It's so strange when you stay sick:
The challenge of chronic fatigue syndrome

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This thesis is original work. The investigations have not been part of any joint study with other researchers.

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Abstract

Chronic Fatigue Syndrome (CFS) remains poorly understood, despite the recent definition of the syndrome by the United States Centers for Disease Control (Holmes et al, 1988), and the growing biomedical and public interest in it. This thesis explores the nature of the condition, its explanations, effects and management. It also highlights important concerns for people who have chronic conditions which medical science has yet to understand or recognise, and discusses doctors' dilemmas about appropriate care for such conditions.

The research relies principally on information gathered from interviews over a two year period with fifty people who have been given a diagnosis of CFS. The related issue of appropriate care is examined from the perspective of people with CFS, but is complemented by the views of twenty doctors.

Drawing on the experiences of people with CFS, I present an account of the illness, beginning with a detailed description of the symptoms over time and their effects on people's lives. This natural history of the condition also reflects people's concerns about their problem. It shows how the erratic and sometimes peculiar symptoms brought feelings of uncertainty and estrangement, feelings that became increasingly pronounced as their health deteriorated.

The account then broadens from a description of the illness and its pervasive effects to encompass the impact of social and medical responses on people as they sought help and advice about their condition. Although viruses were triggers in people's initial deterioration into poor health, the development appears to have been influenced by the medical uncertainties about the condition. The decline into poorer health was moderated when people had understanding and a meaningful framework for interpreting the problems. Over time, two related contrasts emerged. There was a contrast between the long term health and sense of well being of those people whose doctors had been consistently respectful, and the majority of participants who received responses that they felt disregarded their symptoms. Secondly, there was a contrast between people's
deteriorating health prior to diagnosis, and their health afterwards. As the majority of doctors in the study expressed reservations about the value of providing people with a diagnosis for this condition, these findings about the changes associated with diagnosis have important implications for the management and care of this and other conditions which create uncertainty.

The study also suggests that individuals who have developed this illness have characteristics in common. They have been active, productive and conscientious people. Their style of coping with illness has been one of active denial and defiance, characterised by an early and often enduring determination to ignore symptoms and overcome difficulties. In combination with demanding life circumstances, this style of coping with illness and with medical doubt seems to be implicated in the onset and the development of the condition. Many individuals began to question this coping style only after they had a diagnosis. The changes that occurred in people's health over time seemed to be related to their ability to relinquish this coping style. On the basis of this finding, I argue that management of CFS rests on early identification of the problem and change in the individual's style of coping.
Section I:

Introduction and background

Chronic fatigue syndrome can leave its victims severely disabled and can persist for many years, usually during the patient's childhood or early adulthood. This syndrome is not the fatigue so commonly reported in community surveys and primary health care settings (Kendall, 1991). It has become one of the most common medical syndromes in the world. The fatigue, however, is not the only symptom. Other symptoms include muscle pain, aches, and pain in the joints and muscles. These symptoms can persist for years, and they can be debilitating. The condition has only recently been defined and recognized by the United States Center for Disease Control (Hoover et al., 1992) but similar illnesses have been described for at least three decades under many terms, including multisystemic, myofascial pain syndromes (MPS). During the past decade, when these symptoms occur, they have been classified as chronic fatigue syndrome (CFS), chronic fatigue/myalgic encephalomyelitis (ME/CFS), or post-viral syndrome (PVS).
Chapter 1

The challenge of chronic fatigue syndrome

Chronic illness presents a challenge at several levels. Individuals and their families face the challenge of living with its physical, psychological and social consequences. Providers of health services and designers of health policies confront the challenge of developing appropriate ways not only to delay mortality, but also 'to delay disability, to alleviate the toll of suffering and ease the burden of disability' (Rotherberg and Koplan, 1990). In this thesis, my interest in these challenges lies not so much with the structural constraints or strategies relevant to social and health policies, but more with the issues faced by individuals and those who care for them. In particular, I am interested in how people who become chronically ill with a non-specific debilitating condition, chronic fatigue syndrome (CFS), come to understand and live their changed lives, and how their burden of suffering and disability is eased or exacerbated.

Chronic fatigue syndrome can leave its sufferers severely affected, sometimes for many years, usually during their youth and early adulthood. This syndrome is not the fatigue so commonly reported in community surveys and primary health care services (Kendell, 1991). CFS is distinguished from common fatigue because it has other diverse symptoms. As well, the fatigue of CFS is effort-induced. Even very small amounts of exercise or mental effort can cause major disruption to a person's daily activities for several hours or days (Wakefield et al, 1990). This condition has only recently been named and defined by the United States Centers for Disease Control (Holmes et al, 1988) but similar illnesses have been described for at least three centuries, under many names including neurasthenia and myalgic encephalomyelitis (ME). During the last decade when there appears to have been a dramatic increase in its occurrence (Bell, 1991), the illness has also been called chronic Epstein-Barr syndrome (CEBS), chronic fatigue/immune dysfunction syndrome (CFIDS) or post-viral syndrome (PVS).

As the diversity of names suggests, the illness has been poorly understood. Efforts to understand the condition have also been the subject of
controversy. Nevertheless, over the last five years CFS has become a widely discussed public health issue and there has been a dramatic increase in biomedical research. Much of that research has been fragmented but immunological explanations for the condition are currently being given some prominence. As yet though, there are no scientifically established diagnostic tests, treatments or procedures for its management.

In this context, CFS presents individuals and those who care for them with a broad challenge. Not only do they have to encounter the usual difficulties associated with a chronic illness, they also have to face those problems when they have a condition which is poorly understood. Because the condition has only recently started to achieve medical recognition, many individuals have been without a specific framework for interpreting and responding to their disability. Yet like many other chronic illnesses, this one is far reaching in its effects. In addition to creating times of medical crisis or ongoing discomforts, CFS can significantly alter people’s lives. In one epidemiological study (Lloyd et al, 1990a), over 40% of people were completely unable to participate in schoolwork, employment or housework.

It seems likely that this condition takes a toll on a large number of individuals as well as being costly to the community. There are some difficulties in providing a reliable estimate of the numbers of people who have this illness (see chapter two), but current estimates of its prevalence range between 40 per 100,000 in Australia (Lloyd et al, 1990a) and 127 per 100,000 in New Zealand (Murdoch, 1987). It has been conservatively estimated that the financial burden of the condition on the individual and the Australian government through direct and indirect costs is at least $59 million per year (Lloyd and Pender, 1992).

**Origins and purpose of this study**

My interest in this condition arose some two years before its definition by the Centers for Disease Control. At that time a friend and professional colleague was becoming ill. She had caught 'the flu' while travelling in Europe and had not completely recovered by the time she returned to
Australia and work. Over the next four years, I watched as she became sicker, yet doctors with whom she worked and doctors she consulted had no adequate explanations for her declining health. It was a particularly tense time in our workplace, a busy government-funded counselling service, so sometimes her illness was dismissed as 'stress'. As a good psychologist, my friend knew the value of exercise, meditation and other stress-management techniques, but her conscientious efforts to manage her symptoms in these ways made little difference. Financial pressures and personal commitment kept her at work during that time. Eventually she became extremely ill, unable to maintain her workload. She had diverse symptoms including pain in the joints and limbs, gastrointestinal problems, fatigue in combination with extreme agitation, and severe headaches. The symptoms that particularly worried and intrigued me were her memory lapses, language difficulties and cognition problems. Her short term memory became unreliable. Her use of words was sometimes peculiar; she would use a word that was the opposite of the one that she clearly meant to use, as in using the word 'black' to describe something that was 'white'. She could be driving a car and suddenly be unsure where she was, unsure of her right and left hand, unsure about the appropriate response to traffic lights. Eventually, in 1989, she was told by two doctors that she had ME. Coincidentally, another friend followed a similar but shorter path to the same diagnosis during the preceding year.

I could see what this illness had done to my friends' lives. I knew what their illness had meant to me as their friend. However, I was unclear how much of their distress and the bizarre symptoms were part of this illness or whether they reflected their uncertainty and fears about feeling so ill and not knowing what was wrong. I read what I could about the illness, only to discover that the more I read the more confusing the picture became.

Accordingly, I had four aims when I began this study. First, I wanted to develop a coherent picture of this illness, its onset and changing patterns over time. The descriptions I had read differed widely. The condition was said to follow from acute viral attacks though there was disagreement between American and British researchers about whether the virus was Epstein-Barr (the virus responsible for glandular fever) or an enterovirus (Jones et al, 1985; Straus, 1988; Calder et al, 1987; Yousef et al, 1988). There
was also a suggestion that immunisations could trigger the condition (Dwyer, 1988). Still others suggested it was a disease of modern times (Johnson, 1987; Brighthope, 1990; Alexander, 1990), a consequence of environmental contaminants or modern busy lifestyles (hence the name, 'yuppie flu'). Regardless of the proposed aetiology, none of these descriptions suggested that the condition would involve markedly deteriorating health over years. They all described an ongoing illness, but one which usually had a dramatic onset. Despite attention to the fatigue and weakness, few descriptions available at that time spoke of the cognitive symptoms I had noticed, nor did they refer to the range of diverse and fluctuating symptoms I had heard my friends describe.

There were other interpretations too. Some claimed the condition was primarily a psychological condition, an example of 'major depression' or 'an atypical depression' (Powell et al, 1990). Recently Shorter (1992) has described it as psychosomatic, a condition confined mostly to 'lonely and disaffiliated' women. A few have gone further to describe it as malingering (Nielsen, 1990). None of these interpretations fitted with my observations. My friends had only shown a few signs of depression, and those occurred only after they had been ill for some time and might be expected to show grief and distress. They complained of fatigue and lethargy, characteristics of depression, but each maintained a very busy work schedule and my colleague increased her daily exercise to include a six kilometre walk each day. Both lost interest in drinking alcohol. If this was depression they were indeed reacting atypically, as depressed people generally tend to find solace in alcohol and are prone to inactivity. Similarly, their behaviours were not consistent with a desire to mangle and neither was 'lonely or disaffiliated'.

My second aim was broader than the first. It was to provide a phenomenological analysis of people's lives with this illness. Rather than relying on the interpretations provided by psychiatrists (for example, David et al, 1988; Kleinman, 1988) and individual writers with the condition (for example, Jeffreys, 1982; Macintyre, 1989) I wanted to know how a large number of people with this illness interpreted their symptoms and how they saw the effects in their everyday lives. I had my own observations, but I wondered what people observed about themselves. In

1 These terms and their different meanings will be discussed in more detail in chapter two.
particular, I was interested in how they managed the more disconcerting of their cognitive symptoms and the extent to which they were aware of them. I also wanted to know how their experiences overlapped with or differed from those described by people with other chronic illnesses.

The first and second aims provide a basis for describing the natural history of this illness, an account of its onset, its patterns over time, its outcomes and its effects. The need for a 'natural history' has been widely acknowledged (Shafran, 1991; Wakefield et al, 1990). However, with any chronic illness, natural history is influenced by social factors. Sociodemographic characteristics can make a difference. In the latter part of last century, it became clear that both the incidence and the course of tuberculosis were related to poverty, poor nutrition and inadequate housing (Dubos, 1953). Different forms of institutional care have also been shown to influence the way illness manifests itself as well as its outcomes. For example, for a long time it was assumed that violent responses were a feature of schizophrenia. It later emerged that the violence was more a response to forms of care than an inherent characteristic of the illness (Mechanic, 1982). Similarly, people with a variety of disabilities such as blindness, deafness or cerebral palsy have been disadvantaged in the past as much by the care they were given and the assumptions about their limited potential as they were by their physical incapacities. Sacks (1976) notes the different outcomes for patients with encephalitis lethargica (a post encephalitic condition) related to the different institutional care they received.

The third aim of this study therefore was to explore the social and medical responses which influenced the course of CFS. In this context, I was also seeking to understand the effect on people of having no framework for understanding their problems, as well as the effect of having an illness which is poorly understood and subject to controversy. I later sought doctors' perspectives on appropriate responses to people with non-specific conditions, because people with CFS had consistently identified doctors' responses as significant in the course of their illness.

The fourth aim was to describe the efforts people made towards managing this condition. Although I was particularly interested in patterns of response which might alter the course of the illness, I was also interested
in people's ways of 'getting by', their efforts to make each day more tolerable. Management of a chronic illness encompasses people's behavioural patterns in everyday life, their relationships with others and themselves. To manage their lives, people must actively devise strategies which are intended to mobilise resources and improve the outcomes. However, they bring to that process a 'style of coping' (Bury, 1991), influenced by personal beliefs, common social practices and cultural messages about chronic illness.

The 'structured silence' surrounding chronic illness

People with chronic illnesses, pain or disability have lived within a 'structured silence' about their problems (Zola, 1991). Until the last decade or so, silence has surrounded both the suffering and the expertise which individuals bring to the daily management of their problems when they are chronically but not fatally ill. That expertise and suffering has been obscured by other more influential discourses on chronic illness — biomedical, social science and 'new age'— which emphasise in different ways, the moral failings of those who become ill. As these discourses have informed many aspects of medical and social practices, people with chronic illnesses find themselves constantly exposed to, and hurt by, critical assessments of their moral integrity, regardless of the severity of their illness.

Influential discourses and social practices around chronic illness

Biomedical research has provided explanations for many illnesses based on detailed laboratory data. Through this form of research, aetiological models and nosologies have been established which cover many health problems. However, that research and the knowledge and techniques associated with it, may have been given 'cogency and legitimacy well beyond their professed scientific scope' (Comaroff and Maguire, 1981).

When illnesses or injuries become subject to litigation or the scrutiny of social security departments, individual claims may be dismissed if there is no physiological or laboratory evidence for the problem. Yet in many instances, the lack of data may be a consequence of limited research funding for conditions which are not fatal. As well, limited technology and 'fashions' in medical models and research may influence the extent
and nature of research data on a particular problem. However, in the absence of such data, the illness may be interpreted as malingering or hypochondria, psychogenic or functional interpretations which inevitably reflect on people's moral character.

The social sciences have also contributed to interpretations of chronic illness that reflect on the character of the individual. However, whereas only some illnesses are seen as reflections on people's moral character within the biomedical discourse, in the social sciences some influential discourses convey the impression that the origins and continuation of any chronic illness are directly related to moral weakness. Two views which have been particularly influential are those proffered by Knowles (1977) and Parsons (1951; 1960). Knowles has argued that individuals are responsible for their poor health. He has stridently proclaimed:

Over 99 percent of us are born healthy and suffer premature death and disability only as a result of personal misbehaviour ... The individual has the power and indeed the moral responsibility to maintain his own health by the observance of simple prudent rules of behaviour relating to sleep, exercise, diet, weight, alcohol and smoking. (1977, p79-80)

Before Knowles made these claims though, Parsons (1951) had argued that the sick had a responsibility and a duty to seek recovery and that those who failed to do so were showing an 'inadequate motivational commitment to performance' (1960). Between them, these two influential writers depict the person who is chronically ill as morally weak for becoming ill in the first place, and morally weak for staying that way. Of course, others have pointed out flaws in these propositions. Firstly, a considerable amount of ill health arises from circumstances outside the personal control of individuals (Broom, 1989). Social and economic factors such as hazardous occupations, environmental contamination, poverty and the associated problems of inadequate housing and poor nutrition have an influence. Views of chronic illness that ignore these influences are incomplete. Secondly, among those who remain ill, many may not be able to seek a form of medical care that will improve their condition. There may be no treatments which will alleviate the course of their illness. In the absence of any relief for symptoms, they may not be able to rejoin society on their previous basis, no matter how hard they try (Stewart and Sullivan, 1982; Richman, 1987).
However, Parsons' and Knowles' views are not voices in the background; their ideas permeate public health messages and medical practices in diverse ways. Knowles' opinions are echoed in public health messages which provide a 'strong officially sponsored ideological perspective emphasising personal responsibility' for health (Davison et al, 1992). In some public health campaigns, people are encouraged to change to 'healthy' diets, avoid drugs such as cigarettes and alcohol, improve their hygiene and change their leisure practices by increasing their levels of exercise. Some medical practices can also sustain and reinforce these ideas. Doctors are frequently required to act as social guardians of the moral order. Their interpretations of people's symptoms may carry considerable weight, often determining whether a person is able to 'legitimately' withdraw from their usual social obligations for a time. The guardianship however, can be a partisan one, since there is evidence that at least some doctors make distinctions between their patients on moral grounds. Richman (1987) has described how some doctors may assess and respond warmly to patients they deem 'deserving' or 'innocent victims', but patients they consider 'less deserving' because they have 'unhealthy' lifestyles or show signs of 'poor coping' may receive treatment which is significantly different.

Assumptions which link illness not only to 'irresponsibility' but also to an inability to cope with difficult life problems are also common. They have their origin in views such as 'some people who ... find it difficult to cope with the problems of their lives resort to becoming ill' (Balint, 1972) and 'illness is a mechanism for coping with failure' (Shuval et al, 1973). Such assumptions are explicit or implicit in most stress and coping models (Antonovsky, 1987) and in many psychological explanations of illness (Kaplan, 1991). These interpretations of illness appear to have influenced the care that some people receive. In particular, women and people from certain ethnic groups may have their complaints about illness dismissed as signs of an inability to cope, especially if they express emotion during their consultations with doctors (Zola, 1963; 1991; Broom Darroch, 1978).

There have also been arguments that people stay ill, not so much because they are ill, but because they gain some ongoing benefits from their condition. One of the most influential of these arguments has been that of
'secondary gains' (Waitzkin, 1971). Put simply, that argument says that people may be less keen to strive for recovery if illness has been associated with beneficial changes in their relationships and circumstances. Others (Waxler, 1981; Helman, 1984) have also suggested that certain diagnostic labels can alter people's perceptions of themselves, so that they regard themselves as ill. As a result, their symptoms, behaviour and social relationships may change to fit with the label. In other words, diagnostic labels may become a form of self-fulfilling prophecy. Both the 'secondary gains' and the 'self-fulfilling prophecy' arguments assume that being ill is a condition which can be inherently rewarding, so doctors and others should exercise care when responding to their patients lest they make illness a relatively desirable state. As for the chronically ill, these arguments portray them as vulnerable to suggestion and more comfortable living with the 'benefits' of ill health than with facing the demands of day to day life. Although it is possible that illness might offer some people a temporary escape from responsibility, staying ill for a long time also brings burdens such as a more limited life, greater isolation, financial losses and pressures on family relationships (Anderson and Bury, 1988). To describe the changes that illness brings in terms of gains is to ignore the losses that individuals may incur.

Recently, 'new age' ideas on health have begun to contribute to community understandings of health and illness. These ideas are based on a belief that the spiritual side of humans has been neglected and are an expression of a new consciousness about health and body, representing a commitment to finding a new lifestyle, to pursuing a new well-being, and to finding 'natural' ways of achieving this well-being (Coward, 1989, p25).

These ideas can often reinforce the message that individuals become ill through irresponsibility or an inability to cope. Moreover, some 'new age' health practitioners can imply that recovery lies in the hands of the ill if only they can change their attitudes to life (Hayes, 1988; Coward, 1989). People may be told they will not get well until they 'no longer have a need for their symptoms' (Harrison, 1984). They may be told that recovery can only occur if they learn how to love themselves (Siegal, 1990). In other words, recovery is portrayed as a measure of an individual's willingness to change their way of 'being'. Pathways through the quagmire of symptoms
and inadequate self-love are said to lie in smiles and laughter, meditation, and diverse forms of alternative therapies (Chopra, 1989). There is growing scientific support for some of these forms of interventions as a way of easing the discomforts of pain and ongoing illness, and many people appreciate their effects at that level. Too often though, the interventions are described in different media as cures, usually on the basis of one individual's remarkable transformation from poor to better health.

Although these discourses present divergent images of chronic illness and the part that people's character plays in its onset and duration, they each portray chronic illness, particularly non-specific illness, more in terms of human moral weakness or personal failing than in terms of physical and mental discomfort. As Foucault (1980) has argued, the function of any discourse is to constrain what can be said or thought. In this instance, where the issue has been chronic illness, the discourses seem to minimise the threat that illness and disability may represent for an orderly society (Fulcher, 1989). They have influenced social and medical practices around people who become chronically ill, subtly creating a context where 'the victims' are blamed for their problems (Sontag, 1979; Herzlich and Pierrret, 1984, Register, 1987). They have obscured the suffering that people undergo, the reminder of human frailty.

Breaking the 'structured silence': the benefits
Discourses and practices unhelpful to people with chronic illness or disabilities have been sustained by imbalances in the power relations between doctors and patients, the isolation of people with disabilities and illness and the lack of credible spokespeople who have an understanding of the experience (Zola, 1991). These social conditions have only begun to change with the advent of self-help and activist consumer groups. These groups have provided a forum for people with chronic illnesses, and those who live with or care for them at home. In that forum people have had the opportunity to share and extend their expertise about illness and to express their dissatisfaction with medical and other services.

In the main, people who become chronically ill now have greater access to information about their problems, and that information takes account of their experiential concerns. However, many continue to be constrained in
discussing their experience. Subject to others’ and their own judgments about possible moral failure and weakness, they may be left feeling guilty and shamed by their apparent inadequacies. To varying degrees, they may feel that they have not only failed to contribute appropriately to society, but also that they may have brought about their own illness and then failed to approach the illness with the ‘right’ attitudes. They may feel obliged to comply with the advice of doctors and others with whom they disagree to demonstrate their commitment towards recovery or normal social functioning.

Further, they may feel their selfhood has been redefined when others equate them with their illness, as in ‘he’s a diabetic’, ‘she’s a typical cancer personality’ (Conrad, 1987; Sontag, 1979; Zola, 1991). Rather than be cast as ‘damaged goods’ or ‘defective’ (Phillips, 1990), many have striven to remain in step with society’s values insofar as those values are conveyed through slogans, advertisements, the media and significant others. In a society which places emphasis on individualism and self-sufficiency, they have struggled, regardless of their disability and discomforts, to prove that they can ‘stand on their own two feet’, that ‘hard work pays off’. In a culture which has a preoccupation with perfection and conformity (Kleinman, 1988), they have tried to meet cultural ideals of strength and well-being by demonstrating their resilience.

There can be marked benefits for those who decide they no longer need to conform to these cultural and social messages. Zola acknowledges how he has benefited from the new perspectives that have emerged through the efforts of consumer and self-help groups.

No longer was it necessary to prove that I was just like anyone else, if not better, a ‘supercrip’. Though I was still capable of walking long distances, I no longer felt that it was necessary to do so. And so, upon arrival at an airport, after parking a car, or being left off, I would get into either my wheelchair or the airline’s and roll to that distant terminal. Completely unanticipated was the difference in my physical condition at the end of my trip: I now arrived untired and not needing a nap, not sore from sweating legs and tight braces, not cramped from the general strain of extra walking. (1991, p4)
Not only have changing perceptions of illness and disability allowed him to reclaim what he describes as a 'central part' of his experience, they have also eased some of his discomfort and suffering.

The experience of chronic illness

In discussing the 'structured silence' around chronic illness, I have emphasised the ways that discourses have constrained our interpretations. To date, there has been only limited research interest in how individuals perceive or respond to those interpretations or their perspectives about being ill. Indeed, research which attempts to understand the experience of chronic illness is a relatively new development, coinciding with the growing impact of self-help and consumer groups.

Although some (Conrad, 1987; Gerhardt, 1990) have argued that research on the 'experience of illness' lacks a unified theoretical or conceptual underpinning, there have been two common themes. First, the research has emphasised the everyday aspects of people's lives when they are ill. Secondly, the research has been intended to provide information which is useful not only to those who suffer from chronic illnesses but also to those who provide care for them (Conrad, 1987; Anderson and Bury, 1988; Gerhardt, 1990). Within these two themes, the meaning of illness has been accented and explored in terms of its significance and its consequences for individuals (Bury, 1991).

For individuals, the significance of having a chronic illness lies in its impact on their lives, the ways that it introduces or exaggerates discomforts associated with stigma (Schneider and Conrad, 1983; Conrad, 1987; Siegal and Krauss, 1991) or uncertainty (Comaroff and Maguire, 1981; Waddell, 1982; Pinder, 1990), or the way it disrupts their ongoing sense of identity (Bury, 1982; Charmaz, 1983). As I have already pointed out, any chronic illness is potentially stigmatising to some degree, leaving people vulnerable to judgments by others about their moral character (Blaxter, 1976; Conrad, 1987). However, some conditions may make people feel particularly excluded from daily relationships and activities because their condition creates physical blemishes (as with eczema), disturbing effects (as with epilepsy) or specific moral connotations (for example, HIV/AIDS).
Profound feelings of uncertainty are associated with conditions like multiple sclerosis or Parkinson’s disease, that have diffuse and changeable symptoms, unpredictable courses and unspecified prognoses. As well, people’s understanding of their lives can be disrupted when they become seriously ill. Individuals are left feeling that they and the world as they have understood it have drastically changed.

Chronic illness can also have practical consequences which can absorb people’s limited time and energy. People have to reorganise their lives to accommodate isolation, family pressures, financial stresses and treatment regimens (Strauss and Glaser, 1975; Kleinman, 1988). Inconvenience and embarrassment can be common for people, so that arthritis might be associated with clumsiness (Wiener, 1975) and ileostomy with occasional embarrassing consequences (Kelly, 1991). Some illnesses such as kidney failure and diabetes (Kutner, 1987; Peyrot et al, 1987; Kelleher, 1988) involve time consuming and uncomfortable procedures. Simply hoping for an alleviation or cure can have its consequences for the way that people live their lives because people may develop a ‘moratorium psychology’, a ‘wait and see’, ‘something might happen’ outlook (Davis, 1963).

These aspects of chronic illness may only emerge with time, and their relative importance may depend upon the age of the sick person. In the main, chronic illnesses are depicted as conditions of the elderly. However, many chronic conditions can arise in youth and middle age. In these circumstances, people’s expectations and hopes for themselves, and the expectations held by others, will measurably alter their response to being ill. Nevertheless, nearly all chronic illnesses create times of pain and crisis, leaving individuals feeling devalued, with fears of premature aging, limited life opportunities, practical problems and concerns about future discrimination (Anderson and Bury, 1988).

Despite the shared aspects of chronic illness, many illnesses also create their own specific problems (Turk et al, 1983; Anderson and Bury, 1988). As most people want to know the nature of their condition, its likely effects, the ways their activity will be restricted and the social disadvantages they might incur (Stewart and Sullivan, 1982; Speedling, 1982; Schneider and Conrad, 1983; Anderson and Bury, 1988), diagnosis
becomes an important organising framework for this information (Jobling, 1988). Even when people have terminal conditions, or conditions whose identification and prognosis are uncertain, such as Alzheimer's disease and multiple sclerosis, they have generally expressed a preference for having a diagnosis (Stewart and Sullivan, 1982; Cunningham et al, 1984; Elian and Dean, 1985; Vanderpool and Weiss, 1987; Erde et al, 1988; Seale, 1991).

There is a marked discrepancy therefore between sufferers' views about diagnosis and those that were mentioned in the previous section where diagnosis was regarded as a process which might create behaviours and responses that are consistent with being ill. However, that argument ignored the effect that illness has in people's lives, the way it brings changes regardless of whether it has been diagnosed or not. For individuals who find themselves chronically ill, diagnosis is an important way of interpreting and managing their problems (Elian and Dean, 1985; Burish and Bradley, 1983). Just as doctors have tended to rely on diagnosis as 'the most important link in the therapeutic chain joining patients and health' (Laor and Agassi, 1990), patients themselves value that 'link'. In addition to its implications for managing their health problems, diagnosis has an economic importance to individuals. People often need a diagnosis to have continuing access to sick leave and social benefits such as pensions or to have full access to medical insurance benefits in some countries (Rosenberg, 1989). Additionally, diagnosis can have a broader social significance for people who have a chronic illness. Diagnosis has been described by people with multiple sclerosis and repetition strain injury (RSI) as a relief because it is an affirmation of their personal and social credibility, particularly in those instances when they had been ill for a prolonged period without any diagnosis (Robinson, 1988; Reid et al, 1990). In the absence of a diagnosis therefore, people lack information on their condition and they may lack a feeling of credibility. Reid et al (1990) has also suggested that the absence of a diagnosis may contribute to the chronicity of a condition.

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2 An epidemic of RSI (also known as occupational overuse syndrome or carpal tunnel syndrome) occurred in Australia during the 1980s (Bammer and Martin, 1988). The condition was associated with adverse work practices involving consistent and repetitive movements, so its sufferers were eligible to claim workers' compensation benefits. Many doctors seem to have been reluctant to give patients a diagnosis of RSI, although their concerns appeared to be less related to medical issues than a reluctance to become involved in litigation and
Doctors and chronic illness

Doctors (particularly general practitioners) continue to be the most commonly used professional advisors when people are ill (Legge et al, 1992). Although people may be questioning the efficacy of medical care (Coward, 1989), individuals and society still place high expectations upon medicine (Anderson and Bury, 1988). Yet with chronic illnesses, there is often very little that medicine can offer. As well, because chronic illness is mostly lived outside institutional care, even the management of treatment or dietary regimes lies in the hands of individuals not doctors.

Nevertheless, general practitioners (GPs) are increasingly providing services for people who are chronically ill (Cox, 1991). For some, the patient with a chronic illness is a problem patient, a person who becomes argumentative, critical and dissatisfied. In turn, patients often experience their care as problematic (Kleinman, 1988). On the other hand, there is evidence that some doctors in Australia are seeking to improve their relations, as well as increase their effectiveness, with patients with chronic illnesses (Douglas, 1991). Whilst a number of doctors appear to be expanding their range of interventions by developing skills in alternative practices such as homeopathy, acupuncture and chiropractic manipulation (Whillas, 1989), others have acknowledged what Pinder (1990) has identified as distress and uncertainty about the most helpful ways they could respond to their patients.

Research into the experience of chronic illness provides important information for those doctors who want to improve their relationships with patients and their general effectiveness. Although there has been considerable research on doctor-patient relationships, much of it has focussed on the dynamics of encounters, such as those related to power differences between doctors and patients, or those which contribute to patient satisfaction with the consultation or compliance with treatments. With chronic illness, doctors and patients are involved in an ongoing relationship where these dynamics remain important issues but become more complex. As Pinder (1990) points out, with patients who have a controversy. Reid et al (1990) claim that lack of a diagnosis contributed to the chronicity of the illness, because people were subject to a variety of critical medical assessments and inappropriate treatments.
chronic illness, unless the condition is terminal, there is no end in sight to the relationship. The person is unlikely to get better, and is unlikely to die, so that doctors and patients have to negotiate about the explanations and meaning of illness during consultations which may continue for many years (Quill, 1989). As they negotiate these issues, powerful emotions may be at work in patient and doctor alike. Differences in the value systems of doctor and patient may emerge. Patients may become increasingly less 'compliant' as they learn to manage both the distresses of their illness and the complexities of any treatment regime (Bury, 1991).

During this process of ongoing negotiations, doctors are no longer dealing primarily with medical issues, but are encountering the patient's phenomenological reality. The ability to respond competently and empathically to patients may require previous exposure to the reality of the patient (Shapiro, 1990). Hence studies about the experience of chronic illness are a valuable source of insight for doctors into the day to day concerns of their patients.

Overview of the study

CFS is a controversial and poorly understood condition, so some of the dynamics of people's concerns and needs differ from those of people with other chronic illnesses which may be more readily identified. As this illness has only recently begun to achieve some biomedical interest, I have been able to show how vulnerable people are when they are exposed to the social practices which arise from different discourses on chronic illness. It was clear that the absence of a framework for understanding and interpreting their experience had profound significance for people, so the study particularly examines the dynamics associated with diagnosis, from both the doctors' and the patients' perspectives.

Without a meaningful diagnosis, most people were exposed to medical and social judgments about their moral integrity. In many respects though, their experience is not unique. Singer and her colleagues (1987) have described similar feelings of vulnerability in people whose problems
were described as hypoglycemia, another controversial condition. Further, other people who have puzzling but undiagnosed debilitating conditions almost certainly continue to undergo feelings like those discussed in this study. The findings therefore provide insights not only into the lives of people with CFS but also into the lives of people with other non-specific conditions. More broadly, most people who become chronically ill tend to have a lengthy period of uncertainty before they are given a diagnosis (Kleinman, 1988). The significance of diagnosis is therefore discussed in the context of people's need to counter uncertainty and vulnerability when they continue to be ill. Those concerns are studied alongside doctors' comments about the place of diagnosis in the care of patients who are chronically ill.

In addition to exploring these concerns, the study differs from many other studies on chronic illness by its emphasis on time. Changes in the illness are studied through a longitudinal research design, as are changes in people's perceptions of it. Moreover, the ways that people manage their illness are considered as they gradually evolve over time as well as in relation to the social and medical responses their condition engenders.

Although I have touched on the self-care strategies relating to diets and lifestyle (Perreault and Malo, 1987) and the other positive actions that people take (Bury, 1991), these are discussed in the context of people's changing concerns and reactions to becoming ill and then staying that way. The specific stages through which people pass and the changes they have to make are identified, in much the same way as others have identified tasks (Cohen and Lazarus, 1979; Siegel and Krauss, 1991) and phases in the illness (Johnson, 1991). However, I have tried to show the complexity of responding to these changes and phases over time, and the factors that ease and exacerbate people's progression through the phases. Nevertheless, in mentioning these tasks and stages, I am being descriptive not prescriptive. Adapting to illness is an ongoing process that is unavoidably idiosyncratic.

3 Straus (1991) suggests a similarity between the symptoms that were sometimes subsumed under the name 'hypoglycemia' and those that are being included as part of CFS. However, he rejects the explanation that gave rise to hypoglycemia, saying there is no evidence that sudden drops in blood sugar levels could bring the range of symptoms that people described.
Approach
This is 'pathfinding' research. It is not an attempt to explore the
demographics or epidemiology of CFS, nor is it an attempt to test specific
sociological hypotheses. Instead, it complements those forms of research
by exploring the dimensions of the problem, discovering patterns in the
problems, and offering explanations for the underlying variation in
people's experiences and in other existing data.

The patterns that are found in any experience are more significant if they
appear in a diverse group of people. Therefore, for the study on people's
experiences of CFS I deliberately sought to attract participants from a
variety of settings and backgrounds. The one common feature in their
experiences was that of having a diagnosis of CFS. On the other hand, the
fifty people who became participants in this study are not necessarily a
representative group of people suffering from CFS. The majority of
participants were women, so this account tells more about women's
experiences with this illness than it does about men's. As well, most
participants were well-educated, articulate and thoughtful. One advantage
of these characteristics for the research is that participants were able to give
a good account of their lives, the effects of the illness and their efforts to
readjust and maintain day to day life and their dreams for the future. Yet
despite being articulate and well-educated, many had had an extremely
difficult time trying to gain understanding of their condition. Others with
fewer verbal skills and less education may have had even more difficulty,
but their experiences are not represented here.

The research relies on qualitative data generated through interviews. To
ensure that my interpretation and analysis of that data reflects the
experiences of people with CFS, the research has involved a high level of
interaction with participants and other people with the condition. I
wanted to produce a final product in which people who provided the
information would be able to recognise an essential part of themselves.
As Zola (1991) has suggested, to do this, researchers' ideas and their texts
should be shared with the people who have been studied more
systematically than is usually the case. The research reported here has
followed that precept. The range of issues covered in interviews was
determined through discussion with a reference group, an interested
group of people with CFS. Throughout the study, I maintained contact
with a few of these people, and several participants. I often spoke with a variety of other people about my developing ideas; I did so in two university seminars where I formally reported on my progress with the study, in several public talks, in two workshops, and with people whom I met in diverse situations including conferences and social gatherings. In addition, interested participants were given the opportunity to read different versions of this text.

At the end of these consultations and research, I have tried to produce what Van Maanen (1988) has called a 'readerly text', a text which may be read and understood by those who gave me the original data. In these different but related ways, I have sought to ensure that the accounts that people gave of their experiences have not been invalidated by my 'expert knowledge'. With this approach, my intention was also to give participants a voice in interpreting and understanding their experience. I wanted to avoid repeating those practices which have created or maintained a 'structured silence'.

The second group of participants in the study, twenty GPs, were interviewed once only. Their part in the study is small but, as mentioned earlier, people with CFS said doctors had a significant influence, helpful or unhelpful, during the course of their illness. A major assumption in this study is that people with direct experience of illness need to be able to express their problems and concerns, not only to each other, but to carers and to society at large if health care practices and policies are to alleviate people's distress and suffering with chronic illnesses (Rotherberg and Koplan, 1990). In turn however, those involved in providing care also need to be able to express their dilemmas and difficulties if recommended changes in policies and practices are to be relevant. I have included doctors' concerns along with patients' experiences to ensure that both perspectives inform the findings.

**Main findings**

The findings in a study such as this are derived from a comparative analysis of interviews. As might be expected, some contrasts emerged between people's experiences on the basis of age and gender, as well as the duration and severity of illness. Throughout the text those contrasts are
mentioned. Here, however, I am recounting the main findings insofar as they relate to my original aims for the study.

This study has traced the 'natural' course of the illness over time, taking into account the difficulties inherent in describing illness as a phenomenon independent of sufferers' perceptions. From participants' accounts, it seems unlikely that the origins of this condition lie with any one virus, a finding that other researchers are also acknowledging (Wakefield et al., 1990; Bell, 1991). Nor does it necessarily have a dramatic onset. Despite the diversity in its onset though, there was a common pattern in people's health prior to and during this illness. Before they became ill, most were working and living (often with enthusiasm) at the limits of their particular levels of stamina and endurance, and had been for some time. A flu-like illness (or other viral complaint) usually produced their decline into poorer health, but for most, that deterioration continued for several months and sometimes years, with increasing numbers of symptoms and an increasing severity of cognitive symptoms. The illness is not a trivial one, as it seriously interrupted most people's lives. During the two year course of the interviews, none of the participants had a sustained period of recovery.

Participants described their experience as one that was marked by feelings of uncertainty and estrangement. Most reacted to their initial signs of illness as if it were a passing acute condition, a reaction that has been noticed in people with other chronic illnesses (Leventhal et al., 1982). Ongoing fluctuating and diverse symptoms were difficult to interpret, so as time went by people became increasingly uncertain what was happening. The presence of peculiar cognitive symptoms left them feeling estranged from their usual sense of self. Uncertainty and the 'strangeness' of staying sick, together with the 'strangeness' of the illness, made them feel extremely vulnerable. The sense of fragmentation and general debility that characterised their illness was then reproduced at a social level by the generally unhelpful responses that most people, but particularly women, received when they visited their doctors.

The study shows how the 'natural course' of the illness was moderated by the way that individuals reacted to both the illness and the feelings of uncertainty and estrangement. In general, people responded to their
problems with denial and defiance, responses that can be helpful with some illnesses (Burish and Bradley, 1983). In the main that meant that they attempted to continue with the busy and committed lifestyles that had characterised their lives prior to illness. A few had little choice about their response to the illness, since their life circumstances meant they had to continue with their usual commitments, either because they had to earn a living, to care for a family or to care for a sick spouse or child. The longer that people attempted to continue with their previous lives, for whatever reason, the more marked their decline into poor health.

Although these responses to illness and the style of coping were specific attributes of participants, their encounters with doctors considerably influenced their reactions. When confronted by medical doubts, participants became particularly sensitive to their own and others’ imputations that they were not really ill but failing to cope in some way. Most people then struggled even harder to fulfil their day to day responsibilities, to restore a sense of normality. Their response was not particularly perverse. It is a response that is culturally endorsed. In responding in this way, people were demonstrating their allegiance to prevailing cultural values of commitment, diligence and hard work. Nevertheless, the damaging effect of these responses is suggested by the way that people’s health deteriorated while they continued to struggle to fulfil their normal activities and responsibilities.

Diagnosis appears to have beneficially moderated the course of most people’s illness. First, the well-being and health of those who had a diagnosis from an early point in the illness differed from that of other participants in the study. Second, following diagnosis, few participants continued to have deteriorating health. In other words, with a diagnosis, people had a way of understanding their condition which positively influenced longer term health outcomes. The labelling of their illness, contrary to the fears of labelling theorists, produced a beneficial change in the course of the illness.

Ironically, many of the doctors in this study expressed reservations about giving patients a diagnosis for a condition like CFS. They were not necessarily unsympathetic to the idea of CFS, but they did seem to be concerned that a diagnosis that conveyed the idea of chronicity would
have adverse effects on people's lives and long term health. Their views appeared to be influenced by labelling theory and fears of secondary gain. However, 'what may appear irrational and unscientific' from the doctor's point of view may appear 'meaningful and humane to the patient' (Balint et al, 1970). The finding that diagnosis can promote a better health outcome and sense of well-being is therefore an important one for doctors who want to increase their effectiveness with chronically ill patients. With this information, doctors can transform this experience from one that threatens people's identity and sense of integrity to one that is manageable.

In general, people only began to feel they might be able to effectively manage their illness after they had a framework for interpreting its effects. At first they experimented with treatments, diets and changes in lifestyle, discovering in the process that inaction is probably the most difficult response to make to illness. Individuals sought relief and cures from different sources; if they did not discover them for themselves, then they often had family, friends or doctors who would bring them to their attention. However, after a period of trial and error, most described management in terms of an altered lifestyle, one where they took note of their body's limitations and responded accordingly instead of trying to overcome and ignore their problems. They became less influenced by culturally endorsed responses such as striving to overcome. Instead they learnt how to maintain the facade of health and well-being to avoid criticism and judgment. After having feelings of inner fragmentation and fragility, they were able to create new ways of restoring meaning and order to their worlds. Most were eventually able to minimise their tendency to rely on their previous styles of coping, to feel less driven by cultural norms of achievement and commitment and devise ways of living that were more appropriate to their physical capacity. This process was not without complications of course and those are discussed towards the end of the thesis.

Limitations of the study
There are some caveats to place on these findings. To be included in this study, participants had to have a diagnosis from a doctor that they had CFS. Therefore the issue of diagnosis may only be relevant for people who chose to seek medical help. There may well be many people with health
problems similar to those I discuss, who have chosen for a variety of reasons to manage those problems outside the mainstream medical system. However, once illness prevents people from working, most do have to consult a doctor to be given a legitimate exemption, and from that point may find themselves involved in a search for explanation that eventually brings them within the ambit of these findings.

Second, the study has emphasised the role played by doctors in shaping this illness. Social support, in the form of families and friends, has not been given the same attention as the role of doctors, yet it is widely acknowledged that social support acts as a buffer against social distress (Antonovsky 1987). One of my objectives with this study was 'to do no harm', and exploring the nature of intimate relationships can be a potentially harmful process. It was clear that those who were very ill, needed what support they had. They were mostly reluctant to make critical or elaborate comments about the people who had given them any comfort and loyalty during their years of illness. I respected those feelings.

Further, participants in this study appear to represent those who have managed to 'get by'. I have heard anecdotes that suggest that life with CFS can become unbearable for many. If the anecdotes are to be believed (and I do believe many of them), homelessness, isolation and suicide are a part of this experience. Although a few of the participants did have some of these dark times, they were able to maintain sufficient access to support and comfort to enable them to keep 'getting by'.

Finally, although I have tried to reflect faithfully the experiences of people who have spoken with me, I am aware that unique aspects of some people's stories are missing. When suffering persists, people live on a different plane to the rest of us. In my seeking of patterns or pathways, I have reduced years of people's lives to a few paragraphs. It has not been my intention to diminish their suffering, but occasionally that may have been a consequence of this approach.
Organisation of the thesis

In subsequent chapters the thesis is organised as follows. Chapter two gives a brief history of this illness and the social forces that have influenced its recent emergence and definition as a health problem of some importance. After the method is outlined in chapter three, chapter four provides the details of participants' illness, the symptoms and their changing patterns.

The three central chapters (chapters five to seven) give flesh and meaning to the social history and descriptive detail of chapters two and four. These central chapters recount the experiences of fifty individuals. The chapters are arranged chronologically and trace the development and change in people's lives over time. The story commences with the early stages of becoming ill, through people's quest for an adequate explanation of their problem, through diagnosis and then to life after that milestone. Woven into this account is a discussion of how people set about managing their illness over time. In the seventh chapter, the findings of the previous two chapters are summarised in a diagram. That diagram highlights issues relevant to people with CFS, as well as the doctors and other health professionals who provide them with care. In the final chapter, I draw together the findings of these chapters and discuss their implications for understanding CFS and its management. More generally, I point out the aspects of these findings that have relevance to the training of doctors involved in the care of chronically ill people.

In writing this thesis, I wanted to spell out for others and myself the experience of people with CFS. But this is not simply a story about another illness. A study such as this becomes an analysis of the way our own understandings of ourselves can be challenged and shaped by illness, by social and medical practices, and by commonly held beliefs around illness and health. I have sought to show not only my own and my participants' insights about the process of managing these concerns, but also their courage and creativity as they encountered the challenge.
Chapter 2

Chronic fatigue syndrome – a modern illness?

It is not disease which changes.
Disease itself is very old.
It is we who change and see it differently.

Charcot

Although it is now the subject of diverse 'modern' interpretations, CFS is not necessarily a modern illness. Indeed, it appears to be an illness with a long history but medical fashions have always influenced its interpretation. In this chapter, I describe the historical antecedents for this condition, its current explanations and the factors which have influenced its recent definition and naming.

To begin the chapter I provide an overview of the case definition and diagnostic guidelines for CFS and discuss how these have influenced the growing understanding of this condition.

What is chronic fatigue syndrome?

CFS was given its current name and a measure of official recognition in 1988 when the United States Centers for Disease Control (CDC), in Atlanta, Georgia, published a case definition for research and clinical purposes (Holmes et al, 1988). That definition has since been reviewed (Schlueterberg et al, 1992), but in the intervening period, when there was considerable dissatisfaction with the initial CDC definition, the most favoured research and clinical criteria have been those prepared by a group of researchers in Sydney, Australia (Wakefield et al, 1990). These are the criteria that have been used in this study.
In the guidelines proposed by Wakefield and his colleagues there are three requirements for a diagnosis of CFS. A person must have had:

(1) persistent chronic or relapsing fatigue for more than six months; and
(2) evidence of neuropsychiatric dysfunction, such as attentional and memory deficits; and
(3) other possible explanations for these symptoms excluded.

A number of other symptoms are mentioned as being part of the syndrome: myalgia, arthralgia, exceptionally severe headaches and sleep disturbance.

There are many differences between the Australian guidelines and the case definition provided by the CDC in the USA during 1988. The differences between the US and Australian guidelines have created uncertainties for clinicians. As well, the differences explain some of the discrepancies between countries in reported prevalence rates and have contributed to problems in the replication of results from research about aetiology, diagnostic tests and treatment.

Both sets of guidelines include the criterion of fatigue, but they differ in their definition of that fatigue. In the Australian criteria, this fatigue is described as either chronically persistent or relapsing, causing significant disruption to a person's daily activities. The description emphasises the relapsing form of the fatigue, specifying that a person's fatigue must be exacerbated by minor exercise such as vacuuming or walking to the top of a hill. In contrast, the US guidelines describe the fatigue as persistent, reducing a person's functioning to less than fifty percent of normal levels.

Both sets of guidelines require the exclusion of other possible illnesses which might induce or be associated with fatigue syndromes. In the 1988 US case definition, this exclusion has specifically been extended to diagnoses of depression or anxiety disorders. The Australian guidelines acknowledge that depressed mood or anxiety may accompany this illness. This difference is significant, since Canadian and Australian studies have found major depression in as many as 50% of people with this diagnosis.

1 As it is difficult to determine what fifty percent of usual functioning is, and because the emphasis on fatigue trivialises the illness to some extent, Cheney and Lapp (1992) have claimed that very sick people have been excluded from some studies because researchers have regarded them as too sick to have CFS.
with a French study claiming the rate to be as high as 80% (Cathebras et al., 1991). As most researchers have argued that depression seems to be a part of this or any chronic illness, the US guidelines were regarded as too restrictive for research purposes. The recently revised US guidelines (Schluederberg et al., 1992) now include mood disturbances as part of the syndrome.

Wakefield et al. (1990) also specify cognitive or neuropsychiatric dysfunction as a major diagnostic criterion, evidenced by impairment of concentration and short term memory, or difficulty in completing mental tasks that were easily accomplished before the onset of the illness. Although noted as a minor criterion in the original US case definition, the difference in emphasis upon this criterion means that definition in the US has rested primarily upon a persistent physical fatigue, whereas under the Australian guidelines, both physical fatigue and cognitive dysfunction needed to be present.

Neither set of guidelines explicitly assumes that the aetiology of the condition is viral, though each mentions that a marked onset of the symptoms can be a distinguishing feature. The CDC case definition was a deliberate attempt to define the illness without reference to any particular virus. During the early part of the 1980s in the US, the syndrome had been linked to infection with the Epstein-Barr virus, the virus which causes glandular fever (Dubois et al., 1984; Jones et al., 1985; Straus et al., 1985), hence the name Chronic Epstein-Barr syndrome. However, by 1987, there was growing evidence that the syndrome was not specifically linked to Epstein-Barr virus, so the CDC wanted to create a definition which rectified earlier claims (Holmes, 1991).

Late in 1992, the revised CDC guidelines (Schluederberg et al., 1992) were reduced. Some of the differences between the Australian and US guidelines were minimised. The new guidelines also reflected the 1991 criteria put forward in Britain by Sharpe et al. (1991). Overall, the US guidelines have become broader, so that fibromyalgia (or fibrositis) has now been placed under the umbrella of CFS. An attempt has also been made to characterise the 'domains of interest' with this condition. Measures and descriptions are now being sought for the fatigue, mood disturbance, pain, sleep disorder, functional status and global well-being of
people with this condition. Although cognitive dysfunction has not been
included, these 'domains of interest' do cover many of the symptoms that
others have noted. Thus there is growing acknowledgment that CFS
entails more than a sense of fatigue.

Apart from the symptoms I have already mentioned as part of the
Australian criteria, others have claimed that the symptoms of CFS also
include mild fever, sore throat, painful lymph nodes, muscle weakness,
emotional lability and photophobia (Holmes et al, 1988; Wakefield et al,
1990). Ho-Yen and McNamara (1990) include gastrointestinal problems,
tinnitus, paraesthesia, cardiovascular complaints and unusual sensitivity
to heat and alcohol. Komaroff and Buchwald (1991) have noted a high
level of allergic reactions.

With the new guidelines from the CDC, it is clear that researchers from
different parts of the world are now moving towards some consensus
about the characteristics of this condition. To some extent, the earlier
differences arose because of the uncertainties and ambiguities inherent in
the illness itself, since debilitating 'fatigue' in conjunction with this range
of symptoms might be expected to have some distinctive biological
correlates. However, in the absence of any satisfactory diagnostic test,
some of the published descriptions and research into CFS may relate to
different populations.

Epidemiology of CFS

Conditions similar to CFS have been reported in countries such as the US,
Canada, the UK, China, New Zealand, Israel, Spain and France (Shafran,
1991). From clinical studies, estimates of the frequency of CFS in the
population have varied between an incidence of 3 per 100,000 in Scotland
(Behan et al, 1985), to a prevalence of 127 per 100,000 in New Zealand
(Murdoch, 1987). An Australian epidemiological study based on the case
records of primary care doctors estimated that the prevalence was 40 per
100,000 (Lloyd et al, 1990a). Each of these studies used different definitions
of CFS.

There are some striking differences between clinical and epidemiological
claims about sociodemographic features of the condition. On the basis of
clinical studies, people with CFS have been described as well-educated and
high achievers, so that the condition was known for a time as 'yuppie flu' (Shafran, 1991). In the UK, there have been suggestions that sufferers have had occupations in health care and teaching, that is, professional occupations where there is a high level of contact with people (Ho-Yen and McNamara, 1990). In the US, there has been a report that sufferers at one clinic were entirely white even though the clinic was in a district where most people were black (Dubois et al, 1984).

These clinical findings have some limitations. Many of the clinical studies of CFS have been undertaken in specialist clinics. The apparent class and race differences may result from social factors which have influenced the services that people seek and receive. Only well-educated people might be able to fight 'the system' to gain access to specialist clinics when their problems are non-specific. Blacks, on the other hand, may be more reluctant than whites to use medical services (Shafran, 1991).

In contrast to the clinical estimates, the epidemiological findings (Lloyd et al, 1990a) suggest that the illness does not selectively affect individuals in professional occupations. They indicate that CFS occurs predominantly in the lower and middle classes.

Another difference between the clinical studies and the epidemiological study is the claimed proportions of women and men with the condition. In clinical studies, the frequency of CFS has generally been regarded as higher amongst women. It has been estimated that the ratio of women to men is as high as three to one (Ho-Yen and McNamara, 1990; Komaroff and Buchwald, 1991; Shafran, 1991). In contrast, Lloyd et al (1990a) suggested that the numbers of women and men affected were approximately equivalent (1.3:1).

The difference in the ratios of men and women in the different styles of study is difficult to explain. Because the symptoms of this condition are non-specific, it might be anticipated that women would have had their symptoms dismissed more often than men. As chapter five of this thesis will show, women were indeed much more likely than the men to have had their symptoms disparaged or interpreted as psychiatric illness during their early attempts to get medical assistance. This finding has implications for the epidemiological study which was based on doctors'
case records. If doctors tend to dismiss or give other explanations to women's symptoms, the numbers of women may be underestimated in the epidemiological data. However, if women's symptoms are more likely to be dismissed in the early primary care consultations, it is difficult to see why women would outnumber men in the specialist clinics.

The conflicting results around class and gender have been used to different purposes by different researchers. Because the clinical data have indicated that CFS might have a class and gender bias, there has been scope for interpretations of the symptoms that blame the sufferers or diminish the seriousness of the problems they encounter. In particular, gender differences have produced considerable speculation about possible psychiatric origins of the condition, even though there are often disproportions in the numbers of women and men with different diseases. As an example, more women than men develop auto-immune diseases such as systemic lupus erythematosus (SLE) and rheumatoid arthritis (Horgan and Quinlan, 1984), and more men than women develop cardiac problems.

In the introduction to this thesis I claimed that CFS is poorly understood. Despite advances that are now being made towards a commonly accepted definition for research and clinical purposes, and despite a dramatic increase in the research on CFS over the last three years, several important issues remain unclear. It is not clear which people develop this illness although there is general agreement that it is a condition which affects people between late adolescence and later middle age (Shafran, 1991). As yet, aetiology, diagnosis, prognosis and treatment also remain uncertain. However, this is not a self-limiting condition for most people (Cheney and Lapp, 1992), so it therefore deserves continuing medical and social attention.

History of the illness

Over the last two centuries, a number of illnesses with a variety of names have had characteristics similar to those of CFS. Because there are no distinctive biological correlates for this condition, it cannot be certain that these illnesses are early examples of CFS. Nevertheless, the similarities
are marked. Here I have divided the history into three time periods, since these seem to be separated from each other by an absence of reports in the medical literature.

Eighteenth and nineteenth centuries: Neurasthenia
As early as 1772 Cullen wrote of an illness he called neurasthenia. Further detailed references to this illness are made by Beard, Chatel and Osler late last century, and by Kraepelin in the early part of this century. They described the illness as a syndrome of mental and physical fatigue, an 'exhaustion of the nervous system'.

There is general malaise, debility of all functions, poor appetite, abiding weaknesses in the spine and back, fugitive neuralgic pains, insomnia, hypochondriases, disinclination for consecutive mental labour, severe and weakening attacks of sick headache and other analagous symptoms (Chatel, 1870, cited in Kleinman, 1988, p72).

Kraepelin described it as a 'chronic nervous exhaustion, usually occurring as a post infective state'. Osler defined its effects as:

the individual loses the distinction between essentials and non-essentials, trifles cause annoyance and the entire organism reacts with unnecessary readiness to slight stimuli and is in a state which older writers call irritable weakness (Osler, 1892, cited in Shorter, 1992, p224).

An epidemic of this illness occurred throughout the northern parts of America, Europe and the UK in the late nineteenth century. Many famous people of the day were said to have the illness including William and Henry James, Charles Darwin, Florence Nightingale and Elizabeth Barrett Browning (Kleinman, 1988). During the middle part of the century, men were given the diagnosis of neurasthenia more frequently than women. While men remained the principal sufferers of the condition, the condition retained considerable medical credibility. Its origins were explained in the following terms:

A person with a nervous tendency is driven to think, to work, to strive for success. He presses himself and his life force to the limit, straining his circuits. Like an overloaded battery...the sufferer's electrical system crashes down, spewing sparks and symptoms and giving rise to neurasthenia (Beard, 1869, cited in Drinka, 1984, p113)
On the other hand, if women had the same range of symptoms they were more likely to be diagnosed as 'hysteric' (Jacobi, 1888, cited in Shorter, 1992). Their symptoms were thought to be due to:

the daily fret and worrisomeness of lives which, passing out of maidenhood, lack those distinct purposes and aims which, in the lives of men, are like steadying influences of a flying wheel in the machine (Mitchell, 1876, cited in Kleinman, 1988, p74).

The diagnosis gradually fell into disrepute just after the beginning of this century for a number of reasons. Disrepute grew as the diagnosis became increasingly common, especially for women and people in the upper and business classes. William James' biographer (Feinstein, 1984) described the illness as a useful and popular excuse to allow pleasure and leisure in a basically puritanical society which had a strong belief in the value of suffering. Drinka (1984) has suggested that people liked the diagnosis and its famous 'rest cure' (which consisted of absolute rest, a health diet, isolation from the family and daily massage).

Another and more compelling reason for its disrepute had to do with the influence of Freud. His psychoanalytic interpretations of symptoms provided a theoretical basis for a distinction that was already being made between functional and organic disease. After Freud, vague or poorly defined illnesses were seen as the consequence of unresolved neurotic inner conflicts around sexuality, dependency and aggression, reflecting failings of the personality. Neurasthenia was described by Freud as 'neurosis', a label perceived then and now in perjorative terms.

1934–1970: Epidemics of the 'Disease with a thousand names'2
Myalgic encephalomyelitis, Akureyri disease, Royal Free disease, an 'illness resembling poliomyelitis', epidemic neurasthenia: these are only some of the names given to epidemic outbreaks of illnesses that showed remarkably similar features between 1934 and 1970 (Gilliam, 1938; Sigurdsson et al, 1950; Pellew, 1951; Medical staff of the Royal Free Hospital, 1955; Richardson, 1956; Acheson, 1959; Daikos et al, 1959; Henderson and Shelekov, 1959; Hill et al, 1959; Albrecht et al, 1964; Compston et al, 1970). These outbreaks have occurred in many places,

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2 Bell (1991) has used these words as the title for his book on CFS.
including the United Kingdom, United States, Switzerland, Australia, Iceland, Greece, Germany and South Africa.

Controversy about the nature of these epidemics occurred in 1970, particularly the outbreak of what was called myalgic encephalomyelitis (ME) in 1955 at the Royal Free Hospital in London. Nearly 300 staff were affected by this illness, and the hospital was subsequently closed for four months. The medical staff there had provided a detailed report in the British Medical Journal of this epidemic outlining the main features of the illness and its ongoing effects on a large number of the staff (Medical staff of the Royal Free Hospital, 1957). Fifteen years after the epidemic, two psychiatrists (McEvedy and Beard, 1970a) proposed that 'mass hysteria' had broken out at the hospital. They suggested that the source of the hysteria was fear of the poliomyelitis outbreak which was occurring in the hospital at that time. They found further support for their arguments in the disproportionate numbers of women compared with men who were affected. Subsequently, they also claimed that earlier epidemics had been examples of this hysteria, although they said these outbreaks were not such 'pure' examples of mass hysteria as the Royal Free Hospital epidemic (McEvedy and Beard, 1970b).

Staff of the Royal Free contested the claims (Compston et al, 1970; Ramsay, 1988). They argued that the psychiatrists had developed their hypothesis without adequate consideration of the medical records or discussion of the events of the time with staff who were involved or affected by the epidemic. They claimed that hysteria had been considered as a possible diagnosis at the time of the outbreak, but that it was rendered untenable by the occurrence of fever in 89% of people affected, lymphadenopathy in 79%, ocular palsy in 43% and facial palsy in 19% of patients. Ramsay (1988) also pointed out that sporadic cases of the illness had been occurring, prior to the outbreak at the hospital, over a large area of North West London, and that two similar epidemic outbreaks were recorded that year in Cumbria, UK and Durban in South Africa. Further, although poliomyelitis outbreaks had coincided with many of the early epidemic reports of this illness, Acheson (1959) had specifically stated that at the

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3 The coincidence of epidemics of poliomyelitis and this illness has been noticed by several observers. In Adelaide between 1949 and 1951 (Pellew, 1951; Pellew and Miles, 1955), an outbreak of paralytic poliomyelitis commenced in 1949. By August that year, the numbers affected had increased dramatically. In mid-August, the stream of poliomyelitis cases
Royal Free 'no case of poliomyelitis or encephalomyelitis had been nursed in the hospital in the previous month nor had any case of these diseases been notified from adjoining boroughs'.

Nevertheless, there was widespread coverage of the 'mass hysteria' analysis in the British Medical Journal (1970), several other medical journals and popular media such as Time and Newsweek. The illness lost most of its claims for serious research for some time.

When I began this study in 1990, many researchers regarded CFS as the most recent manifestation of the epidemic illness (Dwyer, 1988; Bell, 1991; Shafran, 1991). At that time, any distinction between the epidemics and CFS tended to centre on the appropriateness of the name. CFS was preferred by researchers (Lloyd et al, 1988) as it made no assumptions about the aetiology of the condition, whereas terms such as myalgic encephalomyelitis suggested that the condition was due to inflammation of the brain and muscle. However, the link between these epidemics and CFS has recently been reappraised. The current criteria for CFS specify that a fatiguing illness must have been present for over six months. As such, only those people in the epidemics who developed an ongoing debilitating fatigue in excess of six months could be regarded as having CFS. The initial onset and its causes, although of interest in those outbreaks, are now regarded as less relevant than the factors which make this an ongoing illness for some people (Gantz and Holmes, 1990; Dwyer, 1991).

Nevertheless, as a number of people affected by the epidemics did continue to be ill for many years, a relationship between these epidemics and CFS is maintained, even if it differs in some ways from earlier notions⁴.

ceased abruptly and were replaced by cases of this 'disease with a thousand names'. The differences between the two groups were confirmed by cerebrospinal fluid tests. Cases of the illness continued to occur until April 1951. Over 700 cases were admitted to the hospital. This was a dramatic illustration of a pattern that had been evident in Los Angeles, USA in 1934 (Gilliam, 1938) and Akureyri, Iceland in 1948-49 (Sigurdsson et al, 1950). It has been suggested by Ramsay (1988) that 'only another virus could account for the inhibition of the poliomyelitis virus, probably one of the Coxsackie Group B, since mutual antagonism between poliomyelitis and this group is well known'.

⁴ Exact numbers of those who continued to be affected after these epidemics are difficult to specify because follow up studies have either focussed on a few (Pellew and Miles, 1955) or been restricted by the usual factors which make longitudinal research difficult to pursue (Ramsay, 1988). Dwyer(1991) has given what is probably a conservative estimate of 5%.
1980s: A pandemic of CFS
Over the last ten years there have been increasing reports of this form of ongoing illness from many parts of the world so that some researchers at the First World Symposium on CFS, held in Cambridge in the UK during 1990, were claiming that a pandemic, that is, a world wide epidemic, has been occurring. This has taken the form of a few isolated epidemic outbreaks such as Lake Tahoe in the US (Daugherty et al, 1991) and Tapanui Flu in NZ (Murdoch, 1987) and an outbreak in northern Scotland (Behan and Behan, 1980; Calder and Warnoch, 1984), but the great majority of cases have been people who have become sick following a variety of different onset illnesses and experiences (Shafran, 1991).

Explanations for CFS

Recent efforts to understand the condition have been influenced by the particular medical speciality of the researcher, whether it be virology, psychology or immunology. Each of these perspectives has inevitably emphasised different aspects of the illness, and conclusions have been based on patients whose most prominent symptoms were presumably consistent with the specialist service. As a result, research efforts and findings have been disparate and dispersed. The nature of the research has also been influenced by the particular history of the illness in each country. In the UK there has been a great deal of research into virology and muscle changes because those were the interests of the staff doctors at the Royal Free. Several of those doctors maintained lifelong commitments to research on the illness which had temporarily closed the hospital. In the US, Australia and New Zealand, research has been influenced by immunology, the 'medical fashion' at the time the illness appears to have become prevalent. In addition, social and psychological explanations for the condition continue to have a place in interpretations of the condition.

Social and psychological explanations
Current social and psychological explanations for CFS appear to grow out of the original uncertainties about the nature of neurasthenia and the controversy about the Royal Free disease.
CFS has recently been described as a 'culturally sanctioned form of illness behaviour' (Abbey and Garfinkel, 1991), a socially acceptable way of expressing psychological distress (Kleinman, 1988). The label CFS has also been described as one which accommodates the needs of those people who have a 'range of symptoms in search of a diagnosis' (Shorter, 1992), but who would dislike having their symptoms attributed to psychological causes (Abbey and Garfinkel, 1991). Shorter's argument also relies on psychoanalytic concepts. He links specific neurotic conflicts (such as those of 'lonely and disaffiliated women') to this particular range of symptoms, despite a lack of evidence to support such claims, either in relation to this or any other illness (Lipowski, 1969; Grinker, 1979). He goes on to claim that 'the unconscious chooses symptoms that will be taken as evidence of real, physical disease that will win the patient an appropriate response' (Shorter, 1992). In making its choice, the unconscious is supposedly influenced by the 'medical' and 'media-driven' shaping of symptoms.

To some extent, those who argue that CFS is a culturally acceptable form of illness behaviour are assuming that fatigue is the main feature of the illness. They express concern that 'fatigue' is being defined increasingly as a medical problem rather than as a normal part of life (Barsky, 1988). Their claims ignore the clinical and epidemiological data which show large numbers of people incapable of simple tasks when they have this illness. Instead, they tend to support their arguments with much the same claims as the critics of neurasthenia towards the end of last century. They emphasise the numbers of women and middle class people affected, even though the relevance of that data remains uncertain. They also seem to assume that the diagnosis of CFS is socially benign. In choosing to describe CFS as culturally acceptable, they have neglected to consider the controversy which they and others have created about the condition. That controversy, as later chapters will show, has consequences on people's lives.

At the clinical end of the spectrum of social and psychological explanations are the explanations which compare CFS with depressive disorders. These disorders are themselves poorly understood (Kendell, 1991), with their subcategories in the American Psychiatric Association's Diagnostic and Statistical Manual, revised third edition, (DSM-III-R) showing little or no relevance for treatment (Science, 1991). Nevertheless,
associations are made between depression and CFS because it also creates high levels of fatigue, with estimates as high as 60–97% of cases in several large cross-sectional studies (Wessely, 1989). There are other symptoms in common too, such as sleep disturbance, paraesthesia, headaches, palpitations, breathlessness, vertigo, gastrointestinal disturbances, tinnitus, aches and pains.

Although some people who are given a diagnosis of CFS are not depressed, there is a high level of reported depression or anxiety in people with this illness (Taerk et al, 1987; Hickie et al, 1990; Cathebras et al, 1991). The only study which has tried to assess levels of pre-morbid and postmorbid depression showed that the proportion of people with CFS who were depressed was no greater than it is for patients with other chronic illnesses (Hickie et al, 1990). The depression that is evident in mood and reactions is not necessarily the 'major depression' described in DSM-III, but may be a relatively normal response to feeling chronically unwell, what is sometimes called 'reactive depression'.

Turk and Rudy (1988), in a review of depression in chronic illness, found the levels of depression to be two and a half times higher for people with chronic illness than for the 'normal' population, suggesting that it would not be unusual for over 50% of chronically ill people to feel depressed. They also point out that most measures of depression include symptoms which are equally relevant to major physical problems or depression (for example: the Beck Depression Inventory, BDI, Beck et al, 1961; Hamilton Rating Scale for Depression, HRSD, Hamilton, 1960; Minnesota Multiphasic Personality Inventory, MMPI, Hathaway and McKinley, 1943).
Thus the application of these assessment procedures to people with chronic illness is likely to inflate the estimated prevalence of depression amongst any group of medical patients.

There are several features of CFS that seem to distinguish it from major depression. They include the distinction between effort-induced fatigue and general malaise, the variety of symptoms experienced, as well as people's attitudes towards alcohol, and their general feeling state. Firstly, people with major depression generally give the impression of apathy. They are not interested in activity and feel fatigued as part of their overall feelings of despondency. By contrast, it has been argued that people with CFS do not show a reluctance to be active. Their motivation remains high (Lloyd et al, 1991) but small amounts of activity are followed by physical fatigue. When asked to exercise there is a distinctive difference between the depressed person and the person with CFS as the latter will claim that they would like to exercise but that it causes pains and relapses, whereas the depressed person will express general disinterest and listlessness (Hoffman, 1989). Secondly, although both depression and CFS have a number of symptoms in common, CFS may be distinguished by the presence of symptoms such as fevers, sweats, sore throat, lymphatic pain and swelling, and skin rashes. Thirdly, unlike many people with depression, people with CFS generally develop an antipathy to alcohol, both disliking its taste and finding that it has a rapid and unpleasant effect, much exaggerated in relation to the amount that may be consumed (Hoy-Yen and McNamara, 1990). Finally, in contrast to the overwhelming feelings of guilt, sadness and hopelessness that characterise major depression, people with CFS almost invariably want to work and maintain a social life but find themselves having to limit their lives because of the illness (Behan, 1991). People with CFS may have times when they feel depressed, but in general their condition is associated with emotional lability, not constant sadness. They may have several mood changes in a day.

It has been suggested that these difference in responses between people with depression and people with CFS reflect differences in attribution styles (Powell et al, 1990). People with CFS may actually be suffering from depression but they blame their misfortunes on factors which are not intrinsic to their feelings about themselves, that is, they attribute their
misfortune to external factors such as viruses. In contrast, people with affective disorders typically blame themselves for their misfortunes.

Arguments about whether CFS is a form of depressive disorder are also arguments about the nature of depression. Either the criteria for depression need to be extended to incorporate CFS, or CFS needs to be regarded as a distinct condition. At present there seem to be more reasons to regard it as distinct than as an another form of this affective disorder. In particular, people's response to exercise is a good reason for separating CFS from affective disorders, since exercise is a productive intervention for people who are depressed, but something which produces adverse effects on people with CFS. Similarly, although there is some evidence that some anti-depressants at very low dosages can be helpful to people with CFS (Gantz and Holmes, 1990), interventions which are effective for depressive disorders are generally less effective for people with CFS. As Wessely (1991) acknowledges, CFS is more difficult to treat than depression.

The purpose of some of the attempts to describe CFS as either an existing affective disorder or an atypical form of depression needs to be questioned. What seems to underlie those efforts is a desire by some researchers and practitioners to show that people with this form of illness have brought it upon themselves. People's commitment to maintaining work and other activities has been interpreted as the neurotic response of high achievers, a consequence of 'poor self-image and/or some perceived insecurity in their formative years' (Nielsen, 1990). Their interpretation of their symptoms as illness has been described as an attempt to avoid feelings of personal accountability (Kleinman, 1988). Their self-presentation has also been described as one which attempts to minimise psychosocial difficulties. They have been called 'facultative somatisers', people who

in interviews with internists, family practitioners and other medical practitioners attribute their illness to physical symptoms but in the context of the interview with a research psychiatrist no longer make this attribution and discuss the relationship of their

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Kraepelin (1902, cited in Powell, 1990) described neurasthenia as different to melancholia (or depression), because 'it rarely happens that the feeling of despair becomes intense enough to lead to suicidal attempts' and Oppenheim (1908, also cited in Powell, 1990) claimed that 'mental depression is usually present but is neither deep nor persistent'.
symptoms to psychosocial factors and past psychological disturbances. (Abbey and Garfinkel, 1991, p80)

How people might present themselves without incurring some criticism if standards like this are applied, is not obvious. As understanding of the relationship between body, mind and illness becomes more complex (David et al, 1988), and as evidence of biological underpinnings for many psychological illnesses grows, judgments about individuals who become ill need to become more circumspect, not more elaborate. At present, what these judgments do, is belittle pain and suffering, rather than alleviate it (Bell, 1991).

The physical explanations
Physical explanations for CFS cover muscle malfunction and infection, allergies and yeast infection, viral infection, and abnormalities in immune regulation. Over the last three years, immunological research has provided the most promising data. Nevertheless, most researchers engaged in the search for an organic explanation for this illness would acknowledge that the story that has to be understood is complex and remains incomplete.

Muscle malfunction and/or infection
Although people with CFS describe fatigue and muscular pain and weakness, research into malfunction or infection in the muscles has not been particularly productive. There is very little evidence to suggest that much is wrong with the muscles themselves, despite studies using electrophysiological testing, measurement of muscle enzymes and examination of muscle biopsies under both light and electron microscopy (Wakefield et al, 1990). As well, there is no evidence of muscle atrophy, either as a result of the illness or of inactivity subsequent to the illness (Riley et al, 1990), although some treatment programs have been predicated on the assumption that muscle fatigue arises from deconditioning following a long period of inactivity.

However, one study showed that single muscle fibre electromyelograms were abnormal in 75% people with CFS. This abnormality indicated a possible organic disturbance in the peripheral part of the motor unit (Jamal and Hansen, 1985). Jamal and Hansen (1988) have argued that this finding suggests dysfunction in the muscle membrane, a dysfunction
which may adversely affect muscle metabolism. Consistent with Jamal's claims that there may be abnormalities in muscle metabolism is the finding that there can be abnormal lactic acid accumulation in the muscles of people with CFS following exercise (Behan et al, 1985). Excessive lactic acid in the muscle has been linked to athletes' tiredness after prolonged exercise. The muscle membrane dysfunction may be part of a more generalised membrane dysfunction as there has also been some evidence of abnormalities in the membranes of red blood cells when those cells were examined under an electron microscope (Simpson, 1989).

Efforts have also been made to find signs of viral infection in the muscles of people with CFS, since viral infection in the muscles can cause profound dysfunction. For example, the effects of muscle viral infection can be exacerbated when a sick person exercises. Marathon runners with a viral infection have been known to die when competing. Viral infection is also one of the recognised causes of cardiomyopathy. It can cause such significant loss of muscle contractability that death may occur.

To date, attempts to locate muscle infection for people with CFS have given ambiguous results. Only 35% people in a UK study of 140 people showed signs of viral infection in the muscle. Of these, 24% had positive enterovirus results and 10% had Epstein-Barr virus (Archard et al, 1988). These results were not replicated in a US study and other studies have been even less suggestive.

In general, the research on muscles provides intriguing findings but insufficient data for a satisfactory explanation. Muscle infection or abnormal functioning cannot really encompass the broad range of symptoms that people have reported nor the variability in fatigue that occurs within individuals over time. It seems likely that change in the muscles is secondary to some more general biological response (Wakefield, 1990; Bell, 1991).

Allergies and yeast infection
Allergies or intolerances to foods, medicines and yeast infections in CFS are frequently reported by individuals and 'alternative therapists'. They may be an important aspect of this condition (Olson et al, 1986a; 1986b;
Straus, 1988; Bell, 1991) but have rarely been discussed at any length in medical journals.

With CFS, some (for example, Alexander, 1990) have suggested the symptoms may be brought on by prolonged exposure to chemicals and foods to which individuals are allergic. As yet, there have been no studies which attempt to draw out this kind of history from people. However, food intolerances may play a part in the continuation of symptoms. Loblay and Swain (1986) have shown that symptoms similar to those of CFS may be alleviated if people alter their diets to minimise the impact of salicylates and amines, chemicals which are naturally occurring but also added to many foods.

The 'yeast connection' (Crook, 1986) to symptoms such as those with CFS has been the subject of numerous books and articles, almost all of them published by 'alternative' health practitioners. Some argue that people's symptoms are brought about by an excessive production of candida albicans (the yeast that normally grows in the body). The excessive production may have occurred because a person has had a high consumption of antibiotics which may have killed helpful bacteria in the body that normally control candida. On the other hand, other practitioners argue that poor health may be responsible for creating the conditions which allow candida growth. People with HIV/AIDS and people using some powerful cortisone drugs sometimes develop visible fungal infections in the mouth, the nails and elsewhere.

Advocates of the candida theory claim that candida becomes harmful to the body when yeast cells migrate into the blood stream through the walls of a damaged intestine, thus affecting brain and immune function. There is however, no evidence for how this process might occur. Although there are now blood tests available to measure levels of candida, these tests have not received endorsement from mainstream medical researchers. At present the best support for this theory lies in widespread individual reports of improvement following systemic drug treatments for candida or diets low in sugars, carbohydrates and yeasts (Dowson, 1991).
Viral infection

The possibility that CFS is a result of a general persistent viral infection (as opposed to an infection in the muscles) is supported by the large number of people who report that their illness has started with a viral-like infection from which they do not get better. Many viruses have been implicated but most attention has been focussed on latent viral infections caused by herpes viruses or chronic persistent infection with viruses known to affect the central nervous system. More recently there has been interest in the possibility of a retrovirus infection.

Latent viral infection is not well understood at the molecular level but it is thought that such viruses remain latent in the body and are reactivated when the person is immunosuppressed through exposure to foreign antigens, infection or stress. In the USA, 25–39% people showed evidence of glandular fever also known as Epstein-Barr virus (a herpes virus) (Straus et al, 1985; Jones et al, 1985) in their blood. The presence of the Epstein-Barr virus led to names for the syndrome like chronic Epstein-Barr virus or chronic mononucleosis (Straus, 1988). Other herpes viruses, the cytolmegalovirus and HHV6 (human herpes virus 6) have been implicated, but again findings are equivocal (Wakefield et al, 1988). Overall, the relevance of these findings on latent viruses is difficult to determine. The herpes viruses may have been reactivated only after the person became ill and was immunosuppressed from the illness. They are not necessarily responsible for the onset of the condition.

Alternatively, sources of chronic and persisting viral infection may be the enteroviruses. Entroviral illnesses include poliomyelitis, cardiomyopathy and hepatitis. In CFS, the Coxsackie B viruses appear to have been the most commonly identified of the enteroviruses. Studies in the UK (Calder et al, 1987; Yousef et al, 1988) have found approximately 65% of people in a variety of studies had persisting high levels of enteroviral antibody in their blood. In Australia, Ross River virus has also been associated with CFS.

On the basis of these different findings, it seems unlikely that only one virus is responsible for the onset and continuation of the condition. In addition, trials with the anti-viral drug, acyclovir, (Gantz and Holmes, 1990), have failed to produce any significant improvement for people.
Since there is also evidence that this illness may be triggered by other antigens such as tetanus vaccinations, as well as agents such as toxoplasmosis or brucellosis (Wakefield et al, 1990), a biological process more fundamental than infection may be occurring.\textsuperscript{7}

There remains another possible viral explanation, a retrovirus. During 1990, de Freitus claimed at an international conference in Tokyo that there was some evidence for a retrovirus in CFS (Bell, 1991). The data were part of a preliminary presentation. No peer reviewed papers have emerged from the finding. Others have also postulated a retrovirus as a possible cause (Murdoch, 1987; Dwyer, 1990) partly because of similarities in the onset and development of CFS and HIV/AIDS. However, if a retrovirus is implicated, it differs from other known human retroviruses since each of the four known human retroviruses rely on 'blood to blood' transmission. It is possible though that this could be a novel retrovirus, one which spreads through casual contact such as coughing and sneezing. Such retroviruses are known to occur in animals.

Immune dysfunction
At present, what seems most likely is that CFS is not a result of any one particular virus. Instead, Wakefield et al (1990) have argued that some viruses and microbes may alter some people's immune response and create the syndrome called CFS. The vulnerability of these people may be genetically determined, as Lloyd (in publication) and Bell (1991) have commented on the high incidence of this condition in families, even where members have become ill whilst separated in distance and time. Until recently, evidence to support one particular immunological hypothesis has not been consistent, as there have been conflicting reports about the ratios of T4/T8 cells which can be a measure of immune dysfunction (Behan et al, 1985; Tosato et al, 1985; Caliguiri et al, 1987; Murdoch, 1988; Lloyd et al, 1989).

However, Landay et al (1991) have recently produced results which replicate the data produced by Lloyd et al in 1989. With that replication of

\textsuperscript{7}It is important to remember that viruses remain poorly understood. Oldstone (1989) has claimed that there is now evidence that viruses disrupt the production of hormones and neurotransmitters. With this capacity, viruses may be implicated in the onset of a number of disorders, including hormonal abnormalities in adult onset diabetes, neuropsychiatric disorders and autoimmune diseases such as systemic lupus and multiple sclerosis.
the data produced by Lloyd and his colleagues at the Sydney Prince of Wales and Prince Henry Hospitals, CFS is now being increasingly regarded as a disorder brought about by an over-reactive, not an under-reactive (as in HIV/AIDS) immune system (Dwyer, 1991). In this theory of an over-reactive immune system (Wakefield et al, 1990), it is assumed that an initial trigger (such as a virus) causes the immune system to overreact, especially that part comprising the T cells. In genetically vulnerable individuals, the immune system continues to overreact to this trigger so excessive levels of interferon are produced. Interferon is the chemical produced by the body in response to, and as protection from, microbial invasion of any kind. From tests of interferon as a treatment for people with hepatitus B (McDonald et al, 1987), it is clear that excessive levels of interferon in the body produce the symptoms that most people associate with the flu, such as feelings of headache, lethargy, pain and fever as well as overwhelming fatigue. Therefore, with CFS, the excess levels of interferon may cause the ongoing discomforts that people experience. It is thought that relapses may be brought on by the body's exaggerated response to passing viruses or other antigens.

The immunological findings have been used as evidence for a large treatment trial in Australia of intravenous gamma globulin. Results of the first stage of that double blind trial have shown that 43% of people who received the treatment had improvements in their health whereas there was only a 12% improvement in the placebo group (Lloyd et al, 1990b). However the merits of the treatment currently remain uncertain until the second stage results of this trial are released, as Peterson et al (1990) found no significant benefit in their trial of this treatment.

Other explanations
'Alternative' health providers have suggested that CFS might arise from overconsumption of inappropriate foods such as fats, salts and sugars, the foods most commonly implicated in other diet related chronic disease, as well as excessive consumption of caffeine and alcohol (Brighthope, 1990). However, the nature of the diet is often regarded as less important in these explanations than the environmental contaminants which people might be absorbing in the air, water and foods they consume (Brighthope, 1990; Donohue and Fluhrer, 1989; Austin, 1989). There has been an Australian report that dramatically higher levels of organochlorides can be found in
the blood of people with CFS than would be found in the normal population (Donohue and Fluhrer, 1989). Certainly many of the symptoms that people suffer are consistent with heavy metal and other types of environmental poisoning (Bell, 1991), but as yet this area remains poorly studied. Practitioners with these views have established complex regimens for 'detoxifying' people's bodies, including very high doses of intravenous vitamin C, high levels of oral vitamin and mineral supplements and significant dietary changes. Fluhrer (1991) has reported marked improvements in more than half of those who have undergone combinations of these treatments.

CFS: its emergence as a modern illness

The history of this illness is a chronicle of the changing views about disease over the last century. In many respects, CFS still continues to illuminate trends in the definition and interpretation of disease. Since its aetiology remains obscure, and its identification problematic, the recent definition and increasing social and medical legitimacy of CFS as an illness are worth consideration for what they reveal about current influences on the understanding of disease.

In significant ways, the emergence of CFS as a recognised illness parallels a process which has already been documented by Fox (1989) in relation to the contemporary recognition and status of Alzheimer's disease (AD). AD is no longer the relatively obscure medical diagnosis that it was 10 years ago. It has been transformed in that time to its current characterisation as a leading cause of death in the US. Four factors were identified by Fox as relevant to this transformation: a social movement involving care givers, patrons, scientists and advocates; interest of a specific group of medical researchers; scientific research that caused a shift in biomedical conceptions so that it was possible to see the condition as a major social and health problem; and interaction between the social movement and the media and politicians, resulting in an increasing level of biomedical research funds.

The emergence of CFS as an illness which is increasingly being understood as physical in origin, has also relied upon these factors. Self-help groups,
comprising people who have grouped together around this specific problem, have acted in ways that generally characterise social movements. United not only around shared needs but also shared grievances and generalised beliefs about the causes of their problem, activist self-help groups in the UK, the US, New Zealand and Australia have helped to promote particular explanations of this illness. They have vigorously worked to establish the climate and sometimes the financial base for medical and social research on the illness. For example, in the US and the UK, self-help groups have sought to use governmental processes to legitimate this illness. In the UK, a Parliamentary Bill to bring awareness of the illness and its effects was presented in 1989, and an All Party Parliamentary Committee on ME (myalgic encephalomyelitis remains the most commonly used name for this illness in the UK) was formed and continues to meet to develop policy initiatives in relation to this illness (Annual Report of the ME Association (UK), 1990). In the US, a policy resolution on CFS was passed at the Governor’s Association meeting in February 1990. This is only the second policy resolution on a health issue ever passed by this group (Heart of America News, Spring/Summer, 1990). Twenty-three US states have also declared CFS Awareness Days or Weeks. Funding of research by self-help groups has been significant in the US, the UK and New Zealand. In Australia, the major part of the medical research that has been conducted into this illness at the Prince Henry/Prince of Wales Hospitals (PHH/POW) in Sydney, has been financed by local CFS Societies.

In theory, social movements are successful in achieving desired changes by generating widely acceptable definitions of their problem (Specter and Kitsuse, 1977). With illnesses, that definition and the related social legitimisation is also dependent upon the illness being definable as a disease, a complaint based in biomedical processes (Fox, 1989; Bammer and Martin, 1989). The achievements of CFS self-help groups have been remarkable, since they gained a considerable measure of recognition for this illness prior to 1988, irrespective of uncertainties about appropriate names for the illness or specific criteria for its definition and description.

The efforts of self-help groups were facilitated by the commitment of a small number of medical researchers and practitioners. Particular individuals such as Melvin Ramsey, former head of the Infectious
Diseases Unit at the Royal Free Hospital during the epidemic in 1955 and Paul Cheney, medical practitioner at Lake Tahoe (US) during the outbreak there in 1985, have made devoted efforts to get recognition for this illness. Although these individuals made major contributions, their efforts have been actively supported by many other committed researchers. In Australia, the commitment of the Sydney PHH/POW multidisciplinary team of researchers (principally Dwyer, Wakefield, Boughton, Lloyd and Hickie) has ensured ongoing medical research and public awareness of CFS in this country.

Nevertheless, contributions of individuals and self-help groups have been strengthened by biomedical developments. The absence of any physiological evidence for the symptoms experienced by people with CFS has consistently created difficulties for diagnosis and credibility of the illness. The discovery that people with this illness have unusual immunological profiles over time has helped to give this illness a biomedical basis. The development of immunology, greatly accelerated as it was by the concerns about HIV, has meant that a new way of understanding this illness (and many other illnesses) has been occurring.

Overall, the success of these developments in elevating this illness to that of a significant social and health problem is indicated by decisions at a recent international meeting on CFS sponsored by the US National Institutes of Allergies and Infectious Diseases (NIAID) and Mental Health (NIMH). The meeting, held in Washington in March 1991, decided that CFS was an illness which required further investigation. Over two million US dollars was allocated to its research over the next four years.

**Conclusion**

The history of controversy and the emerging new status of CFS are important contextual factors in people’s experience of this illness. With this illness, individuals have a range of symptoms that can be extremely disabling in some cases. They have to accommodate conflicting medical and social explanations, each of which offers only some prospect of an effective treatment for their problems. As well, these explanations may often be at variance to individuals’ own understanding of their
experience. The controversies and conflicting explanations have been discussed in some detail to provide background to this study, but they will also be drawn upon in later chapters.
Section II:

Method

This research was designed to examine the concerns of people with CFS and the doctors involved in their care. As such, two related investigations were undertaken. The first was a narrative and qualitative study which involved a detailed personal account of twenty people with CFS. The second investigation, a study of twenty general practitioners, The details of the two investigations are separately described in subsequent sections.

The investigations were conducted in Canberra, which has a population of nearly 300,000 people. With a younger age profile than Australia as a whole, the city is generally regarded as unusual by Australian standards. Not only for its demographically characteristics but also in terms of the services. The Canberra community is relatively affluent and well educated (approximately 30% of the adult population hold a tertiary diploma in 2008). Until recently, Canberra has been of unemployment lower than elsewhere in Australia and a higher proportion of women in the workforce. Although the level of community and health services has declined in recent years due to economic constraints, Canberra has a higher than average level of services (National Health 1990). All such people in this study had access to arguably the best services in Australia.

Study 1: Personal accounts of living with CFS

Study group

The purpose of this investigation was to discover in which perspective in people's diverse experiences of the illness. Therefore, 20 participants through a variety of community and medical settings. There were several reasons for this approach. Firstly, as mentioned in chapter one, people the research about CFS may have been influenced by a variety of factors relating to the participants' clinical specialties. Secondly, subjects from the perspective of specialists was clinically derived or medically relevant. People generally exclude those people who manage substantially different
Chapter 3

Method

This research was designed to examine the concerns of people with CFS and the doctors involved in their care. As such, two related investigations were undertaken. The central study rests on the detailed personal accounts of fifty people with the condition. The second and subsidiary project explored the views of twenty general practitioners. The details of the two investigations are separately described in subsequent sections.

Both investigations were undertaken in Canberra, which has a population of nearly 300,000 people. With a younger age profile than Australia as a whole, the city is generally regarded as unusual by Australian standards, not only for its demographic characteristics but also for the standard of its services. The Canberra community is relatively affluent and well educated (approximately 20% of the adult population had a degree or diploma in 1988). Until recently, Canberra had levels of unemployment lower than elsewhere in Australia and a higher proportion of women in the work-force. Although the level of community and health services has declined in recent years due to economic constraints, Canberra has a higher than average level of services (Canberra's Health, 1988). As such, people in this study had access to arguably the best resources in Australia.

Study 1. Personal accounts of living with CFS

Study group
Selection sources and criteria
My intention in this investigation was to discover common properties in people’s diverse experiences of this illness. Therefore I sought participants through a variety of community and medical settings. There were several reasons for this approach. Firstly, as mentioned in chapter two, much of the research about CFS may have been influenced by sample selection biases relating to the researchers’ clinical speciality. Secondly, apart from the possibility of speciality bias, clinically derived or medically referred samples generally exclude those people who manage substantially outside
the medical system (Conrad, 1990; Watson and Kendall, 1983). This is less of a research concern with some illnesses, such as end-stage renal failure, because people's lives are dependent upon medical technology and most potential participants will be included in the clinical sample. However, with conditions such as CFS, many people may choose to manage their condition outside the medical system since there are no available medical treatments that involve people in ongoing medical care. In these circumstances, an alternative approach could have been to seek participants solely through self-help registers. But self-help groups may also create their own biases: they too may influence people's interpretations and management of their condition. Further, having an illness does not necessarily make people want to seek either ongoing medical care or the assistance of a self-help group.

I relied on three main sources for participants. First, I gave public talks to the local CFS/ME society. These talks were advertised through the local media and were open to members and non-members of the society. Eighteen people joined the study at the first of these talks in June 1990; another four people joined in February 1991 following a brief presentation on my work in progress. Twelve of these participants were members of the CFS Society at the time of the talks, and most of them knew each other well, as they were past or present CFS/ME Society committee members. Some of the others subsequently joined the Society, which currently (1993) has over 250 members. The second major source of participants was colleagues and other health professionals. They referred a further seventeen participants. The third source was the advertisement I placed in the newsletter of the CFS/ME Society's newsletter. This advertisement specifically asked for young people to become participants. I placed the advertisement after it became apparent that young people (under thirty years) had had different experiences and concerns from older participants. Seven young women responded to this request. Finally, three people joined the study because they were part of my social network, and one joined after another participant mentioned the study.

Despite this emphasis on diversity, I wanted to be confident that CFS was the unifying thread in people's experiences. Diagnosis of CFS by a doctor became an essential characteristic for inclusion in the study. However, the reliability of the diagnosis was difficult to determine because different
criteria may be applied by different doctors (Feinstein, 1977; Koran, 1975). In some situations, participants can be assessed by the same panel of doctors, and participation can then be dependent on the panel's unanimous agreement on diagnosis. Such assessment was not possible for this study. Instead, I made selection contingent upon people having received a diagnosis of CFS from a doctor and having an illness which I thought was consistent with the diagnostic criteria developed by Wakefield et al (1990). Specifically, they must have been ill for more than six months, other possible explanations for their illness must have been examined and rejected, and they must have had chronic or relapsing fatigue associated with some neuropsychiatric dysfunction. Fifty-five people were interviewed initially, but when these criteria were applied after their interviews, five were excluded from the final analyses. Although two people joined the study without a diagnosis, they were included in the discussion because they were subsequently diagnosed by doctors as having CFS. By the time the study had been completed, thirty-six people had received the diagnosis of CFS from more than one doctor. In summary, twenty-eight people had received a diagnosis from a general practitioner, twenty-four from a specialist (psychiatrist, rheumatologist or

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1 Two of the five who were excluded had been given alternative diagnoses. One had severe multiple sclerosis. He felt he had some symptoms that were more consistent with CFS and that these had actually pre-dated the apparent onset of multiple sclerosis. He wanted to tell me his story because 'no one had ever really wanted to hear it'. The story was poignant. It had many points in common with the stories of those with CFS. It may be almost forgotten, but multiple sclerosis has also had a controversial history. Another person had a diagnosis of post-polio syndrome, which some describe as a form of CFS, but others regard as a separate condition (Munsat, 1991). Two others had been given diagnoses of major depression or CFS by the same doctor. After talking to them I felt their symptoms were most adequately described by a diagnosis of depression. Before the completion of this research both had recovered. Each felt uncertain about the previous diagnosis of CFS at that time and seemed more inclined to interpret the condition as depression. The fifth person had not received a diagnosis of CFS from a doctor. He was given the diagnosis by a naturopath. (This naturopath told me that she had treated over 2,000 people with CFS in the preceding two years. As this represents approximately 1% of Canberra's population I had some reservations about the accuracy of her diagnoses.) The naturopath also found high levels of toxoplasmosis in the person's blood, a condition which had had similar debilitating effects on him several years before. On the present occasion he had been ill for approximately six to seven months, so he only just fulfilled the selection criteria on that basis. It has been claimed that toxoplasmosis can be a trigger for CFS (Wakefield et al, 1990), but the symptoms of toxoplasmosis, when they are present, are very similar to those of CFS (Rickard, 1991).

2 In this way I was able to hear the stories of two people who had not yet had their illness 'officially' named.
physician) and ten had been given the diagnosis from specialists or researchers at tertiary referral centres.

Characteristics of the study group
The study group comprised forty women, ranging in age between thirteen and sixty-four years (mean = 36.4 years) and ten men with an age range between twenty-five and fifty-three (mean = 39.2 years). Table 3.1 shows the distribution of ages. Participants’ personal details (education, marital and family status) at the time of the first interview are summarised in tables 3.2–3.4.

The characteristics of this group are consistent with those that have been noted in clinical populations (Daugherty et al, 1991; Komaroff and Buchwald, 1991; Shafran, 1991). There is a higher number of women than men, and generally people were well-educated and middle-aged. The large proportion of people in marital relationships, living with families or parenting children, casts doubt on Shorter’s (1992) claims that it is mostly the lonely and disaffiliated who develop conditions such as CFS.

Twelve participants had family members who were also affected by CFS. In two instances a sick parent and the adult child participated in the study. A further five participants had an affected partner; both partners were interviewed in one instance. These patterns raise interesting questions, outside the scope of this study, about possible genetic predispositions, sources of infection, environmental factors and behavioural influences.

Tables 3.1–3.8: Characteristics of study group at time of first interview

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to 1940</td>
<td>8</td>
</tr>
<tr>
<td>1941–1950</td>
<td>13</td>
</tr>
<tr>
<td>1951–1960</td>
<td>14</td>
</tr>
<tr>
<td>1961–1970</td>
<td>13</td>
</tr>
<tr>
<td>After 1970</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 3.2: Educational level

<table>
<thead>
<tr>
<th>Years of schooling</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 10 years schooling</td>
<td>5</td>
</tr>
<tr>
<td>10–12 years schooling</td>
<td>3</td>
</tr>
<tr>
<td>Post-secondary</td>
<td>4</td>
</tr>
<tr>
<td>Tertiary</td>
<td>38</td>
</tr>
</tbody>
</table>

Table 3.3: Marital status

<table>
<thead>
<tr>
<th>Marital status</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single/never married</td>
<td>15</td>
</tr>
<tr>
<td>Married/de facto</td>
<td>32</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 3.4: Family status: numbers of participants with children

<table>
<thead>
<tr>
<th>Family status</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants with children</td>
<td>27</td>
</tr>
<tr>
<td>Participants with no children</td>
<td>23</td>
</tr>
</tbody>
</table>

Table 3.5: Severity of illness

<table>
<thead>
<tr>
<th>Illness severity</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>6</td>
</tr>
<tr>
<td>Moderate</td>
<td>25</td>
</tr>
<tr>
<td>Severe</td>
<td>19</td>
</tr>
</tbody>
</table>

Table 3.6: Duration of illness

<table>
<thead>
<tr>
<th>Duration in years</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 10 years</td>
<td>10</td>
</tr>
<tr>
<td>5–10 years</td>
<td>10</td>
</tr>
<tr>
<td>3–5 years</td>
<td>13</td>
</tr>
<tr>
<td>1–3 years</td>
<td>15</td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>2</td>
</tr>
</tbody>
</table>
As with all illnesses, severity could vary from person to person, as well as from time to time. In this study, severity was assessed using a modified version of Bell's disability scale for people with CFS (1991, p185), itself a modification of Karnofsky's Performance Status Scale (Karnofsky and Abenmann, 1948). Figure 3.1 describes this scale. My two modifications of Bell's scale included a time frame for each category, because the effects of the illness can change over time, and a reduction from ten to three categories. Assessment of severity was based on a person having three of the criteria in a given category. Table 3.5 summarises people's state of health at the time of the first interview, whilst Table 3.6 indicates the duration of their illnesses. Employment status and sources of income (Tables 3.7 and 3.8) were also influenced by the severity and duration of their condition. Given the pronounced severity and duration of most participants' illness, this study clearly reflects the experiences of people whose lives have been significantly disrupted by their illness.
Mild
- Mild symptoms occurring more often than not when at rest;
- Symptoms usually worsened by significant amounts of physical or mental exertion (or emotional stresses);
- Some restriction on daily activities requiring exertion or mental effort;
- Relapses (illness periods, when symptoms are significantly increased, which last in excess of three days) are either absent or minimal over a period of several weeks;
- Able to work full time and, with some degree of difficulty, pursue additional outside interests or perform family duties.

Moderate
- Mild symptoms always occur when at rest. Moderate symptoms occurring more often than not when at rest;
- Symptoms nearly always worsened by any physical or mental exertion (or emotional stresses);
- A noticeable number of relapses occur over several weeks;
- Daily activity clearly restricted, with significant need for rest periods during the day;
- May be able to work full time, but this usually means that life is organised around work, i.e., person goes to bed shortly after arrival at home, and spends a significant part of weekends in bed. (Work usually requires minimal physical exertion, or is routine or predictable in significant ways.) Part-time work possible, but activities and interests conducted outside work time are significantly restricted.

Severe to very severe
- Moderate to severe symptoms occurring when at rest. Severe symptoms (including marked cognitive difficulties, weakness, pain or severe muscle spasms) occur more often than not when at rest;
- Symptoms worsened by physical or mental exertion (or emotional stresses);
- Frequent and severe relapses may occur over several weeks;
- Significantly restricted daily activity, either physical or mental. Such activity usually less than three hours per day. There may only be very brief periods of time when activity can occur, and these have to be followed by rest of some kind (from sitting to complete bedrest);
- Work rarely possible because of the limited time for activity. Limited part-time or flexible hours work or study may be possible;
- During a six month period, confined to house or bed either very frequently for short periods or less frequently but for periods in excess of three weeks.
Participants' reasons for joining the study
Participants' reasons for joining the study were varied. They were told the study was examining the management of CFS. However it was clear from participants' comments that only some had joined the study because they had a sense of competence in managing the illness. When asked to identify their hopes and reservations about participation, participants sometimes mentioned more than one issue. Twenty-five said they thought research on CFS and its management was important, twenty-one expressed a hope that their experiences might help others and seventeen said they joined because they thought it would be helpful to talk to someone about their illness. Few expressed fears about the study. A small number of people were worried that their story might not be 'useful' to me. Four had concerns about confidentiality. One of these people later withdrew from the study. The concerns in each case were related to a pending insurance assessment of disability, but the person who withdrew gave me permission to include parts of the previously provided story in my analysis. Because of these concerns, and my own desire to maintain the privacy of participants, considerable care has been taken to maintain anonymity both in individual case outlines and direct quotations.

Size of the study group
The final size of the study group was determined by two factors. Time was an important factor; I had three years in which to complete the study and as my intention was to follow people for an eighteen-month period, I had to allow adequate time for that follow-up. Secondly, as the number of interviews increased, I came to agree with Conrad's (1990) suggestion that fifty participants is an adequate number for studies such as this. When I had completed forty or so interviews, common elements or themes in participants' accounts had begun to recur.

Study design
This research is based entirely on data derived from interviews. Participants who had CFS were interviewed three times over nearly two years (August 1990–May 1992). There was a period of approximately twelve months between the first and second interviews, and another gap of six months between the second and third interviews. For the first and second interviews, most participants were interviewed in their own homes. In the few instances where this did not happen, participants were
interviewed either at my home or at the university, whichever they preferred. Two participants who normally lived together were interviewed at the same time at their request. The third interview was conducted by telephone (mostly due to my time constraints).

Initial interviews
The first interview schedule and a list of symptoms were developed in consultation with a group of seven people. The schedule included specific questions about the characteristics of the illness, its course over time, the history of medical investigations, the social consequences of the illness, the significance for the person, and approaches to management. The interview schedule posed specific questions, rather than outlining the issues that I wanted to discuss, because so many people with CFS complain of their own vagueness and confusion. This interview schedule, together with the list of symptoms, a brief description of the research and its aims, and a consent form were forwarded beforehand to participants. In this way they were given time to reflect on answers and the opportunity to reconsider their participation after viewing the range of issues that interviews would cover. No one withdrew after receiving the questions. On the contrary, over 60% of participants used the schedule to prepare detailed (sometimes very extensive) responses to my questions. They had sought the comments of family members or used information from personal diaries or medical records to assist them.

At the interviews, respondents varied considerably in the way they used this preparation. I provided them with the option of either talking directly to their notes and the interview schedule, or telling me their story of the illness in the way that seemed to make most sense to them. In this way I received answers from most people covering all the areas of research interest, but I did so in a manner which seemed relevant to people. This policy gave me additional rich insights into their experience, and was supported by four main strategies.

3 In this ‘reference group’ each person had received a diagnosis for their illness from a medical specialist. Originally I had hoped to hold occasional meetings to consult with this reference group about the progress of the study. I quickly discovered that it is difficult to organise meetings with people who have a chronic illness, so much of the consultation was done individually, and on a sporadic basis.
4 Appendix A contains copies of these documents.
1) The most important of these strategies was a time line. This was a line drawn on a page where the point at the left-hand end represented the year of the person’s birth and the far point on the right-hand end was 1991. For some people this approach facilitated a relatively orderly recall of past events. Others did not require it or found it confusing, irrelevant or distressing to try to order events that way.

2) At intervals during the interview, I would summarise what had been said to that point, reflect on its significance for the person, link that to the research questions and ask for further clarification.

3) When an interview had been wide ranging and participants were becoming tired, I would ask which questions on the schedule they still wanted to answer.

4) The way in which people told their stories, including their turns of phrase, the different styles of commentary and the levels of emotion that were expressed, often seemed to be particularly revealing about their daily life with, and management of, the illness. Rather than assume too much about these characteristics, I usually asked participants about them so that they could make comments and help me with the interpretation.

This approach was adopted following a pilot study with eleven people, during which the symptom list, interview questions and a two-week diary were used to provide details of the illness. The questions and the symptom list were slightly modified at this point. These two methods of eliciting information were then maintained for the other participants, although it was clear that questioning about these issues would need to be flexible and sensitive. The diary approach was abandoned as most found it too onerous and/or too depressing (I don’t want to see all the things that have been wrong with me each day)\(^5\), or it became one thing too many to remember to do in a day. Only two participants in the pilot study had found the diary a useful or tolerable activity.

These initial interviews lasted between one and a half and five hours. With six people the interview was conducted in two separate sessions, and one person was too sick to be interviewed for more than a few minutes on

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\(^5\) Throughout the rest of the text, comments made by participants appear in italics.
each occasion, and finally wrote her answers to the questions over a four-month period.

Later interviews
For the second and third interviews, three broad areas of interest were identified: changes in health, changes in management and the person's explanations for such changes. Three weeks prior to each interview, I again sent participants an outline of the questions\(^6\). On these occasions the questions were expressed as broad topics of interest. By then rapport had been well established, and I was aware of participants' preferences for a structured or unstructured interview, so I was able to respond accordingly. Second interviews lasted between three-quarters of an hour and three hours. Third interviews, conducted by telephone, were briefer, lasting from fifteen minutes to two hours.

As others (Conrad, 1987; Kleinman, 1988) have pointed out, the essential characteristic of chronic illness is its continuation over time. Second and third interviews were necessary not only to identify any changes in people's health over time, but also to note people's explanations and feelings about them.

In order to trace the changes in people's health over time, I used the modified Bell scale already outlined in Figure 3.1, in conjunction with people's own assessments of change. I chose to complement the modified Bell scale because structured measures of people's health usually fail to recognise that individuals make choices about how to organise their lives when they continue to be ill; as well, people's social and financial circumstances, altered as they are by illness, can influence the choices that they make (Teeling Smith, 1988; McDowell and Newell, 1987). On the other hand, subjective measures also had limits. People readily acknowledged that their own estimates were unreliable as they could not remember why they might have said they were functioning at 50% of their 'normal' level: your ideas change over time as different things become important. A few said that working out a percentage figure was too hard. Instead of seeking a percentage estimate of their health from participants, I asked them to comment on whether they thought they were, on average over the last few months, 'getting better', 'getting worse', 'much the same'

\(^6\) Copies of these documents are in Appendix A.
or 'don't know'. I also asked them what aspects of their health had changed for them to consider it 'better' or 'worse'.

In following the changes in people's feelings and explanations over time, I was aware that I was relying on retrospective accounts. As Bloor (1985) has observed, the process of describing and defining past events and actions can misrepresent the way that decisions and responses originally occurred by giving them a spurious finality. Certainly, as people reflected on past experiences, they became like 'archivists researching a disorganised file of past experiences' (Kleinman, 1988) reviewing the value and usefulness of past actions and events in the light of recent ones. Nevertheless, because this was a longitudinal study with repeated interviews, some perspective on people's accounts could be gained (Burgess, 1984). The main events of people's accounts remained much the same with subsequent interviews. However, as with any narrative accounts, the 'ongoing meaning and sense of events' (Bruner, 1986) often changed between interviews. I was particularly interested in the changes over time in people's interpretations, since new and modified interpretations provided insights into the ways that people were managing their condition.

Particular care was taken about the effect of this research on participants' lives. The processes of reflection and self revelation may have had unpleasant reverberations on people's lives and those around them. People were therefore encouraged to participate in discussions only if they felt comfortable, and to close the interview if they were feeling too tired or ill. On the other hand, this form of research may have a constructive influence on people's management of the illness. It has been noted that there is frequently a placebo effect in any research on chronic illness. People may feel better from an intervention because they expect it to make a difference or because there is an increased sense of well-being due to the increase in attention and interpersonal interaction (Watson and Kendall, 1983). Although two-thirds of the participants commented in passing that the interviews had been 'therapeutic' or 'helpful' (or similar words), the interviews were not intended as a form of intervention in the illness and therefore have not been evaluated in any way. Perhaps inevitably, participants asked me about my views and opinions on management. I tended to restrict my comments to available research data or I would say
things like 'some people have told me...'. I always encouraged people to evaluate or monitor any interventions they tried.

**Study 2. Doctors and CFS**

As mentioned in the introductory chapter, I decided to interview doctors when it became apparent that their responses markedly influenced how people responded to their illness. In this subsidiary part of the study, doctors were asked about their views on CFS and the dilemmas it posed for them in their practices. These concerns were discussed in relation to their beliefs and practices around chronic illness generally, their concerns about professional standing, and the restraints imposed by structural aspects of the health system such as their training.

**Study group and design**

The majority of the twenty doctors who joined this study did so with the assistance of the Royal Australian College of General Practitioners (RACGP) in Canberra. Four doctors attended a RACGP discussion group about the issues involved in the management of CFS in November 1990. That discussion group was organised on my behalf by the RACGP. A further fifteen doctors volunteered to be interviewed in response to an advertisement placed in the RACGP newsletter in December 1990. One doctor joined at my request; he was well-known for his interest in CFS.

Although many Australian doctors have recently reported that they feel isolated and demoralised, and that their skills are not being utilised in the present system of health care (Douglas and Saltman, 1991), the twenty doctors I interviewed did not seem to share their colleagues' feelings of discontent. They were all apparently highly motivated and committed to their work, keen to discuss their ideas and practices relating to chronic illness. They had devised ways of making their work satisfying within the constraints of the present system. Over half of them had developed reputations relating to their specialist interests in women's health, student health, nutritional health, chronic illnesses or chronic pain. A disproportionate number (nine) were working in salaried practices, despite

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7 In 1991, Dickinson estimated that there were 348 general practitioners in Canberra; almost 190 of these were working on a part time basis.
there being few salaried positions in Canberra\textsuperscript{8}. Salaried doctors were perhaps less inhibited by the time constraints that doctors can experience when they work on a fee-for-service basis. The number of female doctors was also disproportionately high (eleven)\textsuperscript{9}. Several of the women had part-time practices, and a few were salaried, so they may have had more time to participate in the study.

The study with doctors followed similar interview procedures to those used in the study of people with CFS which I have already outlined. A statement about the purposes of the study was sent to volunteers beforehand, together with a consent form and summary points about the topics of the interview: numbers of patients with CFS or puzzling chronic illnesses, thoughts and concerns about CFS and its management\textsuperscript{10}. With the exception of the discussion group, which was held at the RACGP Office, interviews were conducted in the doctor's usual workplace and lasted approximately three-quarters of an hour. Interviews were conducted between December 1990 and May 1991.

When this part of the study was commenced, I had intended to use the interviews to develop a questionnaire to determine the level of ACT doctors' interest in CFS. Two events occurred during this time which made me decide that this questionnaire was unnecessary. \textit{Australian Dr Weekly} (Demou, 1989) had published details of a survey of changes in doctors' attitudes towards CFS showing that close to 80\% of doctors were interested and concerned to know more about CFS. Also, Professor Dwyer from the Sydney POW/PHH research team addressed a RACGP meeting in Canberra about CFS. More than fifty doctors attended, which was regarded by organisers as an exceptionally large audience. It was clear that CFS was a health issue that was attracting considerable interest amongst doctors in Canberra as well as elsewhere. It therefore became more pertinent to

\textsuperscript{8} The majority of doctors in Australia work on a fee-for-service basis, thus the level of their income is determined by the number of clients they see. A small minority of doctors are employed in government sponsored health centres where they are paid a weekly (or pro rata) salary for their services.

\textsuperscript{9} It is difficult to estimate the precise numbers of female doctors practising in Canberra, since a doctor may be registered without necessarily also practising. Nevertheless, female doctors are almost certainly fewer in number than male doctors. It was recently suggested that between three-quarters and four-fifths of all general practitioners in Australia are male (Dewdney, 1989).

\textsuperscript{10} See Appendix B for copies of these documents.
structure my interviews with doctors to explore the way their interest in CFS was translated into professional practice.

Analysis

Most interviews were taped and I later transcribed them. Initially this was done as a verbatim report. After the first eleven pilot interviews (which produced 500 pages of single-spaced typing) I produced edited transcripts. Anecdotes which had little obvious relevance to the research were noted only in summary form; nevertheless, the data were extensive. The first set of interviews with participants with CFS produced 1,400 pages of edited transcript. The second set of interviews produced 900 pages. The third round of interviews, conducted by telephone, was not recorded and transcribed. Instead detailed notes were kept of the conversations. Interviews with doctors produced 100 pages of edited transcript.

Two procedures were used for analysing the interview transcripts. The first has been well described by Miles and Huberman (1984). Categories were developed to summarise the main points of the interviews. Some of these categories were apparent from the issues that were explored in the first interview, for example, diagnosis, history of illness, effects on family. Some sub-categories were developed after all the interviews were completed. Each interview was then reviewed, so that relevant segments of the transcripts could be identified by category. To ensure reliability and consistency in this coding process, several interviews were recoded some weeks after they were initially coded. The computer software NUDIST (Richards and Richards, 1989) was used to facilitate the organisation of categories and the retrieval of the coded text.

Some concerns have been expressed about the distortions that may be created by the coding process (Conrad, 1990), since coded excerpts of text may fail to take into account the context of comments, particularly in terms of surrounding comments. Written text also removes the pacing and emotion that characterised people's speech, yet these can be very important in conveying the meaning of certain comments. Because I

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11 Appendix C provides an index of all categories.
conducted the interviews, transcribed them and later coded and analysed them, I was thoroughly familiar with both the context and the emotion.

The second procedure used for analysing these interviews had less to do with the text of interviews. It was closer to what I understand to be the 'grounded theory' approach advocated by Glaser and Strauss (1967) and Strauss (1987). This part of the analysis was based on the notes that I made after interviews, or during the transcribing and coding processes. The aim with this procedure is to move beyond the craft of coding to make the link between participants' words, my impressions, and existing or possibly new theoretical constructs. Through this process, the broader meanings and significance of people's accounts emerged. Although it is these broader meanings that give structure to my account in subsequent chapters, the general discussion relies firmly on the data extracted by careful coding.

Consistent with the approach that is adopted in most qualitative studies, I have generally used 'quasi-statistics' as outlined in Figure 3.2 to support my arguments. However, at times, specific numbers have been used in relation to particular claims; usually that has been done when all participants had given replies to a specific question.

Figure 3.2: Quasi-statistics and their meaning

| 'many'      | > 50% participants |
| 'some'      | 25-50% participants |
| 'few' or 'several' | < 25% participants |

Validity

In addition to the formal interviews conducted during this study, I had at least 350 informal or clinical (in my professional counselling role) interviews with other people who had been diagnosed with CFS, or with their concerned parents, partners or friends. As pointed out in chapter one, some ongoing contact occurred with many participants. In addition, I had over fifty informal discussions with various interested doctors and health professionals. With only two exceptions (specified elsewhere) information gathered during those contacts is not used directly in any
discussion. However, these additional interviews contributed to the overall perspective I now have on this condition and its management.

The validity of a study such as this is assessed by how well the findings correspond to reality, are coherent or useful in the context of a person’s or society’s problems, or have aesthetic and moral value (Kleinman, 1988). I have been primarily concerned to produce useful and meaningful findings for those people who live with CFS or similar conditions, the people who live with them and care for them, and those who have a therapeutic role in their lives. By maintaining a diverse range of contacts with people with CFS and those around them, I was able continually to assess the validity of my findings. The discussion throughout has been influenced by responses from people such as, yes, that’s just like my story; that’s familiar; or I hadn’t thought of it like that, but yes it fits.
Section III:

Findings and discussion
Chapter 4

Dimensions of the problem:
the characteristics of chronic fatigue syndrome over time

Chapter two provided descriptions of CFS as a clinical and social entity. This chapter complements those descriptions by summarising participants' perceptions of their condition and its physiological and psychological effects over time. Following these summaries, I discuss how people's descriptions of their symptoms and health over time could vary according to their feelings and concerns at the time of the interview. Exploring these feelings and concerns provides some perspective on the major difficulties that people had in trying to interpret and manage their symptoms. In this way, the features of the illness that people found particularly pervasive and distressing are highlighted.

Characteristics of CFS

In the first part of this chapter I have used a framework devised by Rolland (1987) to simplify the summary of people's comments about their condition. Rolland summarises the problems and features of chronic illnesses and disabilities according to their onset, the incapacities or disabilities they cause, their patterns over time and their outcome. To illustrate the usefulness of this framework, a few examples follow. The onset of an illness may be gradual, as in Parkinson's disease, so that people may take some time to realise they are ill; or onset may be acute and immediately obvious, as in strokes, so that people make an abrupt transition between health and disability. The incapacities that people may incur can be diverse: their cognitive functioning may be damaged (e.g. Alzheimer's disease), sensation may be altered (e.g. blindness), or movement restricted (e.g. multiple sclerosis). They may be disfigured (e.g. eczema or psoriasis) or have to endure social stigma (as with HIV/AIDS). Courses and outcomes of illnesses are often linked. The course of an illness may be progressive, increasing in severity (as in Alzheimer's disease or emphysema), so that people have few periods of relief from their illness; or the illness may follow a course marked by long term
debility as in rheumatoid arthritis; or thirdly, the illness may be relapsing or episodic, as in asthma or some forms of multiple sclerosis. Each of these different courses and outcomes poses different problems for people with an illness. If the illness is progressive, then a person faces grief and increasing losses and discomforts. If there is a constant deficit, or long term debility, then people need to work out ways to live with its limiting effects. If there is an episodic course, people tend to live with constant uncertainty, vigilant about possible relapses or attacks, as well as frequently entertaining hopes about recovery.

In the following four sections, CFS will be described according to participants' perceptions of its onset, its incapacitating effects, its changing patterns and its uncertain outcome.

**Onset**

By definition, to have CFS, a person must have been ill for over six months; diagnostic and research criteria for CFS also generally favour an acute onset (Daugherty et al, 1991; Ho-Yen and McNamara, 1990). In this study, the majority of participants (thirty-five) identified a major viral (or flu-like illness) episode early in their illness. Fifteen of these thirty-five participants claimed that the acute illness marked the change from feeling healthy to feeling unwell on an ongoing basis. Prior to that, they were fit, busy and productive. Afterwards, life was significantly altered, and five participants were considerably disabled for periods ranging from several weeks to three years. One person required the aid of a wheelchair. Eleven of the fifteen described this onset as the most severe stage of their illness. The onset had been variously labelled: Cocksackie B (one), encephalitis (one), glandular fever (five), rubella (one), gastrointestinal infection (one), and flu or unidentified virus (six).

The remaining twenty of the thirty-five people who had identified a virus (or flu-like illness) early in their CFS, felt it marked a turning point in their health, but they acknowledged that their health had not been entirely satisfactory for some time. In contrast to those who felt that their health went from extremely good to unsatisfactory with the viral onset, this group felt that they were 'unhealthy', 'unfit' or 'stressed'. The viruses included glandular fever (seven participants, one of whom also tested positive for toxoplasmosis), while the remaining thirteen people had
unidentified viruses or flu. Participants’ health histories before the period of viral illness included allergies, extreme weariness, severe emotional stresses, chronic sinusitis and gastrointestinal problems, a series of viral infections, and long histories of ill health relating to severe or minor illnesses during their childhood and adolescence.

Some people did not have a distinct, unambiguous onset of illness, a feature that has been noted in other studies (Komaroff and Buchwald, 1991; Bell, 1991). Fifteen of the fifty participants in the study described a gradual onset of illness over years. Five people had gradually become less well following a rapid succession of minor illnesses. Two had no sense of having had a specific period of sickness, although one had received a positive test for glandular fever. One had been in severe pain for ten years and had been given a diagnosis of Repetition Strain Injury, but with time had been increasingly inconvenienced by a variety of cognitive and gastrointestinal symptoms. Three had been severely emotionally distressed for some time. They said that they had often felt ill during that time, but dismissed their symptoms as stress. They increasingly found themselves feeling disproportionately unwell in relation to the stresses. The illness continued after those stresses were substantially resolved. Three identified a variety of factors involved in the progressive decline of their health: one person had had five major operations over three years, a car accident and glandular fever; another had had a history of severe allergies, a number of severe emotional and physical stresses, several infections and a ruptured stomach preceding the worst aspects of the illness; and the third person had had several neurological abnormalities—in particular, disturbed balance and vertigo—together with glandular fever and exposure to chemicals.

**Incapacities**

People were incapacitated in three important ways: their activity levels, cognitive performance and moods were significantly altered. Some people also experienced unusual sensations. The symptoms associated with these changes are listed in Table 4.1.
### Table 4.1: Symptoms of CFS (at first interview) reported as percentages for n = 50

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Musculoskeletal</strong></td>
<td></td>
</tr>
<tr>
<td>aching limbs</td>
<td>92</td>
</tr>
<tr>
<td>other sore muscles/joints</td>
<td>92</td>
</tr>
<tr>
<td>sore back</td>
<td>72</td>
</tr>
<tr>
<td>double vision</td>
<td>64</td>
</tr>
<tr>
<td>muscle twitching/spasms</td>
<td>56</td>
</tr>
<tr>
<td><strong>Neuropsychiatric</strong></td>
<td></td>
</tr>
<tr>
<td>losing words</td>
<td>98</td>
</tr>
<tr>
<td>other memory loss</td>
<td>96</td>
</tr>
<tr>
<td>depression (self-identified mood)</td>
<td>90</td>
</tr>
<tr>
<td>disturbed sleep</td>
<td>90</td>
</tr>
<tr>
<td>irritability/frustration</td>
<td>86</td>
</tr>
<tr>
<td>confusion</td>
<td>84</td>
</tr>
<tr>
<td>temperature control irregularities</td>
<td>82</td>
</tr>
<tr>
<td>anxiety (self-identified mood)</td>
<td>80</td>
</tr>
<tr>
<td>clumsiness</td>
<td>76</td>
</tr>
<tr>
<td>disturbed balance</td>
<td>70</td>
</tr>
<tr>
<td>loss of spatial perspective</td>
<td>66</td>
</tr>
<tr>
<td>vivid dreams or nightmares</td>
<td>62</td>
</tr>
<tr>
<td>vertigo</td>
<td>60</td>
</tr>
<tr>
<td><strong>Gastrointestinal</strong></td>
<td></td>
</tr>
<tr>
<td>alternating diarrhoea/constipation</td>
<td>70</td>
</tr>
<tr>
<td>nausea</td>
<td>64</td>
</tr>
<tr>
<td><strong>Urogenital</strong></td>
<td></td>
</tr>
<tr>
<td>incontinence</td>
<td>40</td>
</tr>
<tr>
<td>retention of urine in bladder</td>
<td>10</td>
</tr>
<tr>
<td><strong>Endocrine</strong></td>
<td></td>
</tr>
<tr>
<td>hormonal disturbances (women)</td>
<td>86</td>
</tr>
<tr>
<td>thyroid disturbances</td>
<td>20</td>
</tr>
<tr>
<td><strong>Non-specific</strong></td>
<td></td>
</tr>
<tr>
<td>weakness</td>
<td>98</td>
</tr>
<tr>
<td>tired/fatigued</td>
<td>94</td>
</tr>
<tr>
<td>exhausted</td>
<td>90</td>
</tr>
<tr>
<td>headache</td>
<td>88</td>
</tr>
<tr>
<td>sensitive to sound</td>
<td>78</td>
</tr>
<tr>
<td>sweats</td>
<td>76</td>
</tr>
<tr>
<td>dizziness</td>
<td>70</td>
</tr>
<tr>
<td>swollen glands</td>
<td>70</td>
</tr>
<tr>
<td>difficulty in focussing vision</td>
<td>64</td>
</tr>
<tr>
<td>fever (low grade)</td>
<td>62</td>
</tr>
<tr>
<td>pins and needles</td>
<td>58</td>
</tr>
<tr>
<td>shortness of breath</td>
<td>50</td>
</tr>
<tr>
<td>persistent ringing in the ears</td>
<td>40</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
</tr>
<tr>
<td>allergies/intolerances</td>
<td>84</td>
</tr>
<tr>
<td>chronic sore throat</td>
<td>82</td>
</tr>
<tr>
<td>candida</td>
<td>30</td>
</tr>
</tbody>
</table>
Altered activity levels
People’s activity levels were altered by the diverse range of symptoms they had which left them feeling ill in a variety of ways. In particular, however, people spoke of the debilitating effects of fatigue, weakness and exhaustion. Almost every participant had experienced all three symptoms.

Although 'fatigue' is prominent in the name of this condition, the term itself is generally poorly defined. In the biomedical literature, 'fatigue' can convey meanings from generalised exhaustion to a specific response to mental or physical activity (Armon and Kurland, 1991; Barofsky and Legro, 1991; Simpson, 1991)\(^1\). However, for CFS, Wakefield et al (1990) have specified that the fatigue should be related to people's response after mental or physical efforts.

Although most participants tended to blur any distinctions between notions of fatigue, weakness and exhaustion, some of them gave me examples that were specific illustrations of each of these symptoms. With fatigue, several people described it as their response after some minimal activity:

- Cleaning the house felt like a marathon.
- I collapsed after potting three plants.
- Even sewing on a button can bring on a minor relapse.
- I’d come home from work and be unable to eat from exhaustion.

The suddenness of the onset of this fatigue was graphically conveyed by: a heavy veil descending; a wall going up; or a feeling that someone has just turned up the gravity meter.

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\(^1\) Barofsky and Legro (1991) discuss the history of efforts to define this troublesome concept of fatigue. They point out that some definitions are very broad. For example, they cite Piper (1989) who describes it as 'an overwhelming sustained sense of exhaustion and decreased capacity for physical and mental work'. Other definitions have been based on an underlying theoretical construct (such as a specific form of biological incapacity). Still others have attempted to include a measurable decrement in performance over a specified time period. Armon and Kurland (1991) describe fatigue as the discomfort induced by prolonged and excessive exertion; pathological fatigue in their terms relates to the definition of 'prolonged and excessive'.
On the other hand, a few people dismissed the term 'fatigue' because they interpreted it as meaning 'tired': Oh fatigue! That's normal isn't it when you have four children. One person rejected the term because it sounded so feeble and effete.

'Exhaustion' was generally interpreted in its broadest sense, as an inability to do anything, so that even lying in bed it's almost too hard to breathe and living is like moving through honey.

Most people distinguished fatigue from weakness. Weakness was reflected in claims that it was difficult to sit and remain upright, or to stand for any period of time, so that there were several statements like:

- I was often unable to hold my hairdryer.
- At my worst I had to choose between washing myself and drying myself.
- I have to work out what I am doing that day, before I wash my hair, as it takes so much out of me.
- I felt each day was like climbing uphill.
- I stagger everywhere and people have begun accusing me of being drunk.

Muscular fatigue/tiredness/exhaustion/weakness seemed to be physically manifest in a number of other ways: clumsiness, double vision, poor bladder control, difficulty in writing and swallowing, chest pain, palpitations and irregular heartbeats, slurring and stuttering with words, stiffness in the neck, sore back and shortness of breath.

Despite the common experience of fatigue and some related symptoms, most people asserted that the term 'fatigue' trivialised their illness: basically I feel extremely sick; fatigue is not the main problem just one of the main symptoms.

Cognitive changes
For many of the participants, it was the cognitive symptoms that caused them the most distress. They found their inability to think, to use their
memory, to attend to new information or to make decisions very disturbing.

Nearly everyone was able to describe times when they were unable to put words together in ways that made sense to others. They said they had been unable to participate in conversations because they could not follow what was happening. Plots of television shows could become too complex to understand, and books read a week before could be read again the following week without any memory of the previous reading. Cognitive symptoms such as word, name and memory loss were frequently discussed with me:

_The loss of names and words is symbolic of the other losses associated with this illness that are more general and waffly. They represent the ways in which you feel you are losing control of the world._

People also talked about becoming disorderly and unreliable, feeling vague (_foggy_) and extremely indecisive even about trivial matters. Some lost the ability to do simple calculations that were done easily before. Others expressed distress that they were no longer able to spell correctly, or that they mixed up words. Two were unable to do even the simplest jigsaw puzzles. Many admitted to becoming lost in their local surroundings, being uncertain of right and left or their general orientation in space. Distorted spatial perspectives were a significant problem; people frequently described bumping into doorways.

Mood changes
Table 4.1 lists a variety of symptoms associated with mood change. People differed in the ways in which they interpreted those symptoms. Some were adamant that the symptoms were inherent in their condition. On many occasions they felt surprised by the intensity and suddenness of a change of mood, or by their feelings of irritation and frustration. Many remarked upon their new tendency to emotional lability, with an abrupt and pronounced tendency to tears: _I started not trusting my feelings because I would break out sometimes._ Fifteen people reported occasional severe anxiety. This had usually occurred when they were obliged to be with other people, or when they felt unable to follow conversation or contribute sensibly to it. _My brain can hurt. It feels like it will explode_
with too much input. It’s as if it is too big then for the structure it is in. A few people said they could become very hyped up, unable to slow down.

Depression was usually reported by people as a reaction to their illness. Unlike some of the mood swings, people felt that the depressions they experienced were explicable by their changed circumstances: I can’t imagine anything in my life that has been more depressing than this illness. Many commented that the continuing distress, pain, discomfort and boredom of being chronically unwell, especially when they were without an adequate explanation for their illness, left them feeling hopeless, despondent and, at times, suicidal. Two thought that their emotional state may have been exacerbated because they were no longer able to use exercise to cope with their daily stresses. Three people had had experiences of major depression some time prior to developing any of the symptoms of CFS and they distinguished the depression of CFS from these earlier periods of depression by the new variety in their symptoms and the extent of the fatigue and exhaustion.

Altered sensation
More than half of the participants had had some substantial neurological symptoms such as vertigo, disturbed balance, unusual reflexes, paralysis, sensitivity to light and sound, tinnitus, unusual skin sensations and loss of basic senses such as taste, smell or touch. A few people said they had lost sensitivity to heat or cold in their hands. Most had had considerable periods of sleep disturbance, not consistent with either anxiety or depressive disorders. For some, the disturbances were associated with extremely vivid dreams or nightmares, particularly in the early stages of their illness, although the vivid dreams could recur at later stages too. Others said their sleep disturbance was a consequence of their general level of pain and discomfort.

Almost every person mentioned some irregularities in their temperature control. This meant that at times people felt hot when conditions were cold for everyone else. More commonly, it meant that people felt significantly colder than others. At several interviews I sat perspiring on a summer’s day while the person I was interviewing was cold even in front of a heater. Some had very cold extremities, others felt differences between the lower and upper halves of their body.
Other

There were numerous other symptoms. Pain associated with muscles, joints or digestion was frequently mentioned. Several specified that their muscular and joint pains were their worst symptoms. As well, most participants described headaches of unusual intensity and persistence. The pain originated in the upper spine, then gradually advanced up the spine and enclosed the head. For some, these headaches could last several weeks. Others reported migraine headaches, which had not been an aspect of their lives before the onset of CFS.

Nearly three-quarters of the participants had gastrointestinal problems, with frequent nausea, and alternating periods of diarrhoea and constipation. Many reported that mucus was regularly present in their stools.

Eighty-five percent of women had experienced hormonal difficulties. Fifteen women identified significant changes in their menstrual patterns since the onset of the illness, with long periods of amenorrhoea or constant spotting. Two women had undergone early menopause during this illness. Three who were using hormone replacement therapy (HRT) had found it ineffective at normal doses, and one woman who had been given an implant to increase testosterone found that the implant needed to be replaced several months before its predetermined date.

Of the thirty-three people who were prepared to talk about their sexual performance and interest since the illness, twenty-nine said that there had been a significant and distressing decline. Many of the men expressed concerns about inabilities to sustain an erection, and some women described the muscular effort required for sexual activity and orgasm as being more than they could maintain.

Eighty-two percent of participants reported a chronically sore throat: like a collar that is too tight. This symptom was particularly evident during the interviews, as people seemed to be constantly clearing their throats.

Symptoms that were spontaneously reported by about 20% of participants were the slow healing of cuts and injuries; non-specific lumps in the
groin, armpit, neck and breast; mouth ulcers; rashes; sinus and bladder infections that were unresponsive to antibiotics; and painful lesions in the pubic area. A symptom that was not reported but one which I began to notice was that of a sweet, yeast-like smell on the person's breath.

A large number of people commented that they had found the illness exacerbated pre-existing or previous conditions. Such conditions included back problems, menstrual difficulties, damaged joints, depressive tendencies, stomach or sinus problems\(^2\). Many mentioned that they could no longer tolerate alcohol in any form.

**Patterns of symptoms over time**

Almost everyone described their illness as episodic, following a relapsing course and often changing considerably during the day and over longer periods of time.

All participants described 'minor' relapses that may occur within a day. These relapses were characterised mainly by severe fatigue and tiredness, headache, muscle and joint pain. Some were able to specify mornings or evenings as their best times, others found that each day was entirely different. The relapse in this context was described as:

- *I can feel like all the energy has drained out through the soles of my feet.*
- *I can run out of energy and just fall down.*
- *I would feel incredibly exhausted, like energy was being leached out of my body.*
- *I would end up sitting stunned for long periods of each day.*
- *There are times when I just wear out.*

Such relapses could be brought on by exercise or normal activities such as housecleaning, shopping, driving the car or talking with friends for an hour (or less).

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\(^2\) Maros (1991) has noted this characteristic of CFS in over 700 patients. A recent article in *Science* (6 December 1991) discusses possible mechanisms for the way in which such vulnerabilities, particularly vulnerability to depression, may occur.
These minor relapses, which could markedly disrupt daily life were, however, insignificant compared to the major relapses described by people. These major relapses could last between one week and several months:

I make a distinction between being sick, and being sore. I am sore all the time. But if I am sick, then I have an acute bout. This helps me not to think of myself as a sick person all the time.

There were two basic patterns to the major relapses that occurred. The first of these patterns, which described the experiences of eighteen participants, showed little variation over time. Against a background of the person being either relatively symptom-free some of the time, slightly sick all of the time, constantly tired, or constantly sick with a range of symptoms, relapses were pronounced and prolonged periods of the person’s usual symptoms on each occasion. In other words, the same symptoms recurred for the person each time there was a relapse:

My main symptoms are aching all over and feeling exhausted, feeling nauseous. All my glands will be up and my brain can be completely blank and dead. These symptoms keep repeating over and over again.

There was a second pattern (affecting thirty-two participants) which differed from the first primarily by the way that the symptoms changed over time. In this pattern there was variation not only in the intensity or frequency of symptoms, but also in the range of body systems affected. People with this pattern described a change, usually over a long time, in the nature of their relapses. In addition to the usual symptoms of aches, pains and tiredness, these people identified times when cognitive, gastrointestinal or respiratory symptoms became pronounced in relapse. Conversely, some people described improvements in their health in similar terms

3 Five of the seven people in the study who have had intravenous gamma globulin, have described their long-term response as a reduction in the number of systems affected by the illness. For example: I think my cognitive functioning has been better since the gamma globulin, even though I still have all the other symptoms.
Each of the major patterns contained a range of experiences around the intensity, severity, frequency and diversity of symptoms. However, the second pattern was reported by seventeen of the twenty people who had been ill for more than five years at the time of the first interview. At later interviews, six more people described changes in their illness which were consistent with this pattern.

Frequency of major relapses was unpredictable and apparently unrelated to the way the illness began. Many participants had attempted to identify the factors that might exacerbate their illness, through the use of diaries and personal records. Some claimed that they could find no correlates between events or actions and any significant relapse that might occur: sometimes nothing seems to bring this on.

Nevertheless, some common factors were identified as important: major physical exercise and effort (forty), mental effort such as work or study (thirty-one), emotional distress following events such as a mother's death, burglary or the end of a relationship (twenty-eight) and certain foods and medicines (twenty-seven). Sixteen women claimed that their relapses coincided with pre-menstrual symptoms. Three women had had pregnancies during the course of this illness. Two reported significant exacerbation of their symptoms as a result. The other reported an alleviation of symptoms with the first pregnancy and exacerbation with the second.

Sixteen people noted that exposure to viral infections could bring on the symptoms of relapse, rather than the symptoms of the viral illness. However, that was not always the case. At times, it was apparent that the symptoms were the same as those of the 'current virus', best corroborated by symptoms such as vomiting which was not usually one of the problems that people had. Other factors reported as adverse included: rapid weight loss due to radical dietary changes or loss of appetite (nine), physiotherapy (five) which was seen as bringing on disturbed sleep with vivid dreams, weather changes (eight), working in very cold conditions such as cold rooms for food or film storage (three), exposure to agricultural and household chemicals (eight), car accidents or spinal injury after the onset of the illness (four) and poor sleep (seven).
Nine of the fifteen people who underwent operations with full anaesthetic had prolonged adverse effects, as did five of the seven people who were given gamma globulin infusions. Three people mentioned extreme reactions to tick and spider bites; each had had to be treated for anaphylactic shock.

Outcome: changes in health status over time
The outcomes of CFS are not well documented. The literature which has been published about ME, rather than CFS, generally described three possible outcomes: gradual recovery for about a third of people, continuing poor health for another third and gradual deterioration for the remaining third (Macintyre, 1989; Ramsay, 1988). More recently, there have been claims that young people recover faster than adults, and that adults can generally expect to recover within two to three years (Dwyer, 1991). Others however, have portrayed the condition as one with an indefinite and uncertain prognosis (Bell, 1991).

Although five people declared themselves recovered at various stages during the study, only one person maintained this claim for both the second and third interviews (despite the presence of a number of symptoms, in particular, some obvious cognitive symptoms). This section therefore deals less with 'outcomes' than with the changes that occurred in people's health during the study.

Table 4.2 summarises the changes that occurred in the health status of the study group over the three interviews. These assessments have been based on the scale (Figure 3.1) outlined in the previous chapter. Although this summary suggests that participants' health improved with time, there was considerable variability within the group. Ten stayed severely ill for the eighteen months (this figure includes the person who withdrew). One woman became more seriously ill than she had been for the previous eight years of her illness, yet at her first interview she had thought herself close to full recovery. Nine stayed moderately ill and five stayed mildly ill. Ten had significant fluctuations during the eighteen months. Extended periods of ill health, with absences from work or being homebound, alternated with times of better health.
Table 4.2: Changes in health status over time

<table>
<thead>
<tr>
<th>Health status</th>
<th>At worst</th>
<th>Interview 1</th>
<th>Interview 2</th>
<th>Interview 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>-</td>
<td>6</td>
<td>18</td>
<td>17</td>
</tr>
<tr>
<td>Moderate</td>
<td>6</td>
<td>25</td>
<td>18</td>
<td>20</td>
</tr>
<tr>
<td>Severe</td>
<td>44</td>
<td>19</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>49*</td>
</tr>
</tbody>
</table>

*One person had withdrawn from the study by the third interview.

Overall, there were no consistent patterns between the severity of the onset and the severity of the ongoing illness. For the majority of people, the initial phase was not the worst time with the illness.

A different summary of health outcomes is given in Table 4.3. This shows participants' perceptions of their changing health. Again the summary would suggest that many people's health improved over time. However, only sixteen said they were 'getting better' at both the second and third interviews. Similarly, although ten said they were 'getting worse' at the second interview, only four of those were in the group of eleven who said they were 'getting worse' at the third interview.

Table 4.3: Perceived changes in health over time

<table>
<thead>
<tr>
<th>Health status</th>
<th>Interview 2</th>
<th>Interview 3</th>
<th>Interviews 2 &amp; 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>'getting better'</td>
<td>26</td>
<td>23</td>
<td>16</td>
</tr>
<tr>
<td>'recovered'</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>'getting worse'</td>
<td>10</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>'same'</td>
<td>7</td>
<td>10</td>
<td>}30</td>
</tr>
<tr>
<td>'don't know'</td>
<td>7</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>49*</td>
<td></td>
</tr>
</tbody>
</table>

*One person had withdrawn from the study by the third interview.
During the eighteen months of the study, the majority of participants could not detect a consistent improvement or decline. Thus it is difficult to evaluate the interventions that participants used.

Those who said they did not know whether they were improving or getting worse explained their assessment in different ways. One mentioned that she had not been ill long enough to make sense of the constant changes she had, three had had operations or serious infections, two had had severe emotional stresses, two had had car accidents, one had been pregnant (and could not distinguish which effects were due to pregnancy and the birth and which were due to illness), and three simply felt very confused about what was happening to their health. Of those who said they were feeling much the same, most were consistently and severely ill (eight). Four were moderately ill and two were mildly affected. A few said they had no way of really knowing what was happening.

Whichever assessment of health is used, improvement or deterioration was unrelated to age or the severity of the illness. Duration seemed to have an effect. Seven of the people who said they were 'getting worse' at both interviews had been ill for longer than five years. Thirteen of the sixteen who were 'getting better' at both interviews had been ill for less than five years. Gender also seemed to have an effect. Half of the male participants reported getting better at both interviews; only slightly more than a quarter of the female participants reported this.

**Describing CFS**

As people attempted to describe their symptoms and the characteristics of their illness over time, it became clear that discussions of such an illness are complex. People had difficulty summarising a condition which was characterised by diverse and fluctuating symptoms. Their fears, wonder and concerns about their condition emerged, as did some of their moral convictions about managing and living with a chronic illness. As a result, eliciting the details of people's illness was sometimes a very lengthy and convoluted process, taking up to three hours in four instances, or it could be extremely brief, lasting less than ten minutes.
Difficulties with the use of the symptom list

Although a list of symptoms was provided to participants to help them in the discussion, only slightly more than half of the participants chose to address their symptoms by reference to the provided list. For those who did so, the list had some anticipated difficulties. That is, participants were uncertain about the meaning of some of the listed symptoms, or felt that they had related but distinctive symptoms. For example, some questioned the term ‘pins and needles’ and mentioned unusual burning sensations over large parts of their body, or extreme prickling of the skin which made touch unpleasant.

A few participants found that, although they had written some detailed responses on the symptom list beforehand, it was difficult for them to later make sense of the list in conversation. Some people had attempted to approach the task with discipline and attempts at scientific objectivity (by providing specific features of the symptom, intensity, frequency and times), but not all were successful. Reasons why certain symptoms had been ticked were forgotten, the list itself became problematic to read because of vision problems, or general confusion made it difficult for a person to feel confident about a particular response. Some had tried to elaborate on the list by indicating which symptoms were severe or mild, others had tried to indicate whether symptoms were present when the list was completed or there at other times. Ten such attempts remained incomplete, in spite of people’s best intentions, because it was found to be too hard and too confusing to organise thoughts in this way. In part, these difficulties seemed to reflect the effects of the illness on cognitive functioning; in part, they reflected the disconcerting effects of fluctuating, ambiguous, diverse symptoms.

There is no common language for symptoms. Significant differences have been found between doctors’ and lay people’s interpretations of many commonly used medical terms such as ‘heartburn’, ‘palpitations’, ‘diarrhoea’ or ‘flatulence’. Amongst lay people there was also notable disagreement about the meaning of such terms, so that the term ‘flatulence’ was thought by 42% of respondents as passage of wind through the mouth or back passage, 10% thought it a sort of chest pain, 30% thought it was an acid taste in the mouth after eating food, and 16% thought that it was a stomach ache (Boyle, 1980).

Mihевич (1981) and Pennebaker (1982) discuss the way that diffuse or fluctuating symptoms are more intrusive than persistent sensations. In the laboratory, ambiguous and
Many people also commented on the desire to distinguish between symptoms that were trivial and those which might be significant. Others expressed uncertainties about the relevance of some symptoms, since they did not necessarily see all the symptoms they had as being related to CFS. As a result, they did not mention symptoms such as their sore backs or bowel problems in response to the list of symptoms; their concerns about these 'additional' symptoms usually emerged in other parts of the interview. In contrast, some people felt that their array of symptoms was solely due to CFS.

Several participants contrasted their current ability to discuss the illness with other occasions when discussion of symptoms would have been more difficult:

It's only since I've been functioning better mentally that I've been able to tell people about this illness. It was too hard before.

At my worst, I couldn't decide what was happening to my body. It was all too confused.

It's hard to remember how sick I was—you lose perspective.

Feelings and concerns which influenced people's descriptions
Discussion of symptoms was often determined by people's feelings about their condition. Strong feelings could intervene: awe, embarrassment, shame and anxiety. Apprehensions about being seen as weak, self-indulgent or 'crazy' were raised.

People's concerns sometimes related to their experiences with doctors. Several expressed reservations about reporting their symptoms either to me or in clinical consultations since their early attempts to gain some diagnosis or treatment for their symptoms had been regarded with what they perceived to be disbelief, disdain or even ridicule. Discussion of the symptoms with doctors was generally described as extremely difficult and often emotionally distressing; the presence of so many symptoms and strange occurrences meant that most people felt unable to relate the full story to a doctor. They made choices about which symptoms seemed to be changing sensations are associated with people's vigorous efforts to understand and explain what is happening.
the worst (you don’t like to bore people with all these things that are
wrong with you) and what the doctor might find relevant. Women had
rarely mentioned the hormonal changes they experienced as they thought
that would be seen as irrelevant by male doctors. Very few had mentioned
the irregularity in their temperature control (it’s so bizarre), yet when it
was mentioned, this symptom would often gain the doctor’s attention.

In a similar vein, most people were aware of the controversial nature of
their condition. They were especially careful when discussing the
symptom of candida. My views were sometimes sought before people
would say whether or not they thought they had this as a problem: I don’t
know what you think about this candida business? Some just dismissed
it, and some women specified that they had had vaginal candida.
Generally people were more willing to recognise this symptom if it had
been mentioned by a doctor and not by an alternative practitioner.

A few people were worried that the list had alerted them to symptoms
they had ignored until that time. Three expressed horror that they might
develop yet more symptoms, although two people were relieved to see
symptoms on the list that they had never mentioned to anyone for fear of
ridicule. One person wondered if she had a copy-cat illness; she felt she
had become extremely sensitive to any suggested symptoms. However,
others refuted, in passing, the idea that their symptoms were a response to
popular descriptions of CFS:

Before the doctor told me that this was probably CFS/ME, I had
independently, without ever hearing the label, assembled a
collection of symptoms that had me completely mystified. Perhaps
if someone had said I wonder if you have ME, then that might be
different, but I know I had already observed all these strange things
happening.

Occasionally, participants drew attention to the way that time changed
their understanding and description of their illness. Over the series of
interviews, more than a quarter modified their description of how the
illness began. Their changing views usually reflected their ongoing efforts
to make sense of the condition. Some decided that their illness had
multiple explanations:
Now when I look back I realise that I had only been separated from my husband for six months when I got glandular fever. I realise I also must have had a lot of buried emotions. I was always an optimist and I always looked to the future. I had said well that’s over now and I’m going to do all these things. So I was stressed at that time but not acknowledging all the feelings I had.

Being a psychologist, I presented with psychological symptoms. Unfortunately I was better informed on depression than the GP. He seemed to feel inadequate because of my claim. I ended up having therapy for fighting depression, and then it took a very long time before I began to acknowledge how many other things were wrong with me, like I could no longer swim thirty laps of the pool without feeling like I would collapse.

Others linked their present condition to previous illnesses, such as malaria, hepatitis and mumps. One severely ill woman went so far as to suggest that she might have had a disposition towards this illness all her life, since she had had a history of allergies and boils from birth. At least four other participants gave modified versions of this view at later interviews.

A few participants also acknowledged in later interviews that they had felt embarrassed or shamed by aspects of their illness, particularly the mood changes and cognitive effects. They had chosen to deny the changes, even to themselves. When asked about this, one person said:

I was terribly sick in 1990. And yes, the way I was coping was to deny how sick I was even to myself. You don’t get a perspective on that until you start to feel well. At that time I was so crook I used to wonder if I would fall down. Everything was predicated on an enormous output of will as it was all such a struggle ... I will concede now that it has some effect neurologically. I would never admit it at the time but in some ways it is a genuinely depressive illness, a chemical imbalance I think. It interfered with my capacity intellectually. I couldn’t remember things, bits were falling out. I was morbid too. When I was confronted by someone at work about this, who said I was depressed, it felt like an accusation of weakness, deviance. I refuted that. It was important for my own dignity. But it is a problem at the time, as you are aware that things aren’t right. You don’t know where it will take you—will it be a continuum to total madness?
People's feelings and changing interpretations of their condition also influenced their claims about their changing health status. In some instances, people's claims seemed to bear little relation to the severity of their condition. I was concerned that some claims were more an indication of individual optimism or determination than genuine change, and to an extent that was the case. One woman who had maintained a graph of her health over two years described herself as getting better. On that graph she had moved from 8/100 to 26/100 during the previous year, and had had no returns to what she defined as zero health. She was still severely debilitated by her illness, but by her own measures she was getting better.

'Getting better' could mean so many different things: fewer relapses, less frequent relapses, or less severe relapses. A few defined the improvement according to how they felt in between relapses. Two said they thought that perhaps they were not necessarily getting any better but that they were managing their illness more successfully. Two described improvement according to their capacity to cope with more activity or work and three linked it to a declining need for sleep and rest.

I feel that I am getting better. It's slow. But the trouble is you are likely to get a different answer from me about this on different days. It's amazing how quickly the perception can change.

'Getting worse' was something that participants were reluctant to claim. Often it was only after a fairly lengthy discussion of events and symptoms for previous months that people would admit to deteriorating health. For those who had already had years of severe illness, admitting to this deterioration could be profoundly distressing:

Deep down after nineteen years with this I don't believe I will ever get well again but I have to tell myself that I will and focus on that. If I don't, then I might decide to finish things. I'm very scared that I will. There's been no relief from the illness at all over the last twelve months. There have been long periods where I've needed to be completely out of action and they scare me so much. Going to bed might ease my body but it's dreadful for my morale. So I try to be part of the world and what is going on even though it takes so much effort and I am often not really there at all. Had I gone to bed I think I might have packed it in for good or never got going again. Yes, I do know it is definitely getting worse. It's more relentless and
oppressive now, and so many things are going wrong. I am amazed at the sort of symptoms that can still develop. I thought I had had them all.

As this person suggests, getting worse was not necessarily indicated by obvious changes in behaviour. Decline in these circumstances was usually perceived as so threatening that people would struggle to maintain whatever semblance of normal living they could. Ignoring or defying signs of worsening health was a reasonably widespread, if dangerous, practice amongst those who had been ill for long periods. Seven people had accommodated the discomfits of serious but treatable infections because they had thought it was just something else going wrong. One person had endured pain for years without seeking diagnosis or treatment, attributing it to the chronic illness. It was later diagnosed and partially alleviated by surgery for inflamed gall stones and very large ovarian cysts.

People's deeper concerns often emerged as they spoke of their changing health over the years. The process of recall was distressing in many cases as it raised the spectre of loss as well as suffering:

*Everything about this illness has been doing and saying as little as possible—anything to save energy. I wouldn’t know who I was. I was off in a dream. I slept for days and days with small spurts of energy.*

*Each year I have slightly more activity I realise from my diaries, but I can’t say the quality of my life is improving.*

*My life has become grey, like there is an obstruction to my perception. I am losing great chunks of my life, and my children’s.*

Brevity in these discussions was sometimes associated with the person's current condition, so that fatigue, illness or pain limited the time that participants were able to give to any part of the discussion. As well, three people who had been ill for over ten years had scanty details to give of their illness. When asked, they commented (with some surprise in one instance) that CFS was now something that they just lived with; it was not something that they bothered to separate from other daily hassles. Seven people were also reluctant to discuss their symptoms at all, as distraction from, or denial of, their symptoms, was a way in which they coped with
the illness. Consequently they were critically circumspect when they
decided to identify only the central symptoms:

You have to dismiss the little things for the big symptoms.
You just have to live your life.

These people seemed to be expressing the notion that their suffering had
to be seen as relative to other forms of suffering, and if they had seen
relatives dying of cancer, or others in very difficult circumstances, they
tended to try to maintain a sense of proportion by suggesting that they
were less afflicted than others. However, other people found the illness so
overwhelming at times that monitoring the fine detail of their symptoms
was an essential aspect of their coping:

You do become obsessed with the detail of each day's shape. Life
seems so empty when you are that sick, that you fill it with the only
thing you are aware of, your illness and getting through it. It's the
only thing there is at that time.

I now have to monitor myself second by second so that I can follow
what is happening.

Two people emphasised their desire to give a detailed record of their
symptoms. They felt their lives were so difficult to live since the onset of
their illness that one way of giving meaning to so much pain and
discomfort was to document their suffering so that the illness might be
better understood and others would not have to endure what they felt
they had endured.

Conclusions

People were asked to describe their illness, and its effects, so that the
specific problems induced by CFS could be identified. This was not an
attempt to match individual descriptions of illness with laboratory data,
but it was an attempt to provide specific detailed information about this
condition, its origins and its course over time, as well as its effects on
people's lives.
Despite the preference that biomedical researchers have expressed for an initial viral onset, most people in this study felt the onset of this illness was insidious. There was usually an acute illness, but there was no suggestion that the initial illness would become a long standing one. Only 30% of participants had an acute and persistently severe onset. Although these people were mostly rendered profoundly ill for long periods of time, others became gradually sicker, moving from relapse to relapse and repeatedly reappraising what was happening to their health. Because the symptoms were diverse and fluctuating, they continually intruded on daily life. There was little scope for accommodating or ignoring these discomforts. Every aspect of activity, sensation, mood and cognitive performance could be affected at times, to a greater or lesser degree. The worst times with the illness often occurred much later in its course, sometimes as much as three to six years later, usually after the illness had already taken on an erratic, episodic and relapsing pattern. The outcome of this illness remained uncertain for nearly everyone, since serious relapses occurred for a few people, even after periods of relatively satisfactory health.

To date, CFS has generally been characterised as chronic or relapsing fatigue. However, this characterisation trivialises the illness described by most of the participants in this study. Fatigue was a common feature but there was a wide variety of symptoms. These other symptoms often represented multiple systems in the body, with the involvement of each system changing over time in conjunction with major relapses. The relapses were not necessarily related only to physical effort which caused fatigue, but also appeared to be related to diverse situations and triggers, some of which may be seen as antigenic (such as exposure to viruses) and others as situational.

In its effects, CFS has features which overlap with several other chronic conditions. Participants experienced much of the uncertainty that others have described in relation to rheumatoid arthritis (Wiener, 1975), cystic fibrosis (Waddell, 1982), epilepsy (Schneider and Conrad, 1983), diabetes (Mason, 1985), multiple sclerosis (Robinson, 1988) and Parkinson's disease (Pinder, 1990). Although all illnesses have uncertainties to a degree, this feeling is generally exacerbated when illnesses have relapsing and changeable symptoms, or uncertain prognoses. Participants also
experienced feelings of estrangement, related to their loss of cognitive functioning and disorientation. Estrangement describes a uniquely disturbing aspect of this illness, which caused people to feel as if they were on the edge of madness, bereft of a meaning system, or as one man (not a participant) recently described to me:

I feel like I am losing 'it'. It's just not me. It's like I've been taken over by somebody else and that person is a cretin. He can't sign cheques in the right place, he can't find anything (whereas I've always been very orderly), he forgets appointments, he bumps into things all the time and spills things.

Like people with similar cognitive problems, for example Alzheimer's disease or schizophrenia, people with CFS had their sense of estrangement intensified when they were unable to express or make sense of their confusing and puzzling symptoms. At the same time as they tried to manage these concerns, however, they were physically debilitated, experiencing profound levels of fatigue, weakness and pain, as well as having numerous other symptoms including persistent nausea and gastrointestinal problems.

Kleinman (1988) has identified the powerful effect of the individual's 'idiom of distress', the words, language and style of presenting the story of illness. Those with eloquence in this idiom inevitably assist not only the acknowledgement of their own condition but, in an illness like CFS, may also have assisted in the process of its re-evaluation by medical researchers. In this study, individuals were able to deploy their own 'idiom of distress' in as much as they were encouraged to discuss their illness as much or as little as they chose, to describe the symptoms they had experienced in detail and their hypotheses about their origin. They did so in ways that were diverse and individual.

What emerged from this approach was not only evidence that the illness might interfere with the way symptoms can be reported, but there also emerged a story of an illness that can be extremely debilitating and distressing, feeding self-doubt and uncertainty, posing fundamental challenges to individuals:

I had an out-of-control feeling a lot of the time because my body hurt me so much and I couldn't do anything about it.
This illness is chaotic mentally and physically. When you can't use your brain or your senses, how do you find any meaning in your life?

It's like the whole world and what it meant before became irrelevant. The meaning system just fell apart.

With this illness I lost that part of me that was alive in conversations ... I felt I was just old bones that could be bundled up and thrown away ... I was afraid of not having a mind and this took it away from me, but then I didn't have my body either. How was I to cope?

The specific characteristics of this illness mean that individuals live with considerable disquietude about the significance of their symptoms, their immediate and long-term future health prospects and their capacity to make sense of them. Their experience is imbued with feelings of uncertainty and estrangement. Management of these feelings is as much at issue as the management and relief of symptoms, yet how do these processes occur when cognitive functioning is affected as well as physical functioning?
Chapter 5

The quest for explanation

The Blood, the Urine, the Sweat, all have sworn to say nothing,
to give no indication of any dangerous Sicknesse—and yet—
I feel that insensibly the Disease prevails.

John Donne

Descriptions of illness such as those in the previous chapter have informed our understanding of illness for centuries. They offer the detail accumulated by individuals as they attempt to give some sense of order or meaning to puzzling, frightening and debilitating symptoms. However, Rolland’s framework for discussing those symptoms imparts a coherence which is not necessarily apparent to people in the earlier (and sometimes later) stages of a chronic illness. In this chapter, therefore, I provide a different perspective on the accounts of the previous chapter. Here I explore the genesis of people’s feelings of uncertainty and estrangement, beginning with their dawning awareness of ill health and their initial interpretations of that. The focus then broadens to encompass the impact of social and medical responses on people as they sought the help and understandings of others in their efforts to make sense of their symptoms.

This chapter covers a crucial phase in people’s illness. It is during this time, more than any other, that the course of people’s illness appears to be determined. During this phase people relied on their usual styles of coping, not realising that their responses in these new circumstances might worsen the illness. The importance of their life circumstances also emerged. Of greater importance, however, was people’s ‘quest for explanation’ of their symptoms (Hunt, 1985; Singer et al, 1987), a quest upon which all embarked, sooner or later. What people sought in this quest was:

a framework for interpreting and ordering distressing experiences ...
a cognitive structure which ... [would enable] them to classify, interpret, and act upon their experience. (Hunt, 1985, p1290)

Almost three-quarters of the participants discovered that this was a hazardous quest. It reinforced and exacerbated their feelings of uncertainty
and estrangement, indirectly contributing to their deteriorating and prolonged ill health. Marked contrasts eventually emerged between the general long-term health and well-being of those participants whose quest was briefer and more helpful, and the majority whose quest was lengthy and fraught with dismissals and derision. I will elaborate on these contrasts in chapter six, while in this chapter I highlight how people's health was adversely influenced by the conjunction of their personal styles of coping, antagonistic medical responses, difficult life circumstances and cultural norms about chronic illness.

The genesis and growth of uncertainty

Ongoing illness represented a major 'challenge to identity' for participants (Strauss and Glaser, 1975). Without exception, they were confounded not only by having to deal with the uncertainties inherent in erratic and debilitating symptoms, but also by the changes these symptoms wrought in their established self-image.

The challenge

About a fifth of the participants were 'shocked out of their common sense perspectives' (Kleinman, 1988) and lifestyles by the severity and duration of their symptoms at the onset of their illness. They had change thrust upon them.

I remember lying in bed and debating all day whether I had the energy to go to the toilet or eat. I couldn't do either. I never got off the ground after that dreadful time. Even months later I couldn't walk two blocks to the shops.

When I first got sick all I could do was just lie in bed all day with my eyes closed because the light was unbearable. That went on for weeks.

I collapsed on the Monday, whackingly sick, and was taken to the hospital. My brain felt like it was going to burst.

I had been overseas, working independently on the field work for my thesis. I had a responsible job, was very fit and enjoying life. I came back in September, gave a seminar or two, then I suddenly went down very seriously with what was a more profound flu than I had ever had. It matched the dengue fever I had had some time
before that. I slept twenty-four hours a day, often twenty hours at a stretch. It was about ten days before I was able to see the doctor.

These few people were never really in any doubt that they were seriously ill, although most had no idea what might be causing their problems. Their uncertainty had to do with being seriously ill and having inadequate explanations.

It was a period of chaos going on and on. I have no memory really of that time. I walked around in a blur. Had terrible trouble eating at that stage but I didn’t fade away to a shadow so I guess I must have been eating but it also seemed that everything I ate gave me violent stomach pains. I had no idea what was wrong with me ... I hadn’t heard of people having viruses that went on for that long.

For the majority, that is, for the remaining four-fifths of the participants, the onset of their condition was less startling. It was the continuation or constant return of ill health, with its different symptoms, which was puzzling: it’s so strange when you stay sick. It took some people many weeks, months, sometimes years, to regard their problem as chronic, rather than episodic or temporary.

Over the last twelve months it’s been one thing after another. I thought of calling it ‘rent-a-symptom’.

My illness set in gradually, although I had a high titre for glandular fever in March 1990. I wasn’t aware of being sick. But I was aware that I had deteriorated into a feeling of confusion and tiredness, that there were things I could not cope with.

I was working very hard. Politics at work. I think it was a quick decline into illness, but now you mention it, maybe I was going down gradually there for a few months, and then I crashed with illness and flu after flu. It was a difficult job ... I had a bloody sore throat for three months and antibiotics did nothing for it. And gradually my work performance wasn’t what it should have been. Maybe I was getting depressed then? I know I wasn’t handling the politics of it. Or the stress as well as I should have done. I was overwrought and this sore throat. Funnily enough, I realise the sore throat is an indicator that I have overdone it even now ... So there could have been a run-down period where I wasn’t coping with what was going on at work. Then came the flu and it wouldn’t go away and I never really got up from that. I just kept trying to push through. I always had, so why not this time.
In retrospect I can see that I was getting less and less capable. In 1983-84, I was already going downhill. I was absolutely unable to do anything after work. I was burning down.

The threat to identity
Regardless of the severity of their initial illness however, all the participants responded to feeling ill in similar ways. Most struggled to re-establish or maintain their familiar self-image. To whatever degree was possible, they did this by attempting to maintain their usual lifestyles. But what were their lives like prior to their illness?

Nearly all of the participants described their lives prior to ill health in confident terms, whether they spoke of their personal style of living, their beliefs about themselves and their health, or their expectations of themselves. Participants certainly belonged to the categories that Idler and Angel have identified as having positive views of their health:

At any given level of objectively measured physical health status, women, the more educated, those with better health practices, more social contacts and better morale, tend to have more optimistic senses of their health. (1990, p132)

Most participants were well-educated, the majority were women, ten were very active sportspeople (pursuing activities such as rockclimbing, skiing, aerobics and marathon running) and most were actively involved in social activities, relationships and other commitments. Ten people were pursuing combinations of study, full-time work, family commitments and sports-fitness programs.

They used distinctive phrases to describe their previous styles of living. Although I had not asked people for a self-description, seventy percent of the participants made passing comments reflecting similar images of themselves:

I was always a 150% person—a driving personality.

I was a get up and go person.

I’ve always gone at things like a bull at a gate.

I’ve always gone at things full-on.
People used to laugh and describe me as bursting with energy.

I used to be a dynamic, energetic and competent secretary.

I don’t know whether X (a colleague) has told you what I was like prior to this. (She had, and her description was similar.) I think I have always been a very active person. Every moment of my day was full.

Their descriptions portrayed them as capable, conscientious, active and productive people.

Perhaps because they saw themselves this way, these people appeared to have been more than normally reluctant to think that there was anything wrong with their health. Impatience with ill health, irrespective of its duration, was pronounced. They described themselves as having been too busy, or too interested in living, to be ill. Even their way of speaking about their previous health confirmed these claims. The few people who had begun to trace their present health problems to previous and very early illnesses were doing so because they wanted explanations for their present condition; they did not portray themselves as disabled. Four people insisted that they had not been sickly adults, despite childhoods marked by very frequent illness. They were keen to tell me that they were very strong when they were well, and had been capable of strenuous activity, including high-level competitive sport. Similarly, the people who had had previous periods of lengthy poor health (eight had had conditions such as malaria, rheumatic fever, hepatitis, complications from surgery, and a neck injury requiring months of traction) only incidentally mentioned these earlier problems. Two of the people who had gradually become ill had had major surgery, yet their enthusiasm to get on with it meant they had returned to regular activity within days. One woman had had a hysterectomy and returned to all her usual commitments of full-time work and family (including visitors) within a week.

There was a view that sickness was something that should be ignored. Every participant mentioned that it had been important to push through, fitness through, ignore, keep going, get on with life, overcome. Many comments suggested that people had a conviction that any difficulties could be managed by these methods. Several expressed concern that their illness reflected moral weakness or failure:
I would have doubts about my soundness in the beginning. I would think I was sick because I wasn’t pushing hard enough, that I was imagining it.

I thought I should always be earning my own money, out working and looking after myself and it was a real failure not to be able to do that. Later I also felt I had failed to look after my own health.

In conjunction with these beliefs, people also revealed some very high expectations for themselves. Many seemed to think that it was possible to maintain several commitments, or to dance all night, study or work all day and keep fit.

I have been someone who has always subscribed to the culture of pushing myself, believing that everything I do I should do well.

I was partying and working very hard. I used to have lots of flus and colds and things, but it didn’t matter how I felt, I just kept going. Worked and worked. At night sometimes I used to keep going even when I felt I was ready to collapse. I would study until 3.00 a.m. and get up again at 7.00 a.m.

There seemed to be a widespread notion that happiness renders a person immune to illness. Several commented that they became ill at a time when they were at their happiest, having just started new jobs, had holidays or begun exciting new directions for themselves. For example, three women were preparing themselves for a fresh start after some years of childrearing.

When we were overseas I was responsible for the children’s education so my time was taken up with that and educating other children. When we came back here my kids were all at school and I was rearing to go. I had all this time and all these opportunities for studying courses.

Dismissing the threat
Although some people were more concerned than others when they stayed sick, they did not necessarily interpret their symptoms as being warning of an ongoing illness. Many people had symptoms that compounded, but also explained their feelings of burning down. They had extensive periods of sleep disturbances, vivid dreams and, at times, bursts
of agitated energy which seemed to explain their exhaustion and fatigue. In general, as long as their symptoms remained diffuse, fluctuated or were not too intrusive, people did not reappraise their lifestyles or consider treatments for their problems. Indeed, many people countered their uncertainties by dismissing their initial symptoms as functional, a consequence of hard work, hard living or stresses. Circumstances in their lives provided them with ready explanations for some of their discomforts.

I was pushing myself in 1987, burning the candle at both ends, studying, working and social life. I was supporting myself through university, involved in activism like student politics. Two friends were killed in a car accident and a bad flu followed, like an emotional reaction. My mother was unwell. It was a time of change, pressure and responsibility. I just kept struggling and kept going with it all for another eighteen months.

I had a bad flu when we went overseas and didn’t really get over that. Then when I went back to work, there were all those troubles and in-fighting. Work became more and more of a struggle over the next few months, particularly after that elimination diet I was put on for allergies. I lost so much weight at that point.

Basically if you run your horse every day and don’t feed it, it will get sick. I was doing that. Then on top of that no one really thought I was sick. That made it worse.

Most continued with their current lifestyles because of their enthusiasms and responsibilities. It was only occasionally that they suggested that they kept going for security or financial reasons. Almost half the group probably had to try to keep working because they had financial responsibilities, even though they rarely expressed this as the reason. Six were 'breadwinners' for a family and seventeen would have had no source of financial support other than the sickness benefits pension.

Nevertheless, some people did emphasise that they had to keep going. Seven had partners who were ill, so domestic and other tasks had to be performed. Women with young children were particularly stressed:

No matter how lousy you feel you always have to rise to the occasion—there’s always a permission note to sign, a nose to wipe. You have to constantly think of someone else. When I first got ill I
had two babies. I learnt to do an awful lot on the floor! I’ve always had supports, like my mother-in-law and the church, but I did have to keep my mind going. I had to decide what should be done, what should be eaten and how to organise things, even the things that had to be done because I was sick. I was never able to just stop for a while.

A few participants said they had to keep going because their spouses or families could not cope with them being ill:

I was left in a heap. My friends and family could not cope. No one seemed to think about what it was like for me. I looked to the church for support but didn’t really get much.

Four young women had been living with their parents at the time they became ill; their parents actively discouraged them from thinking of themselves as ill.

I would have given anything to be able to throw work away after a time as I felt I was going to collapse. But my parents just didn’t understand ... I think my parents noticed I was sick but didn’t say anything. They were frustrated because they knew what I’d been like and suddenly I wasn’t doing anything. My brother would say I was being lazy.

I started talking to mum and dad about being sick. Dad believed me but the worst thing was that mum didn’t believe me. She thought I was sick of work. And that made things worse as there was no one to turn to, because my dad was really sick then too.

My father just thought I was being egocentric and lazy. I thought I was too and that everyone felt like I felt but just pushed themselves through it. Even though he also said I looked pale and sick, when I said I felt awful, he would say it was because I was doing nothing. There wasn’t anything like spots to suggest I was sick so I just went on.

A few people dismissed their symptoms because they just seemed like more of the same. They were used to feeling somewhat unwell, either because of emotional stresses or because of histories of usually minor but still irritating health problems such as allergies or hayfever.
I always kept going when I shouldn’t have. But when I was stressed I could never see that there were any alternatives. I could get so busy and overstimulated that I would be on the edge of collapse. When I became really sick with this, I was frightened by how close to the edge I was. Too many things had gone wrong at work and with my relationships.

*Memory of illness is so odd. You can forget what it is like to be ill really quickly even after months of it. Then when it comes back you just get on with it. I was run down for years with hayfever and problems that I was told seemed like thyroid problems. So when I became sicker I went along with it for a while.*

From these accounts of the early stages of illness, two patterns emerge. A number of people became dramatically ill with consequent distress at the sudden change in their health and their lives. In the main, though, most people stayed sick after an acute but not very severe condition, gradually deteriorating further with time. From there on, the majority of people followed a common path. To varying degrees, dependent upon what was possible with their symptoms, all participants tried to do what they had always done. They had beliefs and expectations of themselves that meant they wanted to keep going. Many had families and friends who shared those expectations. They had uncertainties though, particularly about the nature of their problem. Were they sick, or were circumstances proving temporarily more trying than was usual? Their response was to defy the symptoms, to deny that they had any meaning. On balance, the disinclination of all participants to think that they were succumbing to a lengthy or chronic illness is not surprising. Few of us would readily entertain such notions.

**Estrangement: the edge of madness**

> We are not ourselves when nature, being oppressed, commands the mind to suffer with the body.

_Shakespeare_

In addition to a 'normal' reluctance to think of themselves as chronically ill, people in this study also had symptoms that they found hard to
interpret or explain to other people. They became confused, indecisive, unable to communicate as they once had, or to do simple tasks effectively. As time went by many had a sense of being different, of no longer being the person they and others had once thought them to be. They increasingly felt estranged not only from their usual selves, but also from other people.

A few people experienced profound estrangement. They were so confounded by the range and extent of their puzzling symptoms that they were lured into a world of continual self-monitoring. They were sometimes not even aware of how much they had withdrawn from their usual activities and responses. Thought, sight, sound and touch became distorted. One woman described these times as being like a wall coming down between me and what has been going on. Another young woman gave a carefully detailed description of the first twelve months after she had had a particularly severe attack of shingles:

I was so weak at first, I couldn't even turn on a tap. And I was so slow—I couldn't coordinate my eye and hand movements. It was funny in a way as I couldn't do anything. Almost so bizarre that I couldn't take it seriously. I felt like laughing at my body. I knew something was wrong then but I was fascinated. I didn't feel pains at that time ... Later the pain set in, the alternating diarrhoea and constipation, the swollen glands, fevers and sweats, difficulty focussing with my eyes and reading, a lot of headaches. My balance was out, I kept bumping into doors, unable to drive. Often it happened quite suddenly. There was persistent ringing in the ears, and I was extremely sensitive to sound. I would listen to music but it became just a jumble of notes. The same would happen with TV. It was awful. I kept thinking that something was wrong with the record player, that it was playing at uneven speeds but it wasn't. That was happening at the same time as my eyes were in a mess. I wasn't bored then though. It was like I had gone on a long walk and all I could think of was resting. Bare survival seemed beautiful. ... I couldn't communicate as I was losing words all the time. I remember my mind picking up things that others were saying and wondering whether I was supposed to answer them. Everything about this illness then was doing and saying as little as possible. Anything to save energy. Losing speech, slow speech, memory loss. I couldn't remember my name for a time. I would ask myself who am I and I wouldn't know ... Until I started trying to work out what was happening, it didn't bother me too much. I had lost touch to
such a degree that it almost didn’t worry me … Depression came later despite having all these symptoms. Until then I used to wake up and say oh what a beautiful day and then clonk. I got very vivid dreams and nightmares and a weird sense of temperature control. My feet and hands would be very cold and the rest of me very warm. I seemed to be allergic to everything—felt very odd and very tired after eating … My symptoms set in over a year really, but because I was denying what was happening it was very hard to work out which was where and what was happening. Often I would seem to be well again.

Over three-quarters of the participants described similar experiences, although most were affected for less extensive periods of a day or a week. Nevertheless, these bizarre symptoms were reasonably widespread, especially when people were at their worst. However, they occurred when people had physical symptoms such as fevers and swollen glands so exclusively psychiatric interpretations were not appropriate.

Like the young woman quoted above, many other participants also tried to accommodate or explain away their odd symptoms. They initially thought the problems lay with the television or the record player, not their perception. One person said she threw a book away because she thought each page had been double printed. She then found out that all the books she picked up had the same problem.

The younger the person, the more difficult they found it to interpret these experiences. In part that was because their experience of the world was so limited. At their worst, some of the young women were unable to decide what was normal and what was not. Given that adolescence is a time when there are many physiological changes and considerable social and emotional pressures, bizarre symptoms were sometimes disregarded as being part of that process of rapid change. Further, young people are generally trying to shape some identity for themselves, but illness, especially chronic illness, is well outside the range of possible identities that most young people would choose to explore.

Another young woman described some of the distress that estrangement caused, the discomforts of being told by others that she had behaved in strange ways:
It happens so slowly—the effects. But when I was really sick last year there were times when I was really out to it and I don't remember and wasn't aware of them. A friend used to ring me every afternoon, but she says now that there were times when it just wasn't me she was talking to, that I was really strange. And my mother says I did strange things like hitting her and shouting at her and I would never do that. It frightens me now to think about it. That was really the worst bit as I didn't even know what I was doing. Mum says there were times when I would go down to her room during the night and she would be holding me because I had such dreadful pain and one time I almost stopped breathing. The rest of this illness I can handle but this deep stuff of not remembering is really hard. Was I protecting myself from how awful the illness is by blanking it out? This part of the illness is so dreadful and it doesn't ever get mentioned.

With such weird symptoms and experiences, young people were extremely dependent upon their parents to help them through these times. Uncertainty and alienation extended well beyond changes between past and present ways of being. Although this last young woman had a supportive mother, the others had parents who were confused or dismissive as their children went through these bewildering periods.

Profound estrangement was not enduring. It was more marked in earlier stages of the illness than at later stages. It was also more distressing in the earlier stages because people usually had no explanation for their condition.

**Beginning the quest for explanation**

Once people sought explanation from others for their condition, they increasingly discovered that an 'inquiry into the meanings of illness is a journey into relationships' (Kleinman, 1988, p186). Through their relationships with health professionals, family and friends, people discovered that illness entails more than biological changes. In being ill, people learnt how much poor health limits a person's ability to fulfil social roles and receive social support and recognition. They experienced feelings of vulnerability and powerlessness when they were made victims of the 'generation-specific repertoire of verbal constructs reflecting
medicine's intellectual and institutional history' (Rosenberg, 1989). They also became sensitive to hidden but potent cultural messages about appropriate social behaviours.

People's 'quest for explanation' began in earnest when their symptoms became alarming or intrusive, or they found themselves unable to live the lives they had previously enjoyed. To ensure that the significance of this quest in the course of people's illness and their lives is not underestimated, I will use the next two sections to outline people's concerns during this time.

The impact of illness on people's professional and personal lives

During this time, most people had problems trying to maintain their previous levels of employment and performance. Only a few got by without a number of extended periods of sick leave or leave without pay. Some changed jobs to minimise stresses and demands, some reduced their working hours to part-time work and half a dozen had to stop working altogether. Two were told to resign by their employers. When people had no understanding of their illness and no diagnosis, employers too had difficulty interpreting their employee's diminished performance. The people who were most disadvantaged were those who had not been in a job for very long before they became ill, so that employers were unable to measure their performance against some earlier standard. To some extent however, people in this group may have had fewer problems than some others. Those who were already well-established in their positions were respected and liked by their employers. Employment by the government as public servants ensured greater security for several participants.

Where people were able to maintain employment, it was not without personal cost. Their confidence in themselves professionally was increasingly diminished. They described themselves becoming incompetent; unreliable; erratic; hopeless; couldn't finish anything I was asked to do; like an old chook; vague. Their professional standing was hindered by humiliating, tearful outbursts at work over apparently trivial incidents.

1 In a recent survey of people in Canberra with CFS and the effects of their illness on employment, six of the thirty-seven respondents had been dismissed from their jobs because of their illness. A further six had resigned and three had retired (Lamont, 1992).
I would get to the stage where I was mentally quite bad. When you are at work you have this professional image. It was like a tension in my mind. I’d talk to people and almost want to burst into tears. And this is at work and when you are a guy who’s been marked out as a high flier, and there you are in tears about something really trivial—then you know you’ve reached an edge that means you have to stop.

At times it felt quite irrational; it would come on suddenly. I couldn’t think what had triggered it, but I would feel profoundly unhappy and couldn’t stop crying. That was a real problem as I was trying to get myself back to work, trying to attend meetings. I would be put on the spot and have to explain something and I couldn’t. It would end up with me bursting into tears or leaving the room and I am sure that has undermined my credibility. I tried to explain but it was always a male I was having to explain it to. I think it was put off as women’s business, in a place where it is very much an old boy’s network.

The effort to maintain a professional life meant that many sacrificed almost every other aspect of their lives.

I loved that job so much, and wanted it very badly ... But I ended up feeling like my life was grey all the time and there was no joy in anything while I was there. I did my job well but I wasn’t saving anything for my husband or my daughters. I’d come home and just crash in bed.

Every student in the study had to reduce commitments and course loads, and three had to give up their course for more than twelve months. The two who tried to work instead of studying found the associated stresses just as wearing as study, and began to realise at that point that their ill health was not related to the rigours of exams and study. Four university students have yet to complete their courses, more than four years after their illness commenced. Prolonged absences meant that the school students whose illness was undiagnosed were questioned about school phobias, even when they tried to make determined but unsuccessful efforts to attend school and complete school work. Young people told me how much they wanted to be at school. They would often try to get to school but after two classes were unable to keep going. Such failures were
associated with humiliation, as that might mean having to rest in the library all day.

Women who had been at home caring for children were locked into that position at a time when they were keen to return to work with part-time study or occasional relief work. They remarked upon the differences between being at home with young children and being at home because of illness. They noted that parents of young children have support structures, networks and services. Otherwise,

*Canberra is a city where people are very achievement orientated. You can feel so out of it, and worthless, as everyone else is studying or working. You are left very conscious that you are not in the mould.*

You lose all sense of being any worth to the world.

People’s relationships came under pressure. Just over half of the participants had had continued support and encouragement from their families. That support varied. It could be in the form of direct assistance so that the sick person could maintain work and family responsibilities. It could be directly related to the person’s illness, so that the sick person might be accompanied on visits to doctors, which meant the story of illness could be less readily dismissed. Similarly, the sick person might be encouraged to rest, or to reject negative responses from doctors and others.

Others, however, were continually or occasionally subjected to doubts, criticism or rejection:

*My partner said that he didn’t think I was sick. I think his theory has been that I was suffering from the aftermath of those traumas I described. I can’t get anything from him as he won’t discuss it. I think his mother has thought that as well. That I have just been suffering from this terrible stress thing.*

This has caused so many hassles with so many relationships. I haven’t had help when I’ve hoped for it, and I haven’t been able to help people who were used to expecting that of me. And my family! My relationships with them have been a mess almost from the beginning of the illness. Before the illness, conflicts were covered up and could be put aside, but once the illness came there was so much extra pressure on me and them that those conflicts
couldn't be ignored any more ... They really couldn't handle this. It was no good for mum ... And they felt rejected by the amount of quiet time I needed. It helps them if they reject me as that means they don't have to understand I guess. That way they don't have to accept the changes in me, or do anything for me.

A few people had no supports at all:

If I am ill, there is nobody to bring me a cup of tea. At the end of '86 I was really sick for two months and saw virtually nobody. I lived in a granny flat, and what saved me I think was the Neighbourhood Watch people. They turned up one day, then they organised ways that I could be looked after a bit more. I used to long for fresh sheets and nighties. A whole day would go by with me trying to make a meal. It was very frightening.

There was a period when I was still comfortable in my own home. Then I got exposed to some chemicals. That really meant I went downhill. I had a big fight with my parents about wanting them to look after me. They wouldn't. I tried to get into nursing homes and hospitals because I was so sick I couldn't look after myself. Nobody would have me. Mum and dad were totally unsympathetic. Mum has always been a bit fragile and just wants you to be happy. If you aren't then she can't cope ... I finally went to live with my older brother but that didn't work out as he got violent. I had to spend six months in a women's refuge ... And refuge life is so difficult as their policy is self support, and that was almost impossible for me.

Regardless of whether families were supportive, all relationships underwent some changes in their dynamics and established patterns:

When I first became sick I didn't get much understanding from my boyfriend and friends or parents. Perhaps they didn't have much information to help them understand what was happening. No intuition there or experience of being sick. I think people were really floundering because I changed so much.

Day to day interactions were changed when a partner was unable to fulfil domestic tasks, maintain activities or interests, sustain conversation or sexual contact. In the absence of other explanations, some people wondered whether the causes for their illness lay within their relationships, especially if both partners had this condition. A number of
people questioned the extent to which their relationship might be implicated in making them sick, particularly when friends, doctors or alternative therapists insinuated that that might be possible. Several couples had temporary separations. One couple divorced and later remarried. Each partner now argues that the illness was responsible for the original break-up, although at the time neither interpreted the woman's symptoms as illness.

Dependency became a major dilemma for people. People who had been independent struggled with becoming dependent on their partners:

*My poor husband has had a dreadful marriage. First with me being a workaholic, then sick, then workaholic, then sick. I do wonder how he has put up with me. I've tried so hard to be 'with it' when he's around, to make sure my waking time has coincided with when he's here, but that's not all that good is it? It means that he is the focus of my life.*

*My partner had to take a lot of responsibility for my life and that cut me off from friends a bit and caused tension. At the time it wasn't something I could do very much about.*

Young people who would normally have been beginning to enjoy a newfound independence became dependent on parents for income, accommodation, care and support. Their needs were frequently in excess of what parents felt they could or should offer, so relations became very tense, particularly when there was no diagnosis.

In summary, life for people became increasingly difficult as their illness continued. Without information about it, people had no way of explaining their changes to their employers or the families they cared about and needed. Many people continued working in some capacity, most relationships continued, and most of the younger people were able to maintain their efforts to establish their lives, but these were remarkable achievements given most people's circumstances. Some had greater struggles as they had to find meaning in their lives when they were no longer able to maintain the links with 'normal' life. It therefore became increasingly important to have an explanation that might account for these changes.
The urgency of health concerns

In general, it is not particularly unusual for people to take some time to regard their symptoms as serious (Mechanic, 1982). As Calnan (1987) has pointed out, most people go through a process of slowly assessing their symptoms, then weighing that information in the light of advice from family and friends. People in this study were no exception, although they may have been more inclined to disregard their symptoms than some other people. Several people seemed to accommodate quite high levels of distress and discomfort:

I would go home from work and be barely able to stay upright even when I was leaning against the sink. I look back on it now and wonder what I was doing all those months, just pushing on like that.

However, explanations became important for everyone once their symptoms were extremely intrusive, alarming or inconvenient. Whether these features occurred with people's initial illness, or developed with time, it was experiences such as the following which began most people's quest:

Every time I'd been to my doctor about feeling low, lack of energy, attacks of diarrhoea, there would always be a virus to explain it—a virus seems to cover a multitude of things! You get to the stage where you can't be bothered going any more, because you think, 'oh well, I'm a hypochondriac, or a person who's always sort of at the doctors' ... It wasn't until 1988, after fourteen years, that I realised something was terribly wrong. All the usual things suddenly got much worse. That was a very, very busy year, and when I stopped rushing and went on holidays I was exhausted, sleeping all the time ... I even found myself driving on the wrong side of the road, not even sure where I was. That made me plead with the doctor to work out what was going wrong. I was very scared then.

I knew there was something very wrong, and that ignoring it was no longer working. And workwise I was worried that I was beginning to be dangerous, to myself and others as I often felt so dizzy on the wards that I had to lean against a wall to recover. I eventually was not confident that I was using the medical equipment properly and being in intensive care work, supervising other people, I knew that I had to stop.
If I went to the toilet I had to use about quarter of an acre of loo paper ... It would have been alright if I could shower afterwards, but that’s not always possible.

I was going to work one day and taking the next off. No one could tell me what was wrong, but my boyfriend kept saying it doesn’t matter what you have, you’re really sick and have to rest. It took me a long time to be convinced that I was sick. He was much better than I was at that.

By then I was desperate to know what was wrong. I was getting flu after flu after flu. My sick record at work was incredible. They didn’t understand, my family didn’t understand, I didn’t understand.

Fears fed into people’s distress by this time. Many told me how they had inwardly wondered whether they were sick with the first stages of terminal illness. They mentioned conditions such as cancers, brain tumours, leukemia, AIDS and multiple sclerosis. Such fears were heightened when people had had family members or friends with these diseases.

Both my parents died of cancer at the age that I am now. My symptoms seemed so similar to theirs. I was very fearful, but it’s hard to express those fears to doctors or other people.

Hazards of the quest

Once people began to consult doctors about their illness, they encountered several difficulties. In the main, they found that the quest for explanation was more likely to be lengthy than brief. They were also more likely to be treated badly than well, especially if they showed distress or were female. When the quest failed to produce an adequate explanation, was lengthy, and exposed people to responses they felt were disrespectful, people were often more disadvantaged than before they began their enquiries. Their health was generally worse, their anxieties and fears were heightened and their confidence in themselves was depleted.

Length of the quest

The length of time that elapsed between people having a diagnosis of CFS (or its equivalent as in ME or PVS) is summarised in Table 5.1. Most had
only been able to get a diagnosis in the last four years, following the
growing biomedical interest in this condition. That meant that some
participants had spent more than five years of their illness without an
adequate explanation for their problems.

<table>
<thead>
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<th>Time elapsed</th>
<th>No. of participants</th>
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<tbody>
<tr>
<td>&lt; 6 months</td>
<td>7</td>
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<tr>
<td>6–12 months</td>
<td>4</td>
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<td>12–18 months</td>
<td>3</td>
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<td>18 months–2 years</td>
<td>5</td>
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<tr>
<td>&gt; 5 years</td>
<td>13</td>
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<tr>
<td>Total</td>
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**Unsatisfactory consultations**

Over time, consultations with doctors were more likely to leave people
distressed and anxious than to address their needs for information,
constructive advice and considered reassurance. If people chose to consult
more than one doctor—and most did—their experiences were often
similar. For the majority of participants, these formal transactions
exacerbated their experiences of uncertainty and alienation, and made
their other social relations much more difficult to negotiate.

*Not knowing I was ill—there was no image in my mind of who I
was. I took it on myself and said ‘you are useless and hopeless’.*

*I blamed myself and aspects of my life because there was nothing
there for me to identify.*

*I struggled for years, kept pushing myself, often not wanting to
know I was sick, and anyway my husband didn’t believe me.*

*If I had had a diagnosis and known that this was long term, I think I
might well have not reached the breaking point that I did. I think I
pushed myself into a hole because I just kept putting it down to
stress. I kept taking on all the usual commitments and more
because I thought that I would soon have this thing licked.*

*I was afraid I was crazy.*
Such encounters left people angry and harmed:

I would hope that no one would ever have to have that frightening experience of disbelief and disrespect and helplessness. I don't think I will ever forget what it was like to feel I was dying, unable to do anything any more. It was such an unusual experience, like going to the moon. And living through all the havoc that it brought to all of us and the constant uncertainty, and no one understood or could give me a good explanation for what was happening.

There were times when I let doctors put me down and feel neurotic but in the long run I felt very angry with them all. I still do.

He (the doctor) told me there was nothing wrong with me and I had trusted him so much. I felt I had to believe him ... But I felt so sick that I couldn't keep going. I know I was on the edge of a kind of breakdown in the end, as so little made sense. I would sit and pull my hair very tightly to feel it, to know that my other feelings were also real. Then at one stage I was rocking back and forth and I thought this is it, and I decided I had to see a different doctor then or I would go mad.

I saw doctor after doctor and not one of them had anything helpful to offer, except the occasional referral to a psychiatrist. I took their medicines but they made no difference. I felt increasingly helpless.

Even where doctors had acknowledged people's symptoms, provided treatments and encouragement, many people felt they had been poorly treated because their doctors did not give them information or offer a diagnosis. In four instances, participants learned that their doctors had withheld a diagnosis in the belief that it might alter the way the person was coping with the illness.

Eventually I asked the doctor whether I might have ME. He said, yes, he thought that was what I have. He then went on to say that he has it too, and knows what it is like. But he thought it would be best not to tell me, as it might alter my response, that I might stop trying to exercise. Up till then he had always tried to reassure me that it was normal to have the range of infections and viral illnesses I was having each year. He even encouraged me to leave my job, agreeing with me that I was probably 'burnt out'. He did this without suggesting that I might have an ongoing illness, so now
I'm sick and I haven't got a permanent job to fall back on and have to rely on this contract work I do.

Although such doctors might have been well meaning, they left people confused. The participants felt they were receiving reassuring medical care, but in some ways the reassurance divorced them from a realistic analysis of their position.

I would come out very confused. I went to see him because I knew I should take time off work as I was so sick. But he kept saying you are looking very well and he would praise the way I had been living my life, the way I was striving to keep fit and keep working. Then after all that he would say do you really think you need time off work and I went with his ideas and kept going. It really did me in in the long run.

Only thirteen participants felt they had been treated consistently with respect and concern by doctors during the time prior to a diagnosis. In their cases, doctors had listened carefully to the details of their story and heard their explanations for the problem. Doctors had acknowledged their symptoms, attempted to assess what was happening and been supportive at times about effects on work and family, and sought to find explanations.

My doctor was straightforward with me so I suppose I was luckier than most. In the end he said I haven't got a clue what is wrong with you but I know you are very sick. He'd even been going through his textbooks for rare blood diseases.

I have never felt with her that she has ever thought this was anything other than a serious illness. That made it easier to go to the doctor and was a vast relief. And to feel that somebody respects your opinion. To be confident that you are being told what she knows and that she will tell you if she doesn't know ... She always takes the things I go to talk to her about seriously and that has been so important.

When I went back and said something was really wrong, he said he didn't know what it was. He then asked me if I would be prepared to go to a naturopath ... He said that alternative medicine has things to offer that conventional medicine doesn't. He said that if he can't do something then there are other ways of looking at things ... Later he worked out that I had this CFS, but he did that only after she (the naturopath) had pointed out to him that I had glandular fever.
The 'lucky' thirteen comprised seven men (70% of male participants) and six women (15% of female participants). Reasons for this disparity between men's and women's experiences are discussed below.

The disadvantages of expressing distress
When people expressed distress in their consultations with doctors, most felt that their distress was misunderstood and poorly handled. As women were more likely to express their feelings, they were particularly vulnerable.

Ironically, most people felt that their initial consultations were satisfactory provided that they were not too concerned about their health. At those times many had low expectations of their visits, they had their own explanations for their symptoms (such as being stressed) or they were seeking only symptomatic relief.

When I look back over my medical records, which I did once, I had to say that this looks crazy. Every time I went to the doctor for three years, I was going with something different. I had all the other things wrong but might only mention the most aggravating things at the time.

I just thought I was run down and it was taking me a long time to get over the flu. I was getting a lot of sinusitis at the time and of course I know now that is all part of the picture, but then ... So I was going back to the staff doctor at work because I was so crook I couldn't keep working and would need a couple of days off work or I would need something to relieve the sinusitis. When I finally asked her for a referral to a specialist two years later, looking back on my record, it seemed that I'd just gone to see her for sinusitis all that time. I was just going for what I knew was treatable.

Although most people did not find these consultations particularly helpful, they did think that their inquiries had been treated with sufficient interest and respect.

People received what they viewed as their most adverse responses only when they were anxious about their symptoms. A few who had gone to the doctor very concerned about their initial illness encountered
considerable scorn, although this seemed to have happened more for people who had become ill some years ago.

He told me that I had a bizarre range of symptoms, that he'd never heard of anything like that. It had to be all in my head—was I finding it difficult to cope with the beginning of the school holidays ... I felt really sick and I had children to look after. I thought if I was going crazy and I didn't feel like I was going crazy, then I must have been really crazy! I had to be very mentally disturbed to have made my body that sick!

I was blaming my own inadequacies and my smoking for feeling sick in the late 60's. I felt I couldn't cope any more when I was unable to work out which way the traffic went in Castlereigh Street in Sydney where I had been working for some time. I went to the doctor who seemed intrigued. Later on he decided to get me drunk and take me to bed to fix me up. It was a time of strange social mores but after that I decided not to go back to a doctor for some time.

The impact of doctors' scornful responses could be of lasting significance. In both these instances the women were still feeling extremely angry more than twenty years later. Their subsequent contacts with doctors were often marked by distrust and disharmony.

Some other participants found that they received good care while their illness appeared to be intriguing or compelling in its severity, but that as time went by and they were growing more anxious at their prolonged ill health, they felt that their doctors lost interest. This was particularly so when laboratory tests failed to show any specific results.

When the test for Ross River fever was negative, instead of being supportive and interested which he had been for nearly six weeks, my doctor decided that my illness was due to being overweight. I was no longer encouraged to take sick leave but by then I was so ill that I realised I had to take time off work. I ended up having to haggle with him for sick leave.

Initially I was diagnosed as having partial MS. The myelograms gave me grand mal seizures, which I have had since I was a child. The doctor kept ignoring these although the staff said that was what was happening—he was never there for the spinal taps—and said they were simply tension headaches. Then he changed his mind
about MS after some more tests, and said wait until there is another attack, and wouldn't see me again. Meantime I could barely walk, I was tripping over all the time.

Several simply felt unheard. One young woman, who tried to give a complete picture of what was happening to her in the months before she got ill, found that the doctor ignored symptoms of sore throats, fevers and headaches, and focussed only on her early story of emotional trauma:

When I saw her I was feeling so tired, depressed, unworthy, self-doubting, confused, that I am sure I simply convinced her that the problem was emotional. However, these feelings were entirely suited to someone with an undiagnosed, becoming chronic, physical-mental organic illness. I argued with her, asserting the validity of my physical symptoms, only to be told that these were being used by me as a prop to opt out on life! I soon stopped arguing. I was getting all teary and took on the fact that she would probably just interpret this as confirming hysteria/hypochondria/depression ... She wasn't offensive in her manner—very gentle actually. She obviously thought she knew what was best for me, regardless of my input. This was probably the most degrading aspect of the exchange, which I found devastating on top of everything else, not to mention the effects of the trauma on my sick body.

I was told my only problem was that I was an intelligent attractive young lady. I had to have him inspect my whole body inside and out, only to be told that! I didn't ever want to face up to another male doctor ever again after that.

Although some women felt that their symptoms had been acknowledged, they were later more distressed to hear that their symptoms had been interpreted as chronic depression, neurosis or poor coping with life.

I know how extreme the symptoms were. And I know I was also very depressed eventually. But it couldn't have been depression that was making me that sick, as I know that no matter how good I had felt in my mood, there were all those other things wrong.

How could I have been that sick with depression? Anyway, when I first got ill, it happened at the happiest and most satisfying time of
my life. If I was depressed when the doctor spoke to me it was because I was so sick and missing out on those joys.

The disadvantages of being a woman

Women were given psychiatric diagnoses and paternalistic, derisive or dismissive responses disproportionately often, suggesting that women receive care that is markedly different from men's. This is not a new finding, as others have noted this before (Broom Darroch, 1978; Broom, 1989; Brozovic, 1989; Zola, 1963; 1991). However, this study confirms that this differential care continues, and it continues at the hands of female as well as male doctors.

Although people who make repetitive use of the health care system are generally more likely to be labelled as psychiatrically ill by doctors (Levanthal et al, 1982), women in this study seemed to have had particular difficulties in having their symptoms acknowledged. Their expressed emotion or signs of distress influenced the diagnosis regardless of other symptoms. Yet when women expressed minimal emotion or distress, that too was seen as evidence of neurosis. One woman was told by her doctor that she was much too content to be as sick as she described herself:

> He said that people who have been as sick as I had been would be much more depressed, but that isn't my way. I had a wonderful supportive husband, a supportive church and help with the kids. What did he want me to do, give up and lie in bed all day?

Another woman whose spouse had only recently recovered from surgery for a brain tumour which had taken some time to be recognised, had gone to some effort to ensure that she presented the medical specialist with a coherent picture and minimal emotional distress. She provided a list of her symptoms and the history of the condition. The doctor cut her consultation short and the physical examination she had expected was never conducted. She discovered that some doctors do not respond well to patients (women patients?) with written descriptions of their illness, but as she said:

> I was having trouble remembering things; short term memory was badly gone. I was very emotionally involved in getting an outcome from this visit to the doctor, so I wanted to be as organised as possible.
One consequence of the psychiatric diagnoses and dismissive responses was that women felt less able to articulate their problem and have it heard and recognised than men did. They generally regarded the unhelpful responses they received as comments on them as women. Some felt so angry that they reacted to the judgments by attempting to appear anything but ill.

_I ended up in hospital and the doctor there suggested it was to do with being a young mother, that it was all psychosomatic. I suppose my attitude was that they can think that but I know they are wrong. I decided that I would just ignore the whole thing ... I was determined not to be one of those 'young mothers from the western suburbs who's ill because she can't cope with having little children'._

_It's an anxious thing. I don't want to be labelled as a neurotic woman ... When he (male doctor) laughed at the idea of ME, I decided that I wasn't going to be seen as a neurotic female, and being a nurse! Well you know what they say about nurses—everyone knows or thinks they know that nurses are neurotic women, so I just kept pushing myself._

A few accepted the psychiatric interpretations and attempted to examine their lives for sources of their depression and unhappiness; three were hospitalised, only to undergo further belittling experiences.

_You know when I was to see the psychiatrist, she didn't even switch her phone through. Every time the phone rang, which seemed to be frequently, I had to leave the room. Being sent out of the room for phone calls—it all puts you down. I think they haven't realised that we are all worthy, irrespective of what short straws you've drawn in life._

_I was very sick, but because my parents had broken up everyone thought that that was why I was like I was. I thought that must have been the reason too. I didn't have any other way to understand it once I was in the hospital. You know, while I was there, I felt like I didn't matter, that whatever I said, people just ignored it. They helped to make me feel helpless as they took away my sense that I could do something for myself. They didn't tell me why I was there or how long I would be there for and I was afraid that it might be for the rest of my life. They treated me as a child and told me I had to take the medicine because the doctor said so!_
In contrast, men’s accounts of their symptoms and men’s choices about treatment were usually given more credence than women’s. Two were told they had glandular fever even though the test results were uninformative. Their doctors had chosen to dismiss the test results rather than the men’s accounts. One man who became very depressed and desperate was treated by the psychiatrist for both CFS and post-traumatic stress syndrome (based on his time as a conscript in Vietnam). In general though, men were also less likely to accept diagnoses that they saw as judgmental; when two were encouraged to enter psychiatric hospitals, they were angry and chose not to see that doctor again.

Unlike women, men have been socialised into thinking that they can and will be heard, and they acted accordingly. Only one said that he felt driven to prove that doctors were wrong by ignoring his condition and acting as if he were entirely well. On the other hand, a few men felt circumscribed by the difficulties of having an illness that made them feel so emotional. One young man specifically complained that doctors tended to ignore his emotions.

They tend to look at your physical symptoms. Are you sweating a lot, a temperature, glands up? Whereas with something that has been this debilitating over a number of years, the physical symptoms are the ones that you can cope with. It’s the mental and emotional problems that really hurt you and hardly anyone wants to address that. Even my doctor who is very good and a counsellor, still focusses on the symptoms. She wouldn’t know that I’ve been bursting into tears in front of people and unable to concentrate.

The effects of unsuccessful ‘quests’

During their quests, most participants became sicker. Only a few did not show deterioration in their health during this time. For the majority who were deteriorating, decisions about how to manage their problems were difficult to make. They were baffled. Most found that they felt extremely unwell, if not all the time then at least some of the time, yet friends and family were telling them that they looked well. At times some even felt well, so they also wondered if they were frauds or failures, people who could rise to some occasions and fail at others. In no longer being able to behave as they had previously done, people felt they were losing their sense of identity and purpose. Judged and dismissed by others, their
feelings of worth were considerably diminished. Without an explanation, they had no way to anchor their fears or give meaning to the ways their lives had changed.

People reacted in diverse but related ways: with defiance, denial or self-doubt. Defiance and denial were responses that allowed people to preserve some image of themselves as they once were. In many respects, the responses were consistent with their previous styles of pushing through, overcoming difficulties and getting on with it. In actively trying to counter the image of moral and physical weakness, people were adhering to prevailing cultural norms about health and fitness, and expectations of social and economic productivity. As such, people's responses were culturally acceptable; inevitably their personal styles were reinforced by approval or, at least, a lack of criticism. In some ways, it was like a round peg readily fitting into the round hole.

Defiance, already touched on in the previous section, was generally something that was motivated by other people's direct or indirect judgments. As has been mentioned, women received criticism from doctors more often than the men in the study. Nevertheless three men felt a degree of criticism from colleagues. Where that criticism played on past experiences of being judged and criticised, defiance could be pronounced.

All my life, no matter what I was doing, I have had to struggle to have people believe me. I suppose it's been a tough and interesting life, but I have felt totally discredited over the years ... There was a lot of emotional abuse at home when I was a child. The messages that came through to me were that to be loved and to be acceptable I had to try harder. I think that past feeds into this illness now as I think the way I have tried to gain care and recognition has meant that I try too hard, I work at it too much. Even now I am so sick I am still doing that even though I know it harms me. Yet for all that, the more I've tried to achieve, the less care and concern I have had from others. And at times, I have been actively undermined.

Some of the defiance could be very assertively expressed. People were keen to prove that they were not morally weak. They wanted to prove that they could overcome illness just as they had overcome other difficulties in their lives. They short-circuited some of the uncertainties
that could be so overwhelming by holding firmly to their convictions about themselves. To avoid further derision, they stopped seeing doctors or any other health professionals for a time. Grief or distress at the change in their lives was deferred because people put all their efforts into being 'normal'.

In retrospect, participants identified this defiant response as perverse because they extended themselves beyond their limits: they worked too hard, they exercised too much, they ignored complications such as injuries, pain and increasing numbers of symptoms until they could no longer keep going. A few said they became almost manic in their efforts to keep pushing through.

Defiance was a reaction to other people's criticism; denial was a way that participants protected themselves from encountering criticism. People recognised the value of not giving boring organ recitals. As long as they appeared to be acting normally, then others had no reason to comment, to laugh or to question. Denial was also one way of getting by, as denial helped some people to cope with high levels of pain and discomfort. Up to a point, denial meant that people could continue to see themselves as competent and capable, with a normal future ahead. In particular, young people practiced denial whenever they could, but in doing so learnt that continuing to live the lives they wanted had its adverse consequences.

I got more and more tired. Then I saw doctors who said, 'there is nothing wrong; increase your sport and activity'. I wanted to be like that; I always had been. You get left out of things otherwise, and anyway I enjoyed them. I couldn't see why being fit and busy would make me sick. So I kept trying that, and then I would crash with the effort. I felt worse and worse.

Denial and defiance were stances that were available only to some people and only some of the time. Their health had to be able to sustain the pretence. Once people were very sick, they had fewer choices. At that point most were left with self-doubt, although the majority of participants experienced periods of this regardless of their health. Without a medical explanation, people had to search their life histories, their current experiences and behaviours for meaningful explanations for their condition. With self-doubt, people succumbed at times to feelings of
failure, defeat and powerlessness. Estrangement and uncertainty were exacerbated. People felt the discomfort of Goffman's (1963) 'communicative incompetence', the feeling that they could no longer express in meaningful ways things that were very important to them. Unable to share their experiences of pain and illness with doctors, or others, many participants lost confidence in their ability to interpret their own experience; they moved into limbo, that place where 'each man is unable to hear his own tune' (Sacks, 1991). Women in particular could be distressed by these feelings, but both sexes had difficulty at times. Men, however, were less vulnerable to self-doubt, in part because they were doubted less, and because it seemed that self-doubt was less a part of their histories.

Through the fears and emotional distresses associated with self-doubt, some people's symptoms may also have been amplified. Mechanic (1982) has noted that emotion creates its own range of symptoms, fosters vivid memories of any discomfort and intensifies people's existing symptoms through physiological arousal. When people were very sick, with high levels of emotion feeding into their experience, withdrawal was often the only response that they found bearable, even though it could also leave them lonely and isolated.

It's hard for me to tell you how bad this has been. I would wake up in the morning and feel terrible but get worse. I might have two to three good hours in the morning then I would have to rest all afternoon. I never went out at night. Talking with friends wore me out. There were some days when I couldn't even get my body to move. The first few times that happened I didn't have a diagnosis and I was really terrified. Terror and fear made everything even worse.

Conclusion

In this chapter I have traced the common features in most people's early experiences of this illness. It could be argued that this account only reflects the characteristics of the people in this study, that what is described here is consistent with what might be expected from a group of people who are prepared to volunteer to be part of a lengthy and detailed inquiry. However, their experiences and attitudes were very similar to those of so
many other people I have spoken with during the last three years, particularly those who had become very ill.

In the main, people's deteriorating health was influenced by their responses to their symptoms, but those responses were mediated by the reactions of doctors and by pervasive cultural mores. For people who had no inclination (or no opportunity because of their life circumstances) to slip into the 'sick role', the conflict between their own sensations and the perceptions and expectations of others was perplexing. During this time, while they were without explanations for their condition, most people were uncertain about how they might interpret or respond to what was an experience marked by bizarre and puzzling symptoms. Once that uncertainty was compounded by disparagement from doctors, people were increasingly thrown back on those activities and responses that had always given shape to their experience. In continuing with these, they were attempting to restore sense and meaning to their worlds, to take control of their lives in baffling and hurtful circumstances. Ultimately, however, these attempts seem to have contributed to people's increasingly poor health, growing social losses and distress.
Diagnosis: ending the quest

Thinking about illness! — To calm the imagination of the invalid, so that at least he should not, as hitherto, have to suffer more from thinking about his illness than the illness itself—that I think would be something! It would be a great deal!

Nietzsche

Diagnosis was a major milestone in the ongoing course of people's illness. It brought to an end the 'unorganised stage of illness' (Balint, 1972) and an end to what I have called people's 'quest for explanation'. As has been shown in chapter five, a lengthy quest marked by dismissals and disparagement from doctors exacerbated and reinforced people's feelings of uncertainty and estrangement and contributed to their declining health. In this chapter, I show how diagnosis eased those feelings and moderated the course of their illness. The beneficial changes associated with diagnosis were, however, unforeseen by the majority of doctors who participated in the study. In the absence of any information to the contrary, most were doubtful about the therapeutic value of diagnosis for conditions such as CFS.

The chapter is organised around doctors' and sufferers' perspectives on diagnosis. First I present doctors' views. Their views are then considered in relation to the views expressed by sufferers. Although most sufferers shared some similar views on diagnosis, the length and difficulty of people's quest for explanation had a marked effect on their feelings about diagnosis and the consequences of diagnosis for their overall health. As a result, I discuss sufferers' feelings about diagnosis from several angles. I cover their shared views on the benefits and drawbacks of diagnosis, and contrast the views and experiences of those who had an early diagnosis (or affirmation of illness) with the views and experiences of those participants whose quest was lengthy and 'hazardous'.

1 This is the only chapter where both groups of participants are discussed. To clearly identify which participants I am discussing at any one time, I have chosen to refer to 'doctors' and 'sufferers'. Some participants with CFS disliked the term 'sufferers', so I have confined its use to this chapter.
The doctors' perspective on care and diagnosis

During the process of interviewing sufferers for the first time, I became aware that many felt their doctors had shown poor understanding of their problems. Although it seemed likely that some of the difficulties people encountered could be explained by dissatisfaction with the communication styles of some doctors, there seemed to be broader issues at stake. There were indications that gender stereotypes were playing a part in doctors' attitudes. Doctors' views on appropriate responses to puzzling and problematic conditions also seemed to be relevant. Although there has been considerable research by others on the first two points (Posner, 1984; Kleinman, 1988; Squier, 1990; Broom, 1989; Zola, 1991), the last point has not been the subject of much study. Baszanger's (1990) study of doctors' responses to people with chronic pain is a notable exception.

In the following four sections therefore, I have followed Baszanger's approach. She showed how doctors' 'practical arrangements of theoretical fact' altered the kind of care they offered to patients. I begin by outlining doctors' views about CFS as a new illness category. In the subsequent three sections, I then examine the different practical ways that doctors arranged the 'theoretical facts' about CFS, about CFS as a diagnosis, and about diagnosis generally. I conclude with doctors' comments about how they came to develop their views on care for people who are chronically ill.

Doctors' views on CFS

Most doctors were somewhat uncertain about the nature of CFS. All but one were aware of an illness called CFS. Almost half were unsure about the illness, and unsure whether they had had patients with it, but they were making efforts to follow recent research. The other half were generally quite knowledgeable about the condition, although they maintained some reservations. Reservations included: scepticism towards 'fashionable epidemics' such as the Royal Free outbreak or more recently, RSI; caution about loosely defined 'umbrella terms' such as CFS; and a concern that both doctors and patients may end up 'medicalising' fatigue.
when it might well be a case of people simply doing too much. A few expressed concern about the legal/professional position of doctors in relation to a diagnosis such as CFS, mentioning their reluctance to become embroiled in controversy or be subject to critical professional scrutiny.

Commitment to the patients' views of illness
Six doctors expressed a strong commitment to working with patients' views about their health. In the main, these doctors were also the doctors that participants in the study had already identified as helpful, so I have placed some emphasis on their views.

They approached their patients in the following ways:

I have always believed people. People who weren't being heard or believed by other doctors did at least get that from me. Maybe that was why they came, even when they had a good idea of what was wrong with them.

It seems to be hard for people to acknowledge how sick they are, or even that they keep overdoing it. Believing my patients is so important for them. For them to have a positive attitude towards getting better requires them to believe, and be believed, about how bad they are in the first place.

I work hard to legitimise their feelings of sickness. I want them to know that I believe them, and that I can understand that their symptoms are spoiling their lives.

It can be a privilege to be with some clients. I can feel tremendous admiration for their struggle.

They expressed a desire to understand the world of their clients, to believe their accounts, to learn from and be edified by their struggles. They

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2 Although I did not set out to attract them, most of the doctors whom participants had mentioned as being helpful volunteered to be part of this study. As a result, it is possible to see how these ‘helpful’ doctors resolved their professional concerns surrounding care and a diagnosis of CFS.

3 An anecdote from a participant indicates the power of a doctors’ expressed belief. Although this woman had been given the diagnosis of CFS from a specialist rheumatologist, her own GP continued to suggest some doubt about the diagnosis. The doctor changed her approach after a discussion group with other doctors and myself, where I had pointed out that patients expressed a strong desire to be believed by their doctors. This doctor subsequently told the woman that she accepted and believed her story, and that she wanted her client to know this. She also mentioned why she had decided to tell her this.
tended to develop a relationship with their patients where all aspects of
the person's health might be discussed, including the alternative
treatments their patient might seek.

Although all six acknowledged the scientific uncertainties about CFS, they
had each found ways to interpret the uncertainties so they could give
patients a diagnosis of CFS. Two doctors responded to scientific concerns
about CFS by becoming extremely well-informed about current research
on CFS as well as developing their own sophisticated explanations for the
illness. They also mentioned that medical knowledge is simply one way
of understanding illness. Each stressed the need for doctors to understand;
to offer patients support, knowledge, reassurance and hope. They said
they liked to be able to offer something: I hate saying 'sorry I can't help
you'. As a result, they tried to offer patients a range of interventions,
including controversial doses of intravenous vitamin C, megadoses of
vitamins and minerals, anti-fungal treatments (for systemic candida),
allergy assessments, intramuscular injections of gamma globulin and
dietary change.

Three of the six doctors were very interested in helping patients with CFS,
but without necessarily developing their own ideas about its aetiology:

I am happy to accept Professor Dwyer's ideas on this. They make
enough sense for my purposes.

I am confused about why CFS happens, but I am concerned about
my patients who have this sort of illness.

Another was keen to offer care to patients with CFS, despite some
discomfort about the scientific uncertainties and the possible adverse
consequences of giving people's symptoms a label.

I was patronising about CFS for a while. I've struggled to come to a
position with CFS. As a medical student, CFS was nothing. Then I
did a course which talked about ME. And there was a woman on
the course who had it. That helped a lot. Now it makes sense to me
that we might have post-viral syndromes. I just wonder what we
called them 50-60 years ago ... I will give a diagnosis of CFS. But I
still have ambivalent feelings about labels and have trouble giving
them. If I give one, it's often easier for me as a doctor. But I am

Even though the woman felt this response was a little artificial, she laughed and said it
made things 'just that bit easier — less of a nervous battle'.

trying to demedicalise people's experience. Putting a label on immediately makes people into patients.

These four doctors had followed current research, but were comfortable with the idea that medical explanations are often incomplete. With the exception of the last doctor, each stressed the importance for any patient of having a diagnosis to explain their distressing symptoms. Because they had read widely, they were aware of the possible treatments for CFS, although they were generally not willing to experiment with more controversial regimes. Instead they would sometimes refer patients to general practitioners who would offer such treatments, and they encouraged or tolerated their patients seeing alternative practitioners. Occasionally they offered their own favoured forms of intervention, usually ones that had been reported in the mainstream medical literature.

The four doctors acted upon their concerns about care and accommodated scientific uncertainty by becoming 'case managers' for their patients. They monitored health changes, gave emotional support and encouragement and passed on any relevant research data or advice based on other patients' experiences.

Support can be a difficult role, but it's one that I enjoy. It's difficult because it's time consuming and because you can't do anything. Support differs. It can be talk, consultation, discussion of treatments or simply a check-in to get analgesics. I always refer people elsewhere as well so that I share the burden of people's health then. And different services are important. It also means they are less dependent on me.

I like to have enough of a picture about illness that can hang together but as a doctor I am more interested in how the coping can go on. I am now prepared not to be the expert. I listen to the patient and her information. I am interested, but I am also open about not necessarily knowing what to do next. I will monitor and do any appropriate tests, show that I am genuinely concerned for them, recommend groups and information. I try to discuss the prognosis and possible management. I will sometimes encourage them to see specialists, even if that may mean a long wait (eighteen months before seeing any of the specialists at the Prince Henry or Prince of Wales hospitals in Sydney). People generally have different notions of management so I try to respond to that. Each person is different.
I like seeing the ways that people cope. I try to help them see their own strengths, and to recognise their past achievements in coping.

The responses offered by these doctors resemble those that are sometimes given to people when they participate in clinical trials. In clinical trials, people are given close and interested attention, their physical changes are carefully noted, and the detail of change is recorded. I mention the similarity here because results from two (as yet unpublished) clinical trials conducted on people with CFS had results which suggest that a climate of support and belief from the medical profession may contribute as effectively to improvements in people's health and well-being as a variety of treatments. In these two trials people in the placebo groups showed the same amount of improvement (as much as one standard deviation on the measures used in the trials) as the groups receiving treatments (Woodward, 1991).

Concern about the therapeutic effects of diagnosis

Almost three-quarters of the doctors I interviewed expressed a reluctance to diagnose people as having CFS. Although several of these doctors had concerns about the scientific uncertainties associated with CFS, most expressed their reservations in sociological terms.

In particular, the majority were worried that labelling symptoms such as fatigue, weakness and tiredness as an illness, would mean that people might inappropriately think themselves irrevocably ill:

People usually like a label but I try not to give it as they may get into a 'sick' mould with a label.

I have a fear of creating a self-fulfilling prophecy when I give a label.

I want to avoid 'disabling' people. I try to make illness just a normal variation on life.

One doctor was concerned about using a label that he could not substantiate because it created too much dissonance for him:

A label can be overrated. I have a strong need for intellectual honesty and giving a label that I can't substantiate bothers me. I think it is better to get away without a label if we can. It can be a disservice to those who have the illness, those without it, and those researching it, if we give a label too readily.
Another thought it was important to avoid labels so that she would be able to maintain a critical and open mind to a person's problems:

*I like to avoid a label so I can hear the differences in a person's problems over time. So I can hear all the details, hear what it is to them.*

A few doctors expressed dissatisfaction with diagnostic criteria for a range of complex chronic conditions. They had a preference for generic diagnoses, such as 'disorder of the musculoskeletal system' over specific diagnoses.

Although many of these doctors would describe themselves as 'case managers' when they had patients with ill-defined conditions, their orientation in that role inevitably differed from the orientation of doctors in the previous section. In maintaining reservations about diagnosis, most were sincerely trying to provide helpful responses. However, had their patient had a well-defined condition, it is unlikely that they would have considered withholding a diagnosis. In this instance, several were worried by the lack of an adequate explanation and specific treatments for CFS, so they thought it was best to encourage people to get on with their lives and disregard their symptoms. Their reservations about providing patients with a diagnosis of CFS seemed to be based on the belief that once people were told they are sick they would stay that way, that the diagnosis would be potentially 'disabling'. In other words, they were concerned that a diagnosis may contribute adversely and unnecessarily to a person's declining health.

In general, these doctors spoke about the complexity of offering care. Several expressed their uncertainties about the extent of the care they could provide, and what it was that patients really wanted from them. They sometimes acknowledged that their confusion was not eased by the way some patients presented their story. They said they felt frustrated by patients who had seen several doctors and then had mixed and confusing stories to tell, often told with great emotion or aggression.

'Doctor knows best': commitment to the professional assessment of illness

Three doctors had well-defined views about the professional's exclusive role in the assessment and management of any illness. They saw the doctor's role as authoritative and directive, and they expected patients to
comply with their assessments and their interventions. All three doctors felt that appropriate care for patients with non-specific conditions comprised either advice and some pushing along, or intensive psychotherapy based on the assumption that the physical pain was psychological in its origin. One doctor spoke of patients needing their symptoms. Another of these doctors, a man who specialised in patients with chronic pain, was adamant that diagnosis or the details of people's pain were unimportant:

*I expect people to do as I say. I tell them they are being resistant if they don't. I refuse to listen to their medical history, or anything to do with their pain. I insist that I have a different approach which is about not giving pain any credence in their lives ... It's my belief that the psyche is enmeshed in locomotor control. I've never come across chronic pain without a history of early trauma, usually sexual abuse for women, and a deprived background. It's as if these people are primed to 'tolerance level' and only a bit more is required to give them chronic pain. You know those phrases, 'the back breaks down under a load', 'pain in the neck'.

His stated goal was to separate the patients' pain from their life-history. Unlike the doctors in the previous section, his approach to care was not based on listening to patients' accounts. Rather, it was based on his own convictions about patients' problems. He made it clear that when he and his patients had differing views about the nature of the problem, then his view would prevail. To a lesser degree the other two doctors shared this view. One commented that these sort of people (people with chronic illness or chronic pain) courted the idea of illness, that they often went from practitioner to practitioner because they were using health concerns to gain attention:

*Patients often come in here telling me about a problem that some naturopath has diagnosed or that they have read about in some book, and they want me to fix it. It's like the people who read the newspaper reports on recent medical research and make an appointment to see me about their problem after they have already decided that that is what is wrong with them."

Preparation for uncertainty
Doctors' responses to people with CFS or similar conditions seemed to reflect their individual efforts to resolve or accommodate uncertainty
relating to inadequate scientific information and complex ethical concerns. This uncertainty lies at the heart of medical care (Kleinman, 1988). It is at issue every time doctors have to face limitations in their own knowledge and limitations in medical knowledge (Fox, 1957). It is present in the process of assessing the costs and risks associated with various interventions (Fox, 1980). On the other hand, as others have pointed out (Atkinson, 1984; Shapiro, 1990), doctors' training does not necessarily equip them for responding flexibly to scientific and ethical uncertainties. Doctors are schooled in models of science that minimise uncertainty, that emphasise discrete pathologies supported by 'facts'.

Regardless of how they handled the issue of care, doctors in this study acknowledged how poorly trained they had been for the task of caring:

Being a doctor is a weird role. Medicine is a brainwashing process, telling us what we are supposed to think, but you really have to hang onto who you are and what others have to tell you.

Our training is about acute care, but chronicity is a major challenge in general practice.

Chronic illness is very much a general practice issue and a family issue, but mostly you just have to work out how to manage it as you go along. When you start out you can be too impatient because it's so hard to understand. It takes time and experience. Something about chronic illness and care in our courses would have helped.

How people react with chronic illness is a problem that will never go away. We know so little about it. It is such a big problem for us doctors. We have to cope with not being 'useful', with being a 'human being' not a 'human doing'.

Over the years I've come not to mind chronic problems the way I did when I first graduated. I would do anything then to avoid them. Now I can see all steps that a patient makes as significant, and I can live with uncertainties better ... This is like a growth stage for me in some ways. I think as a doctor that you have to get to the point where you know you can't cure and you have to be able to communicate that to the patient. As a new graduate that was too hard as it went against our training. Then we were supposed to be able to put people in boxes, and watch them follow a predictable path.
It has been suggested (Waitzkin and Stoeckle, 1976) that some doctors may control their concerns about clinical uncertainties by preserving those aspects of their relationships with patients that leave them feeling more powerful. Certainly some of the sceptical and paternalistic responses that participants described in the previous chapter may be explained as doctors' attempts to maintain social distance and power. However, only a few of the doctors whom I interviewed conveyed the impression that they controlled clinical uncertainties by preserving those aspects of their relationships with patients that left them more powerful. On the contrary, most doctors suggested that their responses had less to do with maintaining power and prestige than with their discomfort and uncertainty about how to provide the most constructive intervention. Learning to manage clinical uncertainties was a professional and personal concern. Experience as a doctor, experience of illness either in themselves or in a family member, or witnessing the changes due to an unexplained illness in a previously healthy patient were all factors that seemed to assist doctors when they responded to their chronically ill patients. As one doctor said:

I was shocked to find out how relieved a friend was to get a diagnosis of CFS. And she was someone who would hate being medicalised, so I have had to think about that ... I knew I would have been reluctant to give her that label.

A few doctors also spoke about the challenge of providing care, how empty it could leave them. Several spoke as though they alone carried the burden for people's illness. One male doctor who had been out of medical school for only three years, described going home after work to fall like a zombie in front of the TV. When I asked doctors about their supports, four said they relied on their spouses when they had concerns about their work. Several had established a small network of other doctors with whom they could talk, but the majority described medicine as a stimulating and interesting, if solitary, enterprise.

**Summary of the doctors' perspective on diagnosis and care**
The doctors who succeeded in offering care that patients appreciated and valued were doctors who acknowledged that medical knowledge has its limitations: it's frightening at times how little we really understand. They were also committed to hearing their patients' accounts of their problems.
They were ready to listen to the evidence that their patients described and to acknowledge that their patients' problems needed to be recognised and appreciated. With these views, six doctors were able to respond to their patients not only with support but also an understanding that diagnosis would be more enabling than disabling. Most of the doctors however, were uncertain about appropriate responses to people with conditions like CFS. They cited labelling theory to explain their concerns that a diagnosis would be a disabling medical response. They were loathe to give a diagnosis that might promote long-term illness behaviour in people who might otherwise just get on with their lives.

**Sufferers' perspectives on diagnosis and care**

Doctors discussed their concerns about the effects of diagnosis in terms of people's future lives. Few had considered the effects on patients' lives of not having a diagnosis, yet from sufferers' accounts in chapter five, it is clear that both health and well-being can be adversely affected by the lack of a diagnosis. When people were left with their own perceptions of their symptoms, their distress and sickness increased. In the rest of this chapter, sufferers' views on the value of having a diagnosis are discussed. Their comments counterbalance the concerns that doctors voiced. As well, an additional measure of the value of diagnosis is provided by the moderating effects it appears to have had on people's health.

Ninety percent of participants nominated diagnosis as the single most helpful event in the course of the illness. Of course, people had to have a diagnosis of CFS to participate in this study, but their views about the value of having a diagnosis do not seem to be unusual. Other people with chronic illness share these views. As was mentioned in chapter one, several recent studies have noted that people prefer to have a diagnosis once their health has become a continuing problem (Cunningham et al, 1984; Erde et al, 1988; Elian and Dean, 1985; Seale, 1991; Stewart and Sullivan, 1982; Vanderpool and Weiss, 1987).

At times, people had shared their doctors' reservations about diagnosis. Several people commented with amazement that they had never thought they would need or want a 'label' for any illness they had, since they had
doubts about both the merits of diagnostic processes and concerns about the negative effect of a label. It was only when the effects of their illness became too disruptive that they wanted a diagnosis.

On the other hand, many people were also reluctant to hear that they had a chronic illness. Contrary to doctors’ concerns, people certainly did not embrace the idea of long-term illness. They sought a second opinion before they were prepared to accept the diagnosis. Twenty-one participants had to have the diagnosis confirmed by a specialist, preferably a specialist with high status, to convince them not only that this was an appropriate diagnosis, but also that it was a credible one; a further ten participants got a second opinion from other doctors. People who accepted the diagnosis when it was first suggested usually accepted it for some of the following reasons: they were given the diagnosis by a doctor who had a good reputation or was trusted; they had already diagnosed themselves; they were less disconcerted by controversial diagnoses, often because their doctors had already been treating them for allergies and systemic candida; or they had already had numerous tests performed so that other illnesses had been discounted. Approximately a quarter of the participants decided that the doctor’s diagnosis fitted only after they read accounts of the illness elsewhere:

One of the things that helped me around the time they were suggesting ME/CFS was that the doctor gave me an article about ME/CFS. It was telling a story that was very familiar. As soon as I read it, all I could think was that that was me. The things I thought about were so similar. For someone who is really sceptical that mattered. It matched my own experience. It was easier to accept something that was almost telling the story you were telling yourself.

The booklet told me something about ME/CFS. But what mattered was that it wasn’t a book telling me what I’d got. I was able to read it and know that someone else had felt what I had had. It wasn’t just me going stupid.

Only two have regularly wondered whether more suitable descriptions of their condition were available. They and their doctors have wondered whether multiple sclerosis may eventually be a better description. One woman who has been mostly mildly ill, preferred at times to think of
herself as having some bothering symptoms and weariness rather than having a condition called CFS.

Whilst people eventually accepted the appropriateness of the diagnosis after they had made further investigations and had additional confirmation, it was not a diagnosis that they felt was accompanied by social and medical understanding. They remained aware of its ambiguities:

*The problem with a diagnosis of ME is that it has carried medical uncertainty. So legitimation is an ambiguous process in itself. I've got something which no one believes in. Even the doctor who gave me the diagnosis told me he had always thought it was hysteria.*

Still, despite the ambiguities of the diagnosis, and despite people's reluctance to think of themselves as chronically ill, participants valued the diagnosis of CFS. The remainder of the chapter explores why they valued it as they did.

**Sufferers with an early diagnosis or affirmation of illness: their perspective on diagnosis**

For the sixteen people whose views and experiences are discussed in this section, the quest was not hazardous. From the beginning, these people had a meaningful framework for interpreting their problems, so they were less vulnerable when exposed to the doubts of doctors, employers or family. As a group, they had either an early diagnosis, or early affirmation that they were ill, or information about CFS. The group of sixteen included the 'lucky thirteen' from chapter five, those people who felt they had been consistently treated with respect by doctors. The other three members of this group were people who had information about CFS early in their illness because they knew others with the condition.

In this section, I show how sufferers felt less harmed by the experience of ill health when they had a framework from the beginning. I also show that when people had a specific framework, that is a diagnosis of CFS (or ME or PVS) they felt less harmed by their experience and they had better health outcomes.
The sixteen participants tended to tell their stories of ill health in different ways to other participants because they had not been left vulnerable by their own or others' doubts. Even when they had been very sick they used phrases such as:

I don't think there is anything remarkable about my experience. I'm just one of many people who have been through this.

This has been just a part of my life, inconvenient and at times, bloody awful ... I've got by as best I could really.

I've coped OK. It hasn't been a life downer. I can accept the fact that if I was like this for the rest of my life that I wouldn't be all that desperate.

They did not diminish the severity of their symptoms, but when they described their experiences, they tended to see their illness in less traumatic terms than the majority of participants.

As well, the sixteen were able to tell their story without a sense of being wronged and harmed by others, although they had difficult times. Several of these people had major changes in their lives after the illness started. Four of them were on their own without any family in Canberra, and had to take very long periods of leave from their work or study. Nevertheless, with some form of explanation from the earliest stages of their illness, these people encountered fewer social problems than the majority of sufferers. Employers and families generally understood and accepted that the person was ill, although they did not always understand the effects of the illness.

However, as has been said earlier, people in this group had different experiences around diagnosis. Seven of the participants had a specific framework for understanding their problems. That framework appears to have conferred additional comforts for people when they stayed sick. They described some periods of doubt about themselves, but were always able to resort to the diagnosis as a way of understanding and responding to what was happening.

I know that having the label from the beginning was reassuring when people at work thought I might be psychiatrically ill. Not knowing what it was would have been awful ... Even now when I
go downhill again I get out my books and read about this as much as possible. Not having a label would make that impossible.

Anxiety was a problem from early on. What was going to happen?... Without a friend (with the illness) and a name for this, I don’t know what I would have done with the information that my body was giving me.

It hasn’t made me want to jump off cliffs. I think uncertainty about this would be far worse than knowing. Knowing that it is bad may not be good, but knowing is much better than uncertainty. Uncertainty could be worse than bad news. You fancy the worst then and the worst times with this may not be as bad as your fears.

Of the seven, three people were mostly mildly ill. Because they were aware that they probably had CFS, and because their illness remained mild, they did not feel pushed into self-doubt by the exigencies of their illness or its impact on their social lives and self perception. In contrast to the four who were more severely ill, their concerns remained with the possible consequences of CFS and its effects on their future. A diagnosis gave them a reason for modifying their lifestyles and for reassuring themselves about their present state of health.

This is not about death but it is about changing my hopes and expectations about the next few years. Like I will be 50 next year and there is the feeling that this is the beginning of being old and I’m not ready for that yet. That’s the scariest thing. Who knows? By the time I get better I may be past what I’d like to be able to do.

It affects my ability to plan and in a social situation that proliferates. Otherwise I make light of it. I haven’t been seriously debilitated by it yet.

I do feel discouraged and down because of being ill, but on the whole, I would say that I haven’t found this particularly depressing. I can imagine having diseases that are far worse than this one ... Diagnosis was a relief because it meant I didn’t have anything serious or permanent. I’m now convincing myself to accept some limitations, perhaps for years to come. That’s pretty hard.

In some contrast, the nine people in this group of sixteen who had had no specific framework for their illness, described how the (often lengthy)
period without a specific diagnosis had left them anxious and prone to fear.

It was worrying because I had so many bowel symptoms and people kept telling me how grey I looked, and the doctors acknowledged that I was ill, so I did wonder about bowel cancer.

They were reassured by knowing that their doctors regarded their health problems seriously, but the absence of a diagnosis still left them feeling confused and vulnerable. Diagnosis helped these people to make sense of their symptoms.

I can still remember the very mixed emotion I felt as I left Dr X’s rooms. I was not at all pleased that this was what I had, but I was very relieved that finally somebody had something sensible to tell me, something with some logic in it. It made a lot of sense and a lot of things fell into place.

It was November 1989 before I got a diagnosis. I remember I told the specialist my symptoms. My husband was with me. The doctor told me straight out that it was CFS. It was such a relief to finally have it diagnosed, because other people would say things like ‘you look alright, what’s really wrong with you?’

The seven people who had a diagnosis from a very early stage (or knew that their symptoms were consistent with the diagnosis) have fared reasonably well in health terms. All of them are now in the group whose illness would be classified as mild, and all of them either describe themselves as getting better, recovered or staying satisfactorily stable. With both information about their condition, and affirmation from doctors, these people took early care of themselves. Most took extensive periods of leave from work and other commitments, and generally returned only gradually to these activities. The onset of their illness remained the worst time with the illness, and most had no serious relapses. In contrast, the nine with doctors’ affirmation that they were ill, but no diagnosis, fared slightly less well, having had relapses to severe ill health; without exception, these people had tried at times to push through during the period when they were without a diagnosis.

Despite doctors’ concerns, diagnosis proved to be enabling for the people in this group, not disabling. It provided people with a specific framework that was helpful in easing their distress and enhancing their health.
outcomes. An affirmation from doctors apparently helped to make a distressing experience more bearable for all of this group. By itself however, that affirmation of illness was not sufficient to ease people’s fears. Nor was it an adequate basis for people to develop a coherent interpretation of, or response to, their symptoms.

Sufferers whose ‘quest for explanation’ was lengthy and difficult: their perspective on diagnosis

The majority of sufferers differed from the sixteen just described because they followed a mostly long and hazardous quest. As chapter five showed, they had been exposed to their own doubts as well as those of their doctors, their families or employers. Most had been through a very difficult time, which had generally become worse with their declining health and passing months. In the main, they had to endure a difficult illness, difficult social circumstances, and the consequences of trying to find some reason for the changes that were happening to them. Those who were severely ill, feeling dismissed by doctors and unsupported by family or friends, were particularly disadvantaged. In this context, people eventually sought an explanation for the changes, losses and negative responses they had suffered, as much as for the symptoms they had endured. The following two sections emphasise the value of having a diagnosis from the perspective of those people who had lacked recognition and a diagnosis for lengthy periods.

Diagnosis and social relations

Paradoxically, people became more dependent upon medical recognition the more it was denied them, especially as time passed. Without a diagnosis, people had to struggle with self-doubt and misunderstanding in at least some aspects of their social lives. They did not have a ‘valid’ reason to explain why they were unable to participate in relationships and other activities as they once had.

However, diagnosis did not act as a magic token. With medical opinion divided about the nature of CFS, the majority of sufferers felt they had only an equivocal legitimacy, a recognition marred by the stigma of controversy. Some found that diagnosis did little to change the way that
others had been interpreting their problems, so that there was sometimes little change in people's social relations.

Six participants have still not received recognition from their families even after a diagnosis had been made. As four of those people are, or have been, very sick, they needed their (mostly distant) families to understand and provide support at a number of levels, including financial and direct care.

I have had to learn the hard way to stand alone. That was cruel for me. I was constantly looking for somebody or something to help me survive as there was so little of me. I never found it. What I found was more rejection.

My father told me that he had made out his will. He said he had left me half his worldly wealth, but my brother would control how I spent it as I was a dependent person, opting out on life.

Nevertheless, over half of the people who had felt unsupported by spouses and families prior to the time they had a diagnosis, did gain new understanding from their families when a diagnosis was received.

By then I at least had a diagnosis which was important because I think that was when my family first realised I was sick, that I wasn't just depressed or failing to join in. Especially my dad began to understand, and he realised I needed a bit of sympathy and help every now and then. It also helped him to understand why I hadn't been doing too well at work.

I came home and read through the information the doctor had given me. It took a while as I was having a lot of trouble with my concentration. When I finally grasped it, I cried and cried and cried and felt incredible relief at first. I'm not crazy, maybe this illness for so many years has made me crazy but I'm not really crazy ... I gave it to my husband to read, as he has had so much difficulty believing what I have said all these years. And he asked me what I thought of it and I said 90% of those things there have happened to me. He said I think 100% have happened to you. This is what you have been trying to tell me about. So at last I had credibility.

A few people mentioned that diagnosis provided an explanation that eased relationships with friends, workmates, colleagues and employers.
Diagnosis linked me back into the world. Before that I was the odd one out. At times that would feel so exaggerated. I would feel hurt when I overheard people at work deciding not to ask me to join in sports or activities, because they thought I wasn’t interested. Me! I used to play so many sports and loved going out. I found all that so strange and depressing that I often thought of suicide. That sounds terrible but it was that bad. I was left so isolated. The diagnosis gave me some legitimacy for being so different, which I really wanted because I wasn’t by nature unlike any of the others.

It could also ease the process of negotiating changes in work practices and usually facilitated occasional or ongoing access to leave or sickness benefits.

The real impetus for finally seeking a diagnosis was that I needed a label for work. They rang me up and asked what was happening to me. I had told them I had a post-viral illness. They wanted justification or evidence. It’s so hard to respond clearly to that sort of request when you have this disorder. I ended up going back to my GP and said ‘look I really want to know what is wrong with me’. My GP sent me to a specialist. The specialist told me I had the classical symptoms of CFS. I have trained as a doctor but this was all new to me. I said ‘does this exist? Is it a real entity?’ She gave me material to read about it, and convinced me there was really such a thing. Diagnosis was a really important justification for work.

However, in the workplace, a diagnosis could prove to be a hindrance as well as a help. Some people felt that it had stigma attached, that it meant their work performance would be more closely scrutinised. When people became so sick that they were unable to maintain their workloads, rather than take sick leave and attract more attention to their problems, they tended to use leave without pay or recreation leave.

Because I have had to have so much time off I hid the illness to establish my career. When I was very sick I would take recreation leave if necessary.

People became acutely aware of the equivocal legitimacy of their condition if they needed to have extended but temporary changes in their employment conditions, or they needed the financial support of sickness benefits or a disability pension. At those times they had to be assessed by a
Commonwealth Medical Officer (CMO)\(^4\), but often received mixed responses. Recognition from CMOs seemed to be assured if people had had a diagnosis from a specialist physician. Where people only had the support of a GP, the appraisals could be difficult and have adverse consequences. Self-doubt was revived.

_I had to go to the CMO. I thought I would get sympathy as I had heard of another person who had been kindly treated. Instead she was very unsympathetic, said she had never heard of ME or CFS. I was devastated all over again. She asked me leading questions about work, like why don’t you like your boss, what parts of your work are making you so unhappy. Everything I said, she twisted it. I couldn’t handle it at all. Then she sent a report to work that caused me a lot of problems. You know, a hundred people may believe you are ill, but as soon as someone questions you like that, you crash._

The medical assessments were only part of the difficulty that people had when they tried to obtain social benefits. They also shared the discomforts of other people with disabilities or chronic illness. The Benefits Office at the Department of Social Security was poorly designed for providing services to the disabled and the ill. Forms were lengthy and complex to complete, and there were no chairs available in the office for clients. One woman said that it took her several months to complete her application for the disability pension because she was too sick to work on it for extended periods of time and was dependent on others for some of the required information. By the time she completed the form she was told that the form had been redesigned and she would need to complete a new form before her application could be considered.

The situation was perhaps worse for the three people who had private disability insurance. They had to travel interstate for assessment and undergo extensive assessments, initially at their own cost. They then waited up to eight months to hear the results of the assessments. As their insurance provided cover only for complete, not partial, disability they were unable to perform any work during the period of assessment, or after the award, as that would prejudice their claims. They were left with

\(^4\) Commonwealth Medical Officers are doctors appointed by the government to assess the health and claims of people applying for government pensions.
increasing debts and uncertainties about their health and their future financial security, while they waited for the procedures to be completed.

In effect these assessments meant that people had to argue about the presence and severity of the illness at times when they were least able to make coherent arguments about their condition. They were severely ill, and anxious about the implications of their decline or their continuing ill health. They were torn between wanting to convince themselves that they would get better and having to convince others that their current health status meant they needed financial support. Every person who went through these assessment procedures had a significant deterioration in their health. Self-doubt, the stresses of being under scrutiny, the conflict between wanting to be well but having to convince others that they were not well, the physical effort involved in visits to doctors and sorting out the details of increasingly disordered financial affairs, took a toll that exacerbated people’s ongoing health problems. An uncontroversial diagnosis would have reduced some of these stresses.

**Diagnosis: a vindication**

Who alone suffers, suffers most
In the mind.

Shakespeare

Diagnosis only partially countered some of the social problems that people experienced when they were undiagnosed for a long time. The longer people went without the diagnosis, the more likely it was that diagnosis would fail to provide the person with the social legitimacy they may have wanted from family and employers. In part that was because people were having to rely on a controversial diagnosis to overcome other people’s established doubts and disbelief. Therefore, for people whose illness had been long, severely debilitating, but unnamed, the primary value of diagnosis lay in the meaning that it gave to their years of suffering.

A few claimed that diagnosis had changed the course of their lives, because it gave them a way of understanding what had been unintelligible.

*For twenty years I thought about suicide every day. It’s only in the last eight months that I have stopped.*

Q: *What changed?*
Having a diagnosis. It made that much difference after being diagnosed and treated for so many different psychiatric conditions. Not one of those had therapeutic value. Have you read Martin Seligman's book, Learned Helplessness? When you feel helpless life doesn't have a lot of promise. But when you find there is rhyme, reason or explanation you don't feel as helpless, even if in fact you are as helpless. Your perception is different.

Occasionally the name of the illness took on symbolic overtones. I call this illness ME and partly I call it that because I know that it is to do with me and a me that has been stressed all my life, and continues to stress me. It's very painful. I'm crying now because it's so horrible, the endurance it takes ... At times it seems to me that I'm living a life which is like that of people in the concentration camps ... being unloved, frightened and in pain.

For people who were severely affected, whose fundamental sense of self was challenged by the uncertainty of debilitating diverse and fluctuating symptoms which impaired mind, body and emotions, diagnosis bridged the quicksands threatening their lives. It meant that they felt some link between their experience and that of others, that they were less alone, less estranged, that they could be heard and understood.

I felt very lonely (crying). I've felt so very lonely at times because I couldn't really explain to people what was going on. I didn't understand what was going on, nobody did.

When I went to doctors I suppose I was hoping for some understanding of what was going on. And so some validity. Even some acknowledgement that they had heard of these sorts of problems before. When I mentioned to the doctor about the deep aching in my feet he didn't ask questions, nor did he say he had read about it or heard of it happening. He left me lonely with my experience. I would think 'how can this be?' My current doctor does at least explain things. He talks about other people too. He even explained a new treatment in terms of other patients. It's the most important thing to know there are other people out there. I found it helpful too to be able to read about this in books. That's why having a diagnosis was helpful. It was a real breakthrough for me to be looking at someone else's history. It was an overpowering feeling of 'that is what has been happening to me'. I would be in the bookstore in tears.
Loneliness and silence were related. Because people were left feeling alone with their sensations, and their efforts to discuss them were not understood, they stopped trying to speak of them. If they did try they felt there were no words they could use that would mean their anguish would be readily understood. Without a diagnosis and without affirmation that they were ill, people felt they had no satisfactory language to discuss their complaints and no way to explain their grief at so many changes. A compelling part of their lives could not be shared. The consequences of that lonely silence could extend well beyond the time when a name was finally allocated and the sensations recognised. One young man (not a participant) who has been ill since early adolescence wrote about this:

You know, Ros, there is one aspect of being a long term ME/CFS person that I am only just beginning to understand. It relates to a 'background, chronic anxiety state', and it's about permission to be myself. I am not sure how to convey this—it definitely has something to do with being a long-term sufferer, without a diagnosis ... Through all the trauma and distress of the last fifteen years, not at any single point has my experience been validated by any of the significant people around me. By significant, I mean family, doctors, members of family, entire circles of friends, counsellors, even strangers. During the last three years (when I have had a diagnosis), by contrast there have been many moments of validation from people and each time I feel set free to accept the reality I experience, but somehow, after so many years before this, I cannot now appropriate that validation in any permanent or solid way. I continue to find myself floating around in a suspended anxiety at times with no feeling of permission to accept my experiences of distress as real events. I keep waiting for the significant people to change their position and acknowledge that my CFS is real and that they have made a mistake. I would like them to acknowledge, with an apology even, for abandoning me only on their suspicions. Because I am not hearing apologies, I keep expecting to learn that all their past beliefs and scepticism will be proved true.

In this context, diagnosis was a sign that others recognised the person's suffering.

As I listened to a number of participants, I was reminded of the feelings of bewilderment, anger and powerlessness so often expressed by people who
have been profoundly abused. Many of the comments here, and in the previous chapter, echo those of women and children who have been abused, sexually, physically or emotionally, as they emerge after being 'trapped in a world of brutal and belittling external authorities' (Belenky et al, 1986). This is not to suggest that people with CFS have been victims of those forms of abuse. Rather, I am suggesting that people with an illness like CFS have been 'silenced' about their experiences, in much the same ways as those abused women and children have been. I am likening the effects of these forms of abuse to the experience of having a severe illness that is not recognised and which is ridiculed and diminished as a problem. A person is harmed, in this case by illness, in the other instances by violence, and in both cases that harm is compounded when society denies or fails to recognise the extent of suffering involved.

Some further parallels between the stories of violence and illness emerge. Child abuse, domestic violence, and rape had to be named as abuse and as violence. Until then, such experiences were largely dismissed or interpreted in ways that condoned the practices. It was regarded as a parent's right (duty?) to punish a child; it was a man's privilege to hit his wife because laws permitted it; myths prevailed about rape, so that the victim was frequently expected to account for her moral standing more than the rapist. People who have been through such experiences have often been subjected to notions that they enjoyed or invited the abuse they suffered. When people have an illness like CFS, they are subject to similar assumptions. The ill, like women and children, have been less able to influence the interpretations of their experience than those who are healthy or able to hold positions of social influence. The voice of those with direct experience of the problem has been submerged over time. A view has prevailed that people who are 'mysteriously' ill (that is without a particular medical explanation) stay that way because they like it or benefit from it (Harrison, 1984; Hayes, 1988; Shorter, 1992; Waitzkin, 1971).

For people who had been ill for many years, naming their symptoms as illness and having that name carry some social and scientific credibility, began a significant restorative process, if not of their health and social

5Several people did acknowledge that these forms of abuse were part of their histories. For them, the denial of intensely distressing personal experiences was like a recurring nightmare in their lives. Two women chose to tell their story of this illness in ways that barely separated the accounts of abuse, violence and illness.
relations, at least of their sense of self. With diagnosis, people whose complaints had been drowned or silenced by the words of others, achieved a meaningful language for describing their experience and for having others recognise and understand it.

Diagnosis and illness management

Whether diagnosis was associated with intensely personal symbolic value, affirmation, social legitimation or explanation, it influenced the way that nearly every participant coped with the illness. It also marked a change in people's overall health. Most participants were at their worst prior to diagnosis. Only four people continued to decline significantly after they had a diagnosis, although one other person had a dramatic relapse which left her sicker than she had been at any previous time.

Management is the focus of the next chapter, but there are some points about management which are best made in the context of this discussion of diagnosis. A diagnosis did not mean that people could necessarily begin a specific treatment regime, since there is none that has been generally validated. Certainly some people were given the diagnosis by doctors who had established notions about treatments. But in the main, people were not given any new treatments.

People also needed to take their time to make sense of the diagnosis. Where some felt relief and affirmation, those feelings were clouded at times by other strong emotions. Some people did not want to know that the symptoms that had caused them so much discomfort would continue for an indefinite period, or that there were no specific interventions or relief. Occasionally their families had a similar response. When acceptance did begin to happen, then people were sometimes flooded by grief, a grief that was made more intense when people had many years of unmourned losses. Several people wept during interviews as they spoke about those losses and the years of suspended grief.

People who had felt very damaged by doctors' responses and denial of their illness over the years, continued to feel powerless. Having been deprived of a voice about their illness for too long, having felt put down
by people they perceived as authorities, they continued to internalise the problem as their own weakness.

I’m so used to thinking that it was me, that I’ve done it with everything now. I’ve blamed myself for all the family crises and robbing the kids of their childhood. The doctor said I couldn’t help getting ME. He wanted to know why I hadn’t blamed the illness instead of myself. But it’s been there so long, and it’s been so very hard, and no one knew what I was talking about when I wanted to have an explanation.

Similarly, some people were too sick to be able to make much sense of the diagnosis.

When I was first diagnosed I felt very depressed. It was terrific that someone had given me a name, and that the name wasn’t MS, but I couldn’t understand what the doctor had told me. I wasn’t really in good form that day. I think he mentioned EB virus and Ig something or other. I remember thinking what are you going on about? But he was good, he gave me a booklet to read, so that when I felt a bit better I was able to read and reread that.

I had blood tests in early December and all of those were negative I think. But even at that early stage he began talking to me about the possibility that this might be ME. I wasn’t well enough to really ask him questions about what it was, and I know I wanted other tests done for more exotic tropical conditions as I had just come back from Asia. I’m still perplexed about why he didn’t do those. And I wasn’t sure what ME was. I was too sick to go to the library or the bookstore for some months, so I just kept going back to see him regularly as he wanted.

They lacked energy and the mental acuity (because of their symptoms) to understand the information. A few resented the way that they had been told the diagnosis. Four people were left very confused when specialists told them they had CFS, but their own doctors ridiculed the idea.

She just dismissed his diagnosis. Said I was just run down, needed a holiday. It was very confusing.

Because I have always been a mainstream science person, I was really wanting some test to confirm that I had something. But the specialist was confident. She wrote back to my doctor a very straight letter. But my doctor wasn’t convinced at all. In some ways the diagnosis hasn’t settled anything for me at all.
For a few, the diagnosis simply came too late for old habits of thinking and behaving to change.

Having a diagnosis made a difference to me, but being in the circumstances I am in, it was difficult for me to act any differently. It sort of gave me peace of mind to know I hadn’t been a hypochondriac all those years. Because that first doctor had said it was all in my head, that doubt lingered all that time! But it’s very very hard to change habits, and it’s even harder when the people around you expect you to behave in a certain way. And with an illness like this, you don’t have a lot of energy to put into doing things differently.

Nevertheless, diagnosis made an important difference in most people’s lives, and it was a difference which seemed to have influenced the course of their illness. Diagnosis was helpful because it eventually provided people with a framework for interpreting events. Even those who said they felt uncertain about the diagnosis were still using it to organise their thoughts and make sense of their symptoms. As a framework, diagnosis helped to counter their uncertainty and estrangement. It provided them with a linguistic distinction between themselves and their illness. With diagnosis they could begin to say: I am not crazy; it’s this illness that is crazy.

Diagnosis provided some rationale for the fundamental change in how they experienced the world. People were able to begin ‘seeing their world’ as coherent and meaningful (Antonovsky, 1987). Armed with an explanation for their symptoms, many felt more in control of the circumstances of their lives, able to work out meaningful ways of understanding and responding to their problems. Knowing they had an illness helped most people to stop internalising the problem as their weakness and inadequacies.

I felt better for the diagnosis because for the first time I really felt in myself ‘now I can do something about this’. I knew what I was up against and what I could do.

Diagnosis was a release because up till then I kept struggling to work and struggling to keep going. It changed the way I lived my life then. And when I stopped pushing so hard I started to get a bit better. I stopped worrying what society thought.
I am basically a person who likes to understand. I like to have good information about what is going on in my body.

I wanted a label in the end. I never thought I would want to be fitted into a box, but I was glad of it in the end. A diagnosis helped to narrow down the possibilities of what might be wrong. Then I knew what I was up against. It gave me the extra motivation to be careful about my health and my diet. It gave me the motivation to do things that might stop it getting worse.

Finding out what was going on was very helpful, even if you can do nothing about it. I had doctors saying to me that it didn't matter if I had CFS as there was nothing I'd be able to do about it anyway, so why get diagnosed. But the point of diagnosis is that it enables you to get some idea of what is going on, to work out things that might help or decide what things might be making you worse. I had so much conflicting advice before that.

Conclusion

Regardless of the medical uncertainties and controversies surrounding CFS, it is clear that the recent definition of the condition has had important consequences in the lives of individuals.

But what was it that the diagnosis of CFS offered people? Some doctors feared that the diagnosis would become a self-fulfilling prophecy, a medical response that would inappropriately reinforce people's feelings of ill health. In this chapter, I have shown that doctors' concerns are probably misplaced. Instead of diagnosis contributing to people's chronicity, as doctors feared, I have shown that an early diagnosis was associated with improvements in people's health and well-being. I have also shown how the lack of a diagnosis contributed to people's worsening health and growing feelings of despair and helplessness. Insofar as diagnosis gave people a coherent 'framework for interpreting and ordering [their] distressing experiences' (Hunt, 1985), it eased both their distress and contributed to beneficial changes in their health. Diagnosis eventually marked an end to most people's deteriorating health or the turning point to the beginnings of improved health.
Most people accepted CFS as the diagnosis for their problems because the published details of the condition matched their experiences. The diagnosis fulfilled people's intellectual and emotional needs for coherence. Intellectually, people had previously been unable to reconcile other professional assessments with the intensity and intrusiveness of their symptoms. Their emotional need for a coherent framework had grown in proportion to their fears about the nature of the illness, the extent of the losses and changes they had to undergo, and the judgments (medical and otherwise) they encountered. Further, unless people were too severely ill, or had been ill for too many years to change their own or their family's responses, diagnosis provided people with a coherent basis for thinking they could begin to shape the course of their illness. For a few, diagnosis gave them reassurance that their words and experience could be understood by others. That reassurance validated and authenticated their sufferings, and placed them within an acknowledged category of experience. They found that they were not alone, that others had shared their adversity, and trodden or endured this path before them.

Sufferers' accounts provide useful pointers to the appropriate structuring of medical care for people who are chronically ill. What people had sought from doctors was attentiveness, understanding and information. As it turned out, people's most important requirement was information that fitted with their experience and gave them a means for understanding how they had come to be the way they were and how their lives might be in the future. And doctors could provide what sufferers wanted. Several doctors in this study were able to specify how those responses could be offered without necessarily abandoning a critical scientific stance. To provide the care that people needed, these doctors operated on the assumption that sick people remain the most important observers of illness, that science is there to alleviate suffering, not to predetermine or circumscribe what is or is not possible.
Chapter 7

After the quest: reshaping a life

The chronically ill learn how to live a long life.

Osler

Those who enjoy good health scarcely realise how much bravery is required by those who do not.

T.S.Eliot

Following the outcomes of their 'quest for explanation', people gradually began the complex process of reshaping their lives. During this time they shifted the emphasis from trying to manage the uncertainty about the nature of their experience to taking actions designed to restore both their confidence in themselves and alleviate their symptoms. Their shift was a difficult one as most participants were severely ill by the time they had a diagnosis. They also knew they were facing the continuing uncertainties of being sick with this changeable and debilitating condition for an indefinite period. Some of the sense of estrangement also remained because people still had ongoing cognitive symptoms and problems with the equivocal status of their illness. This chapter explores three main concerns experienced by people as they entered this new phase of their lives. These three major concerns were: their efforts to minimise the impact of their symptoms, to mitigate their sense of estrangement and to create a meaning for their lives in trying circumstances.

People were indeed reshaping their lives when they began to focus on these three concerns. To establish the extent of the change, I will briefly recount the points I made in chapter five. People in this study had histories of being committed, active and socially productive people. In becoming ill, most participants chose to fight through, push through or get on with things while their health permitted. Many believed that illness should be defied, that in succumbing to ill health they were showing their personal weakness. Some had no choice other than to keep going because of their personal life circumstances. As such, all participants were particularly susceptible to responses from doctors which echoed their own
judgments, or which conveyed what they felt were the even harsher assessments of neurosis or malingering. Except for those who were too ill from the beginning, people mostly strove to behave in their normal ways when their experience was not recognised or labelled as an illness. Several tried to do more than they would normally have done, by including active attempts to restore their health through exercise or careful diets.

In the main, people attempted to maintain their usual activities or were expected to do so by families or employers. Their attempts were followed by deteriorating health. But deteriorating health did not bring any better understanding of their problem, so most people were locked into a debilitating downwards spiral of self-doubt, counterproductive activity and declining ill health. This was a spiral which more often than not lasted weeks, months or years.

Early diagnosis (or awareness of a post-viral illness) in conjunction with doctors' concerned and respectful interest, were the only factors which seemed to attenuate this spiral. In these circumstances, people's illness seems to have been influenced in two ways: first, people had a framework for understanding what was happening; second, with early knowledge and less exposure to doubting doctors, people did not feel the same need to maintain their credibility through fulfilling their usual commitments. They did not follow the spiral of doubt and activity downwards. As there were no specific interventions (such as diet or treatments) in common between them, it may be that early diagnosis with reduced activity for an extended time also meant that people did their bodies less lasting harm. These people had no injuries due to weakness and fewer relapses due to 'viral-like illnesses' or allergies. In other words, these people never became as depleted, so they were able to move towards a better level of health.

The challenge most participants faced after diagnosis was to make the move from the attitudes and behaviours that they had previously pursued, to new ones which would accommodate the changed reality of their lives (Waddell, 1990). People realised they would have to alter their responses from fight it or ignore it to go with it or take it easy. To do this, they had to learn how to monitor what was happening to their bodies and to pace their lives accordingly. This change was facilitated when people
had a diagnosis because diagnosis seemed to restore people's confidence in their ability to perceive changes in their own lives. As Frosh (1991) has claimed, the essence of therapeutic change lies in people being able to perceive their problems and then being able to perceive them differently. After diagnosis, people were freed to adjust their perceptions of how they might live their lives, although the scope for different responses depended upon the severity of people's condition, their past histories and their present circumstances.

As an aid to the discussion in this chapter, I have summarised the main features of people's illness over time in Figure 7.1. The common pathways that people followed during the course of the illness are shown, together with their prevailing concerns or comforts at each of the phases.
Figure 7.1: Phases of CFS

PRIOR TO ILLNESS

People described themselves as having:
- A style of ‘pushing through’, not stopping
- Physically active lives
- Commitment and enthusiasm
- Conscientious approach to tasks
- Busy lives
- Chronic physical pain
- Emotional burdens, long term or recent
- History of allergies
- Recent history of low grade infections
- Recent history of several operations

FLU-LIKE ILLNESS

People responded to becoming ill by:

BECOMING ILL

People responded to becoming ill by:

Feeling puzzled
- What is happening?
- What is causing this?
- Why?

Denying Illness
- Assuming tiredness/stress as causes
- Dismissing symptoms
- Expecting symptoms to be shortlived
- ‘Pushing through’ harder
- Being ‘too busy to be sick’

Consulting doctors/health professionals
- Receiving no explanations/minimal explanations
- Perceiving derision/doubt/dismissal
- Undergoing many tests
- Consulting many doctors

Having fear/self-doubt
- What is this?
- Am I going mad?
- Am I making myself sick?
- Will it be fatal?

EXPERIMENTING AND ADJUSTING

People sought relief from:
- Treatments/vitamins
- Rest/exercise
- Diet
- New information
- Helpful doctors and other health professionals

People tried to adjust by:
- Learning to accommodate changed lifestyle
- Choosing new priorities
- Sifting through past experiences for explanations of illness
- Responding to the reactions of family and friends

People swung between optimism and defeat

DIAGNOSIS

- Relief
- Affirmation
- Grief
- Framework

Health improves
- fewer symptoms
- restored energy
- confidence/optimism

Support
- encouragement from others
- belief
- practical support
- love

HELPFUL PROFESSIONAL SUPPORT
- concern
- monitoring
- ‘sounding board’

GETTING BY

Health remains poor
- severe/diverse/disorienting symptoms
- limited energy and movement
- confusion/despair

Poor support
- criticism from others
- doubts
- no practical support
- no financial support
- demands/expectations by others
- friends/family disinterested
- loneliness

Loss of a sense of future
- few goals foreseeable
- loneliness

Self-love/acceptance
- compassion for self
- awareness

History
- peace with past

Unhelpful professional support
- disinterest
- doubt
- conflicting advice

Rationale:
- a difficult life
- pain and suffering in the past

Getting by
- a future goal
- a present purpose
Minimising the impact of symptoms: learning, yearning and experimenting

The time immediately following diagnosis was characterised by wildly fluctuating emotions. People were grieving the losses brought by illness. They were often angry, frustrated and despondent at their changed circumstances. They were also sifting through past experiences for explanations of their illness, for ways of coping, for understanding and insight into their problem and its management.

However, once people accepted that they were sick and likely to stay that way for some time, they usually experimented with possible treatments and combinations of rest and exercise, while they also began the slower process of accommodating and planning their lives around indefinite ill health. During this time, they swung from optimism, with enthusiastic plans for treatments and ideas about what life would be like following recovery, to pessimism born of relapsing illness and further losses. Younger people were particularly prone to wild swings, wanting to exhibit normal youthful exuberance but later collapsing with the effort. This was a period of intense learning, as most people became absorbed in discovering and rejecting information about their illness and health issues generally.

Specific interventions

In this section I discuss the main patterns in people's responses towards four forms of intervention: dietary change, rest, exercise and treatments. Table 7.1 is a summary of these interventions, and the numbers that tried them, but this table is by no means comprehensive. Every participant tried some form of intervention, at least for a time. The majority tried several. They also experimented considerably within each of the categories. Many people were unable to tell me the extent of their efforts. They said they had forgotten all the things they had tried. A few were embarrassed by their experiments. Often I was told about the interventions that seemed to have made the most difference, those which seemed to have the most 'respectable' rationale or those which had had the most unfortunate consequences. Some people did things because they felt they had no choice. For instance, most people found smoke made them feel ill. Only one person (this person had been mostly mildly ill)
had continued to smoke cigarettes. People who had drunk alcohol stopped drinking it, not so much because they thought they should, but because it tasted terrible, or because a small amount had dramatic effects. Several laughed at this change, saying that that must prove they were sick.
Dietary change
Nearly everyone adopted some form of dietary change. Because of nausea, a few found that their eating habits deteriorated, but mostly, people made fairly determined efforts to have a 'healthy diet'. The 'healthy diet', however, had many forms. Some basically tried to have the generally recognised, conventional healthy diet. That is, their diet comprised foods from the five main food groups, reduced sugars, salt and fat. Four people were vegetarians, and had been for many years prior to getting sick. A few others said they tried to keep their meat consumption low.

People began to diverge from the basic healthy diet when they thought that allergies and candida might be part of their problem. In general, there seemed to be some overlap between foods that might cause allergies (or intolerances) and the foods that have been said to be associated with candida: principally, those foods were yeasts and grains (especially wheat), but several people found some relief by reducing their intake of foods high in sugars, amines and salicylates. Sometimes through trial and error, people made their own decisions about what they could eat; more often people followed the suggestions of 'experts', that is, doctors, dieticians, alternative practitioners and authors of self-help books. Of the twenty-seven who went on the anti-candida diet (eliminating sugars and foods containing yeast from the diet) twenty-three decided it was helpful. In the main, these people had symptoms which affected their intestines (particularly the alternating diarrhoea and constipation) or skin complaints and rashes.

Such diets were not without their problems. During the initial stages of the diets, most people felt somewhat worse. Their decline was explained by professionals as 'detoxification', 'die-off' (of the yeast cells) or chemical withdrawal caused by the absence of foods to which they had been allergic. Of the four who did very strict elimination diets, as a trial for allergies, most had adverse effects. Extreme weight loss followed for three, a weight loss that their already thin bodies were not able to readily sustain. They became dramatically sicker following their trials. Another woman found that she became very sensitive to a wide range of foods, after she had completed two weeks on the elimination diet, so that the diet added to her

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1 Loblay and Swain (1986) have indicated that these food substances could be harmful to people with what they described as systemic intolerances.
discomforts. One woman who went on a fast also became very ill on a diet of fruit juices and water.

The focus on diet brought other problems. Each relapse could mean that people who had found that dietary change made a difference to their health would search again amongst the foods they ate to find the possible problem. As well, people who were already worried about their health were faced with a challenge that many people find difficult at the best of times. They had to stay with a restricted diet. A few found the challenge too great, and thus had guilt and a greater sense of failure to add to their distresses.

I didn't like the dieting. I think I now have a food problem in that I feel guilty about food. Before I used to eat anything when I liked and feel OK about it, but now I binge on things. Being so strict meant that I now want to eat even when I'm not really hungry.

Dietary changes were also difficult to keep private. Social gatherings that included food became uncomfortable occasions. Diet, a strategy intended to help the person feel better, could therefore exacerbate people's feelings of social isolation. Further, with a focus on diet, some people became more concerned about environmental contamination. If the food they ate could make them sick, then they were left to wonder whether it was the food or contaminants on the food, or both.

You begin to worry about whatever goes in your mouth and that makes everything seem that much more threatening. After all, we don't really know what's in our foods any more, do we?

A number of people tried to eat only organically grown foods or home grown vegetables; they also bought and used water purification systems. In addition to the other threats that people felt with their illness, the surrounding environment became threatening. Given the uncertainties about the causes of CFS, and its frequent depiction as a disease of modern times (Donohue and Fluhrer, 1989), people had supports for their concern.

So dietary change could leave some people more threatened and vulnerable. Illness was compounded by personal failure at maintaining a diet, by social stigma, and by fears about the effects of a contaminated and damaged environment. Some were discouraged if diet made little difference to their health. However, twenty people decided that dietary
changes were worthwhile on a regular basis. They felt they were able to control some of their worst symptoms with dietary change, and take some useful action when they had relapses.

Rest
Adequate rest is stressed in most of the CFS self-care literature, especially the earlier self-care literature about ME. As an intervention, rest has two main supporting arguments. In the epidemic outbreaks of ME, only those people who were active and busy became ill. For example, at the Royal Free Hospital, few patients succumbed to the illness which afflicted so many of the staff. Secondly, activity was associated with people's ensuing feelings of exhaustion, fatigue and illness, or with major relapses. Intuitively, then, rest has seemed an appropriate way to avoid these adverse consequences.

However, rest is not favourably regarded, medically or socially, as an intervention for health problems. Medically, there are now many instances (including tuberculosis, myocardial infarction and following surgery) where rest has been shown to have more adverse effects on people's health than activity (Lipkin, 1974). More generally, prolonged inactivity is thought to be harmful to the body because it leads to rapid loss of muscle bulk and power, contributing to a sense of weakness (Swinburne, 1989). Socially, rest is also widely frowned upon on the grounds that it can leave people isolated, with reduced motivation and lowered morale. There are also some underlying moral connotations: a resting person is not a productive person. Rest is portrayed as self-indulgent and too easy.

It is useful to distinguish between voluntary rest and enforced rest. Some people have been so ill they have had to take to their beds for days and weeks, and sometimes much longer.

I was a vegetable, a total vegetable. For six months or more I slept all the time and used to set the clock to wake me up to watch Batman. It used to hurt my arm to turn on the TV. My brain was weird. I couldn't think about anything. It was blank more than anything. I lost time. Totally lost time. Fear. I felt ultimate fear and incredible vulnerability.
Most of the time I was just very sick. I'd lie in bed and be sucked into this blackness and it wasn't refreshing sleep but in the mornings it was like getting out of this hole.

Anyone who has had a very bad attack of the flu knows that illness can hit in this way, even if usually it only does so for a few days.

Voluntary rest, however, was another matter. A small number of people in this study experimented with what is called 'total bed rest'. They said that their morale and general well-being dropped.

I don't think going to bed and staying there will make you better. I did that for three months at the end of '87 and I think I got worse and felt rock bottom emotionally. My self esteem became so low.

In 1984 I gave up doing anything and spent most of it in bed. Most of each day I was in bed and doing nothing. I just managed to write a page of my diary each day. I was very depressed and out of it.

Seriously ill though these people were, complete exclusion left them further depleted.

So what was the role of rest? Most participants named rest as an important form of management. When they did so, it turned out that they were usually not talking about complete bed-rest. Rest was a time of inactivity, physical and/or mental. The extent of that time varied according to the severity of people's problems. Sometimes, cessation of physical activity was important: people described long periods of sitting in a chair, lying down for a time, doing very little. Some people had developed the art of sitting still with very little movement\(^2\). Rest also took other, but related, forms: meditation, relaxation therapies, visualisations and self-hypnosis.

\(^2\) I was aware that I moved a great deal more than any of the participants during all of the interviews. After commenting on this to participants, I discovered that only a few people were aware that they were so still. Those people said they had specifically tried to develop this strategy to minimise wasted effort. Others laughed and said they just had to stay still, they had no energy for excess movements. My observation was shared by others. Following a conference on CFS, attended mostly by people who had the illness, one of the speakers was discussing her impressions of the conference with me. She had been addressing the conference on issues for carers, and said she knew very little about CFS. She had been particularly struck by the stillness of the audience through all the sessions, and wanted to know if it was a side effect of the drugs that people might be using.
Approximately half chose to use rest not only as a recuperative measure, but also as a preparatory one. Prior to attempting some task or activity, they would set aside time to rest. In some instances, preparatory rest meant two or three days of minimal activity beforehand. Following the event, people would also rest for some time. Their aim was to reduce the likelihood of an enforced and longer rest.

Others found rest was difficult to achieve, particularly in the early stages of their illness. Their body might feel exhausted but their brain felt agitated, *racing madly, chasing ideas* or their pulse *was pounding, running wild*. Being still or attempting to meditate could leave them very agitated, but they were simultaneously incapable of doing very much. Some found it almost impossible to experience the peace of rest.

Several described the need to reduce the amount of stimulation in their surroundings or at social events. Noise, crowds, bright lights, more than one conversation: these were all things that could bring on exhaustion in the same ways as activity might do. By reducing the amount of stimulation, people felt they could preserve the energy they had. No one I interviewed had a television or radio playing in the background.

Participants described rest as the most useful intervention, but many showed ambivalent feelings about it. They described their need for rest in association with phrases like *being selfish, grabbing time for myself, putting my needs first for a change*. Others told me stories about the things they could do while they were resting, such as reading to children, making phone calls or reading novels. Others preferred to use words other than rest to convey what they did: *pacing, going with the tide, letting go*. Rest was important and necessary, but it was also a term which left some people feeling ashamed or embarrassed.
Exercise

Exercise has replaced rest in rehabilitation programs for many health problems. It has also been emphasised in public health awareness campaigns as both an antidote to the stresses of sedentary occupations and a preventative measure against ill health (Montgomery and Evans, 1984). So, in contrast to the notion of rest, exercise is seen as both desirable and responsible.

In relation to CFS, there have been claims that graded exercise programs are a remedial intervention (Peel, 1988), especially when combined with cognitive therapy (Wessely et al, 1989; Sharpe, 1990). As there has been no evidence of damage to people's muscles, it has been argued that people's health may be remaining poor because of their extended periods of inactivity and their consequent reluctance to exercise. As well, it has been suggested that people with CFS have an 'altered perception of their degree of exertion' when they participate in aerobic work capacity trials (Riley et al, 1990), so that some of the techniques of cognitive therapy have been introduced to help people adjust those perceptions. Although satisfactory outcomes have been reported from these cognitive-behavioural trials, it is difficult to assess how useful the intervention may be, as more than a third of the patients in one trial refused to engage in the treatment program (Sharpe, 1990). Nevertheless, newspaper reports about the value of exercise programs during 1990, together with personal desires to regain some level of fitness, meant that many participants have continued to follow or have embarked on some form of exercise program.

In this study, participants' ability to do some aerobic exercise seemed to be related to their previous fitness levels, the length of their illness, the time they had had to go without exercise and how or when they attempted to return to some fitness. Nineteen participants had previous histories of being very active and fit, engaging daily in aerobic activities (running, cycling, swimming, aerobics, sports). Most of these people had thoroughly enjoyed their activities, and attempted to return to them whenever possible.

I find swimming good as I never did it before so I am not competing against how I used to be. It's new. So I can be patient with doing it how I do it. I've been getting back into circuits at the gym again but I have to keep that down and it's so hard as I was really keen on that before.
When you have been fit and strong and then you get sick, you lose the things which authenticate you, that give you an identity ... I've decided that because there is no medical evidence that there is anything wrong with the muscles, that the symptoms are like background noise but not evidence of disability ... So that way I can keep going. Mind you, I can still overdo it, and if I do exercise then it interferes with my ability to study. I had to make a decision this year between exercise and study.

Needless to say, despite these people's enthusiasm and commitment, exercise was not directly associated with improvements in their health, and they have had to discontinue exercise at various times. All of them identified times when excessive activity, frequent attempts at exercise, or exercise in combination with too many other commitments, had been associated with relapse. Most found that they had to readjust their expectations of their capacity for exercise. Exercise had to be carefully monitored, so that the swimmer quoted on the previous page said she could maintain a daily swim of one kilometre if she kept her heartbeat below 120 beats per minute. This woman was the only person who maintained exercise throughout her illness, even during the months when she was unable to work. At that time she would spend most of her time in bed, except for her daily swim. It seems unlikely that she was needing cognitive therapy to encourage her to engage in physical activity, yet that exercise was all she could do in a day. Others also had to balance their effort at exercise with extended rests afterwards, so that a short period of exercise might have to be followed with sleep. When people chose to exercise and were able to maintain it over an extended period, they mostly had previous histories of enjoying physical activity, time to give to the effort, and time that they could set aside for recovery.

Exercise comes in many forms. It may enhance endurance, strength, aerobic capacity or flexibility. Some people found they could pursue some forms of exercise in preference to others, with most emphasising that stretching exercises seemed to carry the most immediate benefits of relaxation and the least harmful consequences. Exercise seemed to be harmful when people were determinedly trying to get better through exercise. Apart from attempting intensive activity with high levels of tension and anxiety, not to mention ill health, some people tried to return too quickly to previous levels of fitness.
One of the least helpful things I ever did was to decide that I wasn’t fit enough and that that was the explanation for feeling so lousy. I had always been very fit before I got sick so I decided to get back to that and began riding my bike to work (fifteen kilometres). And I persisted with it even though it made me sicker. I thought I had to break through. This was before I had a diagnosis so I had no way of understanding what was happening.

Less than a fifth of the people in this study group were unwilling to exercise. They were people who were severely ill, people who had been ill for very long periods, people who had injuries making movement painful or difficult and a few people who were not able to sustain exercise when they were trying to maintain their other commitments such as work. A few were people who had never been interested by exercise. Even so, these few people were not inactive, although their activity was less planned exercise than necessary activity.

Exercise carries different connotations to rest. A person who exercises is generally regarded as doing something constructive about their health. The majority of participants wanted to exercise as it was something which had given many of them great pleasure before they became ill or they believed it was good for their health. However, exercise could not always be sustained, and was too often associated with relapses. Ho-Yen and McNamara (1990) have made similar observations. In the main, exercise programs probably reflected people’s priorities or their improved health status, rather than contributing to improvements in their health.

Treatments
The majority of people in this study had rarely used medicines or pain relief in the time prior to this condition. Yet, with CFS, people experimented with what they and many doctors regard as fringe medicine. With the exception of anti-depressants or anti-histamines, even the treatments offered by doctors were unusual and controversial. Indeed, many doctors were offering treatments often regarded as being within the province of alternative practitioners: homeopathy, acupuncture, chiropractic manipulations, psychotherapy, nutritional supplements and radical dietary change.
As was mentioned earlier, there was diversity in people’s experiments, but within each of the categories in Table 7.1 there was even further variety. For example, anti-candida treatments included at least four different prescribed medications, often in conjunction with herbal treatments, dietary change and vitamin or mineral supplements. Further there were variations in frequency, duration and magnitude of dosages of all treatments. With the vitamin treatments, dosages could vary from as high as 30 grams of vitamin C powder each day to a tablet less than one percent of that amount. The form of the vitamin C could also vary between ascorbic acid and a number of compounds which incorporated the vitamin C. Injections of gamma globulin were administered in amounts and with a frequency that seemed to have no pattern across doctors. A few doctors provided weekly injections but others administered the treatment monthly, often in association with injections of vitamin B. Intravenous gamma globulin was administered in a range of dosages. Those patients who had been part of the experiments conducted by Lloyd et al (1990b) sometimes had dosages that were so high they produced extremely adverse and persistent responses. Four people were extremely disabled for most of the three months that the treatment was underway.

Nevertheless, people did develop some ideas about helpful treatments. Half the people who had had gamma globulin infusions decided they had been helpful, even though most lapsed back into poor health within a few months after their initial feelings of improved health. Only three people expressed a wish to go through that process again; one of those people had already undergone the treatment on two separate occasions. Gamma globulin injections, vitamin C infusions and vitamin B injections were seen by about three-quarters of the users as helpful; a few reported adverse responses. Two-thirds of the people who took some form of anti-depressant decided it had been helpful for their depression, although half of these said they had to take very small doses initially. The few women who had hormone replacement therapy (HRT) found it helpful; thyroid supplements (of different kinds) were found useful by four people. Of the remaining treatments, the diversity of approaches and dosages makes it difficult to discern any patterns.

The most severely ill people tended to have the most adverse and pronounced responses to many of the interventions. Their bodies seemed
to be acutely sensitive to changes, so that gamma globulin infusions brought on profound muscle spasms or rigor, or a need for adrenalin. Similarly vitamin C infusions and vitamin B injections were often poorly tolerated, bringing on an immediate and marked adverse response. In one instance, the infusion brought on anaphylactic shock. Other treatments, such as antibiotics and anti-depressants, taken in normal dosages, could induce allergic or exaggerated effects. Conversely, startling improvements were reported by two severely ill people who had undertaken radical courses in vitamin therapies, although similar treatments for other people were less successful.

When ill health persisted, people generally reviewed their efforts, gradually accommodating lower hopes and expectations.

I am less interested in looking at possible treatments now. I recently completed a course of gamma globulin injections. The needles seemed to cause me more and more problems. I had to take sick leave to cope with them. I had the feeling towards the end that it wasn’t the gamma globulin that was making the improvements in my health, just that I was handling the injections better.

Nevertheless, people mostly remained hopeful that some intervention might be effective, or that medical researchers would eventually be able to discover a cure. Few people were able to resist asking me what treatments others had found helpful. Four people who had been ill for more than five years continued to aim for recovery through an expensive and comprehensive combination of megavitamins, herbal remedies and non-prescription medications designed as anti-fungal and anti-viral treatments. Only one person had avoided most prescription or other treatments, having limited himself to high dosages of aspirin for pain relief.

**Decisions about interventions: give me A for effort**

When people decided to experiment with ways of alleviating their symptoms, they discovered that all interventions for CFS are controversial. They sought information from diverse sources, including alternative therapists, doctors and self-help books. Their enquiries ranged from specific treatments for CFS to more general strategies for improving health. Recommendations that people were given about dietary change, exercise, rest, 'medical' or 'alternative' interventions essentially rested on
anecdotes, dogma, popular notions of healthy behaviours, unreplicated medical trials and non-scientific models of medicine.

The recommendations about interventions also occurred in a social context which offered conflicting messages for the ill. People wanted to be able to change their symptoms and they felt that families and friends wanted them to do something, but they were unclear about what they should do, and how they should do it. On the one hand, people had public health messages emphasising that they might improve their health through dietary change and exercise. Self-help books, newspapers and magazines reiterated these messages (Coward, 1989). On the other hand, many people wanted to critically evaluate the interventions. Their scientific training meant that many were sceptical:

I did show up as having some allergies. But I am not really into vitamin therapies being the person I am. I don't know how much scientific basis there is for those ideas. From what I read in *New Scientist* these tests need to be carefully done.

It doesn't seem to me that anything I could have done would have much affected progress—you know: diet, stone age diets, vitamins and all those things. I took vitamins earlier on and did some diets because one of the doctors said he would try those things if he were in my shoes, but I am a sceptical person, so after three months when I had noticed no perceptible difference, I gave them up.

Others with equally well-developed scientific skills, were sceptical not so much of the treatments that they might use, but of professionals.

I have read a lot and think that it is partly 'horses for courses'. People should buy every book they can find about this and other health issues and then be their own physician. That way you can control the situation entirely, take responsibility for your own disease and own cure. You can feel encouraged to be perceptive in relation to experiments, to cause and effect, and not be locked into one rigid idea of what might or might not be effective.

I haven't had that many doctors. Most have been reasonably supportive. The local GP was reasonably forthcoming. But I have had problems with consultants about the sinusitis. That was when I decided to start managing this for myself. They seem to be so locked into their own models of diagnosis that they forget what it can be
like to live with this. None of them helped me to develop a coherent approach to this.

Most people eventually experimented with treatments, sensitive to their own and others’ sceptical judgments, but driven anyway to try any approach which might alleviate the worst of their distress.

Oh dear, when I tell you all this, I realise all the things I have tried over time. You would have to give me A for effort, I guess.

In December ‘87, I began seeing a naturopath and wondered why, as the whole business was even more complicated than with seeing the doctors ... When you start on this, the things you do that you know you would never have dreamt of. Every now and then you stop and think, 'oh why?'.

You have to get something given to you from outside. When you are that sick and there’s nothing left, you can’t give yourself anything, because nothing means anything any more. Like before I got sick, when I got down, I could go and have a hot bath and restore myself. But with this you are too tired to have a bath, and it doesn’t have the same effect even when you can. Your relationships with other people become difficult as you become so unconfident that you worry what others are thinking about you or you worry about what you can give them or you sink into worrying that you are hopeless. If you try to do anything for others, you end up spilling the coffee and you fuss more then and think this is not right, I should have done it a different way. So your relationships don’t give you what you need, your experiences don’t give it to you, so it’s really hard to think what I can do to give me something. And I think that’s why I started going from person to person in terms of practitioners. X (an alternative practitioner) criticises people for looking for a magic bullet, and says it’s our own responsibility. You know that, but you don’t know what you can do. There doesn’t seem to be anything that can give you something. So all you want is that one little bit of something that will give you enough energy to create something that will then help you.

In the main, people’s experiments were most likely to occur within the first two years following diagnosis. Sometimes people continued with strategies they had been using prior to a diagnosis of CFS, such as anti-candida diets and treatments. Generally, though, most people expanded
their efforts at the time of diagnosis, often because that was the time when their health was at its worst, and the losses they faced were most acute. With severe relapses, the majority of participants again resorted to some of their experiments. As time passed, people were less likely to attempt new strategies, although most retained a few basic interventions such as some form of dietary modification, vitamin supplements and rest.

In effect, people took risks when they began to experiment with interventions. They took risks because the information about interventions was often unclear, anecdotes had their obvious limitations and 'experts' contradicted each other. Because they were so ill, and their cognitive symptoms so disabling at times, many people also acknowledged that their efforts were often confused. Sometimes they were unsure about the merits of particular actions because they tried several things at one time. People did this even when they were participants in clinical trials. Three of the seven people who had participated in the clinical trials for gamma globulin infusions acknowledged using other treatments during that time, including high vitamin dosages, Chinese herbal treatments and anti-candida diets.

In the process of experimentation most participants exacerbated their uncertainties. Integral to most of the interventions was the notion that results would take time. People were told that improvement or recovery would not be immediate and that they might get worse before they became better. 'Conventional' and 'alternative' therapies therefore had to be evaluated on a similar basis: inadequate scientific data and gradual, if any, change. In other words, no matter what people chose to do, they had to do it with hope, sometimes trepidation, and always patience. Yet with an illness that follows a relapsing course, and changes its characteristics over time, it is difficult for individuals to separate fluctuations in the course of the illness from the effects of interventions.

It would be difficult to describe changes in people's health throughout this period of experimenting and adjusting to so many changes. A few of the people I interviewed who were still passing through this phase, were too confused about what was happening to them to make any sense of changes. They saw no patterns, or they were uncertain what to expect with
time. Their attempts to remedy their symptoms were confused by all the other adjustments they were having to make.

I've lost the capacity to put things in place. I forget so many things, and there are so many blank spots. And then there's school and coping with what's happening there when I'm able to make it, and trying to work out what might help me with this.

When people did try to evaluate interventions, their evaluations were based on different principles at different times. They often assessed the value and purpose of interventions when they were so unwell they were desperate to notice any improvement. In the early stages, they mostly wanted global relief. Some people were also keen to justify the effort, time and expense that some interventions involved by discovering possible benefits and changes in their health. Others wanted to believe that their interventions had made a difference, because that meant they could influence the course of their illness, not be victims of its apparently random changes. As Kleinman (1988) has pointed out, psychological tolerance and hope stem from a belief that remissions can be correlated with something that a person can control. But people acknowledged that things that seemed to have worked at one stage in their illness did not necessarily work at other times. As time went by, some interventions were adopted basically to relieve specific symptoms, although some people justified what they did because they thought it might prevent further relapse.

**Mitigating estrangement: making new connections**

People's efforts to manage their symptoms were the most obvious of the ways in which they tried to reduce the effects of illness in their lives. However, despite their preoccupation with those diverse strategies, distress was often more successfully addressed by changing major aspects of their way of living. In this section I review the ways that participants tried to minimise the worst of their feelings of estrangement. Previous chapters show the extent of their feelings of estrangement when they were feeling profoundly abnormal, and being told by others that there was no reason for those feelings. Following diagnosis, most tried to mitigate those feelings in two ways. They tried to make new connections between
ideas and experiences by becoming very knowledgeable about their condition. As well, where possible, they made 'new connections' with people, often choosing different doctors and companions with whom they could discuss their problems.

In making efforts to minimise the feelings of estrangement, people were doing what most people with a chronic illness attempt to do. They were trying to ensure that their behaviour would seem as normal as possible to other people, despite the restrictions created by their illness. As Strauss and Glaser (1975) have pointed out, the effort to behave normally in these circumstances challenges people's sense of identity as well as their personal and social arrangements. Nevertheless, no matter how much effort participants may have made to appear normal, most encountered other people who were critical about their health problems.

I was fine at work until the pressures came on because we were short staffed. Up till then everyone knew I was sick with ME and they were OK about it. Then when work got very busy, they began to just think I was lazy.

I had an awful experience at church. This woman rushed up to me and claimed she had a word from God that if only I stood up during the service and went to the communion rail then I would be cured. That left me crying where I was for fifteen minutes. I couldn't win with that one. If I went to the rail and I wasn't cured, then my faith would be found wanting. If I'd stayed in my seat, then I would be accused of not wanting to be well.

As severe illness frequently exposed people to such criticisms, they had to foster ideas and relationships which would sustain them through any similar episodes.

Knowledge and information: I can say I definitely have something

In situations where their illness was questioned, people minimised their self-doubt by becoming 'experts'. There were very few participants who had not read at least one book on the illness, and most were able to speak intelligently and at length on the biomedical models.

Having this information did not necessarily mean that people shared it with critics or other people. Several people found it was easier not to
mention their diagnosis or discuss their illness with other people. Even in the interviews with me, they dismissed the condition with phrases such as *whatever it is* or *this thing* or *whatever they want to call it*. They said their reluctance to name the condition was related to the pejorative associations with 'yuppie flu' or the way that words such as 'chronic fatigue' trivialised the extent of their condition. *It's hard to justify a tag that imparts any meaning at all.* Almost everyone complained that they were weary of other people saying things like 'oh yes I get tired too'. On a day-to-day basis however, information gave people more confidence. If strangers or colleagues asked them about their illness, and responded in dismissive ways to the name, some participants were then able to use their detailed information to explain the illness.

People also valued information because it enabled them to identify more readily what their illness was doing to them and to plan their lives accordingly. For example, they had reasons for their volatile emotions or lapses in cognitive capacity. They were also able to identify their own problems, through diaries, charts or other records, to determine how their illness might be similar to the ones described in books and papers and in what ways it might differ. Men, in particular, seemed to thirst after information, perhaps because objective data was a way of countering some of the more feminising aspects of the condition, such as emotional lability and generalised weakness. They chose to discuss their experience and symptoms 'factually', and were pleased to discuss 'scientific explanations' at length. They were less comfortable discussing the emotional consequences for themselves or their families.

Some people found that once they had information, they also felt less compelled to talk about what was happening to them:

> At some stage I realised that the whole thing about having a diagnosis is that you can stop going around saying to people I am unwell. Instead of having to go around saying I have all these symptoms and reminding myself of them all the time, I can say I definitely have something. So now I just have to go and find ways of living with it.

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3 As a researcher I also found similar comments irritating, if only because I too felt tired but knew that my tiredness bore no resemblance to the condition that participants were describing.
I used to talk about this illness all the time but I don't think I talk about it as much now that it is recognised. Before that I was battling to get some understanding and recognition.

Life used to be like a before and after ME. Now it is there—I get sick and I rest but I don't need to talk about it any more. But I did for a long time. I no longer have to constantly work out what is happening. I think that might have occurred about five years after I got sick.

New carers, better care
Following diagnosis, people had a new basis for selecting doctors or other health professionals. They no longer had to see doctors who left them feeling vulnerable to self-doubt. Instead of having their feelings of estrangement exacerbated by the doubts of professionals, they could seek care from professionals who understood their condition. As a consequence, people usually saw fewer doctors and eventually saw them less frequently than they did previously. They also made more informed choices about alternative practitioners.

People particularly valued information that professional carers provided. Being given written information about their problem was important; nine mentioned their gratitude that they had been given written information about ME/CFS by their doctors. Participants also dispelled their doubts more successfully if they knew that the diagnosis had not been given lightly and that other possible explanations had been explored as far as possible. Biological irregularities in their pathology tests reassured many. Most participants mentioned at some stage that their diagnosis had been supported by minimal responses to the cell mediated immunity (CMI) test, abnormal T-cell counts or measurable allergy reactions.

However, when people visited professionals during the weeks after diagnosis, they were also seeking relief and remedies for their problems. Some wanted direct guidance. Others wanted a doctor who would discuss the options they had. A few wanted a doctor who would act as a sounding board for their own thoughts about the condition and its management. Most wanted to speak with someone who was a 'storehouse of information' (Sacks, 1991). Later, when people had learnt more about their condition, through their own monitoring or from information in
self-help books, they wanted someone who would listen to their particular story, to hear how their condition had developed and was progressing.

When I was feeling particularly confused I went to a homeopath. Now he didn't cure me but what he did do was give me a whole hour to tell him my story from the beginning and go on to where I was then. That hour to hear my own story was wonderful! And I was able to get the picture fuller and better than I had ever had it before. It was so good to have someone sit there and listen, not querying and making rapid assessments, but listening. It was good not to feel the pressure of time and be able to get a whole picture together in my mind. It really helped me come to grips with it all. It was less scary as it no longer seemed like I had all these odd things wrong with me. It all started to fit together.

With this kind of attention, people were able to see events as less overwhelming. They were able to make fresh sense of a sequence of events that had been marked by confusion, estrangement and uncertainty. This was particularly important when people had so many changes occurring.

New companions: kinder friends

Just as people sought responsive and informed medical care, most found that it was necessary to have responsive and informed friends so they were not subject to what felt like scrutiny and criticism. Several sought social situations, such as the self-help group, where they felt safe to talk about their condition.

People's choices about companions were influenced by the responses of their families and friends after the diagnosis. This was often a time when friends and families began to assess the meaning for themselves of the changes in the sick person. Ongoing illness represented a challenge to them too. The basis for many relationships was altered, as people could no longer rely on doing things together. In families, the diagnosis could bring partners or parents some dread.

Two years ago was a crunch as that was when I got a diagnosis. My partner is a positive person and very energetic ... But I think the diagnosis came as a disaster to him as he had always thought I would be better next week, next month or soon. Diagnosis took some of the weight off my shoulders as I had begun to realise that
getting better wasn’t going to be so easy. But it put the weight onto my partner’s shoulders and I think he’s taken some time to recover.

Diagnosis mitigated some aspects of estrangement, but people were still faced with challenges when those around them took time to interpret and assess the significance of their illness.

As it was not always possible to hide the effects of the illness, most people had to learn how to accommodate their failings. They had to learn how to ask for help when they were unable to perform certain tasks. As well they had to learn how to apologise for their clumsiness, their lapses of memory or emotion. Where families and friends were uncomfortable or distressed by the changes, participants had to learn how to make these requests and apologies without always drawing attention to their illness. In that context, it is not surprising that they also sought or discovered new friendships where illness could be discussed without prejudice.

One of the things I learned early on was not to bore people unless they were really interested. I had a stage where I needed to talk so much I ended up friends with people who could take talking about it. And they are friends I still have. I remember reading somewhere that when you are sick you have to make friends with kinder people.

When I am about to have another major relapse, I tend to cry and cry and cry, grieving that I can’t take any more and that it is all too much. After I am cried out I talk with my husband and another good friend. I have this wonderful friend and I call her ‘my crying friend’. When I am going through all this I will just ring her up and she’ll say ‘it’s all right, I’m on my way’. She has a severe chronic back problem so she understands about this chronic thing.

It was great when we were forming the ME Society in 1983 as I had never met anyone with this before that time. It was good to have friends, to be able to talk the same language and share problems, especially around children. When you are a mother you feel so guilty about the way the illness limits what you can do with your children.

The local ME/CFS society was important to many participants because it was both a source of information and a source of ‘kinder friends’ or understanding support. Most participants had eventually contacted the
society for information, even though a fifth had been discouraged from joining the self-help group by doctors (*You don't want to get caught up with that sort*). A quarter had found some of the friendships, social contacts and sense of worth they sought after forming or joining the self-help organisation. The self-help group gave some people an opportunity to feel worthwhile again because they could take on roles as support counsellors, committee members or in public liaison/education. They could use their skills or share their wisdom, but do so in an environment where there was recognition and understanding of their problems.

People who had been able to maintain employment were generally less inclined to seek social contacts through the self-help group. For some, that was because their limited energy was given to maintaining their work and family. Others said it was because they had notions that people in self-help groups were too focussed on their problems—*groups of people who are involved in anything can become distorted and obsessive*. Their main concern was to appear normal and maintain as much of their previous life as possible. In general, these participants had less need of support and understanding because they had been able to maintain important aspects of that previous life. They tried to keep their illness as hidden as possible, particularly if they were trying to maintain professional identities. They restricted the number of engagements they would go to, preferring to be thought anti-social or uninvolved rather than sick. While people were able to perform normally, and keep their illness a secret, they felt a measure of security.

*I have this terrible fear about being judged in the eye of outsiders. I know I am on the edge of long-term disability. Part of that disabled lifestyle would mean I was living with other people's judgments. The loss of dignity would be awful. I want to keep this secret for as long as possible.*

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4 Sharpe et al (1992) did a long-term follow up of 144 patients who had attended an English infectious diseases unit between 1984 and 1988 complaining of fatigue with more than six weeks duration. They concluded that those who had a poor rate of recovery included people who believed that a viral illness precipitated their fatigue, people who had an intolerance to alcohol, and people who belonged to a ME support group. The British paper, *The Independent*, subsequently used these findings to conclude that 'patients who suffer from ME do less well if they join a self-help group for sufferers' (*Perspectives*, 1992). Apart from uncertainty associated with following up people whose fatigue was only of six weeks duration, claims such as this one about self-help groups are spurious. Ill health is not necessarily a consequence of membership. Membership of a self-help group may be merely a reflection of people's poor health status.
However, secrets were helpful only while people were able to maintain a social performance. In the end, there was a limit to what could be hidden from others, and a finite number of ways of avoiding humiliation and embarrassment. Trying to appear normal was not always possible. They then had to work out ways of adjusting their earlier notions of normality and create a meaningful life within new parameters.

**Fresh meanings for a different life**

In this third and final part of the chapter, I discuss how people made the transition from expectations of an active and involved lifestyle to a less active, less participatory lifestyle. To make the transition, people had to be able to extricate themselves from their previous ways of living and the cultural messages which reinforced those ways. They had to learn how to live their lives differently, to allow physical limitations to prevail over enthusiasms and commitments, and to learn how to value those new lives.

The transition was not made readily. It was somewhat easier for those few whose illness had not been severe and whose life circumstances were less demanding. Those people still had to alter their expectations about work, relationships and other activities. However, because they still retained some time and energy for these concerns, they were better able to maintain and cultivate a sense of meaning and purpose. On the other hand, the transition was particularly hard for those whose illness was severe. Apart from the discomforts that illness itself induced, its severity determined the sorts of lives people could lead and the meaning they could attach to those lives. If their condition deprived them of work or study, they discovered what it was like to live a 'provisional existence' (Frankl, 1962) desperately seeking meaning while they were often living as if there were no future. Severity also determined the level of support and care that people needed from doctors and others. At the same time, however, severity could interfere with people's ability to find or foster those supports and care. As a result, severe symptoms could exacerbate people's distress by leaving them isolated and vulnerable, feeling ineffective or defeated in their attempts to 'get by'.
In this study, the majority of participants were struggling with the process of 'getting by'. For many of them, adjusting to this illness was not a deliberate or conscious process. As one participant said:

*You do get a bit better. Generally speaking that is true for long-term people. Things do calm down. It does become manageable with time. It becomes manageable because you have to manage it. There is almost no choice about that.*

In the remainder of this chapter I describe this adjustment process. For many it was a struggle permeated by some long periods of anger, despair, bitterness or misery. For all it was a complex process marked by ambivalence and often fortitude.

**Monitoring and pacing: listening to what my body was telling me**

To ease the transition from wanting to be active to living within the limits imposed by illness, it seems to have been essential for people to learn how to monitor and pace their lives. Although the defiance and denial that most people practised in the early stages of their illness can be helpful for people adjusting to some conditions such as spinal injuries or muscular dystrophy (Mayer, 1991; Burish and Bradley, 1983), with CFS it was apparent that those responses were counterproductive. Nevertheless it could take some time before people came to realise that giving attention to their condition could be helpful. Even then, many participants acknowledged they were often better at describing the benefits of this approach rather than applying it.

Monitoring and pacing did not generally occur until people had either some knowledge about their illness or an awareness of their own frailty.

*It wasn’t until I had the diagnosis that I felt it would be okay to stop. Up till then everybody, me included, thought that it would be best for me to keep going. I really needed someone in authority to tell me to stop!*  

*I got so sick I wanted to be rid of everything and just pare it down to survival … I understood then about the future, and thought about my declining years. I used to wonder when I was younger how I would cope if I had a terminal illness, but I have no worries now as I know it’s reduction and that you just lie in bed coping with the*
moment. All the extraneous things drop out. Once I got to this point I also realised that I had to let things drop out for some time, to listen to what my body was telling me.

In essence, everybody had to learn to do what this last participant has called listening to what my body was telling me. Previously, most of these people had not monitored their tiredness or if they had, they had been in circumstances that meant they had to override the feeling. Often they had been able to overcome discomforts and minor illnesses (or not even notice them), or they had been capable of working through feelings of weariness or exercising despite exhaustion. With this illness they had to learn to notice when they were tiring, to accept that their capacity to push through had limits. They had to learn to hold back on the desire to do things, or the feeling that whatever they started should be completed.

People were often better at pacing their lives than monitoring their responses. As time passed, most came to live their lives with the simple maxim of one day at a time, although a few found that it was better to focus on survival for even shorter periods. At different times in their illness, some had so little energy they could not be sure they would manage even one activity (such as a shower) in a day. In general, limited time and energy meant that everyone had to bypass at least some of their previous friendships, pleasures and relaxations.

Routine and self-discipline took the place of spontaneity in many people's lives: each day is measured time. Once people developed routines and were able to sustain them, they often found the burden of their illness easier to bear. With so much uncertainty in their symptoms, routine ensured that at least some part of their lives would follow a familiar pattern.

Several stressed the benefits of routine for alleviating their cognitive symptoms. Many participants described how they had had to become excessively orderly and methodical to minimise daily hassles. They found it invaluable to minimise the number of things they had to remember at any one time. They wrote lists, so they could remember trivial and important events; a few wrote lists simply to order the events of each morning so they could get to work. (Some of these people laughed and
said they also lost the lists until they became rigorous about keeping them in the same place.) Once people had established habits for action and thought, they were sometimes able to broaden their daily activities and fulfil their commitments with more ease.

To persevere with a carefully regulated life, people had to reorient their lives, to move away from the values that had been associated with their previous lifestyles. Things that had been taken for granted were reassessed. Persistent illness meant participants had to review their hopes, expectations and commitments to determine what was possible.

Redefining the importance of work

In beginning to monitor and pace their lives, people determined their priorities. Financial security became a central concern. Many therefore made work, or the study that might ultimately provide them with a job, a focus in their limited lives. However, to maintain work, they often had to adopt new attitudes towards it.

Only the people who were mildly ill continued to entertain ambitions for greater responsibility. In general, those people were able to cope after devising contingency plans about their future should their health deteriorate.

I am working full time partly to keep the house and where we are, but we were laughing the other night about not continuing to work if money came our way. Even six months ago I think I would still have wanted to work anyway. But now I think it would be nice to let go of it all. We could do it if we chose, sell the house, live very simply.

The survival strategy is to work full time for as long as I can manage it and have a little bit of private life. Now we have very short-term goals. We’re not thinking of overseas holidays any more. But we need to have things to look forward to so we spoil ourselves, like going out to dinner. We are locked into work because we are buying this house and there’s the children. We also want to work, but we have devised an escape strategy. We would rent this house to someone else and go down the coast and live in a caravan very cheaply.
Although a few people did receive promotions during the course of the study, most employed participants chose to avoid such advances. They generally maintained their employment by disregarding pressures from others and themselves to perform their skills at as high a level as possible.

I've made maintaining a full-time job a priority. But I am not looking for any more promotions or extra professional activities.

This has dramatically changed my career prospects. I might well have had the job of Director had I been well. I think with energy I'd have done it well. Mind you, I might have become sick anyway if I had done that! It's certainly changed my ideas about jobs. If I wasn't sick, this job now might be a bit too sedentary.

I think this illness is symptomatic of a work ethic that is profoundly unhealthy. It has come out of a male model. It's the tip of an iceberg about what our culture has done to our lives. All this work - work work stuff has been predicated on women being at home to manage the household. Well I've decided it's not possible, and other feminists have to stop buying that shit. It's not possible to have children, to work and have other interests and commitments. Women do so much— they have networks of friends to maintain, they have meals to cook, school committees ... We can't keep pretending that all these things are possible. Women don't address this problem because it might prove they were incompetent. Well, I'm stopping some of that pretence.

I need work for another fifteen years yet. It's too late to change my field of employment, but I am now working at demoting myself at work, so I do less of the stressful things. I'm not looking for power and responsibility, rather I am trying to get rid of it.

People with poorer health were aware that their hold on work was tenuous. Apart from avoiding promotions, some settled for part-time work and its lower status. A few had well-developed plans in case they could not keep working.

I was on half pay for a long time and had to decide what to do and whether I was really ever going to get back to work again. I had two kids at school then so there wasn't really any choice. That pressure has eased a bit now but I am trying to maintain things until they have finished university. Fortunately I now have a choice between taking invalidity retirement and early retirement. I would prefer early retirement as invalidity would mean I could never work
again, and I still have the idea that there are a whole lot of things that I still want to do.

In general, therefore, work took on a different character for those who were able to maintain employment. Because work was no longer related to following a career path or pursuing new achievements, people defined more carefully what work meant. In addition to financial security, people said work was a priority for them because it provided a sense of purpose and worth, a testimony that they could still contribute usefully to society.

If you see someone you haven’t seen for a while and they say, ‘what do you do?’, it’s good to be able to say ‘I work’. Saying you’ve been on sickness benefits for two years since you left uni—well, there’s no interest in that, is there?

The illness has taken away any sense I had of identity. Without my profession who am I? I’ve tried to live other ways and to find other rewards, and I’ve done reasonably well at that, but none of them give me what my professional standing did.

Several people were prepared to make elaborate efforts to ensure that they could continue to have some of the satisfactions that employment created.

Being able to return to work (nine hours part-time) was very important for my self esteem as I really enjoy teaching. It was only possible because my husband was able to drive me there, carry my books to the room and set things up. It meant I only had to be upright for a bit over two hours and I was so pleased with being able to do it. Lots of support. And I used some of the money to employ a housekeeper to do the things I find difficult at home.

To hold on to my full-time job I do nothing else except work at the moment. I do nothing which will further tax my energies so I don’t exercise, I go to bed very early, like 6.30 or 7 p.m., rest during the day as much as possible and generally try to underextend myself as much as possible. I’ve got almost no other interests, very little time for seeing friends, I’m boring I suppose. But I have to do it until our finances are sorted. And I want this job too. It’s a good job.

Relying less on carers
Doctors and health professionals played a part in people’s efforts to monitor and pace their lives. For some time after diagnosis, as well as in the time after most of their experiments with treatments were over,
people went to doctors for their ability to help monitor the changes that were happening over time, either in their health or their lives.

Although as time went by, most participants became better informed about this condition, and their own experience of it, several still valued the doctor’s perspective on their problems. When they stayed extremely ill despite their own and the doctor's best efforts, they continued to want their doctor to be a sounding board, and they wanted to know that their doctor was still concerned and interested in their well-being.

Participants appreciated doctors who were prepared to understand how much pain and discomfort they had, to review their condition and to discuss symptom relief. They valued doctors who could understand what it was like when there was little more that could be done to change their health. People felt affirmed when they received responses such as this:

I told him I was developing an appreciation for simpler things, a simpler lifestyle. And he (the doctor) said yes, eventually you realise that there are no more mountains that you have to climb. That you can be happy with what you see from where you are. He knew what I meant when I said there is a kind of calm, an inner peace at that point. You know you have to get to that point as there is no more energy any more, and you have to maximise the energy you’ve got and not worry about being unable to do certain things as the price is too high.

Ultimately however, doctors played a much smaller part in people's responses to their illness, as illness gradually became a part of people's lives. From being overwhelmed by its uncertainties and alienating aspects, provided they had some supports, people did come to work out ways of living with it.

In spite of what people say about this illness being self-limiting, I have come to the conclusion that I will never be totally cured of it. I think it will be in my system for a very long time or the rest of my life perhaps, and I will continue to go through cycles with it ... Now I think that I am managing this illness better, not that it is going away ... I am fitting more into my life so therefore my life is better.
Relationships
In their daily struggle to 'get by', people focussed more attention on their relationships. In part that was because they had fewer distractions, in part it was because the dynamics of ongoing relationships were changed by their illness. In general, participants were more sanguine about their lives, regardless of the severity of their illness, when they had relationships that mattered to them, or when they felt that they were needed.

When so much of their lives had become uncertain and strange, participants needed partners or friends who could recognise these feelings and accept their illness. As such, 'good' relationships incorporated practical support, the occasional 'feedback' about inappropriate excessive activity and encouragement that the person was doing their best in the circumstances. Such relationships meant that people felt that they could share the load of work, worry and responsibility. Sometimes these relationships ensured that people had the time to lead a more interesting life.

Nevertheless, most people felt some ambivalence about their relationships. Knowing that their lives contributed to at least one other person's well-being was comfort for some, especially when relationships seemed to be imposing more demands and problems than pleasures. Caring for a family could be more than some could manage, but it remained their main source of purpose.

You ask me what has helped me get by? Mainly the fact that I have so many people dependent upon me. I often think that if I didn't have them it all wouldn't matter. I wouldn't kill myself, but it wouldn't matter. I really have no worth apart from pandering to their whims and keeping them fed.

Occasionally though, caring for others placed too great a demand on people's limited energy. At least three wished they could escape the burden of other people's demands and expectations. One woman organised a temporary separation from her spouse to try to minimise the demands she experienced, despite loving and caring for him a great deal. Without some time to themselves, and the energy to do something with
it, it was difficult for some very sick people to discover purpose and meaning that might transcend their role as a parent or partner.

There were also gender differences in the meanings that participants attached to their relationships. Consistent with the suggestion by Belenky et al. (1986), women were more likely to define themselves in terms of their relationships and connections with other people. In particular, they were likely to express concern at the impact of their illness on their children. Some women talked at length about the effects of their illness on their children, their grief that they had been unable to be ‘normal’ mothers (or their delight when they had been able to play some vigorous game with their children). They commented on the effect their illness had had on their spouse, and described their various efforts to minimise the effects of being ill on their married lives.

Sexuality. Well, we have decided it is important to us so we have made it a priority. Even if the activity means I have to spend all the next day in bed, and he’s then on household chores, we think it is worth it. That’s how we want our lives.

The underlying meaning of the relationship was important. Younger women were uneasy about relationships they had formed subsequent to becoming ill. They disliked the possibility that they might be being pitied, or that the essential dynamic in the relationship might be dependency. Nevertheless, women frequently named relationships as important to their survival.

I’m very fortunate that I have a supportive husband and friends. If I didn’t have them I’m not sure that I’d have kept coming back for more of this.

It has been a very difficult time, but I think it has brought us closer together. We both have a most peculiar sense of humour, and have always been able to see the ridiculous in every situation including this one.

In some contrast to women’s responses, men often discussed their relationships in the same context as work. Relationships were a core concern, but not necessarily the main one:

It has had no positive effects having this damned illness. Not that I can think of. It has nearly destroyed my marriage, it has destroyed
my career, it has destroyed my confidence in my ability to use my brain.

It really hasn't changed my life that much, I guess. Basically my outlook is fixed. I'm in a job, I have a family, the whole frame is fixed. A few details have changed, and there is a sense that the more ambitious physical projects will have to be limited, but that might happen anyway given that I am getting older.

Men less readily expressed their griefs and concerns about the impact of illness on their families. Instead they tended to stress how they had attempted to limit its impact:

I'm just glad that I've had this while the kids are little so they haven't known I was sick.

This has made my life such a struggle and so difficult. I have still managed it all but it is survival stuff. My kids and my wife wouldn't even think about me being sick now. I don't tell them or let on, even on days when I can hardly stand up. I pretend that I am OK.

Younger men seemed to express a preference for making work or their restored health a priority over sexual relationships:

I'm less inclined to have a relationship like that (as a lover) now. In one way you might be more inclined because then you would have someone to fall back on. But I like being independent. Also I wouldn't want to put anyone through having to modify their life so much.

I am waiting to have girlfriends for a while yet (laughter). I would like to be where I once was, an athlete.

Rather than being a possible source of comfort, they saw close relationships as making demands they would be unable to fulfil. Like the young women, they seemed to fear being weak and therefore dependent, perhaps 'less of a man', particularly in contrast to the athletic people they had been. However, two men found comforts in taking on a new partner:

Things have changed immensely through having her. I no longer have to do it all on my own, including the finances ... I feel less angry about things now. Last time I talked to you there was so much anger and frustration because friends can only do so much
and there isn't a single government or medical facility for really helping people in the position I am in. Single ME people do have it bad and that was one factor in marrying. She also takes an interest in me and looks after me.

I got involved with a woman for a few months last year. An old school friend. It was lovely as she was very caring and understanding. It left me feeling good about myself.

Intimate relationships brought people difficulties as well as occasional joys. They took energy that was limited and precious. At their best they gave people a sense of safety and security, acceptance, belief and love. At times of despair, a relationship, demanding or agreeable, could give people some sense of purpose, a sense that they mattered.

When finding fresh meanings is difficult: life without structure

When people were severely ill, they had to find ways of sustaining the significant change illness wrought in their lives, without the structure and meaning that is created by work or study. Whereas others were able to make plans for what they might do if they got worse, severely ill people had quite different concerns. Being ill absorbed much of their time and energy.

In interviews, people who had been severely ill for lengthy periods seemed to want to make the best of unpleasant circumstances. They spoke of past achievements; sometimes they laughed at their plight, often describing it as growing old; and they frequently tried to dismiss what they had lost by comparing their losses with others. Their lives were, however, dramatically changed. I was surprised at how rarely people expressed bitterness about the way their lives had developed. When I asked some people about this, they said they had learnt that such feelings are not easy for others to hear, but they acknowledged that, at times, resignation and submission and bitterness could be pronounced.

I cannot study or work. I do without the sense of achievement and identity which go with work, also the everyday social contact. I don’t know when I’ll be able to work again for a decent income. I have to take life day by day as even humble plans are thwarted. I am confined to my bed/bedroom (or a banana lounge in the garden) twenty-four hours a day, seven days a week. I don’t know when I
will be able to enjoy basic freedoms such as cooking for myself, having an active sexuality, going for walks, having a social life.

From reading my diaries, I realise that each year there is slightly more activity. Apart from that first year when all I could read was Mills and Boon, my brain has never been as dead as I thought it was. I was always thinking about something interesting or reading or crawling around an art gallery or something like that. But although there has been more activity each year, life doesn’t seem to have become less of a struggle for me at any stage. I couldn’t figure that out at first—maybe I was born to be a misery guts—but then I thought that looking at others with this, it almost makes no difference whether you can do nothing or you can work twenty-five hours per week. You are always at the edge of your endurance with this.

I know I said last time that this is about learning self-love. In reality it’s about a hell of a lot of suffering, misery and self-denial. It’s struggle, struggle, struggle.

Now I just switch off. I had to learn how to do that when I was real crook ... Nothing much seems to make a difference any more.

I think this thing has gone on long enough. I’ve been sick for three years. I want it to be over and done with. Bloody hell, three years is a long time to put your life on hold.

Although most directed their bitterness at their illness, a few said that there were also times when they felt extremely angry with other people simply because of their good health, fitness and ability to live busy lives.

Despite their best efforts to reconcile themselves to a more restricted way of living, some could best tolerate inactivity only when their health was very poor.

What I find interesting is that when I was very sick I was very introspective and inward looking. I never thought about skiing or the outdoors. I clung to the immediate. I didn’t even dream about skiing or the things that normally motivate me. Then as I got a bit better I let more in.

Insights and strategies for 'getting by' appeared to be the responses that people have to make, when they are in a situation where time and the ability to act are severely restricted. A number of severely ill people
likened their situation to that of being in a prison, living in a concentration camp, being trapped, locked away. A few acknowledged gaining some wisdom about their situation through reading about life in prison or the concentration camps. From those accounts they said they had learned how to measure out the time they had, to create structures in days that were basically without structure, in lives that had remarkably uncertain futures. As if to confirm these observations, other participants who were very sick at the time of interview told me in detail about their meals, the times they had rests, the passing events of their days. Dreams and hopes were rarely mentioned, as too much depended upon the course their illness took.

I’ve always been a very determined person. Just keep on going. I go to school when I can and that’s that. I can’t break, I wouldn’t let myself. And so the illness has become part of my life now. On good days I completely ignore it and on bad days, well, I guess I get depressed about it. I haven’t really wanted to record how it is changing—how depressing! If I am lucky it lifts long enough for me to forget the bad days. When I am sick I get the sense of not being me, of floating through the days. There’s no opportunity to create memories—it’s all too unpleasant.

After a long time imprisoned by illness several people rushed into living their lives fully as soon as they felt some release, only to find that they were rapidly returned to their prison. Despite feeling well enough at times to want to do things such as enrolling in courses, working part time or taking on other activities, these people found the effort quickly returned them to ill health. A few people were poised at this point for years:

Motivation with this illness is rarely a problem. I’ve constantly tried to do things over the years. But every time I’ve failed in doing what I wanted to do, it’s meant that my hopes and ambitions have had to drop yet another level. Every time an activity doesn’t work out, my ego is really battered. I feel useless and that I can’t do anything. And at the same time there is always this background doubt—is there really anything wrong with you?

I have always tried to have an interest. My attitude to that has had to change. Now I think if I make 50% or more of a course then I am doing well. With other sorts of commitments it’s awful when you don’t manage to do what you’ve agreed to do.
With each return to ill health, these people had to return to and adhere to the routines that took them through previous difficult times.

Others were more fortunate, as they were able to enjoy a sustained taste of their former lifestyle before relapsing. Their readiness to forget the strictures of illness during these periods of relatively good health showed people's fundamental desire to participate in 'normal' life. Even with years of illness, people still wanted a full and rich life, and would grab at opportunities to regain that sense of full living.

You do have to take risks because when you have been sick for a while, you've got to test yourself. You can get so conditioned to being sick. And others have adjusted to me being sick and don't push me either. It's emotionally important to try a bit.

I've put a lot of effort into living my life ... I feel that by being this way I have had more life to look back on, even if most of it I have been ill. I have many more memories to look back on this way. If I'd stopped to think about my health first I would never have had dinner parties here, never had a holiday, never gone on a trip ... I am greedy enough to want those good things of life still. I still hunger for that and want to satisfy some of it.

Nevertheless, only a few people said they wanted to return entirely to the life they had once lived. Many mentioned what they thought would be the lasting value of learning to take time, enjoying small beauties like flowers, listening to music, discovering more about their own spirituality or forming more intimate relationships with their children or friends.

Whether a full return to health would cancel the value attached to these simpler pleasures as people found they were able to pursue their previous lifestyles is uncertain. However, most people with improving health usually tried to return to work and begin some sporting activities or exercise, reasserting in the process their joy in activity.

Poor health, personal history and social circumstances
Cohen et al (1984) have argued that the range and flexibility of people's coping strategies are more significant to how people get by than the particular strategies they might adopt. But poor health reduces the range of options a person might have for responding (Viswanathan, 1991). In general, when people in this study were severely ill, they had fewer
options for responding to their problems. The people who were most disadvantaged were hindered by their poor health in conjunction with their histories and social circumstances.

Although most people had very difficult times, four female participants described their lives as being increasingly arduous over the course of the three interviews, and their accounts highlight the harmful effects of life history and social circumstances when they are combined with this illness. The four people had particularly intrusive symptoms: severe nausea, disorientation in space and time or intense pain. They had also had difficult lives characterised by emotional and physical abuse. Their relationships with their parents, partners or families continued to be complex and difficult. Further, each had grown up believing that their worth was dependent more upon their achievements than upon the person that they were.

The messages that came through were 'try harder and you might be acceptable'; 'you are our child so there is no doubt about your ability and you have chances we didn’t have, so don’t waste them'. My brother never had to work so hard for their approval, but I did because my mother was jealous of my opportunities. Also, I was fed on the idea that I was near brilliant and could do, and should do, my very best to succeed.

Although one woman in this group had been diagnosed relatively early in her illness, the other three had been without a diagnosis for many years. All had had many encounters with unhelpful and dismissive health professionals, encounters which too readily repeated the ways they described being treated as children, and in two instances as wives and sisters: dismissed, powerless, ignored, abused. Having these histories did not necessarily mean that a person was destined to deteriorating health, as three other people had similar histories and had gone on to have improved health. What differed was that these four women had had so few supports from either doctors or family throughout their illness. Two lived entirely on their own, their families having explicitly rejected their needs for emotional, physical or financial support. I had no sense that there was anyone offering support to these two women. The other two were more fortunate. Each had found a supportive doctor. They also had some support from partners, although one felt that she had only just begun to receive that support. As well, three of them had had further
complications because of injuries and operations and all of them had had recent very painful events in their lives.

Three of them had to provide for their own financial support, two having had to negotiate with considerable difficulties for pensions through their private insurance. Without a job, without a family, two of the women made desperate efforts to work regardless of their symptoms because work at least gave them some identity and some purpose. It was also consistent with the messages they had always received: worth is earned by achievements.

These women were really living life at the margins. And the longer they lived that way, the harder it was for them to make any interventions that might alleviate their distress. Being very ill meant they had few resources for changing their circumstances, that much of what they did was directed towards basic survival. They might feel loneliness but could endure only limited contact with people.

There is not enough of me to go around with this illness at the moment. Physically, emotionally, mentally and financially, I am an empty shell. Everything is in bad shape. Yet I have a fantasy that with a secure roof over my head, I might be able to set up my business at home again. That's why I am putting what energy and resources I can muster, and more, as there isn't much, into getting this little house looking OK. Yes, I do know that what I am doing is making me sicker. I have no other possibilities.

As their health deteriorated they also grew further from a foreseeable future when they might be able to do the things which had previously given their lives meaning and shape. In many respects, their experiences with illness confirmed their early difficult lives. In turn, their past problems prepared them poorly for this illness. What they had mostly learnt from their previous difficulties was that battling on, striving to please or achieve, would see them through any difficult circumstances. Although the women told how these responses had carried them through other trying times, these responses were also the ones least likely to bring about some lightening of their burden with this illness. Nevertheless they faced their dilemmas with courage, a courage that they sometimes had to foster by reassuring themselves that few people suffered as much as they did.
Next year I am just hoping that it will be better. I always hope that. I try to keep a positive outlook.

I can't really feel on top of this illness any more (after nineteen years). But I know I cannot foster that attitude as if I do I will go down for sure. It will become a negative spiral ... I still have a sneaking hope rather than an expectation of getting better.

I spend most of my day working on what I can do to help myself.

No one really knows what it is like to be this ill. Even other people with this condition are not in a good position to understand what is happening to me.

'Getting by' with confidence, competence and purpose
When illness rendered people helpless or left them feeling powerless to effect any useful responses, despair could set in. The majority of participants attempted to counter that impending sense of despair by doing what they could to continue feeling as if they were competent, effective people, especially in response to their illness. Several factors could contribute to this feeling. It mattered to people to have a framework for interpreting their illness, information and some responses that allowed them to regard the course of their illness as less random than it had originally seemed. They were then able to give themselves reasons for their declines, and conversely they tended to believe that they could use various strategies they had used in the past to restore their health over time. Much of their earlier debilitating uncertainty was diminished if people could think that their efforts to manage their illness or change their lifestyle were rewarded by changes in their health. Instead of feeling that their illness was directing their lives, they could then see themselves as having some control.

I do like to think that I have been getting slowly better because of my conscious efforts to look after my health. Trying was good for my peace of mind and my sense of control over events.

Rather than being overwhelmed by fears and doubts, these people were then able to relabel events and experiences as positive, or assign new values to accustomed aspects of their lives. With greater awareness of their condition, and the passing of time, people were able to speak of events with different emphasis.
I can get very sick even now, but what is different is that I remain in contact with what I call my core self. Whether I care or not is the main measure. That is, I might feel sick but still want to go out and really want to be well. It’s a sense of really being in touch with the world. When I was really sick all the time I stopped caring. I can remember all the time I would stand and look at something and say to myself ‘this is beautiful. It means something’ but I never felt anything for it. But this weekend when I got up I saw a butterfly flying and I could enjoy it. Even though sick, now I can enjoy things.

I think now that a lot of those feelings I told you about last time, you know, feeling I was on the edge of madness all the time, I think now they had a lot to do with feeling very insecure. I shouldn’t be insecure because as you know I have a happy family and I am moderately secure financially. I realise now that the insecurity really goes back to those years when I was a conscript in Vietnam. It’s not so much going over there and seeing people being shot, but the total experience of what they did to me and the way they dehumanised you. My bad dreams relate to that. My inherent feelings of distrusting my current boss come from that. My feeling of being abused by the politicians of the time, the army for making me do that bloody horrible officers’ training course, and the way they treated me like a bag of shit. You know they did nothing to remedy what they’d done to us. There was no counselling, and we were made to arrive here at midnight so no one would see us. I think it has harmed me very badly sitting on all these feelings for so many years. No one at work even knows about the medical conditions I got during my time over there, the constant bloody tinnitus and high blood pressure.

In being able to give events a fresh interpretation people regained a feeling of being in control of their lives, a feeling that they could set about shaping acceptable resolutions to difficult circumstances.

If people lost their sense of purpose and efficacy, then new meanings were more difficult to sustain. During the course of this study, a quarter of the participants went through times of despair that they discussed with me. At those times, some people felt their efforts to manage their illness were failing, or that the appearance of new and more intrusive symptoms was making life intolerable. People were again visited by fears, by self-doubt and by distressing interpretations of past events and experiences. At these times, they would talk about their losses, the opportunities that they had
missed and their sadness about the effect that their illness was having on their own and the lives of those around them. If people's despair was primarily brought on by recent losses relating to work or relationships, and their health also declined, then illness became an overwhelming and frightening thing. The combination of symptoms and social misfortune was devastating. There were several instances when people were able to cope with quite calamitous personal crises because their health held steady. Knowing that they were able to manage their symptoms, or simply that their health had not declined as well, seemed to buoy people through some very difficult times.

**Control and forbearance**

Feeling some sense of control was one of the most important issues for people given the uncertainties of their condition. As long as people were able to feel their illness was under control, they were able to cope with daily pressures or even major crises. On the other hand, the less control that people felt they had over their condition, the more likely they were to want to control aspects of their relationships and their environment. A few people went to extreme lengths to limit the intrusions into their lives by noise and other stimuli. One woman laughingly described how she had obsessively dismantled her telephone and doorbells so that she could be undisturbed when she was at her worst.

When people were severely ill, the focus of their lives also narrowed to their immediate context. With that narrow focus, in combination with the other pressures produced by illness, people could be very sensitive to events and circumstances which left them feeling out of control. They could feel extremely vulnerable to the powers or actions of partners, families, friends or external 'authorities', whether they were doctors, bureaucrats, or shop attendants. A few people were determined to maintain some sense of control, because they had had too many experiences of feeling powerless. If they felt threatened by relatives or 'authorities' they were more likely to maintain a feeling of control by fighting. In doing so their health often became worse, as the effort was more than they could afford to expend.

However, frequent fighting for control was counterproductive for some participants. Although trying to exercise control and mastery over one's
life is culturally endorsed (Gecas, 1989), trying to control too much of one’s life can be harmful because a person is exposed to more failures (Mirowski and Ross, 1990). It creates the circumstances for people to feel less effective and more out of control. This was perhaps the most difficult lesson for some, especially with their close relationships. Conscientiousness, guilt, love and need, associated with a narrowed focus, meant that some people tried very hard to make their relationships fit with their expectations. They usually persevered with trying to have their expectations met, only to find that the efforts brought them disappointment and resentment. A few people described the relief they discovered when they adjusted their expectations.

I think sick people like us can destroy our relationships with the people close to us, simply by pushing them too far, expecting too much ... Some of the most positive decisions that I made were to change things I had been doing. Like with my children—I made a conscious decision to stand apart from them a little, to let them do things on their own. If they make mistakes, well, that’s how it has to be.

I can now say openly that my kids are not easy. I used to think it was me and I think that left me very depressed. I was worried because my son seemed to be so different to other children and I kept being criticised for his behaviour by other women in the playgroup … Now I have just backed off from trying so hard, and it all seems a lot easier.

Countering the feeling of being out of control was an important change for the people who had been most inclined to want to control all aspects of their lives.

Just as people needed to learn to pace themselves in their daily lives, they also had to learn how to moderate the desire to control too much of their difficult circumstances. As a first step, many learnt the value of forbearance. Abstaining from action and comment was as much an intervention and a means of taking control as those they would previously have made, but one which frequently saved them from conflict and stress. Some learnt to moderate the desire to control simply through exhaustion, from feeling that they could no longer make the effort to fight.

I feel embarrassed about saying this because it sounds like I’m giving up and you get the feeling that that’s not what you are supposed to do. Everyone, including me, has kept saying that you
have to fight this thing. But you know, it really doesn't work, I realise. I've been sick now for three or more years. There does come a time when you have to decide whether the old ways have got any point. Now I am going to do what I can, to go with this thing rather than pushing through all the time. It seems to be time.

A few diminished the drive for control by placing their suffering in a broader context.

I've been influenced by old style catholicism, which is basically socialist I suppose. The common good is more important than almost any individual. So I am prepared to see that I am not that important. It's an existentialist stance really. Whether I am here or not doesn't make a heck of a lot of difference to the world. You just have to do the best by yourself within that context.

I have a very strong faith—with that I can transcend some of this and the pettiness of things. It also gives me hope. And a notion that we matter.

Well, you know, I've decided there is a season for all things.

Well, I live each day now to have some good feelings. That's all any of us do really, isn't it?

Suffering does bring new insights. I can compare the stress and difficulties of busy lives here with the disadvantages suffered by people in countries torn by political strife like Chile, or places where people are hungry or homeless. Through this experience of illness I feel I can be on the same level as some of those people, whereas before I would only have been trying to communicate with them from a distant perspective.

Most learnt how to constructively laugh at their oddities or occasionally show the 'courage of tears' (Frankl, 1970).

I don't have an answer to what makes it all worthwhile. In the end I think it is human contacts and the pleasures of doing something and having interests that are worth pursuing. I have no religious reason ... I did become super keen on nature at one stage ... I've also enjoyed those books where people have written about living a restricted life. Like people in concentration camps—if they can find meaning then it follows that someone in my position can. Mind you, one of these people later jumped down a stairwell.
A few talked of finding self-love. Through that self-love, they spoke of finding an awareness and compassion for others and themselves. With that awareness and compassion they were able to begin letting go of standards and expectations they had held about themselves and the world, to offer themselves and others forgiveness about their wrongdoings and their failures. They noticed their own resilience, rather than focusing on their failures. They found it healing to value what they had, rather than worrying about what they thought should have been possible.

*My whole image changed. Suddenly I had become someone who did almost nothing. And people would say 'what do you do?' I would think 'I sleep'. It was nice because I began to realise that people appreciated me just for being me, for doing nothing. I've realised that this has been a good time for finding out who I am, for enriching myself. A time for reflection, strength and balance. I've begun to learn how to be kind to myself.*

What happens when you get ill is that you get angry with yourself ... And fearful, yet others have always seen me as courageous ... I was encouraged to show myself more compassion. When he (the counsellor) said that I needed to show myself more compassion he really struck chords and gave me a sense of peace. Compassion. I think I was always searching, doubting, but he recognised the fears that I had ... With that feeling of compassion I felt that I had come to the end of a long spiritual journey, I had learnt a very important lesson ... I calmed down, like a burden had been lifted off me. You know you lose touch with yourself when you are sick. You can't do all the things that give you meaning and purpose, like being in nature or cleaning the house. You lose your identity. You stop thinking. Relationships fall away too so there is nothing to define you. And you become a really empty person. I needed some way of defining myself to myself for me to remember. In learning to be compassionate towards myself I got back my essence. I realised just how much I had gone through.

**Conclusion**

In this chapter, I have outlined the three main ways that people reshaped their lives after they began to understand what was wrong with them, together with the circumstances that hindered or helped them in that process. First, there were the interventions of diet, rest, exercise and
treatments. These strategies absorbed people's attention following the diagnosis. During that time most people had felt obliged or had chosen to experiment widely. However, people also felt torn between wanting to be critical, wanting to be careful, and feeling that they might have to be adventurous. They had to make enervating decisions about how to respond to these pressures when they felt threatened and ill, when much of their life was undergoing significant changes. Evaluation of any of the interventions people practised was outside the scope of this study, but it seems likely that people's reactions to interventions reflected their particular health history and prior fitness as well as the severity and range of their symptoms.

Secondly, most people attempted to maintain some semblance of a normal lifestyle within the constraints of their illness. To minimise the estrangement they had experienced before diagnosis, people became knowledgeable about their condition, gathering general information about CFS/ME and becoming more alert to their own specific symptoms. With that increasing knowledge, many felt less need to explain to themselves and others what was happening. They were able to choose amongst their friends, family, colleagues or health professionals to find understanding and interest in their problem.

Thirdly, people sought fresh meanings for familiar aspects of their lives, meanings that reflected the extent of the change that illness had wrought. When people were unable to maintain appearances of normality, or uncertain whether they would be able to go on acting as if they were 'normal', they then had to reassess their basic beliefs and expectations for themselves and their lives. They learnt how to monitor and pace their energy levels, and adjust their activity levels accordingly. They made choices about the concerns that were most important in their lives. Where possible, most people clung to work both for the financial security it assured but also because it gave them a sense of purpose, worth and social identity. Elaborate strategies were adopted by a few people so that they could work or study. To maintain work most participants surrendered some of the clutter that makes up our lives, that is, the diverse interests, small pleasures and some friendships.
When people were severely ill, fresh meanings were harder to contrive. They were reduced to shaping their lives around the barest details, the minutiae of when and how they ate, slept and moved from position to position. In that state, people were scarcely susceptible to their old memories of themselves or the cultural messages that had defined their lives beforehand. Without supports and a reasonable level of health, it was very difficult for people to change their lives. They needed the practical, financial and emotional support that close relationships and good medical care offered. They needed others to provide a safety net rather than having to expend whatever energies they had on providing their own. It was only when people had that safety net that they could begin to become a bit better, a bit calmer. With a safety net, they could begin to find new ways of valuing themselves and their lives; they could find ways to place their own experience in a different light, to move past their pasts, the worst of their pain or discomforts and the cultural messages that reinforced them.
Section IV:

Conclusion

Through exploring the challenge of this condition for individuals and those who care for them professionally, this study provides a new perspective on the condition itself as well as its management. In order, there were a number of common features in individuals' descriptions of their illness. In general, they described a condition which began over time, with the worst point often occurring many years after the initial onset. For some, that decline was only moderated when they had a coherent framework for interpreting their experiences. Often then, their symptoms were associated with marked feelings of uncertainty and a profound sense of entrapment. Those feelings were exacerbated when people perceived doctors' responses to the medical uncertainty about their problems as derivative, disparaging, or dismissive. Following diagnosis, however, it was relatively easy for people to become sicker. Indeed, early diagnosis or awareness about the illness was associated with a better prognosis.

Although viruses appeared to have been significant triggers in people's initial deterioration into poor health, the longer-term consequences of these infections seemed to be related to people's day-to-day coping with these circumstances and their reactions to the dismissive interpretations they felt they were offered by doctors.
It’s so strange to stay sick:
the challenge of chronic fatigue syndrome

A subtle and complex condition, CFS creates many challenges. For sufferers, the condition is a challenge not only because they stay sick, but also because they stay sick with erratic and strange sensations. The challenge for those who care for them, intimately and professionally, lies in easing the discomforts created by the combination of continuing illness and disturbing cognitive and neurological symptoms. The challenge for biomedical and other researchers is to provide an explanation for this condition, particularly now that it seems to be occurring with greater frequency and severity amongst people in their youth and early adult lives.

Through exploring the challenge of this condition for individuals and those who care for them professionally, this study provides a new perspective on the condition itself as well as its management. In brief, there were a number of common features in individuals' descriptions of their illness. In general, they described a condition which becomes worse with time, with the worst point often occurring many years after the initial onset. For most, that decline was only moderated when they had a coherent framework for interpreting their experiences. Until then, their symptoms were associated with marked feelings of uncertainty and a profound sense of estrangement. Those feelings were exacerbated when people perceived doctors' responses to the medical uncertainty about their problems as derisive, disparaging or dismissive. Following diagnosis however, it was relatively rare for people to become sicker. Indeed, early diagnosis or awareness about the illness was associated with a better prognosis.

Although viruses appeared to have been significant triggers in people's initial deterioration into poor health, the longer term consequences of those infections seemed to be related to people's style of coping, their life circumstances and their reactions to the dismissive interpretations they felt they were offered by doctors.
Chronic fatigue syndrome – culturally sanctioned or culturally produced?

If this study’s findings about the illness and people’s responses to it are considered in the broader context of socially and culturally endorsed responses to illness, a new explanation for CFS emerges. Taking into account the findings of this study and the most current medical knowledge, CFS appears to be an illness where the severity of a viral infection is exacerbated by cultural expectations that people should strive to overcome illness and maintain their normal lifestyles. It seems that the people who develop CFS are those who subscribe to these ideas by showing a determination to fight through, fitness through, overcome and ignore when they have a health problem. That determination is associated with characteristics such as diligence, commitment, activity and conscientiousness, characteristics that are culturally endorsed. Life circumstances such as financial obligations, studies, work commitments or families which require care and attention because of the ages of the children or the health of a spouse or child, are also implicated. People with these obligations and the style of coping I have just described, also seem to strive harder towards maintaining their usual lifestyle and commitments if they encounter doubts from professionals about their complaints.

Rather than exhibiting a ‘culturally sanctioned form of illness behaviour’ (Abbey and Garfinkel, 1991), people with CFS appear to have developed their illness following years of maintaining culturally endorsed responses to daily living and to illness. For the people in this study, being ill was a frustrating and difficult experience because it deprived them of the attributes they most valued about themselves. They succumbed unwillingly to ‘illness behaviours’ and feelings such as fatigue and weakness. They disliked being ill. They constantly tried to get better, experimenting widely with treatments. When they grew healthier, their desire to live a fulfilling life always reasserted itself. Ironically, if they had succumbed more readily to illness, or been encouraged early in their illness to give themselves rest and to take convalescence seriously, their health may have been better in the longer term.
It is outside the scope of this study to provide biological data to support this explanation of the development of CFS, but some insight into the biological processes may be gained from the following common points in people's lives after they began to be ill. As has been said, most participants in this study became ill initially with some viral-like illness (or series of illnesses), sometimes at times of great stress, sometimes with a history of stresses and minor health problems or surgery. A few people had a dramatic onset. At the time of that initial illness no one settled for a lengthy convalescence, even those who had been hospitalised. They all tried (or were expected) to maintain or return to their normal lives as quickly as possible. Having previously been people who thought that they should keep going, almost regardless of circumstances, they continued to do so. From there they struggled to continue their daily activities. In doing so, they seem to have left themselves susceptible to further complications. While they tried to maintain their daily lives, many developed ongoing muscle injuries and back problems, possibly due to weakness and neurological problems such as poor balance. Others spoke of the early months as being virus after virus, infections they were possibly more likely to encounter when they maintained their usual occupations, especially if those occupations included work with children or sick people, or if the work was conducted in circumstances where close contact was maintained with people. During that time a few had exposure to chemicals, such as industrial insecticides and fertilisers. A few had operations. As time went by, and the illness became worse, people became increasingly sensitive to changes in their environment or passing viruses. Severely ill people often reacted adversely to their efforts to treat their problems, whether the interventions were conventional or alternative drugs.

The injuries, stresses and illnesses that followed the initial viral illness may have created the conditions for the ongoing overreactivity of people's immune system with this condition (Dwyer, 1991). People whose bodies were already responding to viral infection (or vaccination or anaesthetic or trauma from operations), may have placed further demands upon an already overreacting immune system through their continued efforts to maintain activity and the consequences of that activity. It is possible that when several demands are cumulatively placed upon the immune system, the system may lose its capacity to readjust and may continue to
overreact. The process may be more dramatic if the initial viral illness is severe.

This explanation fits with a number of the features of the illness. It allows for a diverse range of onsets and it accounts for the decline that occurs in most people during the time when they have no framework for interpreting their problems. As well, it explains why people might have had other viral illnesses and not become ill in this way at previous times in their life. To develop CFS, they needed to have both infection and a busy demanding life which exposed them to further complications. At previous times they may not have had to keep striving so hard or they may not have been in circumstances which exposed them to additional illnesses or injuries.

In addition, this explanation throws new light onto the discrepancies between clinical and epidemiological data. It is unlikely that being active and conscientious are characteristics confined to people in higher socio-economic classes. These characteristics represent a style of coping that may be exhibited by people from any social class, but may be exaggerated when people also live demanding or challenging lives. However, those who are more articulate and well-educated are more likely to achieve medical recognition from specialist clinics. In relation to the discrepancies between reported numbers of men and women with this condition, it is possible that women do outnumber men with the illness. They have lifestyles which are often less amenable to rest than men's, since women tend to retain the responsibility for household tasks and childcare, even when they have workforce responsibilities. Women and men may have an equal propensity for the condition, but over time women may develop an illness with longer duration and severity than men's. If women generally experience the dismissal of their symptoms in the early (and sometimes later) stages of illness – which was the experience of the majority of women in this study – then they may struggle, without recognition, for a longer period than most men. As a result, more women than men may become seriously affected, and may therefore turn up in higher numbers at specialist clinics. Further study is needed to add substance to this suggestion.
As adolescents and middle aged people are more likely to lead busier and more active lives than the elderly, they are also more likely to develop this condition. On the other hand, it has been noted that quite young children may develop this condition (Wakefield et al, 1990; Bell, 1991), so coping style does not entirely explain its development. The severity of certain viral illnesses, together with other health problems such as allergies or previous low grade infections clearly remain relevant.

Even allowing for criticisms that the group of people in this study may be unusual, few people in this study could be described as 'lonely and disaffiliated' (Shorter, 1992). Nor was there evidence of hypochondria. Where people attended to the detail of their illness, it was as part of their efforts to manage it. They were often scrupulous critics of their own motivations when they discussed their symptoms. Moreover, in general, most were reluctant to publicly discuss their symptoms, preferring to maintain secrecy about their condition in their professional and other relationships. There was also little evidence of people malingering. Most people seemed to be committed to living as normal a life as possible. They organised their lives so that priority was given to the continuation of relationships and previous employment.

Additional evidence to support this description of CFS tend to be the people I have described comes from the effectiveness of their self-help groups. To have achieved the level of public awareness and sponsored the amount of research that they have, these self-help groups must comprise people with diligence and commitment.

Finally, the explanation that I offer for CFS also fits with the historical descriptions of neurasthenia and the consequences of the epidemic illnesses mostly linked together under the name ME. In the times when neurasthenia had some medical credibility, it was described as a post-infectious condition and related to people who were busy and driven. Those behaviours may also have been a product of the times. As Drinka (1984) says, the nineteenth century was a time of rapid social change, and people were often caught in the malaise and discontent of the times, driven to keep abreast of change and perhaps harmed in the process. As for the epidemic outbreaks, of those who continued to remain ill after the
initial illness, most were active and busy people such as nurses, doctors and teachers (Ramsay, 1988).

Managing chronic fatigue syndrome

Diagnosis was the key to people feeling that they could manage life and illness better. The central principles of managing this condition therefore emerge from examining what diagnosis represented for people, as well as from contrasting people's responses prior to and following diagnosis, together with the related changes in their health.

In itself, diagnosis mattered to people because it represented the beginnings of being able to feel that their world made sense again. It mattered particularly when people had been without a specific diagnosis for a long time and had become increasingly debilitated. With a diagnosis - even a controversial and uncertain one - people began to feel that their symptoms had some coherence. Antonovsky made coherence the core concept in his theory of coping, and the findings of this study bear out his emphasis on this concept and his definition of it as 'a way of seeing the world as predictable and comprehensible with ... form, structure and ... lawfulness' (1987, p17). With a coherent framework, people were able to give some predictability to an unpredictable experience and reorganise their lives accordingly. They were able to feel confidence again in their ability to perceive their problems, a confidence denied them as their bodies were no longer able to perform as they once had and further denied when others disagreed with their own interpretations of the problems. With their perceptions affirmed and validated, and their worst fears allayed, most were then able to begin to review their responses and their circumstances differently. As Frosh (1991) argues, the essence of therapeutic change lies in first being able to perceive the problem and then being able to perceive it differently.

Apart from providing a coherent framework for their problems, diagnosis was associated with changes in the ways that people lived their lives and reacted to their symptoms. Those who had diagnosis early in their illness had a better prognosis, which may in part be explained by their being less exposed to doubting professionals. In the main these people did not
pursue the downward spiral of self-doubt, counterproductive activity and worsening health. As a result, they rarely became as ill as some other participants. They had fewer relapses, fewer systems in the body seem to have been affected and they had fewer injuries.

Diagnosis also brought changes more generally, even for those who had been ill a long time. The contrast between people's actions prior to diagnosis and those they exhibited after diagnosis were substantial. Prior to diagnosis, people were striving to restore their self image by increasing or struggling to maintain their involvement in everyday activities. They were continually pushing themselves. At the same time many were disparaging and doubting themselves. A number attempted to restore their health by sustained aerobic exercise, only to feel sicker. In contrast, after diagnosis, people gradually began to create a new self image. They found kinder friends or created a lifestyle which hid their health problems as much as possible from other people. They found new values, deciding that it was not necessary to complete every task they began and that it was not a sign of moral weakness or personal failing to rest or withdraw from conflict and stressful situations. They learnt how to have restricted and regulated involvement in whatever everyday activities they were able to manage.

People had to change from being active and conscientious to 'monitoring and pacing' themselves. They had to learn to pay attention to their body, to understand its limitations and to heed its warming signals of distress. Rather than pursuing a course of active rehabilitation, people had to learn that reduced or minimal activity was the most acceptable compromise with this condition, that forbearance could be more effective as a way of managing the difficulties in their lives than was their former style of overcoming difficulties through action. People who were fortunate enough to have improving health were able to lead more productive lives, but to stay that way they had to find new meaning in a more restricted way of living. As one said: this illness is my life now, but I've begun to see both in new ways.

Doctors played an important role during people's illness. Doctors influenced the responses which contributed to declining health and they also provided the diagnosis that helped to moderate the course of most
people's illness. Women's health in particular was affected by doctors' responses. They were more likely to have their condition dismissed and many resented imputations that they were neurotic. On the basis of my discussions with doctors in this study, it appears that many doctors indirectly, but often with the best of intentions, encourage people with the symptoms of CFS to respond to their problems in the very ways that are least helpful to their health. These doctors had concerns about scientific uncertainties and a desire to help people continue with their normal lives. As most had had some exposure to ideas such as self-fulfilling prophecies and secondary gains, they were concerned that a diagnosis which cannot be substantiated by tests, was more likely to be disabling to a person than enabling. In effect, their responses encouraged people who were already inclined to strive towards maintaining their normal lives to do so with greater vigour.

In the absence of effective treatments, management of this illness depends primarily upon individuals' capacity to change their style of coping. This change will of course be easier for some people to make than for others. The severity of the illness and its duration may mean that some people have little choice about changing their lifestyle. Some may be constrained in making changes because they have relationships or family circumstances that restrict their potential to change. For instance, they may be expected by others to behave as they have always behaved. Some may have few ideas about other ways of responding. Youthfulness may mean a person has little experience of the diverse ways people may cope with life. Or a long lifetime of struggle may mean a person has become closely wedded to that coping style. Some may be unwilling to change because their previous lifestyle has given them pleasure and joy. It is likely that most will find the change difficult to make because their 'normal' coping style will be constantly presented to them in diverse media as desirable. Nevertheless, the findings of this study suggest that the best prognosis lies with a changed coping style. Further, it seems that the earlier that individuals and doctors or other health professionals identify the problem, and the sooner that individuals make the change in coping style, the better the prognosis.
Implications for care and management of other chronic illnesses

Given the widespread influence of some of the discourses on illness that I mentioned in chapter one, many people who become chronically ill may be left with the distress of being ill, as well as the burden of feeling they may have contributed to the decline and continuation of their poor health in some way. As the people in this study have shown, that burden can exacerbate the effects of the illness. In a society which is increasingly emphasising individual responsibility for health, many people who become chronically ill need to be able to feel within themselves, as well as being able to show others, that they are doing their best to be responsible about their health problems. Doctors who provide care for people who are chronically ill need to be aware that they may have these concerns.

To be able to feel effective in dealing with their health problems, people seem to need a framework for their problems. Although a framework is unlikely to entirely dispel people's negative feelings, this study shows that a framework can help to make a difference between manageable and unmanageable levels of social distress, particularly for those people who may be most sensitive to suggestions that their illness is a sign of personal failure. With a framework, people can counter the sense of estrangement and some of the uncertainty brought by their illness by giving meaning and coherence to their pain and discomforts. They can counter the feelings of isolation as they find and speak with others who share their problems or who understand them. As well, they can avail themselves of the information which is now readily available about so many illnesses and develop confidence and expertise in managing their problems. In being able to take action and explain their problems to themselves and others, they are then in a position to demonstrate to themselves and others their continuing commitment to social values and their moral integrity.

As most chronic illnesses can be relieved only partially by modern medical treatments, doctors play a complex role in the lives of their patients with chronic illness. Responding to the concerns of patients with ongoing or terminal illnesses can be a profound challenge to doctors' images of themselves as competent, as well as a challenge to their images of themselves as human beings who can show concern and compassion.
(Kleinman, 1988; Aiach et al, 1990; Pinder, 1990). They cannot behave as scientists relying only on measurable data. Nor can they act as psychotherapists as most lack the training and the working conditions which permit such practice. So what are the skills they can bring to care that will mean patients see them as competent?

Patients value doctors who exercise empathy and some counselling skills (Pinder, 1990). Participants in this study appreciated doctors who offered them respect and belief by acknowledging them as people with insights into the normal functioning of their bodies and minds. They appreciated doctors who could recognise the fears and anxieties that brought them to the surgery in distress, and who could understand that their distress was a reasonable response to the uncertainties of an ongoing illness. For doctors concerned about scientific uncertainties, participants readily respected those doctors who said 'I don't know', or who raised possibilities, or who said that 'medicine doesn't have all the answers'. However, they particularly valued the occasions when they were given a framework which encompassed their own perspectives of the problems and some guidelines about management or directions about where to get further information.

In general, longer term care was most likely to be effective when doctor and patient had been able to satisfactorily negotiate a shared framework for the illness, one which was meaningful for the patient both inside and outside the doctor's surgery. However, that satisfactory negotiation rested on trust. Many participants suffered from the adverse responses they felt they had been given by some doctors, so that when they consulted a new doctor they often did so with distrust. They mostly expressed that distrust with evasion and aggression. Any doctor faced with a new patient who is describing a chronic condition needs to be able to recognise why the person may be behaving in these distracting ways.

On the other hand, patients may change doctors for reasons other than dissatisfaction. Their needs for care may change with time and one doctor may not be able to meet all those needs. As Figure 7.1 showed, for some time after diagnosis participants were particularly keen to experiment with treatments, so they sometimes deliberately sought doctors who could convey new information or who might provide some form of
intervention. Later as they discovered more about the illness and its effects on themselves, they sometimes wanted a doctor with whom they could discuss ideas about the illness, a doctor who could act as a 'sounding board'. When they grieved the changes in their health and their lives, they valued a doctor who listened to their efforts to place this experience within the broader context of their past lives and their lost hopes and dreams.

The doctor who is fascinated by treatments may not be the doctor who can provide a well informed patient with a sounding board for their ideas about their illness or discuss the distresses of changing lives. It is also possible that the doctor who is able to give time and compassion may be unwilling or unable to go through the process of devising and supporting experimental treatments. The doctor who has watched the person's illness evolve may not be the doctor who is appropriate for the individual who wants to place events in context and review the development and evolution of their problem. Appropriate and skilful referrals not only to specialists but to other GPs and health practitioners, to books and self-help groups, appear to be as much a part of good care as empathy and good communication skills.

With chronic illnesses, doctors are responding to specific individual problems which may have ambiguous outcomes (Atkinson, 1984). If they are to be more effective in the care they offer, they need to learn how to give attention to the everyday detail of people's lives and the detail of their experience. They need to be able to tailor their responses to the particular configuration of an individual's condition, as well as the different concerns the individual may have over time. Scepticism and objectivity are poor substitutes for the skills and perceptiveness involved in providing respectful attention and a meaningful framework that might minimise people's social distress.

New directions

This study set out to discover patterns in the diverse experiences of fifty people with a diagnosis of CFS. As the group of people mostly comprised women, and as the majority of participants had been severely ill, usually
for several years, the patterns that emerged have been influenced by these participants' particular concerns. As most had been ill in the years prior to a definition for CFS and prior to the growing public and medical awareness of the condition, their experiences may also differ from those of people who are now becoming ill in this way.

It seems unlikely that people who are only now beginning to follow the downward spiral will deteriorate as far as some of the people in this study, since they may be more likely to encounter friends or doctors who know about the condition. On the other hand, cultural expectations about individual productivity and fitness seem, if anything, to be even more pronounced, so more individuals may develop lifestyles which could result in a greater prevalence of this condition.

The findings of this study suggest that it may be appropriate to advise people about the possible adverse effects of excessive activity during and following a viral illness, especially in the circumstances I have outlined in this study. That advice may prevent some people from developing an ongoing illness. In addition, there needs to be further research into the management of this condition. Rehabilitation programs need to be designed which incorporate training in learning how to monitor body signals, so that people can become more aware of how to prevent themselves from doing more than their body is able to manage at any one time. As so many participants have said, their problem is not brought about by a lack of motivation. What is lacking is an ability to know when their motivation and interest have exceeded their damaged body's capacity to cope.

Conclusion

Bodily processes fundamentally challenge the 'taken for granted' day-to-day life of people with CFS. Their observations about this experience convey the anguish involved in living with ongoing debility, uncertainty and estrangement. Their comments reveal how cultural values and social relations shape people's perceptions and experience of their bodies as well as how they label, categorise and interpret bodily symptoms and emotions. Although describing one particular life experience, the accounts of people
in this study also provide insights into the processes that create and shape life problems and the conditions that make those problems meaningful.
References


Alexander, P. (1963). "It could be allergy and it can be cured." *Sydney Bulletin*.


References


Appendices
Appendix A

Questions and information for participants with chronic fatigue syndrome

**Personal Information**

1. Sex []
2. Date of Birth [ ]
3. Country of Origin [ ]
   How long in Australia [ ]
4. Education
   - < year 10 []
   - completed secondary college []
   - technical or other training []
   - university []
   - post-graduate []
5. Current marital status
   - married/de facto []
   - single []
   - divorced []
   - widowed []
   - other []
6. Length of current marital status [ ] years
7. Number of children. []
8. Number of children living with you
   - age sex []
9. Others living with you
   - age sex occupation relationship to you
10. Occupation
   hours/week

11. Religion
   as a child
   now

15. Spouse's occupation
   FT/ PT

16. Why did you accept an invitation to join in this study?

17. Have you any concerns about this study, or hopes about what may come out of it?
Interview Outline

Description of Condition

1. What do you call this condition when you talk to other people about it?

2. What are the main symptoms of your condition at the present time? (see the enclosed list of symptoms)

3. Can you describe what happens to you when this condition is affecting you most severely?

4. Have you noticed any patterns or changes in your condition over time? during the day?

History of Condition

5. When do you think you developed this condition? How long do you think you had the condition before it was diagnosed?

6. How do you think you developed this condition?

7. What happened in your efforts to find out what was wrong with you? You might want to comment on:
   - visits to doctors or other health professionals (like counsellors, physiotherapists, natural therapists)
   - responses of doctors
   - possible diagnoses
   - tests done
8. How was the condition finally diagnosed and explained to you? How important was it to you to have a diagnosis and an explanation of what was wrong with you?

9. During the time that you have had this condition, what have been your worst and best experiences with health practitioners?
Effects of the Condition

10. How would you describe the effects of this condition in your life so far? What differences has it made in eg: outlook, relationships, sexuality, job, other ways?

11. What do you fear most about this condition?

12. In what ways do you think this condition may have had positive effects on your life?

Management of Condition

13. What treatments have you received for your condition?

14. What sorts of things (actions, thoughts) do you do to help you manage life with this condition? I am interested in both the practical things you do on a daily basis, and the ways you try to manage your feelings and thoughts about this condition and its effects on you.

15. What influenced your choice of these particular approaches? (eg did your ideas come from past experience, family, friends, books, doctors, ME/CFS Society... etc)

16. What other approaches have you tried over time? What did you do that was least helpful?

17. What things have hindered you most in your efforts to cope with this condition?

18. What aspects of your life have most helped you to cope with this condition. (eg family, friends, work, financial situation, other supports, doctors, your beliefs...etc)

19. What would you most of all hope others would learn from your experience?
LETTER OF CONSENT

THE MANAGEMENT OF MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME

Researcher: Roslyn Woodward
B.A., Graduate Diploma in Science (Psychology)

This letter outlines the purpose of the research project, and the stages of its design, so that you may consider these before agreeing to participate in the study.

The study aims to explore the following issues:

1) the way individuals manage their lives with ME/CFS

2) how factors such as personal understanding of the condition, the response of the health system, and the family and socio-economic situation, influence management of the condition.

There are three stages to the study:

1) an interview which will address the attached questions. It is expected that this interview would take approximately one and a half hours.

2) a questionnaire which will be provided approximately six months after the interview

3) a second interview within 12 months of the first interview, because your condition can be so variable and because your strategies, symptoms and situation may change with time. This interview will also provide an opportunity to discuss the limitations/benefits of the interview and questionnaire, to respond to any questions you may have about the research and any additional information you think may be useful to my understanding of the management of this condition. This may take up to an hour.

All records of interviews and questionnaires are confidential.

If you have any concerns about the research or what may be expected of you, I will be very pleased to discuss them with you. I appreciate that interviews may be tiring, so I would like to encourage you to feel comfortable about asking for the interview to be stopped at any time. If you are willing to participate in the study, would you please sign here:

I, .............................. am willing to participate in this study on the management of M.E./C.F.S. I understand that I may withdraw from the study at any time.

........................................ (signature) .......................... (date)
<table>
<thead>
<tr>
<th>SYMPTOMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>aching limbs</td>
</tr>
<tr>
<td>sore back</td>
</tr>
<tr>
<td>other sore muscles/joints</td>
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<tr>
<td>muscle twitching/spasm</td>
</tr>
<tr>
<td>weakness</td>
</tr>
<tr>
<td>clumsiness</td>
</tr>
<tr>
<td>pins and needles</td>
</tr>
<tr>
<td>tired/fatigued</td>
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<tr>
<td>exhausted</td>
</tr>
<tr>
<td>nausea</td>
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<tr>
<td>diarrhoea/constipation</td>
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<tr>
<td>bladder problems</td>
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<td>sore throat</td>
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<td>fever</td>
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<td>sweats</td>
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<td>difficulty in focussing vision</td>
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<td>headache</td>
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<td>shortness of breath</td>
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<td>loss of spatial perspective</td>
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<td>persistent ringing in the ears</td>
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<td>sensitive to sounds</td>
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<td>losing words</td>
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<td>other memory loss</td>
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<td>confusion</td>
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<td>depression</td>
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<td>anxiety</td>
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<td>irritability/frustration</td>
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<td>vivid dreams or nightmares</td>
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<td>disturbed sleep</td>
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<td>temperature control</td>
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<td>allergies/intolerances</td>
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<td>hormonal disturbances</td>
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<td>candida</td>
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<tr>
<td>other</td>
</tr>
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</table>
Dear 

Management of Chronic Fatigue Syndrome

Last year, about this time, I talked with you about this illness and its management. That was the first stage of my three year research project.

I am now ready to begin what will be the final stage of this study. This is a very important part of the research. It is attempting to develop a picture of the changes that have occurred for people with the illness over the last year. Specifically I want to understand how much those changes are part of the natural course of this illness and perhaps how they might reflect the value of particular management strategies. As you are probably aware, the relationship between changes and management is very complex. I am hoping that I will be able to identify some relevant patterns in this area by following the details of the illness in the fifty five people I have already interviewed.

I hope you will be interested in participating in this final interview. I expect this conversation will take about an hour. The issues I will want to talk about with you are listed on the attached page.

I will ring you about half way through October to arrange a time for the interview. However, if you have any questions about the study and its findings so far, or are uncertain about wanting to participate in a further interview, please give me a call on 2495611.

With kind regards

Yours sincerely

Ros Woodward
Questions for interview. October-November, 1991

What changes, if any, have you noticed in the symptoms and effects of the illness over the last twelve months?

If there have been changes in the illness, what do you think might explain those changes? If there have been no changes in the effects of the illness during that time, what do you think that signifies?

What sorts of treatments or strategies have you tried during the year? Are they basically the same ones you have always used or have you practised some new ones? What would you currently recommend to other people with this illness and why would you recommend those things?
Appendix A: Questions and information for third interview

Management of Chronic Fatigue Syndrome

When I spoke with you some months ago, I mentioned that I would be contacting you again in May this year, by telephone, to find out what was happening with your health.

I hope to be able to ring you some time after Monday 4 May. At that time I would appreciate your comments on the attached questions.

If you would like to speak to me about these questions or the progress of my research before that time, please ring me on 2495611.

Yours sincerely

Roslyn Woodward
The Management of Chronic Fatigue Syndrome

Questions for telephone interview May 1992

- During the last six months how would you describe your health? Would you say that you have been much the same, getting better or getting worse?

- How would you explain the changes (if any) in your health during that time?

- Have there been any significant changes in your:

  work commitments (eg changes to Part time work, retirement, sick leave, study etc)
  family life or close relationships
  visits to doctors or alternative health practitioners
  self management of this illness
Appendix B

Questions and information for doctors

The Management of Chronic Fatigue Syndrome (CFS)
Roslyn Woodward (BA (Hons), Grad Dip Sci(Psychology))

I am currently doing a Ph.D on the management of CFS at the National Centre for Epidemiology and Population Health at the ANU.

Although the main focus of this thesis will remain CFS, I hope to be able to extrapolate from my findings to the management of chronic illnesses generally. In part this reflects my own professional concerns as a family therapist where I am often faced with helping people with chronic illnesses or chronic life problems, and in part it reflects my concern at the lack of information available for professionals and ill people about the management of chronic illnesses.

Proposal

I would like to be able to speak to some doctors individually or in groups about the issues involved in the management of CFS and chronic illnesses. On the basis of these discussions I would hope to put together a brief questionnaire which I would send to all doctors in the ACT.

If you would be interested in participating in a brief interview (no more than half an hour) I would be delighted to hear from you. My telephone number is 2495611(w) or 2474160(h).
Issues for discussion

 approximate numbers of clients with chronic conditions/ with "puzzling" (uncertain) chronic conditions/ with what could be diagnosed as CFS.

thoughts about chronic illness and its management from the doctors point of view, especially where there are no useful treatments. I would like to have some understanding of:- the responses from you that you think are most helpful;- the value of a diagnosis;- the satisfactions or frustrations or discomforts of working with clients with chronic conditions.

thoughts about CFS. This might include discussion of the issues already covered around chronic illnesses generally, but there may be additional issues such as doubts about the existence of CFS, concerns that people are being given this diagnosis inappropriately or self diagnosing inappropriately, hypotheses about aetiology and treatment.
CONSENT FORM

THE MANAGEMENT OF MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME

Researcher: Roslyn Woodward; B.A., Graduate Diploma in
Science(Psychology)

The study aims to explore the following issues:

1) the way individuals manage their lives with ME/CFS

2) how factors such as personal understanding of the condition, the response of the health system, and the family and socio-economic situation, influence management of the condition.

These issues will be examined through questionnaires and interviews with people who have been diagnosed as having the condition based on the criteria put forward by Lloyd et al (1988), and with members of their families and doctors.

In this current part of the study, I am discussing with doctors the issues outlined in the attachment, so that a questionnaire may be developed for completion by all interested medical practitioners in the ACT.

All records of interviews and questionnaires are confidential. If you are willing to participate in the study, would you please sign here:

I, .................................... am willing to participate in this study on the management of M.E./C.F.S.

........................................
(signature) ..................................
(date)
Appendix C

Categories used for coding interview data

1. Sociodemographic Data

1.1 Sociodemographic data/sex
1.1.1 sociodemographic data/sex/male
1.1.2 sociodemographic data/sex/female

1.2 Sociodemographic data/birthdate
1.2.1 sociodemographic data/birthdate/after 1971
1.2.2 sociodemographic data/birthdate/1961-1970
1.2.3 sociodemographic data/birthdate/1951-1960
1.2.4 sociodemographic data/birthdate/1941-1950
1.2.5 sociodemographic data/birthdate/before 1940

1.3 Sociodemographic data/country of origin
1.3.1 sociodemographic data/country of origin/australia
1.3.2 sociodemographic data/country of origin/other than australia

1.4 Sociodemographic data/marital status
1.4.1 sociodemographic data/marital status/single
1.4.1.1 sociodemographic data/marital status/single/T2 single
1.4.2 sociodemographic data/marital status/de facto or married
1.4.2.1 sociodemographic data/marital status/de facto or married/separation T2
1.4.3 sociodemographic data/marital status/divorced

1.5 Sociodemographic data/family status
1.5.1 sociodemographic data/family status/children
1.5.1.1 sociodemographic data/family status/children/children T2
1.5.2 sociodemographic data/family status/no children

1.6 Sociodemographic data/employment,occupation
1.6.1 sociodemographic data/employment,occupation/FT
1.6.1.1 sociodemographic data/employment,occupation/FT/T2 change
1.6.2 sociodemographic data/employment,occupation/PT
1.6.2.1 sociodemographic data/employment,occupation/PT/PT T2
1.6.3 sociodemographic data/employment,occupation/home duties or unemployed
1.6.3.1 sociodemographic data/employment,occupation/home duties or unemployed/T2
1.6.4 sociodemographic data/employment,occupation/sick leave
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1 13 2 sociodemographic data/severity at worst/moderate

1 14 Sociodemographic data/severity T1
1 14 1 sociodemographic data/severity T1/s-vs
1 14 2 sociodemographic data/severity T1/moderate
1 14 3 sociodemographic data/severity T1/mild

1 15 Sociodemographic data/severity T2
1 15 1 sociodemographic data/severity T2/vs-s
1 15 2 sociodemographic data/severity T2/moderate
1 15 3 sociodemographic data/severity T2/mild
1 15 4 sociodemographic data/severity T2/recovered

1 16 Sociodemographic data/severity T3
1 16 1 sociodemographic data/severity T3/vs-s
1 16 2 sociodemographic data/severity T3/moderate
1 16 3 sociodemographic data/severity T3/mild
1 16 4 sociodemographic data/severity T3/recovered

1 17 Sociodemographic data/onset pattern
1 17 1 sociodemographic data/onset pattern/acute from good health
1 17 2 sociodemographic data/onset pattern/acute following self defined stressful lifestyle
1 17 3 sociodemographic data/onset pattern/acute following some ill-health
1 17 4 sociodemographic data/onset pattern/gradual

1 18 Sociodemographic data/self perceived health
1 18 1 sociodemographic data/self perceived health/getting better
1 18 2 sociodemographic data/self perceived health/getting worse
1 18 3 sociodemographic data/self perceived health/same T2
1 18 4 sociodemographic data/self perceived health/dontknow T2

1 19 Sociodemographic data/self perceived health at T3
1 19 1 sociodemographic data/self perceived health at T3/getting better
1 19 2 sociodemographic data/self perceived health at T3/getting worse
1 19 3 sociodemographic data/self perceived health at T3/same
1 19 4 sociodemographic data/self perceived health at T3/dontknow
2) Medical Context of Illness

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| 2 2 2 medical context of illness/experiences with health professionals/best experiences |
| 2 2 3 medical context of illness/experiences with health professionals/worst experiences |
| 2 2 4 medical context of illness/experiences with health professionals/reasons for continuing to see doctor after diagnosis |

| 2 2 5 medical context of illness/experiences with health professionals/reasons for not continuing to see doctor after diagnosis |
2.3 Medical context of illness/management by doctors
2.3.1 medical context of illness/management by doctors/treatments
2.3.1.1 medical context of illness/management by doctors/treatments/unhelpful
2.3.1.2 medical context of illness/management by doctors/treatments/helpful
2.3.1.3 medical context of illness/management by doctors/treatments/not sure

2.4 Medical context of illness/information
2.4.1 medical context of illness/information/given information
2.4.2 medical context of illness/information/no info given

2.5 Medical context of illness/Commonwealth Medical Officer visits

3 Social Context of Illness

3.1 Social context of illness/naming of illness

3.2 Social context of illness/social effects of the illness
3.2.1 social context of illness/social effects of the illness/outlook
3.2.2 social context of illness/social effects of the illness/relationships
3.2.3 social context of illness/social effects of the illness/sexuality
3.2.4 social context of illness/social effects of the illness/job
3.2.5 social context of illness/social effects of the illness/other
3.2.6 social context of illness/social effects of the illness/finances

3.3 Social context of illness/role of family
3.3.1 social context of illness/role of family/supportive
3.3.2 social context of illness/role of family/unsupportive

3.4 Social context of illness/role of others (non-family)
3.4.1 social context of illness/role of others (non-family)/supportive
3.4.2 social context of illness/role of others (non-family)/unsupportive

3.5 Social context of illness/role of self help
3.5.1 social context of illness/role of self help/society
3.5.2 social context of illness/role of self help/literature

3.6 Social context of illness/public perceptions of the illness
4 Meanings of illness

4 1 Meanings of illness/worst fears

4 2 Meanings of illness/positive meanings

4 3 Meanings of illness/hopes that others would learn

4 4 Meanings of illness/making sense of this illness
  4 4 1 meanings of illness/making sense of this illness/explanations for this illness
  4 4 2 meanings of illness/making sense of this illness/beliefs about illness generally
  4 4 3 meanings of illness/making sense of this illness/past experiences
  4 4 4 meanings of illness/making sense of this illness/other

4 5 Meanings of illness/most significant aspects of the illness

4 6 Meanings of illness/general beliefs about life

5 Management of illness

5 1 Management of this illness/strategies
  5 1 1 management of this illness/strategies/actions
  5 1 1 1 management of this illness/strategies/actions/helpful
  5 1 1 2 management of this illness/strategies/actions/unhelpful
  5 1 2 management of this illness/strategies/processes
  5 1 2 1 management of this illness/strategies/processes/helpful
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5 2 Management of this illness/hindrances to mgt
  5 2 1 management of this illness/hindrances to mgt/illness itself
  5 2 2 management of this illness/hindrances to mgt/doctors
  5 2 3 management of this illness/hindrances to mgt/others
  5 2 4 management of this illness/hindrances to mgt/other
  5 2 5 management of this illness/hindrances to mgt/not knowing what was wrong
  5 2 6 management of this illness/hindrances to mgt/finances

5 3 Management of this illness/helpful to mgt
  5 3 1 management of this illness/helpful to mgt/beliefs about the illness
  5 3 2 management of this illness/helpful to mgt/doctors
  5 3 3 management of this illness/helpful to mgt/others
  5 3 4 management of this illness/helpful to mgt/other
  5 3 5 management of this illness/helpful to mgt/dilemmas about mgt