

Department of Professional Nursing Studies
Faculty of Nursing
South Eastern Sydney Area Health Service - Eastern Section

Experiences of Self for Adults Living with or Recovered from Chronic Fatigue Syndrome

PARTICIPANT CONSENT FORM

Investigator: Michele Travers  Telephone: (02) 93510605 (Business)
mtravers@nursing.usyd.edu.au  0410 653357 (Mobile)
Chief Investigator: Dr Lydia Bennett  (02) 93510555

The aim of this study is to examine the experiences of “self” for people living with Chronic Fatigue Syndrome and for people previously affected by the syndrome. The study examines the effects and relationships of Chronic Fatigue Syndrome with feelings, behaviours and attitudes about self. As a participant I understand that participants in this study are required to have a current or past diagnosis of Chronic Fatigue Syndrome by a doctor and the ability to read and speak English. The study and its general purpose and methods have been explained to me. All procedures will be explained to me before being carried out by the investigator. I understand that I am free to ask questions at any time.

I understand that the study will involve interviews of approximately 1 hour and 30 minutes and will be audio-recorded. All information provided would be treated as anonymous and strictly confidential. Audio-tapes will be kept in locked cabinets at the University with all identifying information such as name and address removed. After completion of the study data files and audiotapes will be securely stored for 5 years. After that time audio-tapes will be erased and files shredded.

Refusal to participate or withdrawal at any time will not affect my treatment or medical care in any way. I understand that the study will not necessarily benefit me directly in any way and I am volunteering to be involved in this study without any pressure or coercion. I am aware of the procedures involved in the study and of any inconvenience, risks or possible discomfort involved. I understand that I can withdraw at any time.

I have read and understood this Consent Form and the Participant Information Statement and the risks and purposes of the study. I agree to participate in this research study.

Name: ___________________________________________________
Address: ___________________________________________________
Signature: _________________________________________________

Name of witness: ____________________________________________
Signature of witness: _________________________________________
Date: ______________________

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Appendix 4: Participant Information Sheet

The University of Sydney

Department of Professional Nursing Studies
Faculty of Nursing

Experiences of Self for Adults Living with or Recovered from Chronic Fatigue Syndrome

PARTICIPANT INFORMATION STATEMENT

Date

Dear
Thank you for agreeing to participate in this study. To participate in this study it is necessary for you to have a current or past diagnosis by a doctor of Chronic Fatigue Syndrome and the ability to read and speak English. Please find enclosed a copy of the Participant Background Questionnaire, the Interview Questions I will be asking you and the Consent Form for agreement to participate in the study. I have enclosed these for your information.

The consent form is your agreement to be involved in the study, however you are free to withdraw at any time if you so desire. Please do not sign the form until our interview session. All information provided would be treated as anonymous and strictly confidential. Participation in the study will not necessarily benefit you directly.

The Participant Background Questionnaire will provide general information necessary to the study. It will take about 5-10 minutes to complete. Please complete this questionnaire before the interview session if you are able to. If you are not, I will assist you to complete it at the time of the interview session.

The interview questions have been included to provide you with an opportunity to review the questions, think about any matters you would like to check with me during our session, or to think about your answers. Interviews will take approximately 1 hour and 30 minutes and will be audio-recorded. Audiotapes will be kept at the University in locked cabinets with all identifying information such as name and address removed. After completion of the study data files and audiotapes will be securely stored for 5 years. After that time audiotapes will be erased and files shredded.

I understand that you may become fatigued during the interview. If you wish to stop at any time please let me know and we can finish the session at a later date. Refusal to participate or withdrawal at any time will not affect your treatment or medical care in any way. Any person with concerns or complaints about the conduct of a research study can contact the Manager of Ethics and Biosafety Administration, University of Sydney, on (02) 9351 4811.

I look forward to our interview session to be held _____________________________. Please contact me in the meantime if you wish any clarification. I thank you for your time and energy, and appreciate your assistance in this study.

Yours sincerely,

Michele Travers
Senior Lecturer, (02) 9351 0605

Dr Lydia Bennett
Senior Lecturer, (02) 9351 0555