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# Non - legitimate illness, embodied experience and the moral career: the case of ME/CFS

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**Non – legitimate illness, embodied experience and the moral  
career: the case of ME/CFS**

by

Tracey Jane Collett

**A thesis submitted to the University of Plymouth in partial fulfilment  
of the requirements for the degree of Doctor of Philosophy**

September 2002

The Department of Sociology  
The University of Plymouth

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# **Non - legitimate illness, embodied experience and the moral career: the case of**

## **ME/CFS**

by

**Tracey Jane Collett.**

### **Abstract**

The condition known as myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) is an illness of unknown aetiology which affects over 150 000 persons in the UK. Whilst the cause of the condition is the subject of intense medical debate, the official view is that it is a form of atypical depression or somatisation disorder. This view is at odds with the views of many sufferers who claim that ME/CFS is a pathological disease that renders them severely incapacitated. Sufferers' maintain that, because their condition is regarded as a minor, psychological illness, its' severity is not recognised. Thus, rather than being granted assistance, their appeals for help are often met with accusations of malingering or hypochondriasis. This, they argue, results in significant marginalisation. In short, sufferers' state that they experience bodily change that is profound and disabling, however, their claims to be 'really ill', are ignored.

ME/CFS is one of a number of conditions whose meanings are contested. Other such conditions include Gulf war syndrome, repetitive strain injury, organophosphate poisoning, and multiple chemical sensitivity. These conditions are worthy of sociological study because they 'make visible' the way that social definitions of illness impact on the experience of illness.

The data for this thesis is derived from an empirical study of sufferers' experiences of ME/CFS. Using both qualitative and quantitative research methods, the study explores the embodied experience of ME/CFS and the illness careers of sufferers. The findings of the study are analysed in the light of the sociological literature on 'the cultural expectations surrounding illness', 'embodiment' and 'the experience of illness'. Whilst the past literature has either focused on 'the cultural expectations surrounding illness' or 'the experience of illness', this thesis brings together the two areas and uncovers the complex set of relations and pathways that emerge when ideas about illness clash. The findings have implications for the sociological understanding of the illness experience. They are particularly relevant because, as the chronically ill population expands, there is an increasing emphasis on individual responsibility for illness. Thus, whilst contested illnesses are a blatant example of what happens when sufferers' are held accountable for being ill, the findings have implications for the experience of all chronic illness.



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This study was financed with the aid of a studentship from the Economic and Social Research Council. At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award. Regular sociological seminars and conferences were attended at which work was often presented. Several papers have been prepared for publication.

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16.11.00 'They're Just Nuts They are': Perspectives on Chronic Fatigue Syndrome. Paper to the B.S.A. Medical Sociology Conference.

Signed .....  .....

Date .24.6.03.....

# **Non – legitimate illness, embodied experience and the moral career: the case of ME/CFS**

## **Introduction**

Over the past two decades there has been a steady rise in the prominence of public accounts of illnesses, the causes of which are contested within the medical profession. Examples of such illnesses are repetitive strain injury, organo-phosphate poisoning, Gulf War syndrome and the condition known as myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS). Common amongst the accounts of sufferers is the assertion that the symptoms are often defined medically as manifestations of psychological problems. This, it is argued, has a far-reaching and negative impact on the illness experience. In particular, sufferers claim that first the chronicity, severity and disabling nature of the symptoms is often misunderstood by others and second, access to financial and therapeutic resources is often denied. Sufferers' accounts further suggest that underlying the public response to their conditions is the moral assumption that the individual is to blame. Despite the pervasiveness of sufferers' accounts of having conditions such as Gulf war syndrome and ME/CFS, the problems encountered by persons with conditions whose causes are contested has been relatively unexplored by sociologists of health and illness.

The aim of this thesis is threefold. First, it sets out to study empirically sufferers' experiences of the contested illness known as ME/CFS. Second, it examines the extent to which the sociological literature explains the experience of ME/CFS and contested



illnesses. Third, it considers the contribution that an understanding of the experience of contested illnesses makes to the sociology of health and illness.

Chapter 1 is entitled 'ME/CFS an illness you have to struggle to acquire'. In this chapter, I provide an overview of ME/CFS. Drawing on literature from a wide range of sources, the chapter commences with a description of official and lay accounts of the physical impact of the condition. This is followed by an outline of the two dominant paradigms of ME/CFS: the physical paradigm and the psychological paradigm. I then show how the psychological paradigm has emerged as the official explanation. Finally, I review the literature relating to the impact of the psychological paradigm on the everyday lives of sufferers.

The second chapter is entitled 'Sociological theory and the experience of illness'. This is the first of two chapters that review the sociological literature. In it I consider the extent to which sociological theory explains 'the plight of the ME/CFS sufferer'. Starting with the question of how ideas about illness are formed, I review the work of first, Parsons (1951) on the sick role and second Freidson (1970) on the 'non legitimate sick role'. In a consideration of how ideas about illness impact on the experience of ME/CFS I then turn to Goffman's (1963, 1968) work on stigma and the moral career. Finally, in order to address the question of how individuals react to ideas about ME/CFS I consider the work of Giddens (1984, 1991) on structuration and the use of expert discourses.

In chapter 3, 'The subjective experience of illness', I discuss 'the experience of illness' literature. Again, my aim in this chapter is to consider the literature that might explain

the subject of sufferers' experiences of ME/CFS. In the first part of chapter 3, drawing on the work of writers such as Leder (1990), Charmaz (1983, 2000), Bury (1991), Robinson (1988), Locker (1983) and Williams (1993, 1996), I consider the literature relating to the embodied experience of illness. Here the literature suggests that chronic illness is experienced as loss: the loss of body, the loss of social action, the loss of income and ultimately, the loss of self. Within this overall experience, the meaning of loss varies depending on factors such as age and gender. Despite these variations in experience, the literature indicates that in general, major problems for the chronically ill include 'making sense of the bewildering symptoms', 'reconstructing order' and 'maintaining control'. In the second part of chapter 3, I address how, according to the literature, individuals attempt to 'make sense of the symptoms', 'reconstruct order' and 'maintain control'. As such, it is suggested that the expectations of others play a role in the experience of illness. Thus, it appears that interactions, particularly with the medical profession, influence the transition, from the world of what Goffman (1963) refers to as 'normals' to the world of chronic illness.

The 'experience of illness' literature presented in chapter 3 'fleshes out' a number of the ideas provided by the social theorists in chapter 2. Thus it is possible to construct a model of the experience of chronic illness that summarises the majority of the literature presented in both chapters. Such a model is provided at the end of chapter 3. Within this model, a distinction is made between those illnesses that are seen as 'legitimate' and those illnesses that are seen as 'non – legitimate'. In addition, the careers of each type of illness are mapped out. Thus the model incorporates sociological concepts relating to first 'the embodied experience of illness', second, 'making sense of illness', third 'reconstructing order' and finally 'maintaining control'. The aim of developing

the model is first to provide a theoretical framework within which to explore the experience of ME/CFS and second, to provide a way of exploring how far the literature explains the experience of ME/CFS and those illnesses that are contested.

In chapter 4, 'Researching sufferers' experiences of ME/CFS', I set out the methods that I used to explore the experience of ME/CFS and the extent to which the sociological concepts illustrated by the theoretical model, explain it. First, I discuss the overall design of the research. This includes stating the rationale behind my research strategy and explaining why I used two methods of data collection within the study. The two methods used were the survey method and the method of in-depth interviewing. The idea behind conducting in-depth interviews was to obtain from respondents', biographical accounts of their lives since the onset of ME/CFS. Having outlined the methods used, I then discuss each aspect of the study. Starting with the survey, I describe first, how I designed a questionnaire so that it would meet my research objectives, second, how I obtained a sample of ME/CFS sufferers, third, how I prepared and analysed the data and fourth, the characteristics of the respondents. I then focus on the interview study. In this section I, again, pay attention to aspects of design, sampling, data preparation and analysis. Throughout the chapter I give consideration to issues of reliability, validity and ethics.

Chapter 5, 'The embodied experience of ME/CFS', is the first of four findings' chapters which, using as a framework, the model of illness proposed in chapter 3, explores sufferers' experiences of ME/CFS. In this chapter, I consider the impact that ME/CFS has on the body, social action, material security and finally, 'the self'.



Chapter 6 is entitled 'ME/CFS and the illness career: making sense of the symptoms'. Here, I consider, the respondents' experiences of first, the symptoms at onset, second, seeking a diagnosis and third, obtaining a diagnosis of ME/CFS.

In Chapter 7, 'ME/CFS and the illness career: reconstructing order', I investigate the respondents' experiences of first, seeking 'explanations for' and 'ways of managing' the symptoms of ME/CFS, second, seeking support from family, friends and colleagues and third, seeking financial assistance.

Chapter 8, is my final findings' chapter. Entitled, 'ME/CFS and the illness career: maintaining control', in this chapter I explore how, on a daily basis, individuals with ME/CFS manage the loss of the body, the loss of social action and the loss of self.

Chapter 9, my discussion chapter, is entitled 'Non-legitimate illness, embodied experience and the moral career: the case of ME/CFS'. In this chapter, I consider the three aims of my research in the light of my empirical findings. In particular, I consider the questions of how far the sociological literature explains the experience of ME/CFS and how this study contributes to existing sociological knowledge. I contend that the work of Freidson (1970) and Goffman (1963) makes an important contribution to the understanding of the experience of chronic illness. However many of their ideas are not taken forward in the more recent 'experience of illness' literature. Indeed, within the recent literature, there is little critical engagement with the question of how 'cultural expectations about illness' impact on the experience of illness. Thus, whilst the 'experience of illness literature' provides some valuable concepts, particularly with regards to ideas relating to the loss of the body, the loss of social action and the loss of

self, it tends to assume that, in general, a consensus between patients and others is reached regarding the nature of illness. This leads to a portrayal of the illness career as a linear one that leads eventually to a point of 'accepting illness' or 'accommodating illness'. For example, sufferers are said to embark on a somewhat unproblematic journey through illness that is marked by events such as obtaining a diagnosis and seeking treatments and eventually 'learning to live with illness'. I propose that this homeostatic model of the illness experience presents a simplified version of illness that does not explain the experience of ME/CFS and other conditions where there is confusion over meaning. Further I suggest that, in implying that there is an end point to the illness career there is a danger that the ongoing daily experience of chronic illness will not be seen as something worthy of sociological study. Indeed, with the exception of writers such as Frank (1995) there is at present, little sociological literature that considers the experience of illness beyond its initial stages.

I conclude that, in order to understand in more depth, the experience of chronic illness, it is necessary for sociologists to ask not just, 'What happens to individuals in the face of chronic illness?' but also, 'Why do certain things happen?' This involves widening the parameters of thought to incorporate a consideration of ideas about illness that are prevalent in western culture and the impact that prevalent ideas have on the experience of illness. Further, sociologists should consider the actions that sufferers take to guard against the impact of ideas about illness and the impact that 'actions taken' might have on ideas about illness in general.

Implicit in the findings of this thesis is the suggestion that ideas about illness are essentially bound up with ideas about moral status. Such ideas are based on abstract

notions of the experience of illness that are held and perpetuated by 'non ill' members of culture. In particular, they are related to the biomedical model and the notion that, the legitimacy of chronic illness depends on factors such as the extent to which it is life threatening. The more illness is seen as legitimate, the less the moral status of the sufferer is questioned. That is, the less the sufferer is held responsible for his or her illness. When illness strikes however, ideas about the severity of illness held by the sufferer appear to change. As such, they become based, not on the extent to which the illness is seen as 'life threatening', but on the extent to which illness renders the body incapacitated. These ideas often conflict with general ideas about illness. For example, in general, back pain is not life threatening and thus not seen as severe. However for the sufferer it dominates everyday life and is regarded as severe.

The way in which ideas about illness impact upon the lived experience of illness depends on the extent to which ideas about illness clash. When sufferers claim that their conditions are more legitimate than generally thought, they undergo a struggle for first, meaning, second, medical support and third, social acceptance. Here the path of the illness career takes the form of a journey through illness that involves going down many dead ends and taking many turnings that lead back to an earlier part of the path. This occurs because potential solutions for the problems of illness turn out to be unhelpful and because, once they are reached, doorways to support remain closed.

The type of struggle experienced by sufferers who contest their illness resembles Goffman's (1968) moral career. That is, the individual is compelled to find ways of navigating around the constraints imposed on him or her by the judgements of others. The limitation of the concept of the moral career however is that, like the homeostatic



model of illness provided by the experience of illness writers, Goffman suggests that eventually individuals come to an end point where they accept their situation with 'grace'. This does not appear to be the case with regards to many sufferers of ME/CFS. Indeed, it appears more likely that the moral career is ongoing in the lives of individuals who contest the meaning of their illness. Thus despite drawing on alternative discourses that appear to legitimate their illness as severe and incapacitating, many sufferers exist in a private world of constant chaos and uncertainty. Whilst because of the high profile nature of the debate surrounding ME/CFS the moral career is easily seen, the findings of this study lead to the question of whether a more subtle form of the moral career is experienced by sufferers of other chronic illnesses.

## **Chapter 1**

### **ME/CFS: an illness you have to struggle to acquire?**

#### **Introduction**

The condition known as ME/CFS is a disorder of unknown aetiology that has been the subject of intense debate within the profession of medicine and between medical practitioners and their patients. Part of the problem of ME/CFS is that despite complaints of chronic incapacitating symptoms from patients, conventional medical research procedures tend to suggest that there is no evidence of pathological disturbance. The arguments surrounding the cause of ME/CFS tend to derive from two paradigms. The first suggests that ME/CFS is a psychological illness, stemming from somatising issues, the second suggests that ME/CFS is a pathological condition which can only be understood through the use of sophisticated medical techniques.

Drawing on literature from a wide range of sources, this chapter provides an overview of ME/CFS. It commences with official and lay accounts of the physical impact of the condition. This is followed by an outline of the two paradigms of ME/CFS and an account of how the psychological paradigm has emerged as the official explanation. Finally, the literature relating to the impact of the psychological paradigm on sufferers' everyday lives is reviewed. I conclude that the case of ME/CFS offers a rare opportunity to explore, not only the lived experience of illnesses that are contested, but also, the broad sociological literature relating to the experience of illness in general and the impact of cultural ideas on the experience of illness.

## **ME/CFS: official definitions**

To date there are three official descriptions of ME/CFS. These are known as, the Australian criteria (Lloyd et al. 1988), the Oxford criteria (Sharpe et al. 1991), and the Centre for Disease Control (CDC) criteria (Fukada et al. 1994)<sup>1</sup>. In the UK, it is recommended that the Centre for Disease Control criteria be used as the official tool for diagnosing the disorder (Hutchinson et al. 2002). The Centre for Disease Control defines ME/CFS as:

Clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is not the result of ongoing exertion, is not substantially relieved by rest and results in substantial reduction in previous levels of occupational, educational, social or personal activities (Fukada et al. 1994:10).

Alongside the main symptom of chronic fatigue, the CDC criteria states that, patients experience concurrent symptoms. These symptoms include four of the following: self reported impairment in short-term memory or concentration; sore throat; tender cervical or axillary lymph nodes; muscle pain; un-refreshing sleep; post exertional malaise and multi-joint pain.

According to sufferers, the chronic fatigue that the CDC criteria, refers to, can be understood in terms of energy quotas.

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<sup>1</sup> Each official set of criteria that has been used for diagnosing ME/CFS can be seen in Appendix 1. It is also important to note that the above criteria are used in the diagnosis of Post Viral Fatigue Syndrome (PVFS). PVFS is another name for ME/CFS that was particularly popular in the 1990s (see Shepherd 1995).



The energy quota of the ME/CFS sufferer, it is often argued, is infinitesimal and becomes drained after a minimum amount of mental or physical exertion. This is illustrated in the following quotes:

I spend 21 – 23 hours of my day lying down. Even then it's an effort to use parts of my body. To lift my hand to write a cheque is too much. Last time I tried walking I got to the end of the block and had to lay down for 15 minutes before I had the strength to get back home. (Female ME/CFS sufferer, aged 35, quoted in Anderson et al. 1997:16)

I could only manage two hours of consulting before I was absolutely exhausted. I was forced to move around on a chair with wheels to examine patients. I did not have the strength to inflate a baumanometre bulb and I had to refer my patients to my partners to have their ears syringed as my arms were too weak to draw water into the barrel. (Male GP, six months into having ME/CFS, quoted in Lopis, 1995:16)

The combined experience of fatigue and the concurrent symptoms of ME/CFS are further described below:

Imagine waking up every single morning for months, even years with the certain knowledge that for the rest of the day you will be wandering around feeling as though you have flu; that your brain will soon become fogged and completely unable to function correctly and that even after a short walk to the shops you may be forced to lie down feeling exhausted ... that's what its like having M.E. (Shepherd, 1992: 1).

I am 21 but I feel more like 81, old, weak and useless. About 70 percent of my life is spent resting ... I am unable to walk far, can't bear noise or light, unable to take a bath or wash my own hair ... I am used to remorseless pain ... (Male, aged 21, quoted in Daily Mail, 2000: 28).

### **The impact of ME/CFS on the quality of life**

According to the CDC criteria and, as indicated in the quotes above, ME/CFS brings about a 'substantial reduction in daily activity'. This is documented in several empirical

studies that have been undertaken in the US. For example, Schweitzer et al (1995) found that ME/CFS sufferers have:

... levels of impairment more extreme than the overall levels of impairment reported by a comparable group of multiple sclerosis sufferers (1995: 1367)

Similarly, Anderson et al. (1997) found that the overall scores on the Quality of Life Index (Ferrans and Powers, 1985) were significantly lower in ME/CFS than for other illness groups. Further, studies by Buchwald et al (1996), Komaroff (1996) and Myers and Wilks (1999), have found that patients with ME/CFS have marked impairment in comparison with the general population and disease groups. Moreover, Brujin (1995) found that out of one hundred ME/CFS patients, sixty five percent noted at least a fifty percent decrease in all activities and thirty eight percent of the sample were functioning at less than twenty five percent of their former capacity.

Given the above findings it is perhaps not surprising that, as suggested by the CDC criteria, the incapacity brought about by ME/CFS appears to impact on all areas of life. Thus patients report problems regarding employment, education, parenting, carrying out household chores, and taking part in recreational and social activities. Schweitzer et al. (1995) for example, found that seventy percent of those interviewed had to give up physically active pastimes and thirty percent had to curtail them. In addition, whilst twenty percent of the interviewees said that they did not socialise at all, the typical practice for the remaining eighty percent was to return home earlier with the onset of fatigue. Similarly Anderson et al. (1997) found that sixty five percent of their sample had to give up work because of ME/CFS, forty one percent were unable to meet family

responsibilities, and all of the respondents had to cut down on social activities. Further, Brujin (1995) found that forty three percent of her interviewees could no longer take care of young children or carry out household maintenance, thirty eight percent stated that recreational activities were affected and twenty five percent found it difficult staying in touch with friends and socialising with family members. Studies of ME/CFS in children have also found that the condition is the biggest cause of long term absence from school (Colby and Dowsett 1997).

A review of newspaper articles and books written by persons with ME/CFS draws attention to the salience of the findings above. For example, the anecdotal accounts of patients portray a life that has been severely disrupted by illness and stories of being able to do nothing all day except 'sit on the settee', 'not being able to work, look after the family, read books, pursue hobbies or have relationships', are commonplace:

I can't go to school; I can't even get out of bed. I have to be in a wheelchair to get out of the house. I can't dress myself. My parents have to wash my hair. It is partly mental fatigue – lack of concentration and short term memory loss and partly physical fatigue, muscle and joint pains, I am sensitive to light and noise. (Female, aged 14, quoted in the Guardian, 1996:18)

### **The epidemiological spread of ME/CFS**

Epidemiological research into the prevalence and demographic spread of ME/CFS is confusing. This is due, in part, to the variety of definitions that researchers have utilised in the selection of their samples (Jason et al. 1997). As a result, figures regarding the pervasiveness of the condition vary considerably. Some studies for example, suggest that the number of persons with ME/CFS range from between 90 persons per 100 000



(Reyes 1997), whereas others estimate that the number of sufferers is more likely to be 218 persons per 100 000 (Jason et al. 1997). However, in the UK it is generally assumed that the number of persons with ME/CFS is between 150 000 to 172 000 (Hutchinson et al. 2002). This suggests that the prevalence of the condition is closer to 270 persons per 100 000.

As with the studies regarding the prevalence of ME/CFS, studies that have investigated the condition in relation to gender are unclear. For example, some researchers have found that roughly equal numbers of men and women suffer from ME/CFS (Lloyd et al. 1990, Lawrie and Pelosi 1995, Buchwald et al. 1995). However, others have found that almost twice as many women than men have the condition (Kroenke et al. 1988, Jason et al. 1997). One thing that the research does seem to agree on however, is that ME/CFS is found in all age ranges (Jason et al. 1997). Several studies have concentrated on the prevalence of ME/CFS amongst children, finding that an estimated 25 000 children suffer from the condition (Hutchinson et al. 2002, Colby and Dowsett 1997). Other research has found that whilst ME/CFS is prevalent across the age spectrum, it is most common amongst individuals aged between forty and seventy (Jason et al. 1997). ME/CFS has also been found in the majority of ethnic groups and to affect persons from all socio-economic groups (Wesseley 1995, Jason 1997).

### **ME/CFS and the medical debate**

As stated in the introduction to this chapter, the aetiology, pathogenesis and management of ME/CFS stimulates intense medical debate. One of the reasons for the controversy surrounding ME/CFS is, that whilst patients report symptoms which often

cause extreme disability, conventional medical tests tend to find little evidence of illness. Within the medical arena, the multitude of hypotheses that exist surrounding the aetiology of ME/CFS can be broadly divided into two schools of thought. There are those that tend to support the likelihood of a 'psychological aetiology' and those that support the likelihood of a 'physiological aetiology'.

### **ME/CFS and the psychological view**

Proponents of the psychological view argue that ME/CFS is a new name for what, in the late eighteenth century, was defined by the British medic George Beard as 'neurasthenia' (Abbey and Garfinkel 1991, Wesseley 1995, Showalter 1997).

Neurasthenia was described by Beard as:

A disease ... which may attack any or all parts of the system and is characterised by ... a weakening of the motor energy ... subjects cannot complete the simplest act in one effort, however short, without feeling immediate and insurmountable lassitude, to stand to walk or to talk each causes fatigue ... the commonest manifestation of fatigue is either neuromuscular weakness ... and the capacity for attention is paralysed. (Beard 1869, quoted in Deale and Adams 1984: 216)

During the time in which neurasthenia was 'fashionable' (Richmond 1989), there were three theories regarding its cause. These have been defined by Wesseley (1995), as 'the central paradigm', 'the social paradigm' and the 'psychogenic paradigm'. The central paradigm stemmed from the field of neurology. Supporters of the central paradigm based their rationale on the view derived from the then, new laws of thermodynamics that postulated that the mind is a complex set of energies. Those who advocated the central paradigm argued that neurasthenia was caused by the collapse of the supply of energy within the nervous system. Energy, it was suggested, could be exhausted from

the central nervous system via either the psychological shutting down of the brain, the failure of cerebral blood supply, or through the effects of toxins or infections elsewhere in the body. In a translation of the central paradigm, the social paradigm accounted for neurasthenia by arguing that the condition was caused by the increasing stress and strain of modern life. Thus 'the overworked business man and the woman who is now taking on twice her original workload' were seen as prime candidates for the condition (Wesseley 1995:109). Advocates of the central and the social paradigm believed widely that the cure for neurasthenia was rest.

In contrast to the central paradigm, proponents of the psychogenic paradigm of neurasthenia argued that proof of a lack of energy within the central nervous system was inconclusive. Rather than being the result of pathological abnormality, it was suggested that neurasthenia, was caused by a psychological imbalance causing a lack of motivation. In the first issue of the journal 'Abnormal Psychology' (1906:45), in an article entitled 'On neurasthenia as a disintegration of the personality', Donley for example, criticised the previous 'mechanical symbolism' of descriptions of neurasthenia, arguing that they were based on the false belief that 'for every pathological manifestation, there must be an underlying disease process'. Two years later neurasthenia was described as 'a state of habitudinal valetudinarianism with no corresponding organic lesion' (see, Wesseley et al.1998: 213).

As the psychogenic paradigm of neurasthenia gained popularity, the social paradigm began to change. Thus, it became doubted that neurasthenia was really a disease of modern life but rather individuals had become more 'tender to their ills'. Neurasthenia, it was argued, was more likely to result in idleness than overwork (Brock 1911, White



1921). Consequently, rather than treating neurasthenics with rest, the cures advocated were activity and exercise. As the psychogenic paradigm and the new social paradigm gained recognition, neurasthenia became redefined as a psychological illness. Thus writing in 1911, Dejerene stated that 'manifestations of neurasthenia are, by nature, purely phobic in origin' (1911: 20).

The redefinition of neurasthenia as a form of phobia, coincided with and arguably contributed to, the rise of clinical psychology as a profession (Wesseley et al. 1998). As new categories of psychiatric disorder were formed, the name and hence, the diagnosis of neurasthenia was dropped altogether and the symptoms of fatigue on exertion came to be understood as a sign of 'anxious melancholia'. Anxious melancholia was further classified according to the criteria set out in the new diagnostic and statistical manual of mental disorders (DSM), as a form of depression, a condition that could be 'minor', 'attenuated', 'atypical' or 'masked'. With the reclassification of neurasthenia into a range of psychological illnesses the problem disappeared for some 80 years.

As stated above, today's proponents of the psychological view of ME/CFS argue that sufferer's complaints are directly comparable to the complaints of neurasthenics and that ME/CFS is simply 'old wine in new bottles' (Wesseley 1990). In what appears to be a reiteration of the psychogenic paradigm, today's 'psychological argument' is based on two main observations. The first of these is that any evidence of pathological abnormality in patients with ME/CFS is inconclusive. The second is that a large body of research has found that the majority of sufferers fulfil the official DSM criteria for psychological conditions. These conditions include, atypical depression (Johnson et al. 1996, Wesseley and Powell 1989), major depressive disorder (Demitrack 1994),

anxiety, (Wesseley 1992), general psychiatric disturbance (Taerk 1987, Wesseley and Powell 1989, Katon and Walker 1993), personality somatisation (or psychosomatic) disorder (Swanick et al. 1995, Marshall et al. 1994), disorder of perception, or effort syndrome, (Wesseley et al. 1999) and in cases where there have been clusters of ME/CFS, mass hysteria (Showalter 1997). Other researchers have put forward the view that ME/CFS is a complex interaction of cognitive, behavioural and affective components and that ME/CFS is a sociomatic disorder, that is, a disorder whose symptoms are embodiments of social problems (Kleinman 1982, Ware 1995).

One model that has been put forward to account for these psychological findings is the cognitive behavioural model of CFS (Wessley et al. 1991). Wessley and colleagues suggest that while organic factors might precipitate the condition, behavioural factors perpetuate the condition. They explain that when resuming normal activity levels following a bad viral infection, it is common to experience symptoms of physical de-conditioning. If people attribute these symptoms to signs of ongoing disease rather than de-conditioning they will tend to resort to rest and inactivity in an attempt to cure the symptoms. A cycle of avoidance and symptom experience then develops which can lead to loss of control, demoralisation and possibly depression and anxiety. These psychological states can further perpetuate the illness through generating more physical symptoms and possibly through compromising the immune system.

This model has been developed by Surawy et al. (1995) to include an explanation of predisposing factors. They suggest that predisposed people are highly achievement orientated and base their self esteem and respect from others on their ability to live up to certain high standards. When some individuals are faced with factors that affect their



ability to perform, such as the combination of excessive stress and an acute illness, their initial reaction is to keep going. This leads to exhaustion. In making sense of the situation, a physical attribution for the exhaustion is invented, which protects self-esteem by avoiding the suggestion that the inability to cope is a sign of personal weakness. Thus symptoms of tiredness for example, are interpreted as the result of ongoing disease. Like Wessley et al. (1991), Surawy et al. (1995) maintain that this leads to a perpetuating cycle of activity avoidance in an attempt to reduce symptoms. As time goes by, efforts to meet previous standards of achievement are abandoned and patients become increasingly preoccupied with their symptoms and illness. This results in chronic disability and the belief that one has an ongoing incurable illness.

### **ME/CFS: the physiological view**

Despite the arguments put forward by supporters of the psychological view, many argue that ME/CFS is indeed a 'real' or 'organic' disease. Amongst advocates of the organicity of the condition are individual sufferers, sufferers' organisations, medical research scientists and individual doctors. They argue that the illness is not psychological, rather, psychological problems are intrinsic to the pathological pathway of ME/CFS. Further they suggest that depression is not surprising given the nature of the illness. Thompson writes for example:

Emotional and cognitive problems arise directly from the disease, but also from the disintegration of a healthy life. There is a traumatic assault on selfhood as we lose things by which we defined ourselves: relationships, careers, studies, leisure. (1992:26)



In addition, advocates of the likelihood of a physiological view of ME/CFS argue that many of the psychological studies are inaccurate and biased. For example, Jason et al. (1997) argue that a key problem with the original criteria for the diagnosis of ME/CFS (in particular, the Oxford criteria) was that it was too broad as it included 8 or more minor symptoms that characterised many unexplained somatic complaints. As a result, many individuals with psychiatric problems fell into the category of having ME/CFS. This, in turn, led to findings of high psychiatric morbidity in sufferers. Jason et al. (1997) found that when the narrower and more recent (CDC) definition of ME/CFS is used, psychiatric morbidity in ME/CFS patients drops significantly and becomes similar to that reported in populations with other chronic illnesses.

Advocates of a physiological paradigm further argue that the reason why pathological research into ME/CFS is inconclusive is because there has been a lack of research funding available to follow up exploratory studies. A writer in the magazine the 'CFIDS Chronicle' states for example:

The only United Kingdom government funded research on ME/CFIDS has been a small grant to the medical research council which went towards X's research into the psychiatric aspects of ME/CFIDS (Anonymous, 1993: 20).

This assertion has been backed recently by the Chief Medical Officer's report into ME/CFS (Hutchinson et al. 2002). It has also been suggested that, via the peer review process, advocates of the psychological paradigm have managed to steer academic publicity away from physiological research and use ME/CFS to further their own careers (Interaction 1999:12).

The theories on offer from supporters of the physiological view of ME/CFS present a daunting challenge to the lay person and the summary presented below is offered merely as a basic insight into the medical research that has been carried out. Broadly speaking, the literature suggests that supporters of a physiological aetiology of ME/CFS base their argument on initial evidence suggesting that ME/CFS causes dysfunction to the central nervous, immune and metabolic systems. Neurological tests for example have found evidence for impairments in cognitive functioning. Thus, studies done by Troughton et al. (1992), Costa (1992) and Behan (1991), have found evidence of frontal and lobe hypoperfusion (perforation), brain stem perfusion (perforation) and reduced blood flow to the brain in ME/CFS sufferers. In addition, neuroendocrine tests have shown that ME/CFS sufferers have abnormalities in the hypothalamic pituitary axis, the mechanism that affects the release of cortisol from the adrenal cortex and switches the stress system on and off (Bakheit 1992, Scott et al. 1998).

Researchers working in the field of immunology have also found that ME/CFS sufferers have alterations in the numbers and proportions of T cell subsets in the peripheral blood. Further, low levels of certain lymphocytes have been found as well as deficiencies in certain cell markers (Behan 1985, Tosato et al. 1988, Klimas 1990, Levy et al. 1994). These latter findings suggest that the immune system is activated in ME/CFS sufferers. Finally, studies that have been conducted on the metabolic system have found that ME/CFS sufferers have poor cell function. Cheney (1989) for example, found that this is due to high levels of Rnase-L activity. Rnase-L is a substance in the blood that is responsible for switching enzymes off. According to Cheney, perpetual Rnase-L activity goes on to cause significant damage to liver function, which, in turn, ceases to

flush out toxins from the system. The uninhibited toxins then impact on the central nervous system and the release of hormones becomes affected.

One theory that has been proposed regarding the cause of these apparent anomalies is the viral theory of ME/CFS. The majority of persons favouring the viral theory of ME/CFS argue that the condition is caused by an unclassified enterovirus. There are a large number of the enteroviruses, however, over the course of history, only seventy of the most frequently occurring ones have been classified. Viruses within this group include polio type (or coxsackie) viruses and herpes type (Epstein barr) viruses. Such viruses cause the conditions of polio, herpes, chicken pox, Bornholm's disease, aseptic meningitis, glandular fever and mononucleosis.

Within the viral school of thought there are a number of explanations as to the origins of the new ME/CFS enterovirus. One viral theory asserts that ME/CFS is a form of Epstein Barr virus, the virus which gives rise to glandular fever and mononucleosis. This theory is based on evidence of viral antibodies (Tobi et al. 1982, Dubois et al. 1984, Straus et al. 1985). A more popular argument is that ME/CFS is a form of atypical polio (see for example, Dowsett 1990 and Bruno 1994). This theory is based on both clinical findings and epidemiological research. The epidemiological research has shown for example, that, historically, epidemics of polio have been followed frequently by an atypical or a non-paralytic form of polio and further, that outbreaks of one disease can terminate or block the spread of the other (Acheson 1959). Advocates of the polio theory argue that, following the removal of strains of polio with the polio vaccine, the atypical polio virus filled the gap. For example, Dr. Jane Colby writes



Just a few decades ago, hospital wards were full of children in iron lungs as a result of polio. No longer. The horrific spectacle appeared to abate with the advent of vaccination, but nothing is without its price. The public breathed a sigh of relief and even the medical profession believed, and still seems to believe, that the dreaded scourge of polio was at last being vanquished. We read predictions that it will be wiped out by the year 2000. But a body of evidence is growing linking Chronic Fatigue Syndrome (CFS), also called myalgic encephalomyelitis (ME), to this terrible disease, largely caused by attempts to eradicate polio. An alternative polio seems to be upon us. (1996: 17).

Researchers have also put forward the hypothesis that ME/CFS is a mutant enterovirus. Cunningham et al. (1990) and Clements et al (1995: 67) for example, argue that in ME/CFS the persisting organism is a virus mutant that is defective in the control of 'viral genomic RNA reproduction'. Arguing along similar lines, Martin (1992) argues that ME/CFS is caused by a stealth virus. Martin defines a stealth virus as a cytopathic virus that lacks the antigens required for protective anti-viral cellular immunity. Martin continues that stealth-adapted viruses can acquire additional genetic sequences from infected cells, from bacteria and reproduce. Another viral theory presupposes that no one particular virus can trigger the mechanisms that cause ME/CFS, rather any number of viruses are capable of inducing the disease. This hypothesis is particular to the metabolic theory of Cheney (1989) cited earlier.

An alternative popular physiological view of ME/CFS is that the condition is caused by toxic overload. This view has been put forward by Behan, (1996), who presented findings of detailed clinical trials that compared patients with ME/CFS to those with the neurobehavioural syndrome that occurs following delayed exposure to organophosphates. Behan concludes that:

Patients can develop a neurobehavioural syndrome following exposure to organophosphates. The clinical features of this syndrome are identical to those of CFS. Indeed, when the subjects with this neurobehavioural syndrome are subjected to detailed neuroendocrine studies, similar results are found in CFS and in the organophosphate delayed syndrome suggesting that both entities share a common pathogenesis. (1996:349).

Arguing along the same lines as Behan, Hooper (1997) argues that there are physiological links between ME/CFS, Gulf War illness and multiple chemical sensitivity. He maintains that sufferers have lowered levels of sulphate, blood cell distortion and certain lipids which can create toxic molecules that set off the immune system, all these are synonymous with toxic poisoning.

### **ME/CFS: the official explanation**

In 1996, the government recognised that as a result of the ME/CFS debate, service providers, were offering a huge variation in treatment and advice for the condition. In response to this, they commissioned a report with authorship from the Royal Colleges of Physicians, Psychiatrists and Practitioners (Wesseley et al. 1996). The aim of the report was to review all medical research and put forward recommendations for the treatment and management of ME/CFS. The resulting document acknowledges that ME/CFS is a substantial problem for patients, families and society and argues that a biopsychosocial approach to aetiology, assessment and treatment needs to be taken. However, the authors conclude that there is little evidence to support the viral, metabolic and neurological theories of ME/CFS and that previous personality factors and psychological distress appear to be more important. The report further states that personality problems and psychological problems may also play an important role in

perpetuating disability (1996: 37). Moreover, the authors recommend that the term CFS should be used in clinical practice as the name myalgic encephalomyelitis (ME) is not precisely defined. This is because the term myalgic encephalomyelitis suggests a disease for which there is no evidence (myalgic, meaning, 'of the muscles', encephalo 'meaning of the brain' and myelitis, meaning 'of the nerves').

With regards to treatment, the report recommends that the majority of patients be treated in primary care. Doctors are advised to be sympathetic, however the authors argue that they should not give advice to patients such as 'live within your limits', or 'listen to your body'. This advice, it is stated, only serves to perpetuate disability. Further, the report warns medical professionals against 'over testing' patients for illness as this can make matters worse by encouraging the belief in patients that they have a physical condition. The report recommends that the appropriate treatment for ME/CFS is cognitive behavioural therapy and graded exercise. These treatments aim first, to change the beliefs that patients hold about their illness and second, to show patients that activity can be steadily and safely increased without exacerbating the symptoms (Moss-Morris and Petrie 2000).

Despite being heralded by the government as the official clinical guidelines to ME/CFS the Royal Colleges report has been met with scepticism by the ME/CFS charities and by medical supporters of the physiological view. In general, it is argued that the report is subjective and unscientific, down playing the physical argument and giving precedence to the psychological theory. An editorial in the Lancet stated for example:

The sixteen strong committee was top heavy with psychiatric experts so the emphasis on psychological causes and management of cognitive



behavioural therapy is of no surprise ... psychiatry has won the day for now ... we believe the report was haphazardly set up, biased and inconclusive and is of little help to patients or their physicians ... (1996: 971).

It is further acknowledged by advocates of the physiological paradigm that psychological interventions such as cognitive behavioural therapy (CBT) can not cure ME/CFS. However, if they are carried out correctly, they can help individuals cope with and manage their lives with ME/CFS.

### **ME/CFS: an illness you have to struggle to acquire?**

As with the social paradigm of neurasthenia 100 years ago, a version of the psychological paradigm of ME/CFS is popular today in modern culture. Evidence of this can be seen in the accounts given by the ME/CFS charities of sufferers' encounters with the medical profession and more blatantly in the common conception of ME/CFS in the 1980's as Yuppie flu. However, the reaction of others towards sufferers can be seen most patently in the claims of patients themselves.

As such, sufferers tend to claim that their symptoms are often dismissed, not only by the medical profession but also by the public in general as 'everyday, run of the mill aches and pains' and/or 'all in the mind'. Indeed, newspaper reports, autobiographies and self-help books, abound with tales from sufferers of rejection and misunderstanding from others. Headlines read, for example, 'Bosses don't believe ME' (Daily Mirror 1995: 20), 'They think it's all in the mind, but its crippled me' (Daily Mail 1998: 34) and 'Emily is made to feel guilty over illness that often leaves her too weak to walk' (Daily Express 1995:7). Articles in magazines paint a similar picture:

I tried to keep living my life as normally as possible. But I could only work for a couple of hours at a time because I was growing increasingly ill. At first the doctors told me it was all in my head and then they blamed it on my unsettled childhood (Female ME/CFS sufferer, age unknown, quoted in Chat Magazine, 1999:17).

I get livid when people say there is no such thing as ME they should spend a few days feeling like I do ... I have been bluntly told that I was a neurotic woman and a waste of NHS money. Once the doctor reduced me to tears. I'd taken him an article about M.E. but he said it was rubbish – that there was no such illness (Female ME/CFS sufferer, age unknown, quoted in TV Quick, 1994: 20).

Many sufferers of ME/CFS claim that the unimportance attributed to their symptoms results in significant marginalisation, impacting on first, treatment, second, help with everyday chores and third, personal wellbeing. Indeed, patient accounts tend to suggest that the dominant view of ME/CFS as psychological leads to a set of stressful circumstances that are experienced in addition to the already distressful circumstance of incapacity. The combined impact of the symptoms of ME/CFS and the reactions of others is illustrated in the letter below for example, in which an ME/CFS sufferer seeks help from an Agony Aunt in a popular magazine:

I've suffered from the illness M.E. - Myalgic Encephalomyelitis – for eight years and it's ruining my life. I am only 30 but feel years older and my ten year old son knows me only as the mum who's too ill to do anything with him. The worst aspect is that people neither care about (n)or understand M.E. I still have to explain how I feel to some members of my family and friends. I have no life because of the pain I suffer but the doctor at my local surgery has been completely unsympathetic. They simply don't believe it exists ... I tried to claim disablement but was told I was fit for work, even though I have never been examined. What can I do? (Female ME/CFS sufferer, age unknown, quoted in T.V. Quick 1994: 13).

The accounts of sufferers regarding the reaction of others towards ME/CFS have been investigated empirically via two pieces of research. The first of these is by Norma Ware



(1992). The second is by Lesley Cooper (1997). Both Ware and Cooper found that ME/CFS sufferers experience two kinds of reactions. The first stems from the apparent insignificance of the symptoms. Thus Ware states:

Because everyone from time to time endures aches and pains, sore throat, feelings of depression and fatigue, such complaints can be construed as minor consequences of daily living rather than as indicators of daily living. Perceptions of the trivialisation of symptoms converge for sufferers in the thematic phrase "You're tired, We're all tired! So what!" (1992: 347 – 355).

The second and, according to Ware, more damaging, perception of ME/CFS is embodied in the definition of the illness as psychosomatic – 'all in your head'. Thus, participants in the studies undertaken by Cooper and Ware, repeatedly complained of being disbelieved or not taken seriously because they 'don't look sick':

The thing I hear from everybody is, "Gee you look too good to be sick!" I hear that all the time because I am not emaciated and I'm not staggering about and of course when people see me they see me on my good days. They don't see me on my bad days when I can't get out of bed (Ware, 1992: 351).

Both Ware and Cooper argue that according to sufferers, these perceptions of the symptoms of ME/CFS tend to prevail amongst GPs and other medical specialists. Focusing on this area in particular, Cooper explains that for many sufferers of ME/CFS the experience of the medical profession is as follows: often in initial encounters with the medical profession GPs find no evidence of pathological disturbance in the ME/CFS sufferer. This results in sufferers repeatedly going back to their doctors and asking for more tests. During this phase of their illness patients are often sent to various medical specialists in the hope that 'something will turn up'. Cooper maintains that, because of the lack of evidence for their symptoms, respondents are diagnosed initially with



depression, stress or some other form of psychological disturbance. The cause of the problem is often hypothesised to be 'school phobia', 'malingering', or 'bored housewife syndrome' (1997: 193). Sufferers argue for example:

I was going to the neurologist and he could find nothing wrong with me. "Well, there's nothing wrong on your X-ray but why don't you try taking this, because a lot of "women" – have a lot of trouble with depression that could cause other symptoms" (Ware 1992: 352).

I had an hour with this chap and he just insulted me all the time ... It started off with him bumping the table saying "alright cards on the table now what's wrong with you? Something wrong with your marriage?" (Cooper 1992: 194).

Both Ware and Cooper maintain that sufferers perceived that the dismissal of their condition as 'serious' by doctors and other medical specialists had far reaching implications. Cooper states that the lack of a credible diagnosis barred sufferers from entering the sick role, leading to problems with employers (for example, patients found it difficult to obtain justified absence from work or disability benefit) and family. Further, Cooper (1997:197) states that patients found that their social identities became devalued and stigmatised. As a result of their psychological diagnoses, respondents perceived themselves as 'being at rock bottom': seriously incapacitated by illness yet not taken seriously.

In addition to considering the social implications of having a diagnosis that is not considered as real Ware and Cooper also argue that patients with ME/CFS suffer iatrogenic psychological injury. As such, for the patient, the meaning derived from the severity of the symptoms is that 'there is something seriously wrong'. However, the reaction of others challenges sufferers' interpretations of reality. Ware argues that when

one's subjective meaning of illness is dis-confirmed, four forms of suffering are experienced. These are humiliation, self-doubt, alienation and uncertainty. Humiliation results from having the shame of being mistaken about the nature of reality. Self doubt is experienced because individuals often feel compelled to accept the possibility that what they are feeling might, after all, be 'all in their head'. Alienation can occur because rather than expose themselves to the pain of being disbelieved, individuals may choose to conceal their symptoms completely. Finally, uncertainty arises from believing the illness is physical but not being told by physicians what their symptoms are and hence having no way of fighting it.

Both Ware and Cooper conclude that the non-bodily form of distress created by the reaction of others towards ME/CFS can be understood as a form of 'non legitimation' or 'non justification of illness'. Cooper for example, argues that ME/CFS belongs to a group of syndromes that have been denied the status of 'organic disease'. She maintains that, because they do not have the status of legitimate illnesses, this group of conditions can be defined conceptually as the 'illegitimate illnesses'. According to Cooper other examples of the illegitimate illnesses are repetitive strain injury, candidiasis and multiple chemical sensitivity. Arguing along the same lines, Ware maintains that persons with ME/CFS experience 'delegitimising processes'.

For Cooper, a point of considerable interest regarding what she calls the illegitimate illnesses concerns the ways in which patients react to being labelled and the conditions that such labelling engenders. In particular she is interested in how far sufferers challenge the authority of their GPs and what the outcome of this is. She maintains that when sufferers perceive that the doctor is dismissing their symptoms as non-existent, the

underlying myth of the doctor as a symbolic figure of authority and a healer is challenged. This is also mentioned by Ware who argues that some individuals begin to feel betrayed by their doctors. Cooper suggests that in reaction to their situations individuals with illegitimate illnesses begin to fight back. Thus, some of her respondents spoke of a specific turning point when they began to challenge not only a particular GP but also their own internalised myth of doctors in general. For example, a young girl who had been sent to a psychiatrist said:

Yeah, I don't trust them at all, I don't trust doctors, because I knew I was ill and they were saying I weren't and I knew they were wrong ... I'm not frightened any more, I used to be, but I'm not frightened, I will say what I think you know . I think after the day in hospital, I couldn't put up with being pushed around by this specialist and that specialist and being pushed from pillar to post and I just said 'No more' and that was the turning point. (Respondent quoted in Cooper 1997: 199).

Cooper continues that another major turning point occurs when sufferers actually gain a diagnosis of ME/CFS. She argues that many sufferers continue without a diagnosis for years and often ME/CFS as an entity is discovered by chance, for example, in a newspaper or magazine article. This can lead individuals to self diagnose the condition, to seek a diagnosis from a 'pro-ME' physician or to ask their local GPs for a diagnosis. Cooper maintains that despite gaining a diagnosis however, the stigma of ME/CFS remains the same; many, including GPs still see the condition as psycho-somatic. Regardless of this however, Cooper claims that the majority of her respondents reported that a diagnosis of ME/CFS led towards a psychosocial improvement and offered respite from the chaos of their illness. In addition, she found that the point of diagnosis marked a change in respondents' attitudes towards their doctors. She argues:



At this point ME became both a symbol of the sufferer's own newly acquired empowerment and of the threat to the doctor's position of authority (1997: 196).

Cooper found that after they had received a diagnosis many individuals began to collect their own information on ME/CFS, often becoming as they stated, 'more knowledgeable about the condition than their doctors'. Cooper continues, that when patients started taking a more active role in the management of their symptoms, her interviewees recounted that doctors could not accept this threat to their professional knowledge and power. As such, she argues that GPs attempted to regain control not only over the patient but also over their claim to knowledge, often becoming angry and abusive. When the mother of a young patient asked for a second opinion, from someone who was known to be pro ME' she experienced the following:

He went absolutely scarlet, he went red in the face. We stood in the corridor of the ward, I mean I felt very vulnerable because my daughter was fading away in front of me, nobody could tell me what was wrong with her, and I felt as though I was asking for something I shouldn't be asking for and it was as though I was undermining his judgement ... I said "could I have this doctor Z? and he went red in the face, I'll never forget, he was lost for words he didn't know what to say, and in the end I forget what he called him – a silly old crank or that old Buffoon, or words to that effect ... and he said "Oh if you want to see him take her to see him, a day out will do her good!" I just stood there absolutely speechless, I felt awful, I said to him "Can't he come and see her here?" "Not in my hospital!" he said and walked off. He was absolutely furious and he realised that I must have gone behind his back if you like and gone to the ME society even though he'd asked me not to (Respondent quoted in Cooper 1997: 202).

Cooper continues that the ways in which these doctors were treated in the narratives of her respondents, exemplifies the myth of 'demonisation'. That is, those individuals that had experienced frustration in their attempts to satisfy their internal expectations of the doctor's power to heal were held in great contempt. On the other hand, Cooper argues

that those individuals who had met a particular doctor who took their suffering seriously tended to exemplify the myth of 'idealisation'. An example of this can be seen in the following quote:

He is a wonderful doctor, a lovely, lovely man and without him I don't think I would have been able to have taken it, I really don't. He really has gone into it in great depth ... But on the very first day I saw him I said "do you think I am ill"? and he said "yes" and I tapped my head and I said "do you think it is all in here?" and he said "no – I can see you are ill!" And of course, then he knew that I was ill and he went out of his way to see how he could treat (Respondent quoted in Cooper 1997: 203).

Cooper suggests that many patients eventually drop out of mainstream medicine altogether and go to alternative practitioners instead. Here they find that their illness is totally legitimated as responsibility for their condition is placed outside sufferers and laid at the feet of external stresses such as environmental pollutants. Similarly, Ware suggests that individuals legitimate their illnesses to themselves and others by attributing their symptoms to 'real illness'.

### **Discussion: ME/CFS and the sociology of health and illness**

The subject of ME/CFS is interesting sociologically for a number of reasons. First it provides an opportunity to study the little explored area of 'the experience of illnesses that are contested'. This is of importance given first, the increasing numbers of individuals who claim to have such illnesses and second, the profound form of suffering and marginalisation that such conditions appear to engender. In addition, the subject of ME/CFS offers a rare way of studying a number of ideas and concepts that exist within the sociological literature that relates to the subject of health and illness. These are



concerned with 1) the 'nature' of health and illness in contemporary western society; 2) the impact of prevalent thinking about illness on the lived experience of illness; 3) the actions that individuals take to guard against 'social harm' and 4) the extent to which, the actions taken by individuals actually work.

Cooper (1997) and Ware (1992) provide a valuable starting point with regards to exploring the experience of ME/CFS and the contested illnesses. Whilst they refer to some of the broader sociological issues mentioned above, their analysis is, at present, limited. First, the validity of their findings is questionable. For example, Cooper's study was based on ten interviews. Whilst Ware's study was based on fifty interviews, it was conducted in the US where ideas about ME/CFS differ from those in the UK. Second, Cooper and Ware's ideas regarding the moral status of illness types and especially the concepts of 'delegitimation' or 'non legitimation' need to be unpacked and clarified. Third, both Ware and Cooper's studies document patient's experiences with their GPs and medical specialists, yet they do not give any detail about the reactions of others towards ME/CFS. How for instance, do employers, teachers, employees working in the Department of Social Security, colleagues, friends and family react towards sufferers' claims to illness? Fourth, whilst Cooper mentions the impact of others on the social identity of the sufferer, little evidence is given to back this up. Fifth, Ware and Cooper do not consider the combined impact of bodily distress and the reactions of others. Sixth, there is no comparison between the experience of ME/CFS and the experience of other illnesses. Finally, little systematic attention has been paid to factors such as the age and gender of sufferers in relation to the experience of ME/CFS.



For this PhD thesis I conducted a UK based, large scale, in-depth empirical study into sufferers' experiences of ME/CFS. Through this in-depth study my aim was to first, build on the insights into the experience of ME/CFS and the contested illnesses in general, that are provided by Ware (1992) and Cooper (1997). Second, as I have indicated above, I aimed to explore how far the sociological literature explains the experience of many persons that have ME/CFS. And third, I aimed to investigate how an understanding of the experience of ME/CFS can contribute to the sociology of health and illness.

My specific research objectives were as follows:

- To explore sufferer's perceptions of the impact of ME/CFS on the body,
- To investigate the reported affect that ME/CFS has on daily functioning. (Particular consideration was given to age and gender) and
- To examine illness careers of ME/CFS sufferers.

With regards to this latter objective, my purpose was:

- To find out about the experience of ME/CFS at its onset,
- To study the experience of the diagnosis of ME/CFS,
- To research how others react towards a diagnosis of ME/CFS,
- To explore the ways in which individuals attempt to construct order having been diagnosed with ME/CFS and
- To investigate how individuals with ME/CFS make sense of their conditions.

Having in this chapter outlined the literature that relates to the experience of ME/CFS, in the following two chapters, I examine the wide sociological literature that might explain the experience of ME/CFS. In Chapter 2, 'Sociological theory and the experience of illness', I examine the theoretical literature that is concerned with first the nature of ideas about illness and second, how, or indeed whether, such ideas impact on the experience of illness. This leads me to propose a loose theoretical framework within which ME/CFS might be placed. In Chapter 3, 'The subjective experience of illness', I move from a consideration of the theory to a consideration of the empirical research that has been conducted into the everyday experience of illness. My aim here is to show how, by virtue of their in-depth insights into everyday life with chronic illness, studies into the experience of illness, fit into and 'tighten up', the theoretical framework outlined in Chapter 2. I then, in the proceeding chapters, apply this theoretical framework to the experience of ME/CFS as observed in my empirical study.

## **Chapter 2: Sociological theory and the experience of chronic illness**

### **Introduction**

In this chapter, I consider how sociological theory might explain the experience of ME/CFS. In the first section, I discuss the literature relating to ideas about health and illness and their impact on individual experience. First, I consider Parsons' (1951) model of the sick role and second I consider Freidson's (1970) adapted version of Parson's sick role. I then discuss the value of Goffman's (1963, 1968) theory of the moral career, or 'the process' of stigma, for understanding the particular experience of what Freidson refers to as 'the illegitimate sick role'. In the final section of this chapter, I turn to the literature on how individuals attempt to change the meaning attributed to illness 'types'. Here, I suggest that Giddens' (1984) theory of structuration and the double hermeneutic might be useful in explaining the actions taken by many sufferers of ME/CFS.

### **Illness, deviance and the sick role: the work of Talcott Parsons**

Talcott Parsons' (1951) view of the social system was drawn from biology. The biologist views living organisms in terms of a set of self regulated parts that work together to maintain the homeostasis, or balance, of the whole. Similarly, Parsons viewed the social system in terms of a set of interrelated parts that work together to ensure the smooth functioning of society. The parts to which Parsons referred were for example, the family, the education system, the justice system and the medical system. Each part, according to Parsons, maintains a high level of functioning through providing



roles which members of society take on. According to Parsons, within the nuclear family, the roles attributed to the husband and the wife as providers and caregivers for example, ensure that the family remains a stable unit that contributes towards the functioning of society, in terms of the socialising of children. The husband has an instrumental role whereas the wife has an emotional one.

In his book, 'The Social System' (1951), Parsons set out one of the first sociological analyses of health and illness. His starting point was that health is intimately bound up with the functional needs of the individual. Following this, he argued that too high an incidence of illness in society results in a dysfunctional social system; consequently, illness is a form of social deviance. In order to minimise the social dysfunction brought about by illness, Parsons theorised that the social system operates in a way that minimises all forms of illness. He maintained that the minimisation of illness takes place via the roles of doctor and patient. These roles, he argued, combine to provide a consensual model through which the process of illness can be channelled.

Parsons based this theory on his observation that being sick is not simply a condition. Instead, he argued:

When you look at what is happening you observe a set of institutionalised expectations and corresponding sentiments and sanctions'. (1951: 436).

Focusing first on the role of the patient, Parsons maintained that there are four institutionalised expectations surrounding illness. These can be seen in Table 1.

**Table 1: The 4 institutionalised expectations surrounding illness: Talcott Parsons and the sick role (1951).**

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Expectations	
Privileges	1. Exemption from normal social responsibilities. 2. Exemption from responsibility for getting better.
Obligations	3. Obligation to do everything possible to get better. 4. Obligation to seek technically competent help.

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The first expectation is that when people are ill they should be exempted from normal social responsibilities, for example, the responsibilities of work, family commitments and social engagements. The second is that ill individuals can expect to be exempted from the responsibility for getting better. For example, a person that is ill is not expected to 'will' him or herself to get better, rather s/he is regarded as 'not being able to help it'. The third expectation is that the exemptions from responsibility described above are based on the condition that the ill person behaves in a manner that minimises the duration of the illness. Thus, whilst it is acknowledged that an ill person cannot 'will' themselves to be well, ill health is regarded as socially undesirable and it is expected that the ill person does everything in his or her power to get better as soon as possible. The fourth expectation is that when ill, individuals are obliged to seek technically competent help.

According to Parsons, this set of institutionalised expectations constitutes the sick role. He maintained that the sick role acts as a mechanism which socially controls illness by

providing a set of moral expectations based around the notion that illness is undesirable and the obligation is to get better.

Parsons argued that the role of physician is complementary to the role of the patient and like the sick role, this role also functions as a mechanism of social control. He illustrated this by showing how, when confronted with illness, lay people seek advice from medical practitioners whom they see as 'experts'. In turn, he argued, physicians through scientific testing, organise illnesses into medical categories. This allows each illness to be treated according to the medical specification for that category and acts as a way of processing illness efficiently. As a result, the amount of time spent in the sick role is minimised and functioning is resumed as soon as possible. Parsons argued however, that the privileges of exemption granted by the sick role can either consciously or unconsciously motivate people to act ill for their own personal gain. He maintained that the clinical process operated by medicine allows such cases to be detected and went on to advocate the use of psychoanalysis as a treatment for these incidences. Psychoanalysis, he argued provides a therapeutic context in which a person's motivational imbalances can be readjusted.

Parsons continued that whilst doctors have intimate access to patients, patients are protected because, due to their professional status, doctors are educated formally to, first, focus on disease and second, be objective, detached and committed to the interests of their patients.



## **The value of Parsons' sick role theory for understanding the experience of ME/CFS**

Within sufferers' accounts there is a lot to suggest that Parsons' model of the sick role might be of value in explaining some aspects of the experience of ME/CFS. The findings of both Ware (1992) and Cooper (1997) show that, as Parsons suggested, sufferers draw on the expertise of the medical profession in the defining of illness. Further, the findings of Ware and Cooper indicate that, as Parsons argued, implicit in the wider culture is the idea that individuals do become ill for their own personal gain. For example, many ME/CFS sufferers state that they are often accused of 'malingering' by GPs and others. In addition, the accounts presented in Cooper and Ware's studies indicate that there is a sick role and that this influences the actions of many ME/CFS sufferers. Thus, on being diagnosed, sufferers expect to be allowed time off from everyday responsibilities, be given an explanation of illness that indicates that it is caused by something beyond their control and be given advice about measures that they can take to treat their symptoms. Finally, the experience of ME/CFS sufferers with regards to gaining access to the sick role appears to be bound up with the medical profession. Indeed, where ME/CFS is concerned, it appears that because the medical category into which the condition falls is that of 'non serious' or 'psychological' illness, sufferers are barred from full access to the sick role.

Whilst Parsons' ideas about the sick role makes a useful contribution with regards to explaining the experience of many sufferers of ME/CFS, it is limited. First, it is based on illness that is temporary. As such, in the case of illness such as ME/CFS (illness that is chronic, or long lasting), the obligation of 'getting better as quickly as possible' does

not apply. Second, Parsons suggests that the relationship between the lay individual and the medical practitioner are based on consensus, that is, both parties share the same ideas about illness. Reports concerning the experience of ME/CFS demonstrate however, that this is clearly not the case. Indeed, whilst sufferers appear to share the cultural belief in the ability of the medical profession to define illness, when their conditions are defined as psychological they protest. In addition, Parsons implies that the medical profession provides a single objective view when it comes to the defining of illness. However, again, this does not appear to be the case. Thus, with regards to ME/CFS, whilst the majority of medical professionals are reported to define ME/CFS as a psychological problem that arises from somatic issues, not all experts take this view. Thus, as I have shown in the previous chapter, within the medical profession a wide range of theories are held that espouse that ME/CFS is a physical or pathological illness.

Parsons' theory of the sick role is also limited because, whilst it provides a loose understanding of how health problems that are categorised as 'bonafide illnesses' are culturally shaped, it fails to provide an understanding of how those health problems that are not seen as bonafide illnesses are culturally shaped. Indeed, if the case of ME/CFS is anything to go by, it would appear that, individuals with conditions that are not seen as serious, experience what might be seen as an inverted version of the sick role. For example, rather than being granted exemption from social responsibility, they are expected by others to 'carry on as normal'. In addition, rather than being granted exemption from responsibility of illness, they experience blame for their illness. For example, they are told that the condition is 'all in the mind'. A number of the limitations described here are picked up in the work of Eliot Freidson (1970). His work is the subject of the following section.



## **Eliot Freidson: Illness, deviance and the sick role**

Like Parsons (1951), Eliot Freidson (1970) was concerned with the roles of the doctor and patient. However, Freidson argued that the two parties do not co-operate together in their natural, mutual desire to sustain the functioning of the social system. As a result of this observation, rather than providing a consensual model to explain health and illness Freidson provided a conflictual model. Within this conflictual framework, Freidson argued that the medical profession has a much more dominant role in constructing the social meaning of illness than the lay population. Unlike Parsons, he maintained that the obligations and privileges provided by the sick role vary according to the degree of deviance imputed to an illness and the duration of the illness. Freidson concluded that the dominance of the medical profession over the way illness is perceived socially might have negative consequences for segments of society in terms of quality of life.

For Freidson, the questions of why and how medical practice holds a dominant role in the construction of illness can be answered by looking at the nature of the professions in general. Freidson argued that by organising itself as a profession, the occupation of medicine gained the power to claim that its members are the most reliable authority on the nature of disease, possessing the highest levels of knowledgeable skill and trustworthiness. In claiming expertise in the area of medicine, the profession also has autonomy and governs its own activities, as no other institution is in a position to understand and therefore regulate what the profession does.

Freidson maintained that when the work of a profession lies in the attempt to deal with the problems that people bring to it, the profession develops its own independent



conceptions of those problems and tries to manage both the clients and those problems in its own way. In developing its own approach, the profession changes the definition and shape of problems as experienced by the lay person. Freidson continued that the lay person's problem is re-created as it is managed and a new 'social reality', is created by the profession.

Freidson illustrates how this is the case with medicine. Medical practitioners conceptualise illness in terms of scientifically observable abnormalities, which interrupt the functioning of the whole body. This meaning of illness differs from the meaning that is attributed to illness by the lay person. The lay person looks at illness in the context of her culture and every day life. Thus, what might be a minor irritation for a lay person, might be a serious illness for a doctor. Conversely what might be seen as a 'serious illness' for the lay person might be seen as 'trivial' by the doctor. Freidson maintained that the meanings imputed to illness by the lay population are often such that many people, who would be medically regarded as ill, do not enter the medical practice at all.

Freidson argued that at the point in his or her 'illness career' when the lay person steps over the threshold of medical practice, the medical set of meanings become the dominant set and the person becomes a patient and an object of medical scrutiny. In the following quote he illustrates how this process can be conflictual and how, via what he calls 'a process of leverage, control and bargaining', meanings of illness are changed:

In the case of diagnosis, the consultant must obtain information of the sort relevant to medicine rather than to lay cultures ... The tasks of 'taking a history' - collecting information from the patient about past illness and symptoms ... can be rather difficult. The patient may specify

diffuse rather than localised pain, or express his subjective feelings, rather than analyse the symptoms from the point of view of the physician. In the case of treatment the consultant may be confronted with other problems, the patient may disagree with his recommendations or may not be used to organising his life in such a way as to be able to follow his instructions ... To accomplish his task of diagnosis and treatment the physician may adopt a variety of tactics (including) the long term education or socialisation of the client, by passing the taking of a history by doing a thorough physical examination ...(or) through co-opting the kin and other laymen (sic) around the patient to serve as agents of the practitioner' (1970: 309 - 310).

Freidson maintained that once the medical definition of illness is accepted, the lay person's problem is socially re-created and labelled according to medical categories.

Freidson argued that not only does this imposition of the medical model on to the individual constitute a judgement that 'the doctor knows best', but also, like law or religion, medicine is a moral enterprise. This is because it delineates first, what is illness and what is not illness and second, how individuals with certain illnesses should behave. He argued that:

The judge determines what is legal and who is guilty, the priest what is holy and who is profane, the physician, who is normal and who is sick (1970:206).

This has consequences for the individual with the illness. For example, Freidson maintained that:

As those socially diagnostic meanings vary, so do the consequences for the personal life of the individual vary. On the crudest level he (sic) may be punished or indulged in therapy, he may be expected to perform his normal social roles, or instead adopt a new and special deviant role. He may be expected to take on new obligations while forsaking most normal privileges, or allowed to take on new privileges while forsaking old obligations (1970:327).

It is clear that Freidson sees a number of variations in the sick role that occur depending on the meaning attributed to the illness. He maintained that these variations arise in Western societies due to the influence of the medical profession but they are also perpetuated by the general societal response to illness. Freidson expanded Parsons' (1951) idea of the sick role to illustrate what he meant by 'variations'.

According to Freidson, the degree to which a person is allowed access to the sick role and therefore, has the responsibility for being deviant taken from his or her shoulders, depends on, first, the degree to which the illness is seen as a legitimate illness and second, on the degree of seriousness that is associated with the illness. Focusing on the subject of legitimacy, Freidson maintained that illnesses can be put into three broad categories: unconditionally legitimate, conditionally legitimate, or illegitimate (stigmatised). Illnesses within these categories are either perceived of socially as minor or major deviations. The role that an individual is expected to take on when ill, will depend on where the illness falls within these two categories. This is illustrated in Table 2 below.



**Table 2.** Freidson's expansion of the sick role: the statuses of individual illness by imputed legitimacy and seriousness (1970, 1988:239).

<i>Imputed seriousness</i>	<i>Illegitimate (stigmatised)</i>	<i>Conditionally legitimate</i>	<i>Unconditionally legitimate</i>
	Cell 1	Cell 2	Cell 3
<i>Minor Deviation</i>	<p>"Stammer"            Partial suspension of some ordinary obligations; few or no privileges; adoption of a few new obligations</p>	<p>"A Cold"            Temporary suspension of few ordinary obligations; temporary enhancement of privileges. Obligation to get well</p>	<p>"Pock marks"            No special change in obligations or privileges</p>
	Cell 4	Cell 5	Cell 6
<i>Serious Deviation</i>	<p>"Epilepsy"            Suspension of some ordinary obligations; adoption of new obligations; few or no privileges.</p>	<p>"Pneumonia"            Temporary release from ordinary obligations; addition to ordinary privileges. Obligations to co-operate and seek help in treatment.</p>	<p>"Cancer"            Permanent suspension of many ordinary obligations; marked addition to privileges</p>

Freidson's classification suggests that if an illness is considered conditionally legitimate then the 'deviant' is temporarily exempted from normal obligations and gains some extra privileges on the condition that he or she seeks the help necessary to rid himself of his or her deviance. An unconditionally legitimate illness sees the 'deviant' being exempted permanently from normal obligations and obtaining additional privileges. Finally, the individual with the illegitimate or stigmatised illness is exempted from some normal obligations by virtue of a deviance for which technically he or she is not held responsible. However, he or she gains few privileges and takes on some 'especially handicapping' new obligations.

The extent to which these classifications impact upon an individual depends on the degree of imputed seriousness of the illness. Freidson maintained that only when illnesses are regarded as serious deviations do new roles have to be taken on. Thus an illness falling in cell 5 would mean taking on the sick role and an illness falling in cell 6 requires a person to take on the 'chronically sick or dying role' and an illness falling in 4 would mean the taking on of a stigmatised role. According to Freidson, each role implies different consequences for the individual. This is because each role is managed and treated differently and the deviant must therefore behave differently in turn.

### **The value of Freidson's theory of the sick role for understanding the experience of ME/CFS**

Freidson's extended theory of the sick role appears to explain, in part, the experience of ME/CFS. For example, first, sufferers often have their claims to be 'really serious' interpreted as 'malingering' and despite contesting the medical interpretation of ME/CFS, sufferers often fail to get their illness recognised as 'authentic' and 'beyond their control'. This experience can be accounted for using Freidson's argument that illness is morally ordered and that the medical profession play a key role in the moral ordering of illness.

Second, the reports of sufferers suggest that the experience of ME/CFS can be explained using Freidson's category of the 'illegitimate illness' (with major deviations). As such, sufferers appear to be denied the privileges of the legitimate sick role as described by Parsons, yet take on the obligations of the legitimate sick role as well as extra

obligations in terms of having to defend against being labelled as malingerers or hypochondriacs.

Indeed, Freidson's theory of the sick role might provide a basic theoretical framework within which we might understand the experience of ME/CFS. However at present it is limited in a number of areas. On a pragmatic level Freidson's model is dated. Thus, the types of conditions that Freidson includes in the categories of illegitimate illness, (namely epilepsy and stammer), are now, I would argue, accepted as legitimate illnesses. In addition, the term illegitimate might be replaced with the more appropriate term 'non legitimate'. In Table 3 overleaf I suggest how an updated version of Freidson's model might look.

On a theoretical level, the limitations of Freidson's model for explaining the experience of ME/CFS are as follows. First, Freidson suggests that dominant ideas about illness prevail over individual ideas about illness. However the reports of ME/CFS sufferers suggest that this is not entirely true. Indeed, whilst I have argued that medical ideas do tend to dominate over lay ideas when it comes to defining ME/CFS, Ware and Cooper point out that, in failing to change their situation through mainstream medicine, individuals turn to other experts (medical and lay) for a definition of illness. In doing so they manage to obtain definitions that correspond with their own beliefs. This finding indicates that today, individuals have more power when it comes to the shaping of their own illnesses than Freidson and Parsons might admit. Because of this the dialectic between the members of western culture *vis a vis* the shaping of ideas about illness needs re-addressing.



**Table 3.** An adapted version of Freidson’s model of the sick role (Collett 2002, unpublished)

<i>Imputed seriousness</i>	<i>Non legitimate (The moral career)</i>	<i>Conditionally legitimate</i>	<i>Unconditionally legitimate</i>
	Cell 1 “depression, back pain, PMT”	Cell 2 “a cold, mild food poisoning”	Cell 3 “Non terminal chronic illness - epilepsy, arthritis, controlled diabetes”
<i>Minor deviations</i>	Partial suspension of some ordinary obligations; few or no privileges; adoption of a few new obligations	Temporary suspension of few ordinary obligations; temporary enhancement of privileges. Obligation to get well	No special change in obligations or privileges
	Cell 4 “ME/CFS, Gulf War Syndrome, O.P. poisoning”	Cell 5 “Pneumonia, chicken pox, measles”	Cell 5 “Terminal chronic illness - Cancer”
<i>Major deviations</i>	Suspension of some ordinary obligations; few or no privileges, adoption of new obligations	Temporary release from ordinary obligations, addition to ordinary privileges. Obligations to co- operate and seek help in treatment	Permanent suspension of many ordinary obligations, marked addition to privileges

On a theoretical level, the second limitation of Freidson’s version of the sick role is that whilst he provides a basic outline of the non-legitimate sick role, he stops there. As such he does not go into detail as to what the non-legitimate sick role entails. It could be argued that at the level of macro sociological theory there is little left to be said on this matter and that further insights into the legitimate and non legitimate sick roles can only be found in research that has been carried out at the micro level of individual experience. However, it appears that the work of Goffman (1963) on stigma (as Freidson himself suggested) and further, Goffman’s (1968) ideas about the ‘the moral

career' are of value when it comes to an understanding of the experience of the non-legitimate sick role.

In the penultimate section of this chapter I thus turn to the work of Goffman (1963, 1968) and demonstrate how it might be used to gain a better understanding of the non-legitimate sick role and hence the experience of ME/CFS. I then, in the final section, consider in more depth, the question of human agency and the dialectic that takes place between members of western culture around the shaping of illness.

### **The contribution of Goffman: Stigma and the moral career**

In his 1963 study entitled 'Stigma: notes on the management of spoiled identity', Goffman considered, first how individuals become stigmatised in everyday life, second, the impact of stigma on the individual and third, how an individual manages stigma. Each of these issues will now be discussed in turn.

#### *How individuals become stigmatised*

Goffman claimed that, in any social setting, others identify those they encounter by putting them into social categories. Social categories are frames of reference which label people not only according to structural characteristics such as occupation but also to personal attributes such as 'honesty' and 'goodness'. Goffman argued that by placing people in social categories others impute upon them a 'social identity'. He maintained that if an individual presents, in an encounter, attributes that one would expect, then he or she is categorised as a usual person. His or her social identity is that of someone who

is normal and good. Thus, if a person is in a wheelchair he or she is expected to offer a legitimate excuse for her predicament. If she does, others will impute upon her a positive social identity, for example, one where she is regarded as normal and good.

Goffman maintained however, that when an individual shows signs of an attribute which does not 'fit' a setting (for example, when there is no sign of a suitable explanation for why an individual is in a wheelchair), he or she is categorised by others as unusual and his or her social identity is seen as a deviation from what it should be. Goffman claimed that when this occurs, the individual is seen as less than normal and is discredited as a person of worth. Goffman argued that any attribute which makes a person appear strange in a social setting is a stigma. He maintained that a stigma might relate to an unusualness in physical appearance, a blemish in an individual's character or a difference in tribe, race, nation or religion. He argued however that:

In all three instances ... the same sociological features are found: an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim his other attributes have on us (1963:15).

Goffman argued that a social identity, stigmatised or otherwise, is the only frame of reference for one another that strangers have. It thus pertains mainly to public settings. He maintained however, that the identity of a person who is familiar to another is also based on the knowledge of his or her private history or biography. According to Goffman, this additional knowledge marks an individual out to the person who knows him or her as unique, rather than purely as a member of a socially defined category. Thus, in addition to knowing an individual by his or her social identity, Goffman argued that we also know those familiar to us by their personal identity. Goffman continued that



rather than being of benefit to the stigmatised individual, this additional knowledge can pose further problems in terms of identity. He argued that when a person is known to another, his or her stigmatised social identity can place a shadow on the other's conception of his or her personal identity. Thus, not only can one off events be marred by the presence of stigma but also past and future events might be re-assessed in the light of stigma.

For Goffman then, it follows that the problem of managing stigma in the daily round of social settings is influenced by the issue of whether the stigmatised person is personally known to the other(s). In addition, he argued that the management of stigma is dependent on whether the stigma is known about or whether the stigma is not known about. Goffman maintained that in cases where a stigmatising attribute is known about or may bring discredit, individuals can use techniques of information control to minimise the impact of a stigma in a social setting. This has the affect of reducing the tension between the stigmatised and others. Goffman called this technique of information control 'covering'. When a stigmatising attribute is not known about, or discreditable, he argued that individuals go to great lengths to conceal the attribute and pass as normal.

*Covering: the management of discredited stigma in everyday encounters.*

As has been seen, Goffman argued that in social settings where the stigmatising attribute is visible, or when a condition is not necessarily visible but known about, Goffman implies that others will react in a way that discredits the sufferer's social identity.

Goffman suggested that the way others will react in everyday settings will depend on whether they fall into the theoretical categories of 'normals', 'the wise' and 'the own'.

### *Social encounters with 'normals'*

According to Goffman, 'normals' are the majority of individuals who have little or no knowledge of the experience of stigma. Goffman argued that the very anticipation of contacts with 'normals' can lead the stigmatised to arrange life so as to avoid them. This results in depression and isolation. However, when stigmatised and 'normals' do enter one another's company Goffman argued that the stigmatised individual will feel unsure about how the 'normals' will identify and receive him or her. In other words uncertainty will arise from him or her not knowing which of several categories he or she will be placed in and also where the placement is favourable. Thus, according to Goffman, during 'mixed contacts', the stigmatised is likely to feel that he or she is 'on show', 'having to be self conscious and calculating about the impression he or she is making' (1963:97). In addition, Goffman argued that minor failings might be interpreted as a direct expression of the individual's stigmatised 'differentness'. Thus for example, ex mental patients are sometimes afraid to engage in sharp interchanges with their spouses or employers because of what a show of emotion might be taken as a sign of.

According to Goffman when contacts between stigmatised and 'normals' take place, 'normals' will also find the situation awkward. He argued that 'normals' will feel that the stigmatised individual is either too aggressive or shame faced and in either case too ready to read unintended meanings in to their actions. Given what both the stigmatised

and 'normals' introduce into social situations, Goffman maintained that the encounter will not go smoothly.

### *Social encounters with 'the wise'*

Goffman argued that this tension in everyday encounters is also experienced when stigmatised individuals interact with 'the wise'. However the tension will be slightly different. 'The wise' are those who either by virtue of their work or their special relationship to the stigmatised individual, are privy to the secret life of the stigmatised and sympathetic to it. Because of their informed position, 'the wise' are potential sources of support. Goffman argued that 'the wise' who have a special and close relationship to the individual can often experience the stigma themselves. In other words, he argued, they possess a courtesy stigma. Goffman maintained that in addition to providing support, the person with a courtesy stigma can also make encounters with both the stigmatised and the normal uneasy. He argued:

By always being ready to carry a burden that is not really theirs, they can confront everyone else with too much morality; by treating the stigma as a natural matter to be looked at in a direct offhand way they open themselves and the stigmatised to misunderstanding by normals who may read offensiveness into this behaviour (1963: 118).

In turn, according to Goffman, those who carry a courtesy stigma may find that they must suffer many of the standard deprivations of the stigma whilst not being allowed to enjoy the self elevation which is a common defence against such treatment. In addition, it is likely that they do not feel accepted by those who actually possess the stigma. Goffman continued that a particular source of unease for the stigmatised person stems



from the fear that the wise might revert to normal at any moment. Goffman implied that this fear is heightened when defences are down and dependency is up.

### *Social encounters with 'the own'*

In addition to 'normals' and 'the wise' are 'the own'. 'The own' are those who exist in Goffman's theoretical category of 'sympathetic others', who share the stigma. Goffman maintains that

Knowing from their own experience what it is like to have this particular stigma some of them can provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support and for the comfort of feeling at home, at ease, accepted as a person who really is like any other normal person (1969:132).

On the one hand, Goffman argued that this support can be useful for sharing experience, for talking openly about a stigma and imparting stories of how each individual came to possess the stigma. On the other hand, however, Goffman maintained that the individual might feel that the tales of their sufferers bore him or her and that the whole matter of focusing on the 'problem' is one of the biggest disadvantages of having one.

Goffman showed that whether the interaction is between 'normals', 'the wise' or 'the own', the central feature of everyday encounters when a stigma is visible or known about is 'the management of tension'. He argued that whilst a stigma is known about the individual may make a great effort to distract attention away from it. Goffman maintained that in doing this, the individual's object is to reduce tension: to make it easier for him or herself to withdraw attention from the stigma and thus maintain ease in

social situations. Goffman called this technique 'covering'. This generally refers to acting normal and may involve the use of props to conceal the stigma. Goffman maintained that covering involves 'being alive to the social situation', in other words learning the rules of social interaction which those without a stigma take for granted. An example of covering is when individuals who are hard of hearing learn the appropriate level to pitch their voices and develop elaborate techniques to deal with junctures in interaction that specifically deal with good hearing.

*Passing: the management of discreditable stigma in everyday encounters*

Goffman argued that when a stigma is not known about, the issue is not that of managing tension generated during social contacts but rather that of managing information about one's stigma. Just as an individual can cover, by concealing his or her stigma so that it will not impinge heavily on social encounters, Goffman argued that where a stigma is not known about the individual can pass. Passing refers to hiding the stigma so that it is not found out. However, unlike covering, as those involved in the social situation do not know about the stigma the individual faces the contingencies of first deciding whether to pass or not, second, being found out and third, not 'dropping him/herself in it' by disclosing information about the stigma by mistake. As with covering, people who pass will have to be alive to the social situation. Therefore uncalculated, unattended routines for 'normals' will become management problems for the person with a stigma. Goffman argued that the techniques of passing are the same as those of covering and will typically include; concealing or obliterating signs that have come to be known as stigma symbols; the use of dis-identifiers; presenting signs of the stigmatising attribute as signs of something less stigmatising. Goffman argued that the

more a person is known to an individual the harder it will be to pass. In addition he maintained that passing in front of the own or the wise will be more difficult as they are more likely to be able to spot give away signs of the stigma. Goffman continued that the opposite of passing is voluntary disclosure. He maintained that whilst it can bring great relief, voluntary disclosure is embued with risks of being misinterpreted and rejection.

### **Stigma and the moral career**

For Goffman, stigma appears frequently in everyday life (it is not just confined to Freidson's category of illegitimate illness). Thus, any person with an attribute whether it be a difference in the body, a blemish of individual character, a socially unacceptable habit or an attribute related to family heritage, ethnicity or religion, has the potential of experiencing some form of discrimination. However, Goffman (1963, 1968) maintained that whilst there are a broad range of potentially stigmatising attributes those with the same type of attribute will undergo similar learning experiences regarding their plight and similar changes in their conception of self. Goffman defined the experience of those with the same stigmatising attribute as a moral career.

Goffman illustrated the concept of the moral career by focusing on the moral career of the 'mental patient' (*sic*). He argued that, despite having wide and varying backgrounds and being diagnosed with a wide range of illnesses, people with the psychiatric label of 'mental patient', are confronted with similar circumstances and respond to these circumstances in similar ways. He maintained that since these similarities do not occur because of mental illness but in spite of it, they are a tribute to the power of social forces.



Goffman maintained that the first phase of the moral career is that through which the stigmatised person learns and incorporates the standpoint of non stigmatised persons, acquiring the identity beliefs of the wider society in general and further, the idea of what it would be like to possess a particular stigma. With regard to his example of mental illness, Goffman called this the pre-patient phase. The pre-patient phase is characterised by the discovery by the individual that 'something is not quite right'. According to Goffman, this uncertain phase is marked by apprehension, puzzlement and the fear of 'losing one's mind'. To lose one's mind is seen as synonymous with becoming a failure at being human. For Goffman, this fear arises from culturally derived and socially ingrained stereotypes, which associate certain symptoms with 'illness' and attribute moral meanings to that 'illness'. These stereotypes are not necessarily based on truths, for example, the symptoms of hearing voices, sensing that one is being followed or losing temporal and spatial orientation could signify a temporary emotional upset. However, according to Goffman, as well as prompting fear about being 'less than normal', the meanings attributed to the symptoms are forceful enough to determine that the pre-patient tries and conceals them from others and makes attempts to discover whether others have discovered them.

According to Goffman, the second phase of the moral career is that through which a person learns that he or she possesses a certain stigma and the consequences of possessing it. As has been seen, Goffman implies that others will react in a way that discredits the sufferer's social identity. In short he argues, they will often unwittingly exercise varieties of discrimination upon that person. Goffman maintained that, by virtue of their belonging to the same society, stigmatised individuals tend to hold the same beliefs about identity as the non-stigmatised and feel deeply that they are

essentially 'normal people'. This makes the 'non accepting' behaviour of others stand out. Goffman argued that as a result the stigmatised individual may feel at times as if he or she does indeed 'fall short of what he or she ought to be' (1963:18).

In summary Goffman argues;

The central feature of the stigmatised person's life ... is a question of what is often, if vaguely, called 'acceptance'. Those who have dealings with him (*sic*) fail to accord him the respect and regard which the uncontaminated aspects of his social identity have led them to anticipate extending and have led him to anticipate receiving; he echoes this denial by finding that some of his own attributes warrant it (1968:19).

Goffman continued that where possible, the stigmatised person might respond to his or her situation by attempting to correct what he or she sees as his or her failing. Goffman maintained that because often stigmatised individuals are desperate to get back to normal, they are prone to victimisation in the form of 'exposure to fraudulent servers selling speech correction, skin lighteners, body stretchers and youth rejuvenators' (1968:20).

Continuing with his example of the moral career of the mental patient, Goffman called this second phase the 'in-patient phase'. Goffman maintained that the beginning of the in-patient career is marked by the fact that, once in hospital, the patient may initially try and prevent him or herself from taking on the new identity of hospital in patient and all that goes with it. Consequently, he or she may cut off from the world, however, Goffman claimed that this is a hard act to keep up and eventually he or she settles down to the life of the institution. Goffman continues that the new inpatient finds him or herself stripped of many of his or her accustomed affirmations and satisfactions and is

subjected to a new set of experiences. These include; restriction of free movement; communal living, the authority of others and so on. At this stage, he or she begins to learn about the limited extent to which the conception of oneself can be sustained when the usual setting of supports for it are suddenly removed. Whilst undergoing these humbling moral experiences the in-patient learns to orient him or herself towards the ward system. Goffman continues that the patient proceeds to reconstruct an image of his or her life-course that he or she can usefully recount in his or her current situation. In general, a person's line concerning self brings him or her into alignment with the basic values of society.

During the third stage in the moral career, Goffman argued that stigmatised individuals experience ambivalence and oscillating feelings regarding their new identity and those that they liaise with. Goffman went on to say that as the moral career progresses, new sets of identity beliefs and practices are taken on. At this stage, Goffman argued the stigmatised individual may single out and retrospectively elaborate experiences which serve for him or her to account for his or her coming to the beliefs and practices which he or she has adopted. Goffman continued that after learning to cope with the way others treat the kind of person he or she can be shown to be, the next stage in the moral career is that of learning to pass and cover.

The final stage in the moral career is, according to Goffman, where the individual comes to feel that she should be above passing. At this stage, he argued the individual feels that if he or she accepts his or her stigma he or she will respect him or herself. Goffman argued that this final stage signifies a state of grace (or taking the institutional view).



## **The contribution that Goffman makes to an understanding of the experience of ME/CFS**

Goffman's (1963) concept of stigma enhances Freidson's (1970) model of the sick role because it begins to map out the experience of the non-legitimate sick role (with serious deviation) in depth. Freidson, for example, points out that the experience of the non legitimate sick role is such that the individual will gain few of the legitimate sick role privileges but will take on some 'especially handicapping' new obligations. Goffman provides a clear indication of first, what these new obligations are and second, the extent to which these obligations have an impact on the individual. This is illustrated in Ware (1992) and Cooper's (1997) study of ME/CFS. For example, Ware and Cooper indicate that, central to the experience of ME/CFS is the experience of stigma. Thus, on being diagnosed with the condition, sufferers state that their claims of being severely ill are interpreted as malingering. Sufferers report that they are 'disbelieved', 'made to feel guilty', 'not taken seriously', 'blamed for bringing illness on themselves', 'told to pull themselves together', 'accused of attention seeking' and said to be 'shirking work'. According to sufferers, the reaction of others towards their claims to be really 'ill' amounts to a judgement about their moral integrity. As such, the implication is that the individual is either 'lying' or 'incapable of rational thought'. This type of stigma, it appears, has an affect on relations with others during almost every encounter that takes place on what Goffman calls 'the daily round'. For example, in Ware and Cooper's studies, sufferers report that interactions with 'normals' (that is colleagues, friends or strangers) and the 'wise' (family and close friends) are characterised by tension.

It is clear then that, in his writing on stigma, the strength of Goffman's (1963) work lies in the contribution that he makes to explaining the experience of ME/CFS in terms of how ideas about illness impact on the experience of the individual. In addition to providing an insight into the experience of what Freidson (1970) calls the non-legitimate illnesses, Goffman's description of stigma also begins to explain how individuals with ME/CFS might react to the ideas that others have about their illness'. For example, Goffman's ideas about 'passing' and 'covering' during daily encounters suggest that individuals attempt to minimise the harm caused by stigma by concealing their stigmatising attribute(s). Whilst Ware and Cooper's studies into the experience of ME/CFS do not reveal anything about this aspect of stigma, it is a point worthy of consideration given that sufferers have been shown to experience stigma.

Goffman's ideas about stigma appears to be key to a basic understanding of the experience of Freidson's non legitimate illnesses and thus ME/CFS, however, it is in the concept of the moral career (1963, 1968) that Goffman makes the most significant contribution to explaining ME/CFS. This is because Goffman provides a way of looking at the 'process' of stigma. If we apply Goffman's theory of the 'moral career' to the non legitimate (stigmatised) illnesses then we have a model that considers not only the moral dimension of illness but also the dimension of time. This is of particular relevance when considering illness that is chronic and thus, goes on indefinitely.

By outlining the 'process' by which an individual becomes stigmatised, Goffman provides the following insights. First, by virtue of belonging to the wider culture, Goffman suggests that stigmatised individuals hold the same ideas about certain phenomena as others. This appears to explain the observation made earlier that, at the

onset of ME/CFS, sufferers hold similar expectations to others with regards the (legitimate) sick role. That is, they expect to have their experiences of illness justified by a medical practitioner and they expect, on being given a diagnosis, to first, gain time off work and second, gain exemption from being held responsible for their condition. In addition, Goffman's observation that prevalent ideas are held by the majority of lay individuals, regardless of their situation, might explain why individuals with ME/CFS can not believe that their symptoms are indicative of psychological illness. Indeed, as far as the sufferer is concerned his or her symptoms simply do not 'fit' the cultural idea of psychological illness.

The second important point that Goffman makes is that stigmatising ideas have a powerful effect initially on how the individual thinks of him or herself. For example Goffman argues that the individual, during the initial stages of experiencing stigma tends to believe the cultural view of him or herself and as a result, tries to correct his or her 'failings'. The third point that Goffman makes is that, as the individual continues to experience stigma, he or she learns ways of coping with the way that others treat him or her. This amounts to first, developing 'stories' which defend the moral status of the individual and second, learning the skills of passing and covering. Finally, Goffman argues that the individual learns to ignore stigma and accept him or herself for who he or she is. Again, as is the case with Goffman's theory of stigma, these insights begin to have a bearing on how persons with conditions such as ME/CFS might respond to the ways that others treat them and their illness.

Whilst Goffman makes some important contributions to an explanation of the experience of ME/CFS, his analysis of the moral career does not consider in depth the



ways in which individuals negotiate their moral status with others and the success they have. How sufferers of ME/CFS do this, is demonstrated, to a degree, by Ware (1992) and Cooper (1997). Ware and Cooper indicate that sufferers of ME/CFS, go to great lengths to consult a wide range of experts from whom they receive varying explanations for their condition and that it is through these experts that sufferers tend to move beyond stigma. As such, in seeking personal legitimation of illness through alternative 'experts' both writers show that sufferers can start to adjust to the important issue of managing their lives. The observations made by Cooper and Ware bring to mind the work of Giddens (1984) on 'structuration' and 'the dialectic of control'. Giddens argues that individuals are able to change the social meaning of things by drawing on alternative expert systems of knowledge. Giddens' theory is the subject of the final section of this chapter.

### **When individuals challenge the moral career: Anthony Giddens and the dialectic of control**

Giddens (1984) refers to the relationship between the wider culture and the individual in terms of structure and agency or action. For Giddens, the relationship between structure and action takes the form of a dialectical process. Giddens calls this process 'structuration'. Giddens argues that:

To enquire into the structuration of social practices is to seek to explain how it comes about that structures are constituted through action and reciprocally how action is constituted structurally (1976: 161).

As this quote implies, Giddens does not see structure as something that is wholly external to and constitutive of human action, similarly he does not see human action as wholly constituting structure. For Giddens, under the conditions of late modernity, structure is constantly reconfigured as lay individuals interpret the meanings of experts and experts, in turn, interpret the meanings of individuals. This idea has implications for understanding the experience of the non-legitimate sick role as it suggests that individuals actively draw on resources which allow them to reject and challenge their imputed status as 'amoral'. This is explained below.

Giddens defines structure as a 'virtual system of rules ... that members of societies draw upon' (1976:16 - 21). He maintains that rules influence behaviour at all levels of action. They are either, intensive and weakly sanctioned, such as those influencing daily social encounters, or shallow and strongly sanctioned, such as those governing how to act within the law. Giddens maintains that social rules are followed at the level of discursive consciousness (that is where individuals can explicitly give reasons for their actions), or at the level of practical consciousness (where the rule is so embedded that individuals are barely aware that they are following them). Rules can also be followed at the level of unconscious motivation (where rules are related to cognitive processes that are deeply embedded in the subconscious).

According to Giddens, social rules are derived from countless discourses. He defines discourses as the frames of meaning or interpretive schemas that are used to explain how life is and how life should be lived. At the institutional level, discourses surround for example, health, religion, politics, economics and education. Like Parsons (1951), Freidson (1970) and Goffman (1963, 1968), Giddens argues that the discourses that

influence the structuring of the social system are provided by experts, or expert systems.

He states that:

Expert systems are those which deploy modes of technical knowledge which have validity independent of the clients and practitioners who make use of them (1991:18).

Giddens maintains that doctors, counsellors, therapists, scientists, technicians and engineers, all play a key role in the expert systems of modernity. Again, arguing along the same lines as Parsons and Freidson, Giddens contends that experts gain their understanding of how things are by interpreting how the lay community sees them. He maintains that experts interpret the frames of meaning or 'first order accounts' given to phenomena by lay persons and feed their own interpretations or 'second order accounts' back into the social system. Giddens argues, however, that rather than being a one off event, this process operates continuously. In other words, frames of meaning are constantly being fed from expert system to lay system and from lay system back to expert system and so on. Giddens defines this process as the double hermeneutic. The double hermeneutic, he argues is 'the intersection of two frames of meaning', the meaningful social world as constituted by lay actors and the meta-languages invented by experts, 'there is', he continues, 'a constant slippage between the two' (1984: 374).

Giddens argues that as frames of meaning pass between lay persons and experts two things can happen. The first is that, like self fulfilling prophecies, lay persons can adopt 'expert' frames of meaning and as a consequence the expert account will become a first order account. Like Parsons (1951), Giddens maintains that when expert frames of meaning become incorporated into lay accounts of 'how life is', a homeostatic (or



balancing) loop can occur whereby the rules and thus, structures of the social system are perpetuated by the actions of the majority population.

The second possibility (and this is a particular phenomenon of late modern society), is that individuals do not 'take on' the frames of meaning that expert systems pass down to them. Giddens argues that this second scenario can occur because expert theories have multiplied to the extent that it is becoming increasingly necessary for individuals to reflect critically on what is on offer. Giddens maintains, for example, that in conditions of high modernity, expert systems have expanded to penetrate virtually all aspects of social life. They provide increasing knowledge about the food that is eaten, the medicines that are taken, the buildings that are inhabited, the clothes that are worn and the transport that is used. Because there is such a profusion of knowledge available and because much of this knowledge is often conflicting, individuals are presented with a multitude of choices or 'interpretive schemes' regarding how to live and how to act. In conditions of modernity the individual is forced to filter through the options on offer by expert systems, until he or she comes up with a theory of living which accounts for who he or she is and what he or she does.

In contrast to perpetuating the social structure via the homeostatic feedback loops described above, Giddens continues that by reflexively regulating his or her actions, the individual can either intentionally or unintentionally change aspects of the social structure. For example, an individual, having learnt about theories surrounding alternative medicine, might decide that homeopathy is more natural than conventional medicine. In choosing to take homeopathic remedies, he or she might contribute to a growing acceptance amongst the general population of complementary medicine. As

such, his or her actions become part of a causal loop whereby the rules might be affected by his or her knowledge. In this case, the practice of turning to the medical profession for advice is weakened as the individual looks elsewhere.

Structuration suggests then, that it is possible for lay individuals to block off the impact that expert systems can have on their everyday lives and challenge dominant social views. This is what Giddens calls the dialectic of control: expert systems can oppress, but individuals can become empowered by the panorama of choices on offer by expert systems. To illustrate what he means by empowerment, Giddens considers the person with a back problem (or what Freidson (1970) might refer to as an illegitimate illness with minor deviations). The person with a back problem, he argues, might go to a general practitioner. The general practitioner might then refer her to a specialist. The specialist might offer services that rectify the problem, however it might also be the case that the specialist can offer nothing to alleviate it. Giddens maintains that the diagnosis of problems to do with the back is notoriously problematic and most forms of treatment are controversial. Some medical specialists for example recommend operating on disc ruptures, yet there are studies indicating that patients are almost as likely to recover without surgery as they are with it. If the patient considers back surgery she will discover that there are different views within orthodox medicine. Some surgeons for example, favour microsurgery over more established spinal procedures.

Giddens maintains that if the patient investigates more deeply she will discover a variety of other modes of back treatment on offer, these include drug therapies, diet therapies, osteopathy, physiotherapy, massage, reflexology, acupuncture, Alexander technique and hands on healing. Underlying the range of therapies are different schools of thought,

some for example might regard back problems as pathological whereas others might regard the problem as psychosomatic and related say to stress. Giddens argues that on being presented with this confusing array of expert theories the individual might opt to inform herself more about the nature of the complaint and the vying remedies for it. In learning about the choices on offer she is then in a position to make an informed choice over what course of action to take. Giddens argues that her choice will be informed partly by her narrative of self-identity. That is, her lifestyle values might influence whether she opts for conventional or alternative therapy.

The example of the back pain problem illustrates that far from being shaped by one expert system, individuals have control over what expert systems to 'buy into'. In this sense, Giddens' work departs from that of Parsons (1951) and Freidson (1970) and adds to the work of Goffman (1962, 1968). As the example of back pain implies, in the conditions of late modernity, individuals are in a position to dismiss the frames of reference attributed to their condition by some of the experts 'out there' and draw on other forms of knowledge to make sense of their situations. In the case of the non-legitimate sick role, Giddens' theory suggests that, like the person with back pain, the sufferer not happy with the diagnosis of 'unreal' can look to other systems for an explanation that he or she finds more suitable – for example within complementary medicine. As such, the alternative expert systems on offer might serve to legitimate the illness, thereby acting as a shield against the impact of labels that threaten the moral status of the individual.

This idea leads us back to Giddens' notion of structuration and the dialectic of control. If, like the patient cited earlier, who opted to treat her back problem using



complementary medicine, individuals change their accounts of what things mean to them and thus change their actions, how far do these changes impact upon the rules inherent in the social system? In other words, by legitimising their conditions to themselves do persons with non-legitimate chronic illnesses undermine the cultural idea in the medical profession as the only authority when it comes to defining illness?

### **The value of Giddens' theory for understanding the experience of ME/CFS**

Throughout this chapter I have argued that the theories of Parsons (1951), Freidson (1970) and Goffman (1963, 1968) are limited as they do not consider in depth, first the actions that individuals with ME/CFS might take to block off cultural expectations about their illness and second, the impact that these actions might have on cultural expectations about illness. Parsons for example, implies that the medical profession are a unified voice when it comes to the defining of illness and that persons generally do not argue with the voice of medicine. Whilst Freidson, departs from Parsons by suggesting that lay ideas and medical ideas about illness often conflict, he too does not acknowledge that a variety of discourses about illness conditions can stem from the medical profession. Further Freidson suggests that medical ideas dominate, when it comes to the framing of illness and does not make much room for a consideration of how the conflict between medical ideas and lay ideas 'play themselves out'. Goffman acknowledges that individuals take action to guard against stigmatising ideas, however he is concerned with the practical actions of daily life and does not go into the rationale that is used by individuals when they defend themselves to others.

The ideas of Parsons, Freidson and Goffman, then, do not seem to explain some of Cooper (1997) and Ware's (1992) findings *vis a vis* the experience of ME/CFS sufferers. Indeed, Ware and Cooper show that there are a number of expert theories available within medicine and outside of professional medicine which the individual with ME/CFS can draw on in order to find an explanation that 'fits' their experience. As such it appears that the discourses on offer are used as a personal guard against stigmatising ideas. It is in this observation that Giddens's (1984) theory of the dialectic of control has some resonance. As such, Giddens' ideas emphasise the importance of considering not only how cultural ideas are passed down to the individual but also how the individual passes up his or her own ideas to the wider culture. This is of particular relevance to the non-legitimate sick role as, within this role, individuals appear to struggle more vehemently for a change in the definition of illness.

## **Discussion.**

In this chapter I have outlined some of the main sociological theories that might help to explain the experience of many ME/CFS sufferers. I have proposed that Freidson's (1970) model of the sick role provides a useful theoretical framework within which the experience of ME/CFS might be understood. Freidson argues that illness is categorised in terms of its perceived severity and that the degree of seriousness that is imputed to it will have a bearing on how illness is experienced. For example, individuals with those illnesses that are considered 'authentic', or 'beyond the control of the individual' are granted access to a 'conditionally legitimate' or 'unconditionally legitimate sick role', depending on the chronicity of their illness. Within each category, the privileges and obligations of the sick role are gauged according to the degree to which illness stops the

individual from functioning. (For example, chronic disease and illness that results in death fall into the category of the unconditional sick role with major deviations, whereas non-terminal conditions such as epilepsy might fall into the unconditionally legitimate sick role with minor deviations). In contrast, individuals with those conditions that are seen as 'not being authentic' or being 'within the control of the individual', are granted access to the non-legitimate sick role. Here the individual is not granted access to the sick role and takes on some new obligations. Again, the experience of the non-legitimate sick role varies according to the degree to which the non-legitimate illness stops an individual from functioning. For example, general conditions that are thought of as 'health problems that are not illnesses' might fall into the category of the non-legitimate sick role with minor deviations, whereas ME/CFS appears to fall into the category of the non legitimate sick role with major deviations.

Having outlined Freidson's model of the sick role and argued that it can be updated to include ideas about contemporary illness, I suggest that Goffman's (1963, 1968) theory of the moral career can be used as a framework within which to explain first, the experience of the non legitimate sick role and second, the actions that individuals take to guard themselves against the effects of stigma. Finally, I argue that Giddens' (1984) theory of the dialectic of control might explain in more depth, the actions of sufferers who take on the non-legitimate sick role. In addition, I propose that Giddens' theory of structuration, aids an understanding of the impact that the actions that individuals take in the face of illness, might have on changing ideas about ME/CFS.

In the following chapter I consider the literature that has a bearing on two out of the six categories of the sick role as described by Freidson (1970, see page 50). These are first,



the unconditionally legitimate sick role with minor deviations and second, the non-legitimate sick role with major deviations. My aim in the following chapter is to flesh out these roles in more depth and thus, develop a refined theoretical framework within which both can be juxtaposed and compared. My reason for isolating these two sick role categories is to arrive at a preliminary understanding of the non-legitimate sick role (and hence the experience of ME/CFS). This is important because, to date, there is a gap in the sociological knowledge surrounding this particular subject. I have chosen to compare the non-legitimate (serious) sick role with the unconditionally legitimate (minor) sick role, because descriptions of ME/CFS tend to suggest that the condition is chronic but not terminal. In this respect, the subjective experience of the conditions that fall into these two sick role categories might hold some similarities in terms of the impact on the body and everyday life. Because of this, a comparison of the social experience of both types of illness categories might highlight any differences that there are. I develop the concepts of the unconditionally legitimate and non legitimate sick role through drawing on the valuable body of knowledge that exists within the literature that has based its understanding on empirical research into the lived experience of chronic illness.

## **Chapter 3: The subjective experience of illness**

### **Introduction**

In this chapter, still focusing on how the sociological literature might explain the experience of ME/CFS sufferers, I move from theory to empirical research and consider the experience of chronic illness from the perspective of the patient. In part one, I consider the overall impact of chronic illness. Here according to the literature, chronic illness is experienced as loss: the loss of body, the loss of social action, the loss of income and ultimately, the loss of self. Within this overall experience, the meaning of loss varies depending on factors such as age and gender. Despite these variations in experience, the literature suggests that in general, major problems for the chronically ill include making sense of the bewildering symptoms, reconstructing order and maintaining control. The second part of this chapter addresses how, according to the literature, individuals attempt to make sense of illness, reconstruct order and maintain control. I conclude this chapter by proposing that the adapted version of Freidson's model presented in the previous chapter is expanded to incorporate a consideration of the key points along the illness career. This model can then be used as a framework within which to empirically explore first, sufferers' experiences of ME/CFS and second, the explanatory power of the literature.

### **Chronic illness and the loss of the body**

Within popular literature, descriptions about the impact of illness on the bodies of sufferers, are central to stories about the experience of illness. Indeed, the impact of

illness on the body would, it seems, be the best place to start in an empirical analysis of what it is like to live with a chronic condition. However, it has been argued that the body has been largely neglected within the field of medical sociology (Pinder, 1995, Kelly and Field, 1996). Kelly and Field state for example, that within the sociology of health and illness, the physical reality of symptoms such as pain, deteriorating sight, muscular wastage and incontinence, tends to be treated in two broad ways. First as an 'a priori' category which legitimately belongs to other realms of discourse: for example, medicine or biology and second, as something that is socially constructed and/or socially mediated. According to Kelly and Field however, biological facts are sociologically significant because first, they impinge directly on the self, second, they provide signals for identity reconstruction and third, they act as 'limiting' factors on social action for the sufferer (1996:251).

Whilst the extent to which sociologists of health and illness have 'ignored the body' has been questioned (see for example Williams 1996), the issues raised by writers such as Kelly and Field have sparked off a resurgence of interest in the subject. This growing interest has also been influenced by the call for sociology in general to 'bring the body back' (Pinder, 1995).

Within the emerging literature, the theory of philosopher and phenomenologist Marcel Merleau-Ponty (1962) is often referred to as providing the 'way in' to exploring the sociological relationship between the body and chronic illness. Merleau-Ponty argued that the 'lived body' is at once both objective and subjective. It is objective because it is an independent organism. For example, each of us has a body, however it is also subjective because human perception takes place from within the body and is thus



dependent on the body, for example, each of us is a body. Merleau-Ponty argued that in everyday life we constantly move between an awareness of both bodily states:

Man (*sic*) is not a psyche joined to an organism, but a movement to and fro of existence which at one time allows itself to take a corporeal form and at others moves towards personal acts' (1962:88).

For Merleau-Ponty the lived body is central to the analysis of experience as experience is mediated through it.

Building on Merleau-Ponty's idea of 'the lived body', Leder (1990) argues that in the normal course of events our relationship to our bodies remains largely unproblematic; our bodies are only marginally present, giving us the freedom to act in the social world.

He maintained:

Whilst in one sense the body is the most abiding and inescapable presence in our lives, it is characterised by absence. That is, one's body is rarely the thematic object of experience (Leder, 1990: 1).

Leder argues that whilst we act through our bodies we are often unaware of them. Thus, we use our senses constantly but we are not aware of the physical act of doing so: we are not aware of the eye seeing, or the mouth tasting.

Leder continues however, that when the body becomes damaged, for example, through pain, disability and death, the normal mode of bodily absence becomes profoundly disrupted. Under such circumstances the body becomes central to experience. He argues that in the case of bodily damage, the body does not simply reappear, rather it appears in a 'dys' state: the prefix 'dys', signifying 'bad', 'hard' or 'ill'.

An illustration of bodily dys-appearance can be found in the work of David Locker (1983). In his study of the experience of rheumatoid arthritis, Locker cites Mrs T. who states:

Whenever anybody has asked me to explain the pain my description has not been on the pain itself but what it does to you; the loss of energy because all your energy is concentrated on trying to cope with it, the tiredness and the weariness and the monotony of the continual, not necessarily violent but the continual nagging pain that's there when you eventually go to sleep. You wake up and the first conscious thing that is there you think "O God", and you know its going to be with you the whole day. (Mrs T. suffering from rheumatoid arthritis, quoted in Locker, 1983:15).

The quote from Mrs. T above illustrates clearly how chronic illness, or more generally any form of bodily damage, brings about the loss of 'normal bodily functioning'. To use Leder's terminology, for Mrs T. the body is no longer absent but present, dys-functional and demanding.

Leder's idea of bodily dys-appearance is developed by Williams (1996). Like Leder, Williams argues that in the normal course of everyday life we both feel and are embodied, that is, our bodies are there in the background, working as expected and largely unproblematic. However, when illness, or disability strikes we become dys-embodied. Williams describes dys-embodiment as a phase during which the body becomes a 'thing' and alienated from the self. In other words, according to Williams, the body emerges as an estranged presence in the life of the sufferer. This, he maintains, brings about the resurrection of dualism in a person's life. Examples of this imposed dichotomy between the body and the self can be seen in both academic and lay literature on chronic illness. For example, describing the experience of chronic pain, Mariet Vranken writes:

Through the unpleasantness of pain, the body and the 'I' instantly seem to have parted company. For the sake of the integrity of the personality we make an 'it' of the body and an abstraction of pain ... pain makes us believe that we can cut ourselves off from the body. Through rationalising pain 'I' and myself become two separate entities (1989:442).

Similarly Carol Roughton an ME/CFS sufferer writes:

Mind and body no longer work together  
as one  
But fight continually  
like squabbling children  
pulling in different directions.  
Mind is the busy active one, racing ahead,  
full of doing and opportunities to be grasped,  
and life  
But body moves to the beat of a different drum,  
plodding wearily along  
but never keeping up.  
Lagging behind like a weary child  
who doesn't want to go there anyway  
And feeling so very much older  
and slower  
than the rest of the person  
that is me.

(‘Mind and Body’ by C. Roughton, private correspondence, 1998).

William's idea of dualism or dys-embodiment, moves the focus beyond the practical description given by Leder (1990) and draws attention to bodily loss at a deeper level of personal meaning. Within this field of study, there are a number of academic books and articles that document the subjective experience of the loss of bodily functioning. As suggested by Williams (1993) and illustrated in the quotes above, this literature suggests that when the body becomes damaged the relationship between the body and the mind becomes conflictual. Thus, shock, confusion, grief, bodily hate, uselessness and the feeling that the damaged body has betrayed or disobeyed the individual are common themes. Thomas (2000) argues for example:



The chronic pain experience had profoundly altered patient's perceptions of their bodies. Once familiar and predictable they were now baffling ... the body was seen as damaged, inert, useless in contrast to the body that was previously active and productive (p. 690).

Similarly Kleinman writes:

The fidelity of our bodies is so basic that we never think of it – it is the certain grounds of our daily experience. Chronic illness is a betrayal of that fundamental trust. Life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion, shock, anger, jealousy, despair (Kleinman, 1988: 44 – 45).

For Vranken (1989), the major consequence of dys-embodiment is that the very stocks of knowledge upon which action is based become destabilised. That is, the individual becomes aware that, far from being predictable and meaningful, life is characterised by uncertainty. Vranken likens this experience to being in an existential vacuum. This experience of the loss of meaning is also articulated by Buytendijk (1962: 27) who writing about the experience of pain argues:

Pain ... teaches us how un-free, transitory and helpless we really are and how life is essentially capable of becoming an enemy to itself.

Arguing along the same lines, Murphy (1987) likens the onset of chronic illness to a form of entropy whereby everything that was known becomes fragmented and dispersed into chaos. Similarly, talking about his own experience of chronic pain, Frank (1991) argues that pain is one of the first experiences that an ill person has of being cast out.

Arguing along the same lines as Frank (1991), Murphy (1987) and Vranken (1989),

Charmaz (2000) summarises the personal experience of bodily loss as follows:

Order becomes disorder, the controllable becomes uncontrollable, the understandable becomes the unfathomable... the surge of extraordinary

events usurps an ordinary flow: life is out of control. (Charmaz 2000: 280)

### **Chronic illness and the loss of social action**

If having a damaged body is the first form of loss in chronic illness, the related impact of chronic illness on the ability to act in the social world is the second. As a consequence of chronic illness or disability, the routines of daily life become severely restricted. Physical stamina, for example, might become inhibited, impacting on the ability to walk, lift and concentrate. This, in turn can affect work, education, family responsibilities, leisure activities, friendships and relationships. An illustration of the loss that this engenders can be seen in the following quote:

Being in prison all day would be a lot better than having ME. At least you could read or watch television ... my girlfriend left me. My friends moved out. It has ruined my life (Male ME/CFS sufferer, quoted in the Harefield Gazette, 1997:21)

Bury (1982) defines this upheaval in the lives of the chronically ill as 'biographical disruption'. This is a useful term as, not only does it make the important point that chronic illness puts a brake on life's plans, it also draws attention to the fact that the experience of the loss of social action will vary depending on the individual and thus on factors such as, age, gender, ethnicity and socio-economic background. Despite Bury's use of the term however, little systematic research has been carried out in relation to these differences. Indeed, sociological accounts tend to reflect the general experiences of white males and females aged twenty and over. As a result, as I will indicate below, there is a rich literature on the impact of chronic illness and disability on a range of experiences particular to what might be defined as 'general adulthood'. Yet, in contrast,

there is a lack of writing about the experiences particular to the stage of early adulthood or (roughly speaking), late teens. This is quite an exclusion given first, the numbers of individuals of this age with chronic illness (and particularly with ME/CFS) and second, the difference of this transitory phase of life in comparison to the stage of general adulthood.

### *The impact of chronic illness on early adulthood*

For the individual in his or her late teens, social action is often based around attending educational institutions and/or starting work. At this stage individuals are thinking about, as Jones and Wallace (1992) put it, becoming ‘independent citizens’. On their minds might be leaving home, finding a partner, earning a secure income and gathering knowledge about the world. Peer groups or friendship networks are particularly important at this stage during the life course, offering places to escape from the gaze of adults and explore emerging independent personalities (Boice 1998).

Chronic illness however, disrupts the routines of everyday life. As the person at the beginning of adulthood falls back into his or her body, he or she often has to drop out of education or work, leave his or her friendship networks and return to his or her family. As life moves on for others around the young adult, expectations of him or her self are dashed: independence appears to be swapped reluctantly for dependence as he or she becomes trapped in his or her body and unable to ‘flee the nest’. The literature suggests that with dependence comes the realisation that future dreams might not be possible:



I had to reappraise my career prospects ... and I was upset at the thought of perhaps having to give up my independence .. but my main reaction was that I would never get married now - I thought that even if someone wanted me I would be too much of a burden to them. (Female multiple sclerosis sufferer, quoted in Robinson, 1988:56)

My dad thinks I'm \*\*\*\*! Right before camp he said I'd never be able to earn money like my brother and I'll have to live off the government. It makes me feel like I'm so much less than he is! ... my brother in law let me drive a tractor but he won't let me drive a car. He doesn't think I'm worth a damn (Male cerebral palsy sufferer, in Boice 1998:929)

Such accounts show the salience of typical male and female identities in chronic illness. In particular both accounts indicate the loss of self worth that not being able to conform to such identities entails. Further, both accounts suggest a perception that in the eyes of others, the person with a chronic illness is seen as a burden, is overprotected and generally as invalid.

### *The impact of chronic illness on adulthood in general*

Whilst for the individual in what I have termed early adulthood, chronic illness can put a stop to the daily activities of work, education and social relationships with peers, for the older individual, chronic illness brings with it a different set of consequences. These are likely to relate to one or more of the following: long term relationships with a partner or spouse, parenting, work and (as mentioned above) social contacts such as wider family and friends. These areas are better documented within the literature, so it is possible to consider briefly, the impact of illness on each area in turn.

*Relationships with a partner or spouse.*

Robinson (1988) argues that within relationships the expectation is that of mutual reciprocity. This implies that social roles are based on the equal input of both persons. Robinson argues that when a partner becomes chronically ill however, social roles within relationships have to be restructured. The restructuring of social roles is illustrated by Locker (1983) who found that when one person becomes chronically ill, the healthy partner takes on extra responsibilities. These might include working longer hours in order to provide an income for two persons, doing domestic chores and being involved in the personal care of the chronically ill partner.

Robinson (1988) argues that the restructuring of social roles within a relationship undermines the ill individual's sense of their reciprocal value in a relationship. However, the sense of not being able to contribute is not only confined to the inability to provide to the domestic maintenance of the household. The inability to provide companionship also appears to be a source of loss:

I think deep down what has worried me is that I have not been able to do the things with him that I should normally have done. To go out and about a lot you know (Female ms sufferer quoted in Robinson, 1988:46).

Strauss (1984:61) argues that in many cases individuals are unable to shoulder the responsibility of their changed partners and opt out 'by divorce, separation or abandonment'. Whilst Robinson (1988) refutes this, the implications are that the onset of chronic illness for those in partnerships brings about, amongst other things, the fear of ceasing to be the person that one's partner wants to be with.

## *Parenting*

For those individuals with children, chronic illness or disability has, as might be expected, been shown to impact severely on the role of parenting. In his study on the experience of rheumatoid arthritis, Locker (1983) found that the experience of parenting with chronic illness was different for males and females. For the females in his study, parenting was problematic because, the everyday organisation of the household was interrupted by the disability. Thus tasks such as cleaning, shopping, doing the laundry and cooking became hard to keep up with and fulfilling the parental role in terms of taking the children out, having their friends round, going on family holidays and attending school meetings became increasingly impossible. Further, for some, the symptoms of the illness caused them to be short tempered with their children and others around them.

Locker found that the main concern for the men in his study regarding parenting was largely confined to their inability to share activities with their children. Such activities had to be abandoned or given over to others. These problems were particularly acute when the children were too young to understand their father's disability or attempts had been made to conceal the disability from them. Locker argues that the inability to participate in any of these kinds of activities not only excludes the disabled person from one face of family life but it also underlines the extent of his or her limitation. In addition, he states that parents with chronic illness often feel inadequate and guilty. They feel guilty for first, not being able to provide their children with what they need and second for placing extra responsibilities on their children and those that are asked to



help care for them. Not surprisingly Locker concludes that parenting with a chronic illness can cause a considerable amount of distress.

### *Work*

Traditionally, as argued above, it has been the role of the male in the household to earn the money. Indeed Giddens (1997:307) argues:

For men in particular self-esteem is often bound up with the economic contribution that they make to the maintenance of the household.

Similarly, Simon Williams (1993) argues that work is a major source of value and identity and the loss of work may have profound implications for the individual both at the practical and symbolic levels. In a study of the impact of chronic obstructive airways disorder (COAD) he cites Mr T. who, on losing his job because of illness said:

I felt as if my whole world was crumbling around my ears ... you can't do anything without work as far as I'm concerned. You feel out of the main stream of society, a reject, bleedin' (*sic*) useless, on the scrap heap can't do nothing. 'Cause you're not pulling your weight, you're not doing nothing in society are you? You're dependent on others all the time, the state, your family. You lose your independence and self respect (Male with COAD, quoted in Williams, 1993: 91).

The literature suggests that the impact of the loss of work on identity is not just confined to the male breadwinner however. For both male and female the loss of work signals the end to potential careers:

I had planned to combine motherhood and a career ... I am not sure if I have the stamina to do that. (Female ms sufferer, quoted in Robinson, 1988: 35).

Illness has permeated my life and had a profound effect on me .. it has forced me to be less ambitious in career terms. (Female, ms sufferer quoted in Robinson, 1988: 36).

Locker found that both females and males experienced job loss acutely and few were content to settle down to the role of being at home. Men tended to talk about boredom, loneliness and frustration while the women talked about problems of independence, identity, achievement and involvement. Both reported being depressed and miserable on giving up work:

I didn't want to stop work but it helped ... but after being used, you know, you get used to all the people in the office, you know you have your laughs and your jokes and you're seeing people everyday, then all of a sudden I was thrown back home and stuck indoors just sitting there on my own (Female ms sufferer, quoted in Robinson, 1988: 114).

### *Social life*

As with work, Williams (1993) argues that a common experience in the lives of the chronically sick and disabled concerns the decline of social life. In his study of persons with COAD, Williams found that the symptoms of the illness often limited the amount of time that sufferers could go out and meet others, Mr Riley for example argues:

Well I've got no social life these days it is non existent. I get out and about very little these days ... I'd put it down to being as I can't get about very well and the limitations and restrictions of the illness where can I go like and what can I do? (Male, COAD sufferer, quoted in Williams, 1993: 101).

In addition to the restrictions posed on social life from the physical inability to 'get out and about', another reason for a dwindling social life is that having limited energy and restricted movement requires the chronically ill person to prioritise the activities in

his/her daily life. The main priorities are those that are essential for everyday survival such as managing treatment regimens or maintaining some organisation in the household. As a result, the chronically ill person does not have adequate time to maintain his or her past relationships. Another significant problem in maintaining social contacts is the problem of what Kelleher (1988) terms the loss of spontaneity. In his study on diabetes, Kelleher found that when talking about social events, his respondents often stated how arrangements had to be made beforehand. Activities for example had to be carefully planned and made conditional upon how one felt on the day.

Williams (1993) maintains that faced with such problems, the demise of social life in the wake of illness may generate a profound sense of loss. As Mr O Riley stated:

Oh I miss it, I miss it, very badly I miss it. I mean take going down to the pub, its not that I used to drink, but it was the company, you know you could wander down there of an evening or a weekend and have a few drinks with your mates, spend a couple of hours or so there, you know I miss that very badly. Nowadays there's nothing to do but look at that television. (Male COAD sufferer, quoted in Williams, 1993:103).

### **Chronic illness and the loss of material security**

In addition to the symbolic meaning of not working it is worth noting the obvious fact that the loss of work brings with it the loss of income and the very real fear of not being able to survive. Both Williams (1993) and Locker (1983) refer to the extreme worry caused by this. Their respondents, both male and female, talk about the constant worry about how they are going to live next week and how they are going to afford to fix things when they go wrong. They also speak of having to cut down, 'tightening the belt' and 'just managing to get by'. In particular, the interviewees state that they have to



prioritise what is the most important expense and go without other things in order to pay for them. Both Locker and Williams add that at the same time as losing money, many individuals with chronic illness also incur additional expenses. For example, these include, the need to buy medications and pay for certain tasks to be done like cleaning or shopping. This puts an added pressure on the weekly budget, so much so that Locker found that many persons attempt to carry on in their employment, regardless of the detriment of their diminishing health.

### **The world of chronic illness: loss of body, loss of social action and loss of self**

For Charmaz (1983), as chronically ill individuals are forced to retreat into their bodies, the opportunities for having valued images of their selves fed back to them begin to wane. Under such conditions, Charmaz argues that, illness structures the world of the chronically ill and shapes their self-concepts. According to Charmaz, the self-concepts of chronically ill persons will be negative in a society that values independence and activity. Indeed she maintains that the physical restrictions posed by chronic illness are often seen as failings. Charmaz (1983) argues that the idea of the failed self can be perpetuated by the individual and by others.

At the level of the individual, as has been seen above, Charmaz maintains that persons with chronic illness often feel that their condition has rendered them useless as workers or as partners within a relationship, or as parents. Charmaz maintains that when individuals discredit themselves, feelings of guilt and self-blame can follow:

Women sometimes bemoan the unclean house, unsorted laundry, uninteresting meals etc. (*sic*). When surrounded by the visible symbols of their present level of functioning and when compared negatively to past levels and their personal performance standards these individuals suffer tremendous amounts of self blame and guilt ... the inability to control one's self and the life in ways that had been hoped for clearly may lead to self discreditation. (Charmaz, 1983:187).

At the level of having the self-discredited by others, Charmaz maintains that, regardless of whether an individual has an obvious stigmatising impairment, many individuals with chronic conditions suffer discreditation related to their decreased participation in the normal world.

Charmaz maintains that discreditations of the self can arise from the unmet expectations of significant others. Such expectations range from sexual activity, to household tasks and companionship. For Charmaz, others are most likely to feel as if their expectations have not been met if they do not recognise or understand the affects of their partner's/parent's/child's/friend's illness. In such instances she argues others frequently pressure the ill individual to remain functioning as before and define the reason for them not functioning normally as poor motivation. Others, she argues, might see the reason for not fulfilling one's obligations as a deliberate attempt to undermine them.

Charmaz argues that discreditation of the self can also occur when the everyday activities that persons used to partake in before they became ill, get taken over by others. Examples of this are when a parent is replaced by a housekeeper and a childminder, when a senior partner of a company is replaced by his or her junior or when a person has to be bathed and dressed by strangers. Charmaz argues that it is at this point that

individuals with chronic illness begin to accept their discredited selves and see themselves as permanent failures and burdens to others.

Charmaz maintains that becoming a burden demeans identity because under such circumstances ill persons have little power over their situations and the quality of their lives. Indeed, she maintains that the sense of becoming a burden affirms immobility and as such illness becomes the major source of social identity: an identity that stands in symbolic contrast to the ways which individuals normally like to see themselves. Further, the sense of becoming a burden brings with it an ever-increasing feeling of guilt and shame at burdening others, feelings that according to Charmaz, worsen as individuals see their carers working increasingly harder and becoming increasingly more tired as time goes by.

### **Learning to live with loss and regaining a sense of self: the illness career**

So far I have suggested that according to the literature, the experience of chronic illness is characterised by the loss of bodily functioning and consequently by the loss of functioning in the social world. This, it has been argued, can lead to the loss of self, whereby persons suffering from chronic illness see themselves as useless and burdens to others. However, to conclude that the permanent plight of the chronically ill is one where the body is the 'victor' over the self would be misleading. As such, the sociological literature departs from the idea of the sufferer as the passive victim of circumstance when it considers the experience of chronic illness over time. In particular writers such as Strauss et al. (1984) and Bury (1998), have argued that the experience of chronic illness can be seen as a series of stages or transitions that individuals go



through. As sufferers pass through each consecutive stage of illness it is suggested that in many cases uncertainty and confusion can give way to an understanding and acceptance of the illness and consequently to the development of ways of living a meaningful life with illness. In short, the literature suggests that, (to borrow from Kleinman, 1988), it is possible for individuals who find themselves initially in an unfamiliar landscape to find a map with which to navigate.

Charmaz (2000) argues that the experience of chronic illness involves a mission on the part of the actor to regain control. Thus she states:

Becoming ill poses three major problems (1) making sense of the bewildering symptoms. (2) reconstructing order and (3) maintaining control over life. Making sense of the symptoms spurs a quest to define illness. Reconstructing order leads to efforts to manage illness and regimen ... maintaining control over life derives from concrete daily action and regaining continuity and coherence of one's self and one's world (2000: 280)

The aim of the final section of this chapter is to show how, over time, according to the literature, individuals with chronic illness can regain control. It is in this section that the literature referred to in the previous chapter: the work of Parsons (1951), Freidson (1970), Goffman (1968) and Giddens (1984) applies. This is because 'the experience of illness' writers demonstrate how, at the level of individual experience, pathways through particular illnesses are influenced by cultural expectations and norms. Thus, the socially influenced actions of the individual and others, in particular members of the medical profession, are shown to play a key role in influencing how persons come to understand, account for and manage their conditions. It appears that successful interactions with others result in a less complicated transition from the world of what Goffman refers to as 'normals' to the world of chronic illness. However the literature

implies that when interactions are problematic, individuals with chronic illness find it more difficult to make sense of their conditions. Using the three problems stated by Charmaz (2000) above as headings, the literature relating to the pathway through illness is described below.

### *Making sense of the symptoms*

The impact of cultural expectations about health and illness on what Charmaz calls 'the mission to gain control' can be seen right from its onset. Robinson (1988) for example, argues that initially, the experience of illness is influenced first, by the nature of the symptoms, second by the mode of onset and third, by the meaning that the individual attributes to his or her symptoms. Robinson maintains that some symptoms might occur all of a sudden, for example in the case of an epileptic attack, or a stroke, in which case the cultural interpretation of the symptoms as 'illness' is often prompt. However, the symptoms of other conditions are more insidious and are often perceived of initially as general everyday tiredness or run of the mill aches and pains.

In cases where the symptoms are obviously signs of illness or disease, the 'first step' in making sense of one's condition, is to seek a formal diagnosis from the medical profession. However, the literature suggests that due to the ambiguous meaning of the symptoms, for many, this initial move to find out what is wrong can be delayed. In the case of multiple sclerosis, Stewart and Sullivan (1982: 1399), for instance, indicate how sufferers tend to 'carry on regardless' putting their symptoms down to 'ailments, minor illness or symptoms of other treated illnesses, injuries or pregnancies'. Similarly, in his study of the experience of the same illness, Robinson (1988) shows how individuals

interpret their initial symptoms as, 'getting older', or 'a pulled muscle' for example.

One respondent states:

I think it started with me bumping into things with my left leg – then tripping up and falling over and a peculiar sensation in the soles of my feet ... [however] I'd stand at the foot of the stairs and tell myself "there's nothing wrong – it's all in the mind". Then up I'd go and as was becoming usual practice I'd trip and fall ... I would say "I'm not doing it now- there's nothing wrong – it will pass". But over and over I would go, again and again – more bruises – and if anyone offered assistance I would be angry and aggressive. (Female ms sufferer, quoted in Robinson 1988: 16)

According to the literature, for those whose symptoms are easily attributable to the aches and pains of everyday life, the delay to seek medical advice has an important consequence with regards to two areas. First, the individual will continue to be unsure of the seriousness and nature of the symptoms and second, he or she might face unfavourable reactions from others if the symptoms interfere with the activities of daily life. This is recognised by Bury (1988) who after studying the experience of persons suffering from rheumatoid arthritis maintains that in responding to their symptoms, individuals experience a situation of 'meanings at risk'. By this Bury means that individuals have to constantly test the meanings attached to their altering situation against the reality of everyday experience. Bury (1988) claims that this is a situation of risk because individuals cannot be sure that their own developing perceptions and definition of the situation will be shared by others. Bury maintains that calls for help, for example, may turn out to produce unwanted dependence and calls for sympathy run the risk of rejection.

This situation of 'meanings at risk' is illustrated by Robinson (1988) who shows that patients with multiple sclerosis report being at risk of having their symptoms interpreted



as signs of mental illness, malingering or even being drunk by those who do not know that they are experiencing unusual symptoms. Robinson continues that even with those 'in the know', 'any claims which allow people social exemptions are likely to be scrutinised by others' (Robinson 1988:113).

The length of time that persons spend in what might be called the pre-patient phase can vary. Studies have shown that this period can last for years (Stewart and Sullivan 1982, Locker, 1983). Indeed, it is generally demonstrated that the realisation that the symptoms might be more serious than originally thought only occurs as symptoms begin to interfere more and more with everyday life. Thus, with reference to multiple sclerosis, Robinson concludes that:

It appears to be their continual persistence over long periods of time, their continual recurrence, an increase in their perceived seriousness, or the gradual appearance of other symptoms, which precipitate the quest for external help (1988:16).

Similarly, arguing about illness in general, Irving Zola (1973) argues that there are five triggers that prompt the individual to seek professional advice regarding initial health problems. The first is the occurrence of an interpersonal crisis. For example, a car accident, a family argument or work pressure. The second is 'the perceived interference with special and personal relations'. Examples of this are when the symptoms prevent someone from socialising with friends without feeling discomfort or embarrassment, or when the sufferer worries that significant others might notice and respond badly. The third trigger is 'sanctioning'. This occurs when someone else takes the responsibility for action over the symptoms. The fourth trigger refers to the 'perceived interference of the symptoms with work or physical activity' and the final trigger is, according to Zola,

the 'temporalising of symptomology'. This refers to the setting of external time criteria. For example, when an individual says 'if it's still the same next Tuesday I will make an appointment'.

### *Entering the medical system*

As suggested above, according to the literature, the first step in what Charmaz (2000) refers to as 'the mission to gain control' involves seeking medical advice. For many individuals the initial consultation with a member of the medical profession leads quickly to a diagnosis of illness. This is often the case for the majority of conditions where scientific testing can detect the presence of disease. The literature suggests that despite the often traumatic experience of being told that one is chronically ill, the diagnosis of illness has three major implications for gaining control. The first of these is that much of the uncertainty as to the nature of the symptoms is brought to an end. Related to this is the second point, that a diagnosis also offers 'something to go on'. These two outcomes of gaining a diagnosis are recognised by Kelleher (1988:17) who in his account of the experience of diabetes argues:

Diagnosis may bring relief, as for the first time they (sufferers) have an explanation for the worrying symptoms ... once diagnosed the diabetic must start to come to terms with the requirements of monitoring and treatment.

Similarly one of Locker's respondents claims:

I went to the doctor. He said you must go to the hospital - you've got rheumatoid arthritis. Funnily enough I was glad because I thought "I can't keep losing so much weight and looking so dreadful". Once I knew I thought that I could contend with it. I knew what I was battling with (1983:57).

The third outcome of gaining an official diagnosis of illness is that in many cases, individuals feel that others will now believe that they are ill: they are not making it up.

Thus, Robinson claims:

The diagnosis formally incorporates the symptoms within a legitimising framework, thereby externally validating the status of an individual as a sick person. A medical diagnosis provides a solution to the cognitive problem posed by signs and symptoms; they are thereby legitimated and explained as surface manifestations of an underlying pathological process. (1988: 47).

As such, the diagnosis can be seen to put an end to the meanings at risk described above. Evidence for this can, again, be seen in Kelleher's (1988) study of diabetes. For example, one respondent claims:

It was a good thing really that they did find out. It was starting to cause a bit of animosity, with the tiredness affecting ... It wasn't very nice. You'd come home from work and the next minute you were away [asleep] and the missus (*sic*) getting very upset ... but once she found out it sort of helped things, you know. (Kelleher, 1988: 17)

### *Exceptions to the rule*

Whilst for many, this sequence of events might be the norm in the mission to gain control in chronic illness, the literature implies that there are two exceptions. The first is that for some individuals the length of time in between the initial consultation with GPs and diagnosis might be lengthy. The second is that whilst a diagnosis might provide a meaning for the symptoms, in terms of a medical explanation for their cause, prognosis, treatment and management, it is not always the case that diagnosis means that others will believe that the individual is ill. Each of these exceptions appears to cause



particular problems with regards to gaining control in the face of the losses engendered by chronic illness.

Information regarding the experience of waiting a long time for a diagnosis can be found in the work of Robinson (1988) on multiple sclerosis and Locker (1983) on rheumatoid arthritis. Robinson claims that diffuse and intermittent symptoms, particularly those which can bear a variety of other medical interpretations are not likely to be quickly located by doctors as indicative of disease. Locker argues that the consequences of this are that, in many cases, doctors do not produce explanations that justify the personal experience of discomfort. Instead, he maintains that persons may find themselves labelled in a variety of derogatory ways. This situation is cognisant of the situation of meanings at risk described by Bury (1988). However, when the medical profession become involved, it appears that in addition to putting oneself at risk of having ones interpretations of illness dis-confirmed by disclosing the symptoms to others such as family, colleagues and friends, the individual also puts him or herself at risk by disclosing his or her symptoms to a GP or hospital consultant. Given this it is perhaps not surprising that Locker (1983) argues that individuals who fail to gain a diagnosis during the early stages of their illness careers may also come to doubt the reality of their increasingly problematic symptoms.

Robinson (1988) maintains that initial non-diagnosis or mis-diagnosis marks a new phase in the relationship between physicians and patients. He claims that, from a broadly consensual relationship, there may develop one of mistrust and conflict, as patients become dissatisfied with the physician's understanding of their condition. According to Robinson (1988), one consequence of this is that the patient becomes

involved in a quest to find medical explanations of the situation which are congruent with his or her own view of its seriousness and origins.

Robinson continues that this endeavour to solve the problem of what is wrong can involve a lengthy phase of medical encounters that can be either doctor initiated or patient initiated. He likens this phase to being on a 'medical merry go round' and illustrates the experience of this by referring to the case of Ruth, a multiple sclerosis (MS) sufferer who underwent a series of hospital consultations after she found that 'putting her feet up' did not work. Ruth states:

By August I was afraid to walk down a slope and found an incline or stairs difficult. So once again I went to see my GP who arranged an appointment at the neurology department at my local hospital. Early September found me at the hospital for an initial test, and after answering a few questions and walking a few steps I was staggered to be asked to arrange for a week's stay in hospital for further tests. So a week later I was back again, ... then followed lumbar puncture, brain scan, myelogram, blood tests etc. .. I was sent home with the knowledge that I had an infection in my spine. After hospital followed a daily injection of ACTH ... there followed two weeks without injections and a further report back to hospital. When I saw the specialist he thought I was much better ... and could return to the office. This I did, working few hours, but found this even together with the travelling too much, so once again I sought medical help. (Ruth, suffering from MS, quoted in Robinson, 1988: 23).

As implied above, Robinson maintains that the main strategy to overcome the perceived discrepancy between medical explanations of symptoms and the patient's own experience of symptoms is to 'seek a satisfactory endorsement using the powerful legitimising role of the medical profession' (1988: 23). Robinson continues that the aim of drawing on the expert system of medicine is to first ensure greater congruence between patient perceptions and professional judgement and second to maximise the opportunity for gaining access to the sick role via family friends, and relatives. With

regards the latter point, he maintains that the negotiation of such a role may be vital in the establishment of a tolerable personal and social life.

Robinson maintains for those who have spent a long period of time on the medical merry go round, the discovery of a diagnosis may be an event simultaneous with formal medical confirmation, however he maintains that the discovery may precede the latter. In an earlier (1983) study of the experience of MS he found, for example that approximately a third of those with multiple sclerosis had discovered the diagnosis before being told by a medical advisor. Similarly Elian and Dean (1985) document how individual entrepreneurship as well as chance encounters can lead to the discovery of what is wrong before an explanation is given by a professional. They maintain for example, that sufferers may draw parallels between their symptoms and the symptoms of friends or acquaintances with multiple sclerosis, or from textbook descriptions, or from interviews, conversations or reports on radio, television or in the newspapers.

Needless to say, for those individuals for whom diagnosis takes a long time to receive it appears that the relief described above is magnified. This is illustrated in the quote below, where after years of uncertainty the patient appears to be literally 'jumping for joy'. This is because first, she perceives that that her integrity has been restored: she has not been imagining her symptoms and second she can now prove to others that her symptoms are not a figment of her imagination:

“You have multiple sclerosis”, the doctor at the hospital said. I couldn't wait to get out of the outpatients' department and into the car. Once in the car I turned to my husband and said gleefully “thank God, I now know what's wrong with me, I'm so pleased”. You see I had been under that hospital for two years had test after test and been in and out a couple or so times and on my two monthly appointments had always asked



“what’s wrong with me?” Only to be told, “We are not sure. We have to be certain”. So I asked to be told what I hadn’t got – to no avail. Now I knew and could tell people who asked what was wrong with me – I was not imagining things or going mental – Yippee!’ (Female MS sufferer, quoted in Robinson 1988: 32).

It was argued above that there were two exceptions to the normal sets of events that tend to follow the initial consultation with the doctor. The first (that diagnosis can take a long time), has been described above. The second exception, it was suggested was that despite being diagnosed with an illness, it can be the case that others still tend not to believe or understand that an individual is actually unwell. Evidence for this can be found in the work of sociologists who have documented the experiences of individuals with conditions that are associated with the category of health problems that are not considered illnesses (Cornwell, 1984). Thus Locker (1983), writing about the experience of rheumatoid arthritis and Williams (1993), in his study of the experience of Chronic Obstructive Airways Disorder (COAD) both found that despite their diagnoses, the severity of both illness was little understood by others. Drawing on the work of Friedson perhaps, Locker states:

One problem common to many of the respondents is that of legitimation – having others accept the reality of their distress and the inevitability of the constraints imposed upon them. This requires others to define their complaints as valid indicators of subjective experiences and their incapacity as disability created by a chronic condition and not a wilful deviance ... the problem is not, as Parsons’ original discussion might suggest, confined to the pre-diagnostic stage of the disease; it is never wholly resolved by the provision of a clinical label ... doctors and other accredited gatekeepers may separate the disabled from the deviant during the diagnostic process but family, friends, colleagues and strangers, while accepting the person’s status as disabled, continue to monitor his or her performance in that role. The meaning of diagnosis fluctuates, being negotiated and renegotiated over time (1983: 131)

Similarly Williams argues that:

The image of a wheezing, coughing, yet not apparently disabled older man elicits little sympathy or understanding particularly if it is thought to be self induced (for example as the result of smoking). The various categories and labels linked to the condition do little to establish the legitimacy among others. Whilst a respiratory condition such as cystic fibrosis occurring earlier in the life course, has become the centre of considerable scientific, medical and public concern, sufferers of COAD continue to suffer in silence. The continuing moral dimension of beliefs and practices surrounding different health states is thus underlined (1990: 114)

As with initial mis-diagnosis or non-diagnosis, the consequence of being diagnosed with a condition such as COAD or rheumatoid arthritis appears to be that sufferers continue to experience 'meanings at risk'. This is acknowledged by Williams (1993) who continues that, for the COAD sufferer, the conditions of uncertainty and meanings at risk experienced by sufferers in the pre-diagnostic stage continue to be experienced post diagnosis. Thus many of his respondents felt that the legitimacy of their condition was either overtly or covertly challenged by others and that there was a general lack of understanding regarding the reality of their predicament.

### **Reconstructing order**

According to Charmaz (2000), the second problem of chronic illness is reconstructing order, this involves managing the illness and illness regimen. This can be seen as the second step towards gaining control in chronic illness because, as suggested above, only when an illness has been defined as such, can it be managed. Bury (1991) argues that once individuals are diagnosed with a condition they first begin to make sense of it to themselves and others through learning about it. This involves collecting information regarding its aetiology, its prognosis, its treatment and its management.

The most immediate source of information is the GP or hospital consultant. The search for information after illness has been diagnosed is not just confined to visiting the doctor however. Other sources of information include support groups, books, magazines, the internet and health programmes and the television. Indeed, it appears that in the late 20th/early 21st century, the number of reasons and treatments available for chronic illness has increased exponentially. This is recognised by Gerhardt (1990), who claims that many new and effective forms of treatment have been developed which have expanded the role of medicine to effect the quality of life as well as clinical outcomes. This can be seen in the increasing popularity of complementary therapies such as hydrotherapy, acupuncture and homeopathic remedies.

The consequence of this is touched upon by Jobling (1988) in his study of the experience of psoriasis. Jobling argues that in their search for treatments and ways of managing their illness, patients can be faced with a vast array of information regarding sources of treatment. This information might come from the GP, hospital specialists, fellow sufferers, newspaper articles or books. In trying out each treatment hopes can rise and are often dashed again when it does not work. Often treatments have side effects or require making significant changes to one's daily routine, for example in terms of diet, expense, or travelling to specialist clinics for treatment. Jobling continues that treatment may be part of the problem of chronic illness as well as the solution. Thus, he maintains that patients are often caught up in what he calls the 'Sisyphus syndrome'. In Greek mythology, Sisyphus was condemned by the gods to roll a boulder up to the top of the hill, only to see it roll back down again. Similarly, Jobling argues that patients can go through many rituals of treatment regimens, only to find their condition has changed very little.



Gerdhardt (1990) argues that a further consequence of the increasing numbers of remedies advertised publicly is that expectations of medicine are higher than ever. Given this, it appears that GPs are seen as gatekeepers to an increasing number of treatments. As patients become more informed of what is on offer they are likely to try and persuade the doctor to accept their point of view and proceed accordingly. Again, Locker's (1983) respondents found that this was a process fraught with trouble. GPs were likely to see the patient's request as a reflection of their competence and conversely patients were likely to take a refusal to comply with their request as a reflection on them. Locker argues:

Different definitions of what is needed thus give rise to covert if not overt conflict and patients may shop around for a doctor who will provide the treatment they think they need (1983: 57).

Bury (1991) suggests however, that as individuals become more informed about their conditions, they tend to start coming to terms with their altered conditions and thus, slow down in their pursuit of treatments, learning instead, ways of managing the illness that suit them. This phase of 'arriving at an understanding' can be said to correspond with Charmaz's (2000) third problem of chronic illness, that of 'maintaining control over life'.

### **Maintaining control over life.**

#### *Learning to live with the losses to self bought about by chronic illness*

With regards to answers questions such as, 'Why me? Why now?', many studies have found that patients go beyond the medical explanations offered and situate the aetiology

of their condition within the broader context of their own biographies. For example, in his study of rheumatoid arthritis, Gareth Williams (1984) found that medical explanations were often supplemented by 'narrative reconstructions' that attempt to place medical information within a more meaningful biographical context. Similarly in a study of childhood leukaemia, Comaroff and Maguire (1981) found that parents went beyond the explanations on offer within the medical encounter building their own explanations to establish a wider picture of the condition and its possible aetiology. Such stories included referring to hazards in the environment, for example the role of nuclear power and living close to electric pylons.

At the deeper level of accepting the changes that chronic illness can pose to the body and to future life, the literature suggests that persons have varying reactions. These can be described crudely as ranging from non-acceptance or, to use Radley's (1989) phrase, 'active denial', to acceptance or 'accommodation'. Within the field of sociology the reactions of individuals towards their situations has, as with the work above, been explored through the investigation of illness narratives.

Frank (1995) argues that amongst the millions of individual stories that individuals tell about their experience of chronic illness, there are three types of illness narrative. These are, the restitution narrative, the chaos narrative and the quest narrative. The main plot of the restitution narrative is 'yesterday I was healthy, today I am sick, but tomorrow I will be fine' (1995: 77). In general, the restitution narrative assumes that the body, like a machine will be fixed at some time in the future and that the 'miracle cure' is just around the corner. As such, it suggests 'my body may be sick but I'm fine!' For Frank, the restitution narrative is based on an imaginary image of the self, one that is taken

from a number of cultural representations of illness seen, for example, on the television and advocated by the discourse of the sick role and the profession of medicine. Frank maintains that the restitution narrative does not accommodate the body in illness, rather it relies on a continued separation between body and self. Frank continues that the implication of the restitution narrative is that the individual remains passive in the face of bodily damage.

In contrast to the restitution narrative, Frank maintains that the plot of the chaos narrative is one that imagines life never getting better. As such, according to Frank the chaos narrative, feeds the sense that the body is swept along by the contingencies of illness and every day life and suggests that there is no way out. For Frank, like the restitution narrative, the chaos narrative does not reconcile the body and the self and again, the individual remains passive in the face of illness.

If the restitution narrative and the chaos narrative can be seen to offer little hope to those with chronic illness, the quest narrative does the opposite. According to Frank, the quest narrative 'meets suffering on the head ... accepts illness and uses it' (1995: 115). Frank continues that the quest narrative is defined by the ill persons' belief that something is to be gained through experience. In other words, through illness, the quest narrative suggests that the individual has realised a new sense of purpose. The quest story is thus often presented as a journey via which the individual undergoes a positive transformation. Through this transformation the individual gains special insights that can be passed on to others.



### *Learning to live with the loss of the body and the loss of social action*

Whilst the work of Williams (1984) and Frank (1995) described above, shows how individuals might begin to come to terms with some of the more personal, existential problems posed by chronic illness, it does not address the practical steps that individuals take to minimise the impact of the symptoms of chronic illness on the body or on the activities of everyday life. Strategies that have been found to be common across many of the chronic illnesses are those of minimising the physical impact of illness on daily activities through the carefully planned use of treatments and periods of rest and through adapting activities so that the effects of illness are less noticeable. Thus Kelleher states:

By reducing the significance of any symptoms experienced and reducing the importance of diet and social activities which may produce problems for them they were thus able to see themselves as healthy (1988: 98).

Obviously, disability varies in degree and severity and consequently the degree to which it creates practical problems of daily life may similarly vary. Thus it would be naive to assume that all strategies are the same and that indeed it is always possible for persons to minimise the impact of illness on everyday life. The strategies used by sufferers of Chronic Obstructive Airways disorder (COAD) are different from the strategies used by diabetics for example. Williams (1993) shows that for COAD sufferers strategies revolve around making the most of life whilst having limited movement. Such strategies involve complex decision making at the level of micro action. Thus, Williams argues that individuals employ a number of gauging techniques every time they undertake an activity. One of these techniques is referred to by Williams as 'routing'. As the name suggests routing involves a consideration of the route taken

from A to B and of the rest points available on the way. 'Routing' is described by Mr. B as follows:

I mean, for someone like you, you don't let it cross your mind, you think, "Oh I've got to pop across the road and buy something" and off you go. But me, I've got to stop and think about the pitfalls of that same shopping expedition which for example, might be two, three hundred yards down the road. I've got to stop and think "is it too far for me? Can I manage it? ... where can I rest in between?" ... So you've got to make all these decisions before you go. You've got to stop and study, plan and judge, every movement you make (Mr. B, suffering from COAD, quoted in Williams, 1993: 61).

For Williams' respondents, strategies that enable some form of coherence in everyday life also involve, taking long periods of rest between activities, organising certain tasks so that movement is minimised and even moving house so that the distance between rooms is reduced.

Implicit in the literature relating to the strategies that individuals take toward minimising the impact of their symptoms on the activities of everyday life is the need for careful planning and thinking ahead in everyday life. The need to think ahead is also demonstrated in another common strategy, that of covering or passing. As described by Goffman (1963) individuals tend to cover or pass when they wish to draw attention away from any potentially stigmatising attribute and appear as normal. In this sense covering and passing can be seen as attempts to be accepted as one of the crowd rather than being defined by disability. This may have the effect of again, regaining the self and placing the damaged body back stage. Attempts at passing and covering are demonstrated in many studies. For example Pinder (1988) shows how individuals with Parkinson's disease often make appointments with others when they are not in the semi paralysed state that the illness sporadically engenders. Similarly, Kelly (1991)

demonstrates how persons with ulcerative colitis hide their colostomy bags and make arrangements when out to be situated near the toilets in case an accident occurs. Further Scambler (1989) states that due to the felt stigma of epilepsy individuals might only disclose their conditions to significant others. In addition to hiding the symptoms of illness themselves, as shown by Goffman (1963), it has been found that individuals use others (the wise) to help them conceal their condition.

## **Discussion**

My aim in this chapter has been to provide a context for the more abstract theoretical arguments presented in chapter 2. Thus, in contrast to the previous chapter, I have referred to literature that discusses subjective experience (in this case the experience of illness) from the perspective of the individual, rather than the social theorist. This literature has provided a rich illustration of the problems experienced in everyday life by those persons suffering from chronic illness. In addition it has shown the strategies that individuals use to overcome such problems. As such, this literature tends to back up the general assumptions of Parsons (1951), Freidson (1970), Goffman (1963) and Giddens (1984) by suggesting that the experience of chronic illness cannot be separated from the culture in which it occurs. However, it goes further by illustrating how, at a micro level this might be the case. Thus, the experiences of individuals at the onset of illness and the experience of diagnosis particularly appear to be influenced by cultural expectations. Indeed, it appears that the sick role is a key factor in the processing of illness. Moreover there is evidence to suggest that there is an alternative to the sick role. This can be seen in the comments made by Robinson (1988) on the consequence of mis-diagnosis and in the comments made by Locker (1983) and Williams (1993) on the experience of



individuals diagnosed with those conditions that are seen culturally as ‘health problems that are not illnesses’.

The concepts presented in this chapter enrich the work of the theorists presented in the previous chapter. Because of this it is valuable to add them to the theoretical framework described above. Indeed, by adding the insights provided by recent research on the subjective experience of illness, it is possible to arrive at a summative model of how illness is shaped within the context of both what Freidson would call the ‘unconditionally legitimate illnesses’ and ‘the non legitimate illnesses’. Such a model would, I believe, provide a framework within which it is possible to consider the experience of ME/CFS. Alongside this, it is possible, through this model, to examine first, the extent to which mainstream sociological ideas explain the experience of ME/CFS sufferers and second, whether or not an empirical study of the experience of ME/CFS can add to the literature.

In order to incorporate the ideas gained from the empirical studies into the existing sociological theory, I propose a version of Freidson’s model of the sick role that extends an understanding of the unconditionally legitimate sick role and the non legitimate sick role by incorporating a consideration of the illness career under the headings provided by Charmaz (2000). This extension to Freidson’s (1970) framework is shown, in isolation from the rest of Freidson’s model, below. In this model I do not make a distinction between those conditions that are seen as minor deviations and those conditions that are seen as major deviations’ (although this is an important factor that I recognise will have a bearing on both types of illness career).

**Table 4.** The experience of legitimate and non-legitimate illness: an expanded version of Freidson's model\*

	<i>Non- legitimate illness</i>	<i>Unconditionally legitimate illness</i>
<i>The embodied experience of illness</i>	Loss of body Loss of social functioning Loss of finance Loss of self	Loss of body Loss of social functioning Loss of finance Loss of self
<i>Making sense of the symptoms</i>	Meanings at risk Seeking a diagnosis The medical merry go round Obtaining a diagnosis	Meanings at risk Seeking a diagnosis The medical merry go round Obtaining a diagnosis
<i>Reconstructing order</i>	Denial of access to sick role Lack of social support Not allowed time off Blame for being ill  Little access to medical treatments and information.	Access to the sick role Lot of social support Allowed time off if necessary Exempted from blame for illness.  Access to treatments, medical support and information.
<i>Maintaining control over life</i>	Learning to live with illness on a daily basis	Learning to live with illness on a daily basis

\*Experience varies according to factors such as age and gender

Having proposed a theoretical framework which addresses the question of how illness is culturally shaped and within which the experience of the non- legitimate illness and hence ME/CFS might be explored, I will now turn to the empirical part of this thesis.

## **Chapter 4**

### **Studying sufferers' experiences of ME/CFS: methods used**

#### **Introduction**

In order to explore sufferers' experiences of ME/CFS I undertook two studies, a questionnaire study and an interview study. In this chapter, I outline in detail, the process of conducting both studies. I start by discussing the overall design of the research. This includes stating the rationale behind my research strategy and explaining why I considered the methods of postal questionnaires and interviews to be the most appropriate. I then discuss each study in turn. Starting with the survey, I describe first, how I designed the questionnaire so that it would meet the research objectives, second, how I obtained a sample, third how I prepared and analysed the data and fourth the characteristics of the respondents. I then focus on the interview study. In this section I, again, pay attention to aspects of design, sampling and data preparation and analysis. Throughout the chapter, I give consideration to issues of reliability, validity and ethics.

#### **Designing the research**

##### *Deciding on a research strategy*

Colin Robson argues that the general principle of research design is

... that the research strategy or strategies and the method(s) employed must be appropriate for the questions you want to answer (1993: 38)



In considering the design of a piece of exploratory research that would best address how sufferer's experience ME/CFS, two research strategies stood out as having something of value to offer. These were the survey approach to research and what Robson refers to as the naturalistic approach. Because of its potential to access the views of large groups of individuals, the survey approach appeared to be appropriate for two key reasons. First, it presented the opportunity to explore the possibility of there being any trends that are particular to the experience of ME/CFS and second it provided the possibility of gathering data that could be compared directly with data from other studies. The naturalistic approach seemed apposite as, because of its focus on the words or actions of the individual, it offered the possibility of obtaining rich and detailed knowledge regarding first, the lived experience of bodily change in ME/CFS and second, how sufferers experience and negotiate the pathways through illness.

Whilst, the naturalistic approach is associated typically with exploratory research (Marshall and Rossman, 1995), I was keen to incorporate both research strategies into the design of my study. As I have hinted above, I considered that the use of two approaches would enhance the research as each one had the capacity to investigate the research question from a different angle. I perceived that the advantage of this would be that I would be able to gain a wide range of data on the same subject. This would enable me to explore the experience of ME/CFS in greater depth.

My initial enthusiasm for incorporating two different approaches in to the design of the research was supported by the work of writers such as Denzin (1970) Mason (1996) and Brewer and Hunter (1989). Denzin (1970) argues that the benefit of adopting more than one approach to a research problem is that the inaccuracy of one method will

complement the accuracy's of another. In other words, whereas survey research can access large samples with relative ease but is limited in terms of getting at the subjective meanings held by respondents, interview research is flexible and can access the everyday worlds of informants. Denzin calls this multi-method approach to research 'triangulation'.

Arguing along the same lines as Denzin (1970), Brewer and Hunter (1989) maintain that triangulation enables the researcher to focus more sharply on research problems, as the use of a combination of methods increases the possibility of making more discoveries. For example, fieldworkers are more likely to make discoveries as a result of finding new data sources and examining new situations, whereas survey researchers are more likely to make discoveries through techniques of data analysis, which may generate unexpected findings. For Brewer and Hunter, the multi-method approach is particularly appropriate for researchers conducting exploratory studies. They argue that the researcher who is exploring a research problem need not necessarily be bound by methodological boxes and that one of the advantages of multi-method research is that it encourages more innovative theorising.

Whilst the arguments put forward by Denzin (1970) and Brewer and Hunter (1989) provide the rationale for designing a study that utilises two approaches, it is important not to attribute the multi-method approach with more credit than it is due. For example, claims that triangulation can produce something close to the 'complete picture' must be treated with caution. Indeed, Hammersley and Atkinson (1983) argue that it would be 'naively optimistic' to assume that the aggregation of data from different sources will validate research findings. This view is also held by Silverman (1995) who suggests

that there is a danger in presupposing that by obtaining the respondent's version of the truth in different settings and adding these versions together one might get closer to the real truth. Silverman maintains that this is problematic because first, the context bound character of social interaction will be ignored and second, the assumption is conveyed that the researched are 'cultural dopes' who need a sociologist to dispel their illusions (1995: 157). Similarly Mason (1998) argues:

The idea that if you measure the same phenomenon from different angles or positions, you will get an accurate reading or measurement of it is problematic because different methods and data sources are likely to throw light onto different social or ontological phenomena. Furthermore it implies a view of the social world which says there is one objective and knowable social reality (p. 149)

Bearing these comments in mind, it is important to clarify that the decision to use two approaches in the study of sufferers' experiences of ME/CFS was made in order to assist the generation of theory by enabling the exploration of a wide range of data. In agreement with Silverman, I do not hold that one approach validates or reinforces the findings of the other.

### *Choosing the methods*

A key aspect of research design is deciding which methods of data collection are the most appropriate. Typically surveys are conducted through the use of either postal questionnaires, or structured, face to face, or telephone interviews. Naturalistic research on the other hand, is associated with various qualitative methods such as observation or semi-structured and unstructured interviewing. With regards to researching sufferers' experiences of ME/CFS, I considered two methods of data collection the most



appropriate. These were the postal questionnaire and the semi-structured, in depth, interview.

The key advantages of postal questionnaires were first, they are relatively cheap to implement, second, they can be designed so that they are quick and easy to answer and third, they can be completed by the respondent at a time that best suits him or her. Indeed, given the material restraints placed on the study with regards to time and money and due to the reported situations of the respondents, it appeared that a survey conducted by a postal questionnaire was the only feasible and ethical option. It would not, for example, have been possible to conduct a survey using structured interviews with a large number of persons with ME/CFS. First I did not have enough time to do this on my own and second, structured interviews would have been costly in terms of travel or telephone expenses. Moreover, given the severity and the unpredictability of the symptoms, I anticipated that it would be difficult to obtain a sample of persons with ME/CFS to take part in a structured interview survey.

The advantages of semi-structured interviews were first, that the interviewer can maintain a degree of control over the direction of the research and second that he or she can select a broad range of respondents, thus taking into consideration the experiences of individuals of different ages and genders. In addition, semi-structured, in depth interviews can be conducted in the homes of the respondents. With regards to exploring sufferers' experiences of ME/CFS, this had the benefit of minimising first, the preclusion of individuals who are housebound from the research and second the potential for harm. Moreover, in terms of obtaining a sample, I anticipated that semi-

structured interviews were likely to appeal to respondents and be seen as 'something worth doing'.

Whilst there appeared to be many advantages to using the semi-structured interview as a method of data collection, it was important not to dismiss immediately other methods that might also assist the gathering of rich data related to sufferers' experiences of ME/CFS. Such methods associated with the case study approach include observation and focus groups. A consideration of the observation method led to the idea of attending and recording support group meetings. However I decided that this would yield a small amount of data from only a small group of sufferers. Similarly I perceived that focus groups would have been implausible as, again they would only obtain information about a small group of sufferers: only those who were well enough to travel would have been able to attend the sessions.

A summary of how I used both methods to address the research objectives can be seen in Table 5 overleaf. I will then discuss, in detail, the design, implementation and analysis of first, the questionnaire study and second the interview study.

**Table 5. The relationship between the methods used and the research objectives.**

Study objectives	Method used	Questions asked
<b>(Exploring the embodied experience of ME/CFS)</b>		
<i>To explore sufferers' perceptions of the impact of ME/CFS on the body</i>	Postal questionnaire*	SF - 36 quality of life measure (Ware et al. 1997)
	In-depth interview	Exploring the topic of the impact of ME/CFS on the body
<i>To investigate the reported affect of ME/CFS on daily action</i>	Postal questionnaire	SF - 36 quality of life scale (Ware et al. 1997) Occupation (before and after diagnosis)
	In-depth interview	Exploring the topic of the impact of ME/CFS daily activities
<b>(Exploring the pathways through ME/CFS)</b>		
<i>To investigate how sufferers' experience ME/CFS at its' onset</i>	Postal questionnaire	Length of time between onset and first visit to GP.
	In-depth interview	Exploring the topic of ME/CFS at onset
<i>To study the experience of being diagnosed with ME/CFS</i>	Postal questionnaire	Length of time between first visit to GP and diagnosis
	In-depth interview	Exploring the experience of seeking and obtaining a diagnosis
<i>To explore how individuals manage ME/CFS</i>	Postal questionnaire	GPs – number seen, level of satisfaction with, current frequency of visits per NHS consultants – types of consultant seen, level of satisfaction with Private consultants - types of consultant seen, level of satisfaction with Complementary therapists - types of consultant seen, level of satisfaction Do sufferers think ME/CFS is physical, psychological, both? Is respondent member of support group?
	In - depth interview	Exploring topics of seeking help, treatments and management of ME/CFS
<i>To examine how sufferers experience the reactions of others</i>	Postal questionnaire	Have DSS benefits ever been denied? What do the respondents think that the general public think of ME/CFS?
	In-depth interview	Exploring the topic of the reactions of others.

\* The questionnaire also included an open ended question asking, 'What would most improve your quality of life?'



## **The questionnaire study**

### *Designing the questionnaire*

As I suggested at the beginning of this chapter, I considered that one of the advantages of doing a survey lies in its potential to observe any basic patterns that might be common to sufferers' experiences of ME/CFS. As I have shown in Table 5, the objectives of this study were; to explore the impact of ME/CFS on the body and everyday life and to explore how ME/CFS sufferers experience the pathways through illness. With regards to the objective of exploring the impact of ME/CFS on the body and everyday life, I asked the respondents to state their occupation before and after becoming ill with ME/CFS. In addition, to finding out about the occupation of the respondents, I also chose to explore the impact of ME/CFS on the body and everyday life by incorporating into the survey a 36 question quality of life survey known as the SF-36 (Ware et al. 1993, Jenkinson et al. 1999). The authors of the SF- 36 define quality of life as having eight dimensions. These are: physical functioning; role limitations due to physical restrictions; role limitations due to emotional problems; social functioning; vitality; mental health and general health perceptions.

Physical functioning is measured by asking questions such as, 'How far does your health limit you in vigorous activities such as running' and 'How far does your health limit you in moderate activities such as lifting and carrying groceries, walking a mile, climbing stairs etc?' Role limitations caused by physical problems are measured by questions such as, 'During the past 4 weeks how far have you had to cut down on your regular daily activities because of your health'. Role limitations due to emotional problems are

measured by questions such as, 'How far have you cut down on your regular daily activities because of your emotional problems?' Social functioning is measured by questions such as, 'During the past 4 weeks how far has your health interfered with your normal social activities such as visiting family or friends, neighbours or groups?' Vitality is measured by asking respondents to give an indication of how tired or worn out they have been over the last 4 months and bodily pain is measured by asking, 'How much pain interfered with your normal work during the last 4 weeks?' Mental health is measured by asking, for example, whether patients have felt nervous and finally, health perceptions are measured by questions such as: 'How true are the following statements: I seem to get ill more easily than other people I know', I expect my health to get worse'.

I considered that the advantage of incorporating the SF – 36 into the questionnaire was that, not only would it provide an insight into the general impact of ME/CFS on the body and every day life, but it would also yield data that would be comparable to SF –36 data collected through other studies. Such studies include for example, research on 'normal health', MS, depression and back pain (Jenkinson et al. 1999, Garrat et al. 1993, The Counselling Versus Antidepressants Study Group 1999 and Rothwell et al. 1997). I judged that a comparison of findings would be interesting, as I would be able to explore the experience of ME/CFS within the context of the experience of health and illness in general. At present, little research exists in the UK that has considered ME/CFS from this angle.

With respect to the second research objective of exploring the pathways through illness, I constructed a number of simple questions. These were designed to explore general aspects of the illness career from onset to management. As I have shown in Table 5, I

first enquired about the experience of obtaining a diagnosis. This involved asking a question concerning the length of time between the first visit to a GP and diagnosis. In order to explore how individuals manage their ME/CFS I asked about the number and types of GPs, NHS consultants, private consultants and complementary practitioners that individuals had consulted. I also asked how satisfied the respondents were with each health professional seen.

In addition to the above questions I asked the number of times per month that the respondents visited their GPs at the time of filling in the questionnaire. I considered that this question would give an indication as to whether patients eventually manage their conditions on their own without assistance from their doctors. Finally, in order to explore how sufferers rationalise their condition I asked whether the respondent considered ME/CFS to be physical, psychological, a mixture of both, or whether they were unsure. This question can be seen below:

<b>Understanding about ME/CFS/PVFS</b>	
<p>Which of the statements opposite best describes your understanding of ME/CFS/PVFS?</p> <p>(PLEASE CIRCLE <u>ONE NUMBER ONLY</u>)</p>	<p>It is a physical disorder ..... 1</p> <p>It is a psychological disorder ..... 2</p> <p>Not sure whether it is physical or psychological ..... 3</p> <p>It is both physical and psychological ..... 4</p> <p>I Do not know what it is ..... 5</p> <p>Other (please state below) ..... 6</p>

As I have shown in Table 5, in order to explore the reactions of others towards being diagnosed ME/CFS, I included in the questionnaire, a number of questions that looked at the experience of gaining benefits from the social security. Here, I asked whether the respondent was in receipt of benefits and if he/she had an application for benefit turned down. I included these questions in the survey as it is reported frequently that persons



down. I included these questions in the survey as it is reported frequently that persons with ME/CFS experience problems obtaining financial assistance because of disbelief and the inability of the disability test to pick up the severity of fatigue related conditions. The only other question that I included in the 'reactions of others' section was 'how do you think others in general understand ME/CFS?' For this question, the same response options were given as those in the question printed above.

Finally, I included in the questionnaire one open-ended question. This asked: 'what would most improve your quality of life at present?' The purpose of this question was to obtain an idea of the issues relating to living with ME/CFS that are considered most relevant by sufferers.

In addition to the above, I considered it important to include in the questionnaire a range of questions that would enable me to explore patterns in the data. For example, I was interested to see whether the sex of an individual had an impact on the length of time before ME/CFS was diagnosed. The questions used for this part of the research related to age, gender, ethnicity, marital status, annual income, the size of the household and the duration of illness.

#### *Acquiring data through questionnaires: a note on reliability and validity*

When designing a questionnaire it is important to take into consideration its ability to generate data that is both reliable and valid. According to Litwin (1995: 41) an unreliable questionnaire is one that will provide misleading data because its questions are inconsistent and can thus be interpreted in a number of different ways by the

respondents. A questionnaire that is not valid is one that does not measure what it sets out to measure.

Within the field of survey research tests of reliability are often conducted to test:

... the degree to which the finding is independent of the accidental circumstances of the research (Kirk and Miller, 1988:13).

The main way of increasing the reliability of the survey data was to ensure that the respondents who filled in the questionnaire comprised a homogeneous group. To this end, I included in the survey, only those individuals who claimed to have a diagnosis of ME, CFS or post viral fatigue syndrome (PVFS). Individuals who claimed to have a diagnosis of PVFS were included as the term is synonymous with ME and has been used frequently in medical diagnoses (Shepherd, 1995). In addition to having a diagnosis of ME, CFS, or PVFS, I chose to only include in the survey, those individuals who had been diagnosed with the above conditions by a GP, an NHS consultant or a private medical consultant. This was because due to the diagnostic procedure, I judged that those individuals with a conventional medical diagnosis or ME, CFS or PVFS were likely to be suffering from similar if not the same symptoms. Finally, I considered that if respondents were diagnosed with any illness(es) other than ME, CFS or PVFS the questionnaire would be unreliable as, the presence of other symptoms in addition to ME/CFS might impact on the way that the respondents answered the questions. To this end, I included in the questionnaire a question that asked the respondents whether they were diagnosed with any other illness at the time of filling in the questionnaire. This enabled me to exclude from the survey any person that had another illness alongside their ME/CFS/PVFS.

As well as checking the degree to which the findings are independent of accidental circumstances it is generally held that reliability in surveys can be maximised if the questions are unambiguous, unbiased and are not leading or couched in overly complicated language (deVaus, 1995). With this in mind, I subjected the questionnaire to four consecutive pilot studies, each one involving ten respondents. The sample for each study was drawn from a group of volunteers belonging to ME/CFS support groups in the areas of Plymouth and South East Cornwall. Through these studies and with the advice of my PhD supervisors, Professor Ettore and Dr. Chandler from the University of Plymouth, I was, over a period of three months, able to iron out the initial difficulties associated with completing the questionnaire. As a result, both the respondents and myself were satisfied that the questionnaire contained simple, unbiased and unambiguous questions.

In terms of checking whether the questionnaire was getting at all the information necessary to answer each question properly (validity), I paid careful attention to the construction of the sets of possible responses that individuals could give to each question. The responses to the question about occupational status for example, were taken from the census as this question has been subjected to rigorous testing. Similarly, in order to make sure that all of the possible responses were covered in the question, 'What financial assistance do you receive from the Department of Social Security?', I obtained information from the Benefits Agency about all of the benefits available. Following this, each benefit was included in the response set. In cases where there were potential responses that I might not have included I added a category entitled 'other(s) - please state'. By taking this careful approach to the construction of each question, the



respondents in the pilot study were satisfied eventually that all of the possible answers to each question were covered.

As my questionnaire was designed only to measure the frequency of events and did not involve turning concepts into variables I did not need to test the robustness of any abstract indicators. The only exception to this was the part of the questionnaire that contained the SF -36 quality of life survey. However, I was confident that the SF-36 had a high degree of reliability and validity as it has been considered to be so valid in previous work. (See for example, Bowling et al. 1999).

### *Coding the questionnaire*

In order to ensure that the data generated from the questionnaires could be organised quickly and efficiently, it was necessary, at the design stage, to consider coding. With the exception of the age question and the open-ended question, most of the questions asked, as I have suggested, offered the respondent a variety of responses. As the question shown on page 124 demonstrates, I gave all of the responses to each question a code and put on the questionnaire the instruction to circle the number that corresponded with each answer given. This made it easy at the data preparation stage to input the answers into a spreadsheet. In a few cases respondents were asked to circle all the answers that applied. Here I anticipated that at the data input stage, the questions would have to be re-coded to provide categories that were easier to analyse. However, I deemed that this was necessary, as to ask a range of short questions about each option would have made the questionnaire long and arduous to complete.

### *Formatting the questionnaire to ensure maximum response*

A final consideration in the design of the questionnaire was that it was appealing to the respondents. This was important not only for ensuring a good response rate but also because the researcher can hardly expect respondents with limited energy and poor concentration levels to fill in a twelve page questionnaire with complicated instructions. Again, the comments made by the respondents in the pilot study proved useful on deciding the layout and structure and with their help the final questionnaire was easy to follow. Thus, I standardised the font and redesigned the questionnaire so that the respondents only needed to adhere to one instruction throughout. Importantly the respondents in the pilot study suggested that I divided the initial questionnaire into two small questionnaires that would each take under seven minutes to complete. This it was argued would cause less stress for the respondent, as he or she could complete the survey in two feasible stages. Having done this the respondents in the final pilot study were satisfied. The final questionnaires along with the cover letter can be see in Appendix 2.

### *Obtaining a sample for the questionnaire survey*

Given the difficulty of gaining access to patient records and the cost of doing a survey of the general population, I realised at the outset that it would be impossible to obtain a representative sample of persons diagnosed with ME/CFS. Because of this and the further logistic and access problems related to asking busy GPs to distribute questionnaires, I judged that the only way to explore the experiences of a large number of ME/CFS sufferers would be through the ME support groups. There are two national

support groups, 'The ME Association' and 'Action for ME'. Both groups have a membership of over 100 000 persons. Each group produces a quarterly magazine that contains information about the latest developments regarding ME/CFS. Further, each group provides advice for sufferers, funds research and campaigns on behalf of its members. Moreover, each group co-ordinates over 100 local support groups across the U.K. In addition to the national support groups, other regional organisations exist. One such organisation is the charity 'Westcare'. Westcare is a regional support group based in Bristol. As well as providing support and advice for sufferers, Westcare runs an M.E. clinic and conducts research into the condition (see for example, the Task Force Report, 1994).

Initially I set out to obtain a list of all of the names of the members of the national support groups. From this list I had intended to select a large random sample. However, due to issues of confidentiality, both groups were unable to offer me access to their records. Following this initial attempt, I decided to recruit a sample through what is known as 'snowballing' (Sarantakos, 1993). Snowballing is often used when it is hard to obtain a sample that is representative of the study population. It involves making contact with respondents through meeting a person and then asking that person if he or she knows anyone suitable who would be interested in taking part in the research.

On the 17<sup>th</sup> of February 1999 I arranged a meeting with the chairperson of the Plymouth branch of the ME Association. As a result of the meeting we agreed that I would write a letter in the May (1999) issue of the support group newsletter. In the letter I would explain my research and ask the reader to take part by filling in and sending back the



questionnaire that was also to be enclosed in the newsletter. (A postage-paid envelope addressed to myself at the University of Plymouth was also enclosed). Using this method of obtaining a sample I secured 41 responses out of possible 80, from the Plymouth ME support group, a response rate of 51 percent. The editor of the Plymouth newsletter then sent a copy of my article to the editors of other ME support groups with whom she had contact, asking them if they would let me recruit respondents from their groups using the same method. As a result, the ME support groups in Gloucester, Cheshire and a small group in London became involved. Consequently a further 310 questionnaires were sent out, of which, 155 were sent back (a response rate of 50%). The letter that I wrote in the ME newsletters can be seen in Appendix 3.

In an attempt to improve my recruitment strategy, I also explored a second avenue. This involved placing two adverts in the national newsletters of Action for ME, and the ME charity, Westcare. These letters explained my research and asked for volunteers. As a result of this precautionary measure, a further 109 potential respondents were recruited. Thus the final sample size was 499 and the number of respondents was 305. The advert that I placed in these newsletters can also be seen in Appendix 3. A summary of the overall distribution of questionnaires along with the response rate is given in Table 6 below.

**Table 6. Sample recruitment (N=305)**

<i>Support groups contacted</i>	<i>Number of questionnaires sent out</i>	<i>Number of questionnaires received</i>	<i>Response rate (%)</i>
Plymouth	80	41	51
Gloucester	220	109	50
London	20	10	50
Cheshire	70	36	51
Action for ME	70	70	100
Westcare	39	39	100
<b>Totals</b>	<b>499</b>	<b>305</b>	<b>61</b>

*Preparing the data*

Having collected all of the completed questionnaires, the first step in preparing the data was to remove from the study, any of those questionnaires where it was stated that the respondent was diagnosed with an illness other than ME/CFS/PVFS. This yielded an eventual sample of 265 ME/CFS sufferers. In addition, because the majority of the respondents had written their names on the questionnaires it was possible to make sure that each respondent had only replied once. After ensuring that the sample met the criteria for inclusion stated above, I designed a spreadsheet in SPSS(PC) for windows into which the answers given by the remaining respondents could be inputted. This involved turning each question into a variable and creating labels for the range of answers pertaining to each variable. Each label corresponded with the coding on the questionnaire. Each set of questionnaires then took approximately seven minutes to input. Having input all the data into the spreadsheet I had to take a further step to ensure that the data from the SF - 36 and the social support scale was ready for analysis. This involved using the algorithms provided by the authors of each scale (Jenkinson,

Private Correspondence, 4<sup>th</sup> of April, 1999) to transform the raw data into the relevant score for each of the dimensions referred to above.

The final step in the preparation of the data involved organising the answers that had been written by hand. This meant cataloguing first, all those instances where the respondents had written something by a response: 'other please state' and second, all of the responses to the question, 'What would most improve your quality of life?' In order to study these responses, I wrote all of the comments down by hand in my research note book.

### *Analysing the data*

I analysed the majority of the questionnaire data using the basic frequency commands in SPSS. Through doing this I was able to obtain counts of the answers to each variable. As most of the data was nominal, where I needed to obtain the most frequent answer given to each question I worked out the modal average. In the case of variables that comprised of interval or ratio data, (for example in the case of the variables of age, income, physical functioning and so forth), I calculated the mean as well as the modal average.

With regards to searching for patterns in the data I was only able to cross tabulate the findings and make tentative suggestions. This is because, given the spread of the data and the size of the sample it was impossible to carry out any tests of significance. For example, each homogeneous group within the survey was too small to be able to calculate chi square.

With respect to making comparisons between the quality of life of ME/CFS sufferers and others, I obtained research articles that contained the results of studies that had used the SF - 36 to investigate healthy males and healthy females, depression, ms, low back pain, epilepsy and diabetes. (See for example, Jenkinson et al. 1999, Rothwell et al. 1999, The Counselling Versus Antidepressants Study Group, 1999 and Garratt et al. 1993). I then simply documented the difference between each score.

Finally, all of those comments that respondents had written by hand were subjected to a rigorous content analysis. With regards to the open ended quality of life question this involved, sorting the comments into themed categories and counting how many times each theme occurred.

*Characteristics of the questionnaire sample (N=265)*

**Table 7.** The age of the final questionnaire sample (N= 265)

	<i>Number</i>	<i>%</i>
<i>11 – 20</i>	11	4
<i>21 – 30</i>	25	9
<i>31 – 40</i>	50	19
<i>42 – 50</i>	90	34
<i>51 – 60</i>	54	20
<i>61 – 70</i>	32	12
<i>71 - 80</i>	3	1

The ages represented by the final sample were distributed evenly between 16 and 75 years. As Table 7 shows, the mean age was 45 and 73% of the respondents were aged between 30 and 60 years.



**Table 8: The sex of the questionnaire sample (N=265)**

	<i>Number</i>	<i>%</i>
<i>Male</i>	58	22
<i>Female</i>	207	78

Over three-quarters of the sample were female. It is not possible to tell whether this represents the general spread of the ME/CFS population, whether more females than males belong to support groups or whether for some reason females are more likely to respond to surveys of this nature. Indeed, it may be the case that less males than females obtain a diagnosis of ME/CFS and attempt to carry on as normal due to the common attribution of the symptoms to normal everyday aches and pains and concern about being seen to be ‘not pulling one’s weight’. Table 9 below shows the number of males and females in the sample of different ages.

**Table 9. The age and gender of the final sample (N =265)**

	<i>Age ranges</i>							
	16 -20	21-30	31- 40	41-50	51-60	61-70	71-80	<i>Total</i>
<i>Male</i>	3	4	12	18	10	9	2	58 (22%)
<i>Female</i>	8	21	38	72	44	23	1	207 (78%)

As can be seen above, whilst the sample contained a range of males and females from all of the age groups, with the exception of those aged between 71 –80, on average each age group contained 3 times more females than males.

**Table 10: The relationship status of the respondents (N=265)**

	<i>Number</i>	<i>%</i>
<i>Living with a partner</i>	155	59
<i>Not living with a partner</i>	110	41

A frequency count of the persons in the questionnaire sample showed that 59% of the group that were surveyed were living with a partner and 41% were not living with a partner.

**Table 11. The name given to the condition by the respondents (N=265)**

	<i>Number</i>	<i>%</i>
<i>M.E.</i>	213	80
<i>C.F.S.</i>	40	15
<i>P.V.F.S.</i>	13	5

All of the respondents claimed that they had ME, CFS, or PVFS. 80% of the respondents called the condition, ME, 15% of the respondents called the condition, CFS and 5% of the respondents called the condition PVFS. There were no apparent patterns in these findings. For example, the names given to the condition did not appear to be related to a persons gender, age or the duration of the illness. However these findings are of interest because they suggest that individuals suffering from the condition favour a disease label that favours a physical aetiology.

**Table 12.** The length of time that the respondents had had ME/CFS (N=265)

	<i>Number</i>	<i>%</i>
<i>Less than 5 years</i>	85	32
<i>5.1 – 10 years</i>	103	39
<i>10.1 – 15 years</i>	42	16
<i>15.1 – 20 years</i>	16	6
<i>20.1 – 25 years</i>	7	3
<i>25.1 – 30 years</i>	2	0
<i>More than 30 years</i>	8	3

The length of time that respondents had had the condition ranged from 6 months to 46 years. The mean average duration of the condition was 9 years, the modal average was 5 years.

**Table 13.** The occupational status of the questionnaire respondents (N=265)

	<i>Number</i>	<i>%</i>
<i>Unable to work due to long term illness</i>	175	66
<i>Retired</i>	27	10
<i>In part time work</i>	16	6
<i>Self employed</i>	7	2
<i>looking after the home or family</i>	12	5
<i>In full or part time education</i>	12	5
<i>Working full time</i>	8	3

66% of the respondents said that they were unable to work due to long term illness or disability. A further 10% were retired, 6% were working part time, 2% were self-employed, 5% were looking after the home or family and 5% were in full or part time education. Of those that were in education, the majority were under the age of 30 years. Only 3% of the respondents were in full time work.

**Table 14.** The annual household income of the respondents in British Sterling (N = 265)

	<i>Number</i>	<i>%</i>
<i>Less than £5000</i>	46	17
<i>£5 001 - £10 000</i>	67	25
<i>£10 001 – £20 000</i>	71	27
<i>£20 001 – £30 000</i>	53	20
<i>£30 001 – £40 000</i>	23	9
<i>More than 40 000</i>	5	2

A frequency count of the annual household incomes of the sample showed that 17% of the respondents had annual household incomes of less than £5000 and 25% of the respondents had annual household incomes of between £5001 and £10 000. 27% of the respondents had annual incomes of between £10 001 and £20 000 and a further 20% had annual household incomes of between £21 001 and £30 000. 9% of the respondents had yearly household incomes of £30 001 - £40 000 and 2% of the respondents had an annual household income of over £40 000. Those with annual incomes below £10 000 were predominantly aged over 20 and living in households on their own or with one other person.

The findings of the questionnaire study are discussed in depth in the following three chapters. However, before I turn to these chapters it is necessary to discuss the second part of this study, the semi-structured, indepth interview study.



## **The semi-structured in depth interviews (N= 40)**

I stated at the beginning of this chapter that, in addition to conducting a survey, I chose to explore the research question by taking what Robson (1993) calls the naturalistic approach. I chose to take a naturalistic approach to the study of sufferers' experiences of ME/CFS as first its aim is to investigate an issue within its real life context and second, it assumes little prior knowledge on the part of the researcher. Indeed, if I was going to gain detailed knowledge about 'the experience of ME/CFS', I considered that it was essential that I speak to persons with the condition about their everyday lives, within a setting that was natural to them. I judged that only by doing this would I obtain in depth knowledge about sufferers' experiences of bodily change and sufferers' experiences of the pathways through illness.

In keeping with the naturalistic approach I chose to use in-depth interviews as a method for exploring the experience of ME/CFS. In depth interviews are recognised for yielding insights into people's biographies, experiences, opinions, values, aspirations and feelings (May, 1997). They can generate this rich information because of the circumstances that are created during the interview process. For example, in depth interviews often take the form of 'a conversation with a purpose' (Kahn and Cannell, 1957: 149) that lasts for about forty to sixty minutes and takes place in the informal setting of the interviewee's home. Ideally, the role of the researcher is to set up the conditions in which the interviewee feels comfortable talking freely about a particular experience that he or she has had. To this end, the interviewer acts as a prompt, listener, probe and observer. By prompting the interviewee to talk about, in this case very general aspects of the experience of having ME/CFS and by listening to his or her comments, the interviewer

can obtain first hand information about the research issue. Further the interviewee can follow up interesting aspects of the verbal account and investigate any messages given by non-verbal cues.

### ***Preparing to conduct the interviews***

When conducting a survey, as I have shown, the preparation stage is concerned largely with the rigorous process of designing the data collection instrument (in this case a questionnaire). Preparing to conduct interviews contrasts markedly with this process. As such, the interviewer, rather than the questionnaire, is the data collection instrument. Because of this, in preparing for interviews, much of the work concerns preparing oneself. During this stage of my research I found that the emphasis was on three things. These were, first, deciding what to ask, second, deciding how I was going to obtain accounts of experience that were reliable and valid and third, being clear on how to avoid causing harm to the respondents.

With regards to deciding what to ask, rather than compiling a list of predetermined questions that are carefully tested for their reliability and validity, it is common practice in preparing for interviews, to draw up a short list of general topics that relate to the research objectives. Indeed, as the researcher assumes little knowledge of the subject and sees the respondent as the informant, there is little point in compiling a long list of questions: the aim is to let the participant do the talking. Patton (1990: 280) refers to the practice of drawing up a short list of topics, as the 'general guide approach'. The aim of the general guide is to act as an *aide memoir* for the interviewer during the

conversation that ensues. It is a way of checking that the conversation does not stray on to other issues that are not related to the research.

In accordance with Patton's general guide approach, during the design phase of the interview study, I compiled a list of general topics that corresponded with the research objectives (the research objectives can be seen in Table 5 on page, 121). The resulting guide consisted of the following topics. First, the impact of ME/CFS on the body and everyday functioning; second, the experience of the pathways through illness. This second topic included looking at: ME/CFS at onset; the experience of gaining a diagnosis; the experience of ME/CFS post diagnosis and finally, the reactions of others in general throughout the experience of ME/CFS.

Having compiled the topic guide, I knew it was important to test that it actually met my research objectives. In order to do this I conducted two pilot interviews. These were invaluable, as through doing them I got the feel of how to use the guide. Essentially I learnt that if I asked the respondents to talk about each consecutive topic in turn, there would be a danger that the conversation would be stilted and the research objectives would not be met. Indeed, during the pilot interview, I first asked the respondent about the impact of ME/CFS on the body and daily life. This resulted in a forty-minute conversation containing numerous examples of the effects of ME/CFS. When I reflected on the interview, I found that hardly any of the research objectives had been covered. Bearing this in mind, during the second test interview, I simply asked the participant 'how it all started'. This prompted the respondent to give an account of what had happened to them that incorporated all of the topics on the guide and more. As such, the pilot interviews emphasised the point that essentially the main objectives of

the research (those of finding out about the illness career of the sufferer) amounted to finding out about the biographies of the interviewees throughout the course of having ME/CFS. As this fact dawned on me the interviews became semi-structured in the loosest sense of the word. Indeed, in order to get at the respondent's biographies of their lives since the onset of ME/CFS, my role ended up being that of polite listener and occasional prompt.

I stated above that there were three main things to consider in the preparation of the interviews. The second of these was deciding how I was going to obtain accounts of experience that were reliable and valid. In terms of collecting data through interviews, both reliability and validity are often seen as problematic, precisely because the researcher is the instrument of data collection. Indeed, it has been argued that, as the researcher is human and involved in interacting with the participant throughout the interview process, he or she is unlikely to be able to take part in a series of conversations that are both consistent with one another and free from the influence of external constraints. Gender, age, ethnicity, class, professional status, clothing, speech and the beliefs of the participants, for example, all have an impact on social interaction between two persons. In the interview situation there is a danger that such factors will influence the kinds of accounts that each individual respondent will give (Silverman 2000, Cornwell, 1984).

Whilst I would argue that in many respects, flexibility and non uniformity are the very keys to good interview research, I agree that in order to ensure that the data acquired during the interview is trustworthy, the relationship between the researcher and the researched must be kept in check. Ideas relating to how this is done vary and depend to



a large extent on the methodological position of the researcher. Those adopting the positions of hermeneutics and discourse analysis for example, tend to see the data acquired, as a joint construction of meaning composed by the interviewer and the interviewee. To this end, the responses tend to be treated as actively constituted narratives involving activities which themselves demand analysis. However, those adopting a phenomenological or pluralistic approach argue that if certain measures are taken, the interview can give direct access to individual experience. The responses can then be treated as providing meaningful descriptions of what happens to individuals and how they react to this (Marshall and Rossman, 1989).

Although I recognise that there are more complex ways of addressing the data, the intention of my research was to conduct a descriptive study based upon how persons perceive their experiences of ME/CFS. As such, I felt that if certain measures were taken, the interview could gain direct access to individual experience. In this sense my position is similar to that of Kirk and Miller (1986) and Perakyla (1997). Kirk and Miller (1986) argue that whilst qualitative researchers have no technology for making the kind of reliability check that quantitative researchers make, other, more effective, forms of reliability can be employed. They continue that:

The sensitive intelligent fieldworker, armed with a good theoretical orientation and good rapport is the best check we can make (Kirk and Miller (32).

In order to maximise reliability in qualitative research, Lincoln and Guba (1985) argue that, the researcher should keep a reflexive journal in which his or her values and interests are kept, along with a log or methodological decisions and accompanying rationale. The benefit of this is that problems of reliability can be anticipated and

resolved before the interview takes place. In addition, Sarantakos (1993) claims that power relationships can be minimised in the interview setting if the interviewer dresses neutrally, is polite and respectful and does not ask leading questions.

Bearing this advice in mind, I spent a lot of time thinking about the interview situation before hand. I resolved that I would try and obtain a good rapport with each respondent so that he or she would feel comfortable and free to say what was on his or her mind. In addition, I saw it as essential that I appeared neutral. ME/CFS is an emotive subject that many sufferers feel passionate about, the last thing I wanted to do was to empathise too much with the interviewees or develop a conspirational type of alliance. To this end I decided that I would be friendly, polite and respectful and take care not to react to the individual stories with too much emotion (for example in terms of shock or deep sympathy). In order to meet both of the above objectives I also took care to dress in smart neutral casuals as opposed to wearing business clothes or clothing that suggested a particular political bias. Throughout the research I kept a research journal. In this journal I wrote notes about each interview and messages reminding myself not to ask leading questions and not to let my objectivity become clouded.

Another consideration regarding the issue of reliability in acquiring interview data is that of making sure the interviewer takes away with him or her a version of the interview that is consistent with what actually went on. Writers such as Perakyla (1997) argue that a degree of reliability can be reached by recording the interview and ensuring the inclusion of all vocal aspects of the vocal encounter. In addition, Perakyla argues another advantage of turning recorded interviews into transcripts is that the researcher is able to study the interview thoroughly. By reading and re-reading each

transcript, he or she can check that what he or she thinks the interviewee is saying is consistent with what was actually said. In order to ensure this kind of reliability I endeavoured to tape all of the interviews and write them up verbatim.

To maximise validity, during the preparation stage of the interview research, I learnt the topic guide and the aims and objectives off by heart, this helped me to ensure that the conversation did not stray too far off the tracks. However, as mentioned above, I found that many of the research objectives were met as the accounts of the participants unfolded.

The final consideration during the interview preparation stage related to ethics. Research undertaken with chronically ill individuals, has the potential to cause distress to the respondents both physically and emotionally. In relation to ME/CFS, physical distress might arise from causing the respondent to become over tired thus triggering a prolonged period of recovery or in the worst case a complete relapse. Emotional distress on the other hand might arise from asking the respondent to recall traumatic events such as the reactions of others or the impact of the symptoms on the body and everyday functioning.

With regards to the physical problem of ME/CFS, I anticipated that interviewees would want to be either sitting or lying down during the interview and that actions such as answering the door, standing to chat, making tea or fetching things for me to look at would be energy consuming. As a result I undertook first to try and foster an atmosphere of trust, so that interviewees would not waste energy by 'putting on any airs and graces'. This included attempting to minimise the amount of time that the

interviewees spent fetching things and so forth. Also, I realised that I would have to make it clear to the respondent that he or she could ask me to leave at any time, if he or she became too tired to continue. Moreover, I considered that it would be vital for me to be a good timekeeper and not stay any longer than the time agreed between myself and the respondent. I thought that if I stayed longer than arranged, the respondent might become over tired and this might trigger a relapse. Finally, I resolved to be alert to any signs of tiredness and leave immediately.

As I have already argued, in addition to causing physical distress, interviews that require a person with a chronic illness to reflect on his or her illness history, have the potential to cause emotional distress. This is further confounded by the fact that emotional lability is reported to be one of the symptoms that some persons with ME/CFS suffer from (See for example, Shepherd, 1992). Thus, even though an interviewee might have consented to the interview taking place, I was aware that it might be impossible for them or myself to predict fully how talking about their illness might affect them. In anticipation of this factor, I resolved to mention at the beginning of the interview that whilst it was not my intention to upset people, some might find that talking about their ME/CFS distressed them. In addition, I decided to take the telephone numbers of qualified counsellors and doctors in the event that the interview did bring up painful unresolved issues.

### *Obtaining a sample for the interviews*

Having prepared for the interviews, the next stage in the interview process involved obtaining a sample. In order to explore the experience of ME/CFS across the age



spectrum and in order to take into account gender differences I decided to recruit a quota sample. Quota sampling is defined as a method of obtaining respondents that is based on first deciding a number of specific groups that are required within the sample and second, deciding on the number of respondents required per group (Sarantakos, 1993). To this end, I first drew up a list of the groups that I wanted to sample. These groups consisted of age bands. Thus in my sample I required individuals whose illness had started in each of the following age bands: eleven to twenty; twenty one to thirty; thirty one to forty; forty one to fifty; fifty one to sixty and sixty one to seventy. Having decided on the groups that I wanted to incorporate into the sample, I then chose to interview a quota of four men and four women who fitted the criteria for each group. In addition to gender and the age at which the illness started, other criteria that I deemed essential in the recruitment process were, that each individual had to have a diagnosis of ME/CFS given by a medical professional, and each individual was to have no other diagnosis of illness. For the ethical reasons associated with interviewing children, I chose not to interview any one under the age of sixteen.

I drew the main sample from a list of individuals who had indicated on the questionnaires that they would be willing to take part in the interviews. This list contained a wide range of persons and choosing men and women that fell into the middle age ranges was not difficult. For the reasons of time and money, those individuals who lived in Devon and Cornwall and thus in relatively close proximity to the University of Plymouth were given priority over the other persons on the list. Each person that was deemed suitable was contacted by telephone and I explained the interview part of the research. I then asked him or her if he or she would consider taking part. If he or she agreed, I arranged an interview. On the day of each interview, I

phoned to check that the interviewee was well enough to proceed. If he or she was willing to go ahead, I went to his/her home and conducted the interview. I continued to do this until each quota was full.

In cases where the quotas were not met by members of the Plymouth ME support group, I asked respondents from the other ME groups to participate. Despite going further afield however, there was still a shortage of people who became ill with ME/CFS in between the ages of eleven and twenty and sixty and seventy. I eventually recruited persons who became ill with ME/CFS in between the ages of eleven and twenty via an online chat room for young people with ME/CFS ([www.afme.com](http://www.afme.com)). However, recruiting older interviewees who suited the interview criteria proved impossible. This was because there was a higher incidence of co-morbidity within this age group. The final spread of respondents is shown in Table 15 below.

**Table 15.** Number and age of persons interviewed (N = 40)

	<i>Age ranges in which illness ME/CFS began</i>					<i>Total</i>
	11-20	21-30	31-40	41-50	51-60	
<i>Male</i>	3	4	4	4	4	19
<i>Female</i>	4	5	4	4	4	21

### *Conducting the interviews*

The majority of the interviews were carried out on a one-time basis, in a face to face situation, in the houses of the respondents and lasted for approximately one hour.

However, due to the fluctuating nature of the symptoms, the differences in the severity of the ME/CFS for each individual and the geographical location of some respondents, some exceptions had to be made. For example, six individuals were interviewed over the phone. In addition, one respondent was so ill that she could only be interviewed for 15 minutes at a time, this resulted in the need to make several visits.

In general, most of the interviews went well and I felt that I achieved the rapport with the respondents that I sought. Some of the respondents said that they had enjoyed the interview and others said that it was cathartic. In the case of two interviews however, the respondent broke down in tears. In those instances I suggested that I terminate the interview, however in both cases the respondents wanted to carry on talking. During another interview I was asked to leave as the respondent felt too ill to continue and in another interview the interviewee wanted me to interview her whilst she was lying in bed. Another respondent answered the door to me on his knees and in other cases I was asked to do small chores for the interviewee, such as prepare some lunch or go to the shops. These experiences made me appreciate the value of good preparation before entering the field. Because I had considered first the possibility of emotional harm and second the conditions that persons with ME/CFS find themselves in I felt I was able to deal with each situation professionally.

After each interview, I sent the respondent a thank you card. I also gave each person a contact number should they wish to get in touch with me and assured each individual that the final results would be written up as an article in the newsletter of their local support group. When I had finished my analysis I presented a summary of the findings

to the Plymouth ME support group and wrote an article for the newsletters of the support groups that took part in the study (see Appendix 4).

### *Preparing and analysing the interview data*

It was argued above that at the stage of preparing to conduct interviews it is important to show those persons who read the research report that they can trust the data that is acquired. This is also a significant issue with regards to the preparation and analysis of the data. Thus, again, it is necessary to ask 'how can the reader be sure that the findings that are presented actually represent the experiences of the respondents?' The aim of this final section is to describe not only how the interview data was prepared and analysed but also to show how, throughout this process, careful attention was paid to matters of reliability and validity.

In order to prepare the data for analysis, thirty-three of the interviews were recorded and transcribed verbatim, however one of the respondents did not want me to use a tape recorder and six of the interviews were conducted over the telephone. In these latter cases the only option was to write notes about the interview as it was occurring and then type them up afterwards. With regards to transcribing interviews, Lincoln and Guba (1985) maintain that if a degree of reliability in qualitative research is to be achieved, the sensitive researcher should strive for rigour by asking the informants to check the accuracy of his or her transcripts. Whilst this might be the ideal scenario, it was impossible to ask all of the face to face interviewees to read the transcripts, given the limited energy that they had and the length of the transcripts. However I was, in the case of five of the telephone interviews, able to e-mail each respondent with my shorter,



written notes on our conversation. In several cases the respondents altered aspects of my version of the interview and expanded on points that they had made.

Having prepared the data, I was then in a position to analyse it. Before doing so however, it was important to consider once more issues of reliability and validity. One of the main criticisms of data analysis in qualitative research is that it is not rigorous enough. For example, Bryman argues:

There is a tendency towards an anecdotal approach to the use of data in relation to conclusions or explanations in qualitative research brief conversations, snippets from unstructured interviews ... are used to provide evidence of a particular contention. There are grounds for disquiet in that the representativeness or generality of these fragments is rarely addressed (1988:77).

As with maintaining a high degree of reliability and validity when acquiring interview data, I believe that a high degree of reliability and validity can be achieved when analysing interview data. Indeed, my position regarding the validity of the findings is consistent with that of Silverman (2000). Silverman argues that in order to convince their audience and themselves that their findings are genuinely based on a critical investigation of their data and not on a few well-chosen examples, the researcher needs to think about his or her data analysis in a particular way.

For Silverman (2000), a key word in the analysis of qualitative data is comprehension. The comprehensive approach to data analysis involves: inspecting and comparing all data fragments that arise in a single case for consistency; repeated inspection of the evidence for any generalisations made and seeking out and addressing deviant cases. Central to the comprehensive approach to data analysis is counting. Silverman argues

that by counting, the researcher is able to test and to revise his or her generalisations, removing nagging doubts about the accuracy of his or her impressions of the data.

In line with the views of Silverman, I endeavoured to adopt a comprehensive approach throughout the data analysis stage. The first step in the analysis involved immersing myself in the data. As such, I simply spent many hours reading and re-reading the transcripts that the interviews had produced. This was a lengthy process as there was a wealth of data. The process of reading however allowed me to get a feel for what was said and who said it and for the issues that were common in the respondent's accounts. As Marshall and Rossman (1989) note, through reading, 'people, events and quotes sift constantly through the researcher's mind' this enables the continued formation of ideas and aids the categorisation of data into possible themes. Indeed towards the end of the reading process, my notes suggested fifty-one broad themes that related to the study objectives. Indeed, contained in the biographical accounts of having ME/CFS given by the respondents there were rich descriptions of, the experience of managing ME/CFS; the impact of ME/CFS on friendships; work, school life and family life and the reactions of friends; family, colleagues and the DSS. Further themes included the experience of the onset of ME/CFS; the experience of doctors and consultants; the experience of seeking treatments; feelings about having ME/CFS, feelings about the reactions of others and illness beliefs.

In order to confirm that my initial themes were relevant to the majority, if not the whole sample and further, in order to analyse, in more depth, the text relating to each of my themes, it was necessary to organise the data and begin, as suggested by Silverman, counting and comparing. This started off as a problematic process. Indeed, it took three

attempts to devise a system of classifying the data that worked. The first two attempts comprised of 'organising the findings by hand'. However, both approaches proved to be time consuming and messy and as such I kept losing track of the data and my ideas. As a consequence of this, I decided eventually, that the only way to manage the data comprehensively would be to use a computer programme, designed to assist with analysing qualitative research data. The programme that I chose to use was NUDIST. NUDIST allows the researcher to code his or her transcripts on the computer. To do this, he or she must first set up a list of initial themes or 'free nodes'. Having set up a list of general themes or 'free nodes', the researcher can then cut and paste chunks of text from the transcripts into each relevant node. Because the transcripts are stored on the computer, a piece of text can be cut and pasted to as many nodes as are relevant, but at the same time the original transcripts remain in tact.

The value of NUDIST is that the researcher is able to first, store his or her data in one place (for example the computer, as opposed to in a large number of files), this allows information to be located with ease. Second, the researcher can see easily all of the text that corresponds with each theme. This enables the themes to be refined further. Third, the researcher can count the number of persons that referred to each theme and check to see whether there are any patterns in the data with regards to say gender or age. Fourth, the researcher can jump between the text that is stored under each node and the original transcripts. This enables him or her to see where the text is situated in the context of the original interview and thus allows him/her to check whether individuals present the same view about a particular topic throughout the interview.

I used NUDIST to first organise the data into the themes that I had made notes on whilst reading the transcripts. I then printed off all of the information taken from the transcripts that related to each theme. Then, in keeping with Silverman's comprehensive approach I first counted the number of times that each theme had occurred throughout the interviews. Second, I examined the findings for patterns and third checked to see that what the respondents had said about each theme were consistent with other statements that they had made during their interview. As a result of this process I was able to pull out the dominant themes.

Having done this I then began working on each theme in earnest. Using the objectives of the research as a guide I filtered each theme into the 4 main areas. The first was entitled the embodied experience of ME/CFS. The remaining three areas corresponded with stages in the respondent's life (or to put it another way, stages in the illness career). I defined these stages as 'the experience of ME/CFS pre-diagnosis'; 'the experience of being diagnosed with ME/CFS' and 'the experience of ME/CFS post diagnosis'. Having sorted the data into the 4 broad themes described above, I then began exploring each theme systematically. This involved checking, refining and unpacking the data. This process can be illustrated by focusing on one area of the findings: 'the embodied experience of ME/CFS'. Contained within the data on the embodied experience of ME/CFS were three sub themes. These were; 'the experience of the symptoms'; 'the impact of the symptoms on the activities of everyday functioning' and 'the management of ME/CFS'. From these themes, further themes emerged. With regards to the 'experience of the symptoms' for example, there were, again, three sub themes. These were, first, 'the combined impact of the symptoms: (symptoms general)'; second, 'the experience of each specific symptom (symptoms specific)' and third, 'feelings about



symptoms: (symptoms emotional)’. As I explored each of these themes further, I found that specific themes began to emerge. For example the comments made about the combined impact of the symptoms (symptoms general), referred to a sense of overwhelming unpredictability, uncertainty or lack of control. These comments are typified in the following statements: ‘the symptoms come and go at random’, ‘sets of symptoms can suddenly change’, ‘the severity of the symptoms fluctuates’ and ‘because of the nature of the symptoms, you can never be sure whether certain symptoms signify ME/CFS or another illness.’ Similarly the respondents stated: ‘ you have good hours and bad hours’, ‘you can have good days and bad days’ and you have ‘good spells and bad spells’, all of which come and go at random. As one respondent put it ‘ME is a minefield’. The consequence of the uncertainty that surrounds the experience of the symptoms of ME/CFS is picked up on in a strand of the data that related to the management of ME/CFS. Here it was stated that attempts to regain control of the symptoms include ‘chasing explanations’, ‘chasing treatments’ and ‘constantly reviewing one’s own behaviour to look for symptom triggers’.

Whilst in the case of ‘the symptoms in general’ the comments made tended to be the same regardless of factors such as age and gender, other themes did contain differences that were related to such variables. This was particularly the case with the impact of ME/CFS on the activities of daily life. The above example offers a small window on the rich findings that emerged from the data and as such they are just a part of the puzzle that appears to be the experience of ME/CFS’. The findings of the interview study are reported in full over the next three chapters.

## **Discussion**

In this chapter I have outlined in detail, the process of conducting my research into sufferers' experiences of ME/CFS. In short two methods were undertaken, a questionnaire study and an interview study. The purpose of each method was to explore the experience of ME/CFS in relation to the embodied experience of illness and the illness career of the sufferer. In order to conduct this study I used two different methods of gathering data. The reason for using two methods was to obtain a wide range of data. All that remains to be discussed is the question of ethical approval and the extent to which my findings are representative of the population of ME/CFS sufferers as a whole. The subject of ethics has been referred to indirectly throughout the chapter, however it is important to reiterate that ethical issues were taken extremely seriously in the conduct of this research. A detailed list of ethical considerations was submitted to the University of Plymouth Ethics committee. The ethics committee was satisfied that I had considered the ethical problems associated with research of this nature and that I had taken measures to prevent them. Thus they subsequently gave the project ethical approval.

With regards to the issue of 'the degree to which the findings presented in this thesis are representative of ME/CFS sufferers in general', I would argue that the application of my findings to 'all' ME/CFS sufferers must be carried out with caution. Aside from the problems associated with issues of reliability and validity discussed earlier in this chapter, the group that took part in this study had a number of things in common that might not apply to other individuals who have experienced ME/CFS. First, the sample was taken from sufferers of ME/CFS that reside mainly in the South West of England. Because of this, their experiences of GPs and others might be particular to this region of

the country. Second, the sample comprised of individuals that were suffering from ME/CFS at the time of the research. There was no inclusion of individuals that have had ME/CFS and recovered from it. Because the sample only included people suffering from ME/CFS at the time, there is little coverage in the findings of, for example, experiences of treatments that have worked. Indeed, it may be the case that individuals who have recovered from ME/CFS have experienced a very different pathway through their illness. As such this study serves as the first step along the route to finding out about ME/CFS. Any theory that might be generated should be subjected to further empirical investigation. Having discussed the process of conducting the research I shall now, over the following three chapters discuss the findings of both studies.

## **Chapter 5. The embodied experience of ME/CFS**

### **Introduction**

In the following four chapters, using an adapted version of Freidson's (1970) model of the sick role as a framework, I explore the findings of the study outlined in the previous chapter<sup>1</sup>. In this first chapter, I consider the embodied experience of ME/CFS. In the second chapter, I explore the respondent's experiences of 'making sense of the symptoms'. In the third chapter I focus on how sufferers' of ME/CFS go about 'reconstructing order'. Finally, in the last chapter, I consider how individuals with ME/CFS 'maintain control'.

In this chapter on the embodied experience of ME/CFS, I consider first, ME/CFS and the loss of the body, second, ME/CFS and the loss of social action and third, ME/CFS and the loss of material security. The findings presented here suggest that in ME/CFS, the 'dys-appearing body', is characterised by chronic fatigue, acute pain and a range of additional symptoms. The incapacity brought about by these symptoms is such that many individuals are housebound and unable to do much beyond the bare minimum for themselves. In addition, because of the disabling nature of ME/CFS, sufferers are excluded from most forms of social action. For many, this extends to paid employment and results in financial dependence and/or hardship. Alongside the practical losses

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<sup>1</sup> I have adapted Freidson's model of the sick role to take into account first, the embodied experience of illness and second, Charmaz's (2000) categories of 'making sense of the symptoms', reconstructing order' and 'maintaining control'. This model can be seen at the end of chapter 3 (page 111). I have adapted Freidson's model in order to enable a comparison of the illness careers of individuals with non-legitimate and legitimate chronic conditions. To date such a comparison has not been made in the literature pertaining to the sociology of health and illness.



brought about by the loss of the body and hence social functioning, sufferers of ME/CFS experience profound emotional trauma. Feelings of grief, frustration, uncertainty and bewilderment appear to be central to the experience of bodily loss in ME/CFS. In addition, for younger sufferers', feelings of total exclusion, isolation and purposelessness arise from not being able to participate in the transition to adulthood and independence. For older individuals, the loss of social action is bound up with a sense of not being able to fulfil the obligations associated with typical gendered roles. Further, for the older respondents the inability to work results in extreme worry and financial uncertainty. In general terms, ME/CFS can be summed up using Charmaz's (1983) concept 'the loss of self'.

Key to the findings presented in this chapter is the issue of time. As such, it appears that the practical consequences of losing the ability to function fully remain a constant feature of the daily lives of sufferers throughout the illness career. However as ME/CFS progresses, sufferers somehow work their way through the loss of self and arrive at a way of finding meaning in life. These findings suggest that regardless of its status as a legitimate or non-legitimate illness, in terms of the embodied experience of illness, ME/CFS has much in common with those chronic illnesses described in the literature.

### **ME/CFS and the loss of the body**

In the following section I map out a profile ME/CFS in terms of what Leder (1990) refers to as the 'dys-appearing body' (See chapter 3, pages 76 - 77). First, I give a summary of the symptoms of ME/CFS, second, I consider the experience of each symptom in turn and finally, I show how the dys-appearing body in ME/CFS is

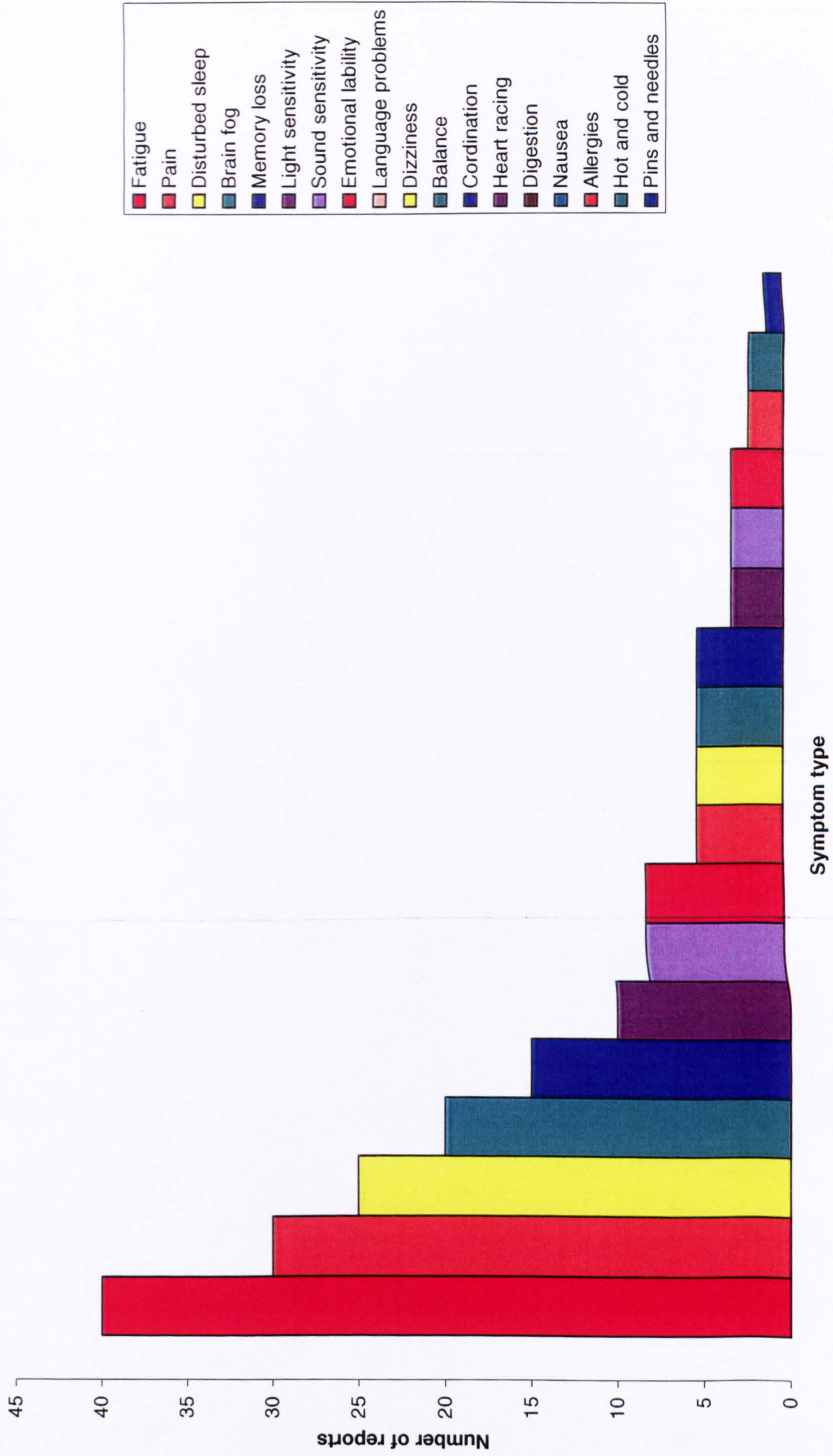
characterised by the accumulation of a variety of symptoms. I then explore the extent to which the dys-appearing body in ME/CFS is reported to dominate daily life. Having compared the extent to which bodily functioning is affected in ME/CFS to the extent to which physical functioning is affected in other chronic conditions, I turn to how sufferers react to the changes that take place in their bodies.

*The symptoms of ME/CFS: a summary*

Figure 1 overleaf, provides a summary of the symptoms of ME/CFS as reported by the interview respondents. This shows that, first and foremost, ME/CFS is characterised by chronic fatigue and in the case of most individuals, constant pain. Indeed, all of those interviewed (100%), suffered from chronic fatigue and 80% of the sample stated that they suffered from pain. In addition to these 'main symptoms', Figure 1 shows that the respondents suffered from a diverse range of 'additional symptoms'. For example, 53% of the interview group, reported suffering from sleep disturbance, 53% said that they suffered from 'brain fog', and, 43% claimed to suffer from emotional instability. Further, 33% of the sample stated that they experienced memory loss, 23% reported being overly sensitive to light and 23% reported being overly sensitive to sound. In addition to the above, the respondents reported problems with balance, allergies, a fluctuating temperature, problems with co-ordination, nausea and swollen glands. The total number of symptoms experienced by each individual at the time of the study ranged from 2 to 15. The modal average was 4 symptoms per person (the mean being 6).



**Figure 1.** The symptoms of ME/CFS as reported by the interview respondents (N = 40)





### *The experience of chronic fatigue*

The definition of fatigue in ME/CFS given by the interview respondents went far beyond the dictionary definition of fatigue as 'extreme tiredness' (Oxford English Dictionary 1997). Indeed, it was stated that when an individual has ME/CFS, physical energy is finite and in very short supply. When it is used up, the respondents suggested that there is no 'well of energy left to draw from'. This, it was reported, leaves the sufferer in a state of 'no energy' and therefore forced to 'do nothing'. The length of time spent in this state of 'no energy' appears to vary from person to person and according to the amount of energy used. As such, the respondents said that it might be a matter of hours, days, or months, until the energy slowly trickles back. Three of the interviewees used mechanistic or organisational metaphors to convey this general experience of fatigue:

The body is like a leaky battery. It has a certain energy capacity and can hold no more. As you move, or do things this energy quickly leaks out and you have to keep resting to recharge. (Fiona, aged 45, has had ME/CFS for 10 years)<sup>2</sup>

What stands out in the accounts of the respondents, is the 'amount' or 'quality' of the energy that individuals with ME/CFS have. To use Fiona's analogy of the battery, it appears that, in ME/CFS, the voltage is grossly under par and often inefficient for using the body in ways that most individuals take for granted. As one respondent said

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<sup>2</sup> The details in brackets after each *verbatim* quote indicate the fictitious names of the respondents, their age and the length of time that they had suffered from ME/CFS at the time the interviews took place. From now on a shortened version of this system will be used. Thus the information in brackets after each quote will consist of (name, age, duration), i.e. (Fiona, 45, 10).



'everything is an effort, every single thing'. With regards to lifting for example, it was stated:

I can't fill the kettle, it gets too heavy' (Denise, 43, 3).

The other day I bought a small bag of potatoes I could lift them into the boot but when I got home I was too tired to lift them out again ... I can't even hold the mixer for the Yorkshire pudding. (Jenny, 48, 5).

With regards to walking, standing and climbing the stairs it was reported:

I can walk roughly about 100 paces, that gets me from my here (the front room) to the kitchen and back ... I can just about manage to the front door ... I answer the front door on my knees because I cannot stand there (Geoff, 40, 10).

According to the interview respondents, just as fatigue restricts the ability to do tasks that require physical stamina, so fatigue restricts the ability to carry out those tasks that require mental stamina:

My other major limitations are reading and writing. Reading is slightly worse than writing and I have to limit myself to just scanning not reading. If I start reading whole sentences, every word, it's crucifying. Just scanning for information and I mustn't really do more than 5 minutes so on an average day I will just scan the post and you can see that in the first sentence and throw it away. Even TV watching has to be rationed. I mean my mind cannot ... you know, it's just too tiring (Geoff, 40, 10).

### *The experience of bodily pain*

In addition to the experience of constant fatigue, 80% of the interview group reported experiencing acute bodily pain. Bodily pain was often defined as 'aching', however the word 'aching' appears to belie the intensity with which the pain is felt. Indeed the

respondents also used words such as 'tremendous', 'massive', 'absolutely crazy', 'exhausting' and 'horrible' to describe its severity. A major characteristic of the pain in ME/CFS appeared to be that first it is always present. In addition the respondents reported that despite trying many different treatments, the pain still persisted.

*The experience of the 'additional symptoms'.*

Above and beyond the symptoms of fatigue and pain, the two most frequently reported symptoms were disturbed sleep (periods of insomnia) and 'brain fog'. Disturbed sleep was reported to be extremely distressing as the respondents stated that, despite being fatigued they were 'awake to the symptoms' for long periods of time. A number of the respondents said that during periods of disturbed sleep, they experienced a 'buzzing' or a 'fizzing' brain. Further, as with the reports about the treatment of pain, many of the respondents pointed out that during phases of not sleeping, none of the available treatments work. In addition to not being able to sleep, a minority of the respondents (8%) claimed that, they had phases of falling asleep all the time.

The second most frequently reported additional symptom, 'brain fog', was likened to 'having a layer of cloud in the brain' that, as one respondent put it, 'prevents information from penetrating the brain'. Brain fog was also described as 'having a brain like glue', 'being prematurely senile', 'mental confusion' and 'processing information wrongly'.

The third and fourth most frequently reported additional symptoms were emotional instability and memory loss. The experience of emotional instability was described as 'not being on an even keel', 'being up one minute and down the next', 'having PMT',

'suffering from increased anxiety', 'losing one's nerve', 'feelings of apprehension', 'panic attacks', 'feeling frightened' or 'bursting out crying for no apparent reason'. The 'loss of short-term memory', was described as the tendency to 'just go blank'. In particular, the interview respondents stated that they found it hard to remember words that they had been planning to say, the names of people or objects or familiar routes. Many of the respondents said that the problem of memory loss was such, that for safety reasons, they did not do any of the cooking in the home.

Less frequently reported, were 'problems with vision', 'problems with hearing', 'problems with balance' and 'allergies'. Problems with vision included sensitivity to light and/or blurred vision. Those who had hearing problems stated that they were overly sensitive to noise, for example routine sounds were experienced as being unbearably loud and being in a crowd was said to be intolerable. Problems with balance were described as, 'unsteadiness', 'not being able to walk in a straight line' and 'constantly bumping into things'. The allergies that were reported to be associated with ME/CFS included intolerance to alcohol and intolerance to wheat.

The other 'lesser mentioned' additional symptoms, were speech disturbance, for example 'slurred speech' and 'words back to front'; fluctuations in temperature, for example, 'feeling extremes of hot and cold' and problems with co-ordination, for example, 'losing a sense of spatial awareness'. Some of the respondents also mentioned heart problems, referring in particular, to 'heart pounding' and 'palpitations'. In addition, digestive problems were also mentioned. These included 'being constipated' and 'stomach pain'. Finally, a number of the interview respondents mentioned having 'muscle twitches', 'throat problems' and 'pins and needles'. Muscle twitches were described as 'the shakes',

'like having Parkinsons' and 'spasms'. Throat problems were described as 'having something stuck in the throat' and finally pins and needles were described as 'having tingling skin'.

### *The cumulative affect of the symptoms of ME/CFS*

The findings presented above suggest that, an understanding of the dys-appearing body in ME/CFS has to incorporate, not just chronic fatigue *per se*, but the fact that according to sufferers, at any one time they will be experiencing chronic fatigue, likely pain and a host of other symptoms. Whilst the transient nature of the additional symptoms makes it difficult to provide a single snapshot that characterises the exact experience of 'all' sufferers, the quote below provides a general example of the dys-appearing body in ME/CFS that is close to all of the respondents' accounts:

The main thing, now I suppose, which has to be the worst symptom, is the fatigue and every thing that goes with it. The fact that when you do any small exercise whether it is physical or mental ... you feel utterly exhausted and drained ... too much sound drives me absolutely crackers, even someone talking loudly gives me a jolt ... I've got permanent headaches, I've always got pain in my eye. I'm very sensitive to light ... I've got continual joint and muscle pain ... I can't think straight. (Jill, 44, 10)

### *The extent to which the body in ME/CFS 'dys-appears'*

For the respondents in this study, the dys-appearing body dominates everyday life. The extent to which this is the case is brought into focus by contrasting the reported impact of ME/CFS on the body with the reported states of the bodies of first, the 'healthy population' and second, persons with other chronic conditions. It is possible to situate



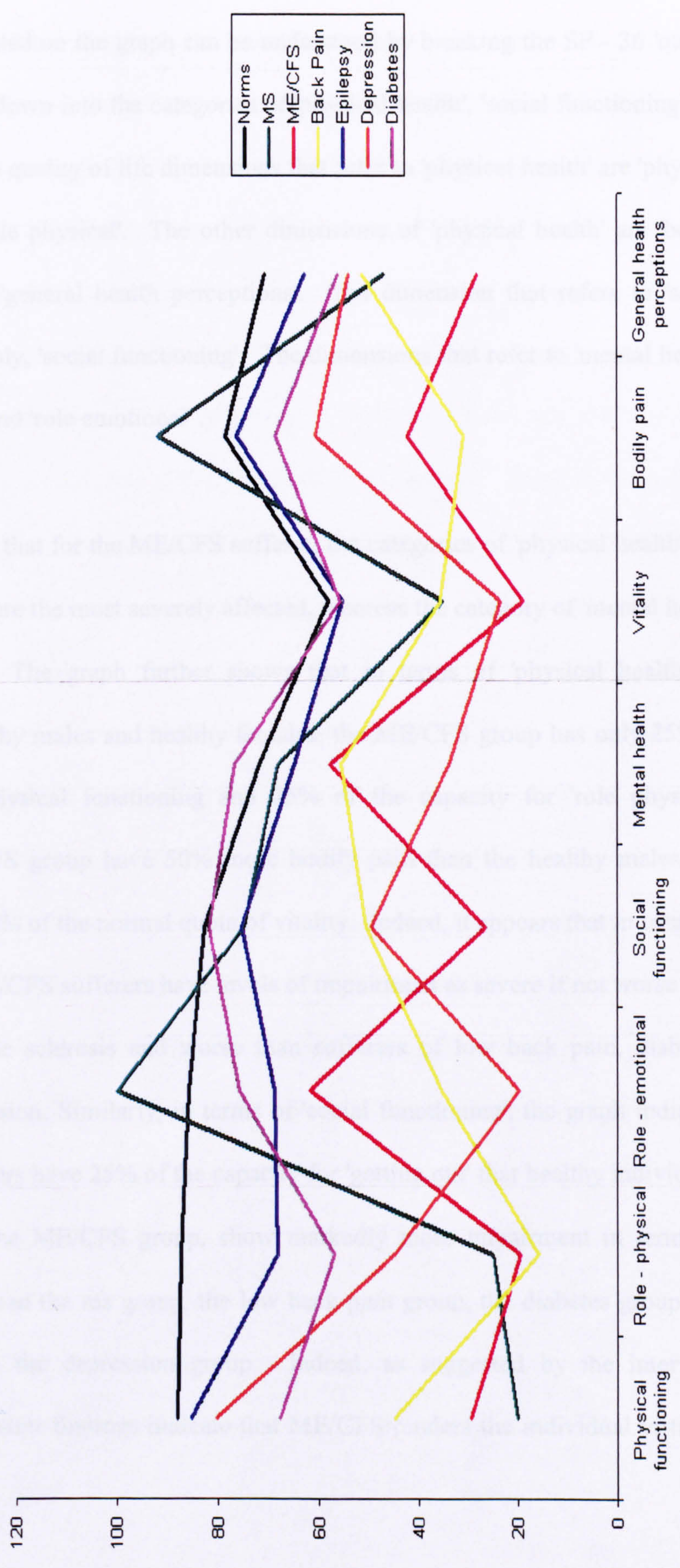
the reported experience of ME/CFS within the context of the experience of illness in general, by comparing the results of the SF-36 quality of life survey (Ware et al. 1992), with SF-36 data taken from studies that have been published. Such a comparison is presented in Figure 2 overleaf.

As I have shown in chapter 4, the SF-36 measures the quality of life by breaking it down into 8 dimensions. These include physical functioning (measured by asking respondents about their ability to walk, climb stairs and lift things); social functioning, (measured by asking respondents how far physical health has restricted them getting out to see, for example, friends and family); 'role physical' (measured by asking how far daily activities are restricted by physical health); 'role emotional', (measured by asking how far daily activities are restricted by emotional problems); vitality and general health perceptions.

The graph in Figure 2 shows the levels of impairment reported by individuals for each dimension of the quality of life. The X-axis lists each quality of life dimension and the Y-axis shows the range of possible scores for each dimension. The scoring of the SF-36 is such that, the lower the score, the worse the quality of life. Charted on the graph are the mean average scores for each dimension for the ME/CFS group. In addition, the published mean average SF – 36 scores for healthy males, healthy females and groups of individuals with MS, low back pain, epilepsy, diabetes and depression are also charted. (These are taken from Jenkinson et al. 1999, Rothwell et al. 1997, Garrat et al. 1993, Hermann et al. 1996 and The Counselling Versus Antidepressants Study Group, 1999).



**Figure 2:** A comparison of the quality of life of ME/CFS sufferers with the quality of life of healthy males, healthy females, and other disease groups, using the SF – 36.





The findings presented on the graph can be understood by breaking the SF - 36 'quality of life' dimensions down into the categories of 'physical health', 'social functioning' and 'mental health'. The quality of life dimensions that refer to 'physical health' are 'physical functioning' and 'role physical'. The other dimensions of 'physical health' are 'bodily pain', 'vitality' and 'general health perceptions'. The dimension that refers to 'social functioning', is simply, 'social functioning'. The dimensions that refer to 'mental health', are 'mental health' and 'role emotional' .

The graph indicates that for the ME/CFS sufferer, the categories of 'physical health' and 'social functioning' are the most severely affected, whereas the category of 'mental health' is less affected'. The graph further shows that in terms of 'physical health', in comparison to healthy males and healthy females, the ME/CFS group has only 25% of the capacity for physical functioning and 25% of the capacity for 'role physical'. Further, the ME/CFS group have 50% more bodily pain than the healthy males and females and only 30% of the normal quota of vitality. Indeed, it appears that in terms of 'physical health' ME/CFS sufferers have levels of impairment as severe if not worse than sufferers of multiple sclerosis and worse than sufferers of low back pain, diabetes, epilepsy and depression. Similarly, in terms of 'social functioning', the graph indicates that ME/CFS sufferers have 25% of the capacity for 'getting out' that healthy individuals have. Moreover, the ME/CFS group, show markedly more impairment in terms of social functioning than the ms group, the low back pain group, the diabetes group, the epilepsy group and the depression group. Indeed, as suggested by the interview respondents, these latter findings indicate that ME/CFS renders the individual virtually housebound.

Whereas physical and hence social functioning appear, according to the respondents, to be drastically affected in ME/CFS, mental functioning appears to be affected, but to a much lesser extent. For example, with regards to the dimension of 'mental health', the ME/CFS group have, on average, 50% lower functioning than the healthy males and females. In addition, the respondents have on average, 65% of the capacity for the 'role emotional' that the healthy males and females have. Moreover, general mental functioning is higher in the ME/CFS group than it is in depression and low back pain and much closer to the mental health of the other illness groups. These findings might explain why, as I show in the following chapter, sufferers' claim that their condition is a 'physical' illness as opposed to a 'psychological' illness.

The salience of the findings presented above is highlighted in the accounts of the general impact of ME/CFS on daily life given by the interview respondents. For example, all of the interviewees reported being virtually housebound and confined for the best part of their daily lives, to either the bed or the settee. Indeed, the need to spend hours 'recharging' or 'doing absolutely nothing' results, according to respondents, in an average day that is spent lying down 'staring at the ceiling'. As such, it was stated that the impact of ME/CFS is such that sufferers can barely attend to their bodies, let alone carry out typical daily activities:

You have to dress yourself, you feel slovenly if you don't and that is a step down. When you have to go and get something to eat and you physically have to go to the toilet and after going to the toilet you have to go back again ... drying your hair something like that. I just put my elbow against the wall and just hold it like that ... I just let it go now ... it takes too much effort to have a bath ... you've got to run the bath and have to test the temperature of the water which means bending down and straightening up again. You then have to undress. And then once you are in the bath you have to physically wash yourself ... It's a lot easier to have a shower ... If I can get to the bathroom, I shower for



about 3 minutes, you just stand there and let the water do it you know, bending over and rubbing your legs I just can't do that or else I've stayed in bed and my husband will bring a soap and a bowl of water, it's not the same (Margaret, 63, 12).

I get up in the morning and take my daughter to school, I come back I go straight back to bed. I can't get up. I also have a toddler he has to be pretty much left to his own devices in a room that is made as safe as possible so that I can get as much rest as possible. I rest pretty much all day and only get up again to go and pick my daughter up from school (Martine, 30, 6).

Whilst the type of day described by Martine above was described as 'an average day', the respondents reported that they also experience 'bad days' and 'bad phases' or 'relapses'. On bad days and during relapses, it was suggested that the fatigue is such that the individual can do nothing at all:

I'd stay in bed all day. If I'd come downstairs I'd sit in the chair, still in my bed clothes, if I got on the floor I couldn't get up, you've got no energy whatsoever, all your muscle strength is gone. I couldn't even lift up my right arm I had to lift it up with my other arm ... I could do nothing all day except for lie on the settee (Jenny, 48, 5).

### *Sufferers' reactions to bodily loss*

The findings presented thus far suggest that, according to the respondents, the experience of ME/CFS in terms of bodily loss have marked similarities with the experiences of those individuals with other chronic conditions. That is, when ME/CFS strikes, the body reappears and becomes a continuous presence in the everyday life of the individual. The findings further suggest that the extent to which the dys-appearing body in ME/CFS, dominates the lives of sufferers is more marked in terms of the restrictions it poses to physical functioning than it is in the majority of other chronic conditions, resulting in almost total physical disablement.

Williams (1996) suggests that when the body dys-appears, individuals undergo a period of mourning the body that has been lost and resenting the new body that has taken its place. For Williams, this is a dichotomous situation whereby the individual, in the face of his or her suffering, separates the mind from the body. There is much in the respondents' accounts to back up Williams' assertion. For example, a number of the respondents saw their bodies as holding them captive. This can be seen in comments such as 'I am a prisoner in my own body', and 'my body has just switched off'. Similarly, other respondents stated:

... almost overnight a very active lifestyle was transformed into a very prudential one ... It came upon me so suddenly. I am by nature a very physical active person. My mind was still thinking along those lines, wanting to do these things. I'd be sitting in the lounge resting, looking around at all the jobs I really wanted to be getting on with and it was just a torture (Christine, 42, 6).

It disrupts your whole way of life, you change your life to accommodate the illness and that's what annoys me, I can't get up and do what I want to do (Margaret, 63, 12).

Above all however, the dominant reaction to bodily change was reported to be 'a feeling of emptiness'. This finding corresponds with the claims made by writers such as Vranken (1989), Butendjik (1962), Frank, (1991), and Kleinman (1988), that when the body 'dys-appears', the individual is faced with an existential vacuum, where past meanings are shattered and one becomes, as Kleinman puts it, 'a stranger in an unfamiliar land, without a map to navigate' (1988: 18):

All of a sudden you feel as though a door's closed on you, because that's how it felt. As though, one side of the door you've got plenty of energy, the other side you've got nothing. All of a sudden that door closes and you've got nothing there. You just sit here (Jane, 54, 6).

When it really hit me was 1991 I think. It was a totally black time for me ... I was stripped of everything physically, all the things that I enjoyed to do physically I had been stripped, my mental capacity had been completely diluted ... (Rob, 60, 12).

### **ME/CFS and the loss of social action**

In chapter 3, I suggested that according to the literature the loss of the body might be seen as the first form of loss in chronic illness. The loss of the body brings with it the inability to take part in the normal events of daily life. This 'falling out of the social world' might be seen as the second form of loss in chronic illness. Bury (1982) defines this type of upheaval as 'biographical disruption'. This is a valuable term as it introduces into an analysis of the experience of illness the key point that 'what has to be given up' will vary in terms of who the individual is. In the following section I acknowledge this by considering where possible, ME/CFS and the loss of social action in relation to the 'time in life that illness occurs' and gender. First, I consider the impact of ME/CFS on the lives of the younger persons that took part in the study. Second, I consider the impact of ME/CFS on the lives of the older persons that took part in the study. The categories of 'younger' and 'older' are meant as loose analytical categories only. Broadly speaking 'younger' refers to those individuals under the age of 25 years and 'older' refers to those individuals over the age of 25.

#### *ME/CFS, younger persons and the loss of social action*

For the younger persons in the study ME/CFS cut across the key life transitions that lead to adulthood. Indeed, the onset of ME/CFS appears to put a stop to attempts at gaining independence, propelling the young adult into a situation where he or she is more



dependent than ever. The social activities of education, work, meeting friends and having intimate relationships, for example, were said by the respondents to have been relinquished because of ME/CFS. These activities were replaced by spending every day and night resting in the homes of their parents and in most cases being cared for by their parents.

There was little evidence within the accounts of the younger persons to suggest that gender makes a difference as far as the impact of ME/CFS on social action is concerned. Rather, for the younger individuals that took part in the study, accounts relating to the impact of ME/CFS on life in general were largely bound up with descriptions of feeling, 'excluded', 'lonely', 'isolated' and 'cut off' from the world. Many stated, for example, that life had 'just stopped' or 'stood still'. This situation was often compared to the situations of peers, for whom life was seen to be 'carrying on'. Thus the overwhelming feeling was reported to be that of 'missing out' or of 'life moving on without me':

You feel cut off and everything else is going on and you've stopped still haven't you? And everything else is trotting on and you think, "oh hang on a minute" they've left me behind (Sarah, 24, 3).

The feelings of missing out on life, expressed by the younger respondents, are perhaps not surprising, given the stage of the life course that they are at. Indeed, when an individual is prevented from going through the stages of transition, the sense of not being able to move on appears to be emphasised. Further, this sense of 'missing out' appears to intensify over time, because, as the individual stands still his or her peers rapidly move on.

This 'process' of social exclusion is clearly emphasised in the respondents' accounts. For example, first it was implied that young individuals with ME/CFS lose contact with their friends by virtue of having less and less in common with them:

At that time, my friends used to come round and visit me. Although I found it difficult relating them being out of the school environment, I sort of missed out on all the things they were doing and I just thought they didn't quite, know how to cope with me being ill they tried to relate to me (Liz, 25,10).

According to the other young respondents this, 'falling out of social life', tends to result eventually in losing contact with friends and partners altogether:

I haven't got any (friends). The ones I went to school with when I first started to get ill at school they just disappeared and then I went to college with a couple, but then after I had to leave college, that was it I never saw them again. I haven't seen most of them for about 5 years and then I didn't have anybody (Anna, 22, 6).

As time wears on, the accounts of the younger respondents suggest that the gap between the private world of the individual and the social world of their peers becomes more marked. This exaggerates the feeling that they might never move on in life or catch up on those things that they have missed:

I remember feeling really down when I was about 18 when A level results came out and it would have been when I would have taken my A levels and I just felt that I had missed out on those two years I was way behind everybody. I had no qualifications and I was just feeling very low in self esteem and I just felt that I'd never get better. I'd never get anywhere really and it was very difficult when they all went off to university and college and I was left behind and I felt really isolated once again and lonely and my whole world seemed to have fallen apart really and I just didn't know whether I was ever going to get better and that used to worry me such a lot (Liz, 25, 10).

As the above quotes suggest, for the younger persons that took part in this study, the feeling of exclusion from life was characterised largely by a sense of loneliness. This is typified in the comment made by one of the questionnaire respondents below. In response to the question 'what would most improve your quality of life', she stated:

I would like the social services to find me a "befriender" who would talk to me. I don't go out at all. My mother is my only true friend and mental and physical support (Female, aged 16, had ME/CFS for 4 years at the time of the study, written response to quality of life question)<sup>3</sup>.

Further, the younger respondents in this study spoke of experiencing regular bouts of depression, as well as worry about the future, boredom, a lack of self-confidence and shattered hopes.

#### *ME/CFS, older persons and the loss of social action*

Like the younger interview respondents, those who were older were equally disabled by ME/CFS and for the best part of their daily lives rendered bed or settee bound. Unlike the younger respondents however, who dwelt mainly on the sense of 'life moving on without them', the older respondents tended to dwell more on, 'the types of activities that had to be given up'. The reason for this might be because the older respondents did not become ill at a key stage of transition in the life course. Rather, at the time of becoming ill, set routines and patterns in life had been established. Thus, the accounts of the older respondents tended to be bound up with not being able to fulfil the

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<sup>3</sup> Where quotes have been taken from the written responses on the questionnaires I have given the sex of the respondent, the age of the respondent and the length of time that they had ME/CFS at the time of the study. From now on these details will be written as follows: (sex, age, duration, written response to quality of life question), i.e. (Female, 16, 4, written response to the quality of life question).



responsibilities that they had had previous to the onset of illness. These, were mainly, 'being parents, partners, workers and friends'.

As such, there was a specific gender dimension with regards to the types of activities that were referred to. For example, all of the married women in the study spoke about how their condition rendered them unable to do household chores such as cleaning, washing and cooking. This, they argued, impacted on the running of the household. Thus, many tasks had to be left, or taken over by their husbands and children. The inability to carry out such tasks was said to undermine their sense of worth:

I rely on my husband a lot. Yesterday he did the bathroom and toilet floors and then he hoovered right through, and its a tremendous help, but when he first had to do it I felt terrible. I thought I can't see him doing this and that frustrated me terribly, it builds up tension within you ... it took me a long time. If you can't perform your functions. But everybody ... you have a split level of responsibilities and duties don't you? Unconsciously you do. I mean the wife normally prepares the meal, I say normally - its a normal function you don't give it a second thought do you? And you suddenly realise that you can't. You feel useless ... useless (Margaret, 63,12).

As with the impact of ME/CFS on doing household chores, it also tended to be the married female respondents who talked about the affect of ME/CFS on parenting. In addition to not being able to clean and cook for their children, these respondents bemoaned the fact that they could not look after their young children. Further, they spoke about not being able to do things with their older children such as play with them, take them out, have their friends over or go on holiday with them:

The kids (*sic*) come in from school and then go out with the dog and then come back, get the tea it's hard on the kids. I'm very much a 'mother's mother'. I believe that kids were here to play and they've got the rest of their lives to work. I don't like them coming home and having to work, it's tough. We never go in town, all of those things that used to

take for granted. My daughter used to say "Oh I want a new top, can we go in to town?" Those days are over. I worry about the kid's health all the time. Days out and the meals out ... we used to like to take the children out about once a month, go for a pub meal or something just so we'd have that family time together away from the home because it's ... We don't sit round the table anymore for family meals because I'm usually in bed or on the sofa you know, everybody's eating at different times and all of these little things that are really important (Denise, 43, 3).

With regards to the impact of ME/CFS on relationships with their partners, little was said, although those that did mention their partners spoke generally about not being able to 'muck in' with the running of the family:

I tried to get up to make cups of tea because Nick was decorating one of the bedrooms at the time and I thought, "If I could just make him his cups of tea", you know, "It would help". Because I felt so guilty just lying there being ill for days on end, so I'd get up and try and make these cups of teas but I couldn't do it (Christine, 42, 6).

The inability to do things in the home was mentioned much less frequently by the men in the study. Indeed, as far as 'falling out of the social world' was concerned, the men most frequently referred to the impact of ME/CFS on work. Implicit in their accounts was a sense of 'uselessness', of 'not being a productive member of society', of 'not having a purpose'. In addition the male respondents referred to a sense of loss related to the camaraderie associated with work:

I found it very difficult to come to terms with. You feel so useless. I mean that's the purpose in life that everybody wants. I'd sort of built a career up over 20 odd years ... it doesn't help from a depression point of view, feeling your useless and things like that and then I think it took a long time to adjust. I'm not sure I've ever adjusted fully to that. In your reflective moments you feel like everybody should be, everybody says "people must work" and you get this thrown at you on television all the time don't you? Its in bred in you over the years that your purpose in life is to work and you miss the work you miss the social side of things and its a funny thing to say, you even miss the hassle if you like (Pete, 52, 16).

In addition to giving up work, the second major theme related to the loss of social action referred to by the men in the interview study, was the frustration of not being able to partake in sports. Thus six of the respondents mentioned feelings of grief at not being able to take part in activities such as bike racing, car racing, squash, climbing and football.

I stated above that the majority of the older interview respondents referred to the impact that ME/CFS had on their roles as parents, workers and partners. An exception to this was those respondents who were single and childless. Like the younger respondents who were also single and childless, these respondents placed emphasis on the affect that ME/CFS had on their social lives. However, unlike the younger respondents, they suggested that their friends had not moved on, but stayed around. Thus they were still able to enjoy a degree of social support.

My friends have been very good, but you do drop a load of people on the way. Because if you're not well enough to go out clubbing and because you don't do the same sport now, you drop those friends so you do drop a hell of a lot of people on the way. You're just so lucky that you can keep the friends that you have really and they've just been brilliant (Esther, 34, 5).

Implicit in the above quotes is the sense that, for the older respondents, feelings related to the loss of the ability to act in the social world are primarily feelings of uselessness and guilt. Whilst feelings of uselessness and guilt might be the primary feelings associated with losing the ability to act in the social world, like the younger respondents, the older respondents also mentioned feeling excluded from the social world. For example, Jill states:



I mean I would just love to be able to do what everyone else is doing; I mean I would love to go up on the Hoe for the fireworks but I know its sort of out of the question this is what you live with. This is what I've lived with all these years (Jill, 44, 10).

Contained within accounts such as the one above, is the implication that, for the older respondents too, the feeling of 'life passing you by' articulated so avidly by the younger respondents, does not stop. For example, many of the interviewees commented on the fact that the longer life stays in one place the more you miss.

I'll never be the same as I was, but I don't know what I should be like because I've aged 15 years (Bob, 50, 15).

If I'm ever in that situation I find it's always the past I'm having to talk about. Because I can't talk about anything that I have done recently you know and that's hard as well (Jill, 44, 10).

### **ME/CFS and the loss of material security**

In chapter three I argued that if the loss of the body and the loss of social action are the first two forms of loss in chronic illness, for many older individuals, a third form of loss is the loss of material security. This aspect of illness is, I argued, important to consider because as with the loss of the body and the loss of social action the loss of material security brings with it a number of particular stresses that impact on the overall experience of illness. In this penultimate section, I consider the impact of ME/CFS on material security and the affect that this had on the everyday lives of the respondents.

According to the results of the questionnaire, the occupational status of 89% of the sample had changed due to illness. Moreover 66% of the sample said that, at the time of filling out the questionnaire, they were unable to work due to long-term illness or

disability. A further, 10% had retired, 3% were working full time 16% were working part time, 7% were self employed and 5% were in full or part time education. These findings are shown in Table 16 below.

**Table 16.** The impact of ME/CFS on employment and education (N=265)

<i>Nature of employment</i>	<i>Before the onset of ME/CFS</i>		<i>After the onset of ME/CFS</i>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
<b><i>Paid work</i></b>				
<i>Working full time</i>	135	51	9	3
<i>Working part time</i>	33	12	16	6
<i>Self employed</i>	30	11	7	3
<b><i>Education</i></b>				
<i>In full time education</i>	35	13	5	2
<i>In part time education</i>	2	1	7	3
<b><i>Other</i></b>				
<i>Looking after the home or family</i>	21	8	12	4
<i>Unemployed</i>	3	1	0	0
<i>Retired</i>	3	1	27	10
<i>Unable to work due to long term illness or disability</i>	0	0	175	66
<i>Other</i>	3	1	9	4

The extent to which 'not being able to work' impacted on the lives of the sufferers can be seen in the data for income. For example, as I have shown in the previous chapter (Table 14), 78% of the sample said that their income had decreased as a result of the condition. A closer look at the data shows that 16% of the respondents were in receipt of annual household incomes of less than £5000. This annual figure is below the minimum amount that one individual over 25 years requires in order to survive (DSS leaflet number GL23, April 2000). Moreover, of those individuals whose household incomes were less than £5000, 20 lived in households of more than one person, this

suggests that a number of families that contain an individual with ME/CFS, have incomes that are far below the poverty line.

Whilst 17% of the households that were surveyed were in poverty, 42% were living on incomes lower than the amount specified by the Council of Europe as the decency threshold for one person per year (Source: [www.lowpayunit.org.uk](http://www.lowpayunit.org.uk), 3<sup>rd</sup> August, 2002). Moreover, over 69% of the questionnaire sample had household incomes below the average UK income threshold of £24240 per year (Source: [www.blackbooks.co.uk](http://www.blackbooks.co.uk), 3<sup>rd</sup> August 2002). These findings are shown, once again, in Table 17 below.

**Table 17: Annual incomes per household of the questionnaire respondents (N=265).**

<i>Income levels per year</i>	<i>Frequency</i>	
	<i>n</i>	<i>%</i>
<i>Less than £5000</i>	46	17
<i>£5001 – 10 000</i>	67	25
<i>£10 001 - £20 000</i>	71	27
<i>£20 001 - £30 000</i>	53	20
<i>£30 001 - £40 000</i>	23	9
<i>More than £40 001</i>	5	2

For those in the interview study who lost a significant amount of income due to illness, the fear of 'not being able to make ends meet' meant the onset of extreme worry about mortgage repayments, bills and unexpected costs such as repairs to the house or car. Martine, a mother of three, whose husband was made redundant at the same time that she became ill, conveys the uncertainty caused by financial insecurity:

At the same sort of time I found out what it was, my husband got made redundant. At that point everything was coming tumbling down ... the prospect of being so ill and not being able to just go out and work our



way out of the awful situation. Everything that we'd ever had was on the line and we could have lost it all. I got a lot worse even though I was trying to do all the right things I got a lot worse there were days when I couldn't get out of bed ... We were lucky enough to be one of the people that got a pay out from the Halifax when they converted to a bank so that paid of some off the debt. We got a little bit of redundancy money so that paid off some more debts and we've been jumping from one thing to another pretty much since that point. You know, little bits of good news that have happened and obviously the DLA being sorted out helped immensely, but waiting 8 months for it to be sorted out was a nightmare (Martine, 30, 6).

Others stated too, that they had been forced to make significant cut backs in order to make ends meet.

We are short of cash, every month we run out of money. His (my husband's) wages are just not enough to cover everything We live off cheapies from the supermarket (Denise, 43, 3).

The first thing we did was got rid of any HP or credit we had and since then we've never had a credit card or bank card or anything we always pay cash and if we haven't got the cash we don't buy it. We went to the plainest of foods and the second hand charity shops for clothes and everything (Margaret, 63, 12).

### **Discussion: ME/CFS and the loss of self**

In this chapter I have outlined 3 major features of the experience of ME/CFS. These are the loss of the body, the loss of the ability to act in the social world and the loss of material security. Whilst these experiences of loss appear to vary according to factors such as age and gender, each pragmatic aspect of loss seems to be a central part of life with ME/CFS. That is, the physical problems posed by the body and the practical problems posed by not being able to participate in the typical activities of everyday life remain constant throughout the illness career. In this sense, the experience of ME/CFS

appears to be no different and if anything worse than the experience of those chronic illnesses described in the literature.

Alongside the practical consequences of the loss of body, social action and material security, I have also documented the respondents' personal reactions to the losses of ME/CFS. The cumulative affect of the losses described above can be conceptualised in terms of Charmaz's idea of 'the loss of self'. Charmaz (1993) argues that as chronically ill persons are forced to retreat back into their bodies, the opportunities for having valued images of their selves fed back to them begin to wane. Under such conditions, Charmaz maintains that the self-concepts of chronically ill persons will be negative in a society that values independence and activity.

The loss of self, engendered by the losses that accompany ME/CFS can be seen in terms of a situation of powerlessness and worthlessness. Powerlessness appears to occur as a result of having no control over the changes that ME/CFS engenders. It is implicit in the sufferers' accounts of losing control of their bodies and becoming uncertain about the new reality in which they found themselves. Worthlessness can be seen in the comments made by the male respondents who felt that their forced absence from work rendered them 'without purpose' and in the comments made by those females who could no longer look after their homes or children as they wished. Worthlessness can also be seen in the accounts of the younger persons with ME/CFS whose withdrawal from education, work and social life in general, made them feel low in self-esteem and depressed:

I felt unconfident (*sic*) and I didn't have the self esteem about myself and I just thought "I can't do anything" and "What's the point I might as well just go and jump off a cliff because I'm useless" (Joanne, 26, 8).

All your self-confidence, credibility, family, friends, job - lost (Claire, 48, 8).

Both powerlessness and worthlessness can be seen in the comments made by the respondents about having their daily responsibilities taken over by others:

It took a long time to actually reach the point of actually accepting help in my home. That was something I fought for many months. I really wanted to maintain that degree of independence and wouldn't accept that I could no longer do that. (Christine, 42, 6).

This sense of powerlessness and worthlessness appears to be further reinforced when others take over one's personal care:

It was awful thinking I'm going to have to get somebody else to help me with the chores, doing personal things for me like washing me (Jill, 44, 10).

A key finding in this thesis is that, whilst the practical problems of ME/CFS are ongoing and change very little throughout the illness career, the emotions associated with the losses incurred by ME/CFS, change over time. That is, over time the respondents appear to have gone some way to regaining their sense of self. This point is made clearly by comparing the retrospective accounts of how sufferers felt about their illness at onset, with the SF-36 data that asked the respondents to describe how sufferers felt at the time of filling in the questionnaire.



For example, at the time of the study, the majority of the questionnaire respondents had had ME/CFS for an average of 9 years and at this point, the respondents had relatively low levels of depression and high levels of mental health. In contrast, a quarter of those interviewed said that, during the early stages of ME/CFS their levels of depression were so high that they had thought about or actually attempted committing suicide:

I remember one day a particular person said "how are you?" and I sat sobbing and said "I'm sorry but I just want to die" it is just sheer hell (Jane, 54, 10).

By September I was back into building my suicide machine ... I've even been on the internet trying to find the easiest way to commit suicide (Barry, 52, 3).

I've spent a lot of time just sitting in the window looking at people walk past and things and you begin to think if I have another 5 years of this, I'll kill myself" (Geoff, 40, 10).

I tried to commit suicide because of the emptiness of the illness. (Viv, 65, 7).

The suggestion in the data, that individuals with ME/CFS take action in the face of loss tends to back up Charmaz's assertion that 'chronic illness involves a mission on the part of the sufferer to regain control' (2000: 280). As I have shown in chapter 3 (page 93), Charmaz argues that this involves, first, 'making sense of the symptoms' and second, 'reconstructing order'. According to Charmaz, 'making sense of the symptoms, 'spurs a quest to define illness' and 'reconstructing order leads to efforts to manage illness and treatment regimens'. The indication that sufferers take action to regain control in the face of illness raises the question of whether the experiences of ME/CFS sufferers with regards to making sense of the symptoms and reconstructing order are similar to the

experiences of individuals with other chronic conditions. As I show in the next two chapters, whilst the embodied experience of ME/CFS appears to have much in common with the embodied experience of other chronic conditions, the 'mission to regain control' differs considerably. The question of how individuals with ME/CFS make sense of their symptoms and reconstruct order are the subject of the following two chapters.

## Chapter 6

### **The illness careers of ME/CFS sufferers: making sense of the symptoms**

#### **Introduction**

In this chapter I consider the first stage in the illness career of the ME/CFS sufferer. As I have shown in Table 4 (page 110), Charmaz (2000) suggests that this stage involves 'making sense of the symptoms'. In exploring how sufferers make sense of their symptoms I consider the respondents' experiences of first, the symptoms at onset, second, seeking a diagnosis and third, obtaining a diagnosis of ME/CFS.

The accounts of the respondents during the initial stages of ME/CFS resemble closely Goffman's (1968) description of the pre-patient phase of the moral career. This is due to the fact that their experiences appear to be influenced by prevalent ideas about the status of individuals suffering from 'non serious illness'. In the first instance, general ideas about the 'seriousness' of illness, are held by sufferers of ME/CFS themselves. As a result, at the onset of illness, they dismiss their symptoms as trivial and carry on with the duties of everyday life. When, because of the incapacitating nature of the symptoms, sufferers eventually seek medical advice, despite extensive medical testing, GPs and hospital consultants find no pathological sign of illness. Consequently, medical practitioners do not diagnose sufferers as chronically ill. The dominance of medical ideas about their illness is such that sufferers find themselves propelled into a situation that appears to match Freidson's (1970) description of the non-legitimate sick role. A central characteristic of this role is the stigma of malingering and/or



hypochondriasis. A consequence of the stigma of malingering of hypochondriasis appears to be a lack of practical, social support and further, humiliation, uncertainty and a sense of social isolation.

As a result of being forced into the non-legitimate sick role, many individuals begin to consider that their condition is, after all, 'in the mind'. However, eventually, rather than accepting the cultural view of their illness, sufferers opt to struggle against it. In doing so, they continue to draw on cultural ideas about what constitutes serious illness in their own interpretations of their symptoms. Further, sufferers continue to invest power in the medical profession in defining their illness as serious. The finding that eventually sufferers do obtain an official diagnosis of ME/CFS (a condition that they consider to be a 'serious illness'), suggests that, despite the initial dominance of medical ideas, there is room in medical/lay interactions for negotiation. Indeed, at the stage of obtaining a diagnosis, sufferers appear to succeed in their struggle with the medical profession. This success can be seen in the finding that a diagnosis of ME/CFS is met with total relief, because, as such, sufferers expect that their claims to be 'really ill' will, at last, be socially accepted.

### **ME/CFS and the experience of the symptoms at onset**

An analysis of the illness careers of the individuals that took part in this study provides, right from the beginning, an insight into how illness is thought about in western culture. Indeed, in the accounts below, it is possible to see that, as argued by Parsons (1951) and more specifically by Freidson (1970), ideas about illness have a moral dimension. First, the accounts suggest that some conditions are seen as more serious than others. Second,

they indicate that when an individual is suffering from a 'non serious illness' he or she is not granted access to the sick role (rather, he or she is expected to carry on with his/her daily responsibilities and take on the responsibility of 'making him/herself better'). Finally, the findings suggest that when an individual fails to live up to the expectations placed on those individuals with minor illnesses, he or she runs the risk of being labelled as a 'malingerer' or 'hypochondriac'.

These ideas about illness, it appears, are not just imputed onto the sufferer by others. They are also, as suggested by Goffman (1968) in his discussion of the pre-patient stage of the moral career (see chapter 2), held by the sufferer him or herself. Indeed, during the initial stages of illness, the actions of the ME/CFS sufferer seem to be primarily influenced by his or her own, culturally derived judgements. For example, the findings indicate that, unprompted by others, during the initial stages of illness individuals who interpret their symptoms as 'minor' first, make stoical attempts to carry on regardless, despite their symptoms. Second, they take on the responsibility for 'fighting illness off' and third, they go to great lengths to protect their moral integrity by concealing any problems that they might have. The extent to which cultural expectations about illness influence the actions of the individual during the initial stages of ME/CFS can be seen in the finding that despite becoming increasingly incapacitated by their symptoms, the respondents 'soldiered on' for an average of two years. Indeed, the majority of the respondents only re-evaluated the meaning of their symptoms when they literally collapsed and were taken to hospital. These findings are illustrated below.

### *Initial ideas about the symptoms*

At the onset of illness, the respondents in this study attributed their symptoms to 'run of the mill tiredness', 'a flu-like virus', 'ageing' or the ailments that a person might get from 'the everyday stresses and strains of life'.

I put it down to what I'd been through, i.e. my mum dying and my girlfriend leaving (Adam, 42, 11).

That was the start of it because from having a bug and being unwell it was quickly followed by minor irritating non-description (*sic*) ailments (Margaret, 63, 12).

I felt that I wasn't as fit and my mind wasn't functioning ... I felt that maybe it was just because I was getting older (Rob, 60, 12).

### *Initial reactions to the symptoms*

Because the respondents thought that symptoms were trivial, they decided that first, they did not warrant any special (medical) attention and second, the symptoms did not warrant 'taking time out from daily responsibilities'. Consequently, they took it upon themselves to carry on as normal:

You simply shrugged off. You thought, "Well I've got an aching shoulder it doesn't mean anything", you just carry on working (Margaret, 63, 12).

As the majority of the respondents 'carried on as normal', many found that the symptoms continued and indeed, worsened. Despite this, rather than take time off, they continued working and thinking of their symptoms as minor:



I was a music teacher and I always had deadlines to make. If I caught a virus or anything I worked through it, I was feeling very lethargic and not having the energy that I used to have, just feeling unwell basically, but I carried on. I always found as long as I carried on I could cope. By the end of term I was feeling utterly drained and exhausted but I always do feel drained and exhausted at the end of term. You know, because when you've been working you go through and you work hard and its not until you stop you think, "Gosh I feel awful" and it takes a few weeks to adjust. I always had a cold or something when I finished for summer. But all through the summer holidays I felt awful ... I deluded myself that, "Oh it'll pass when I get back to school, whatever it is" (Jill, 44, 10).

In addition to not allowing themselves any of the sick role privileges, such as time off, or medical help, many of respondents started to take on extra responsibilities. This finding indicates that sufferers' reactions to illness at onset are influenced by gender. For example, those respondents who took on extra responsibilities during the initial stages of their illness were male. The responsibilities that were taken on were related to spending extra time trying to 'make themselves better', by upping their fitness levels:

At the time I picked up flu and didn't think anything of it and carried on working and felt absolutely miserable and it just didn't seem to go away. I didn't think anything of it at the time. I'm carrying on working and at the same time I wanted to get my physical fitness better because I was noticing at the end of the race I was beginning to get tired. I thought well okay, we'll increase the fitness, go down the gym and work out down there. So I'm working out down the gym and I'm beginning to think, "Cor blimey I'm aching all over" and I thought "Well that's because I'm working hard down the gym". Then the muscles really started aching and I thought, "That's a bit strange", so I stopped going to the gym for a while and it still carried on so I thought, "Well I'll go down the gym even more perhaps that's what's the problem". So I cracked on (Richard, 29, 6).

### *ME/CFS and 'meanings at risk'*

Further to not seeking medical advice, carrying on and taking on extra responsibilities to make themselves well again and despite finding activities such as work an increasing

struggle, many of the respondents chose not to reveal their problems to colleagues and friends. Whilst no direct explanation was given for this, the quotes imply that in admitting to others that they were failing to get over their symptoms, the respondents felt that they might invite upon themselves allegations of 'hypochondriasis' and 'malingering'. This situation is cognisant of the situation of 'meanings at risk' as defined by Bury (1988, see chapter 3), whereby during the initial stages of illness, sufferers are uncertain how others will react. Indeed, the experience of meanings at risk can be seen as the first experience in the illness careers of ME/CFS sufferers of stigma. Whilst, during the initial stages of illness they did not experience stigmatising attitudes from others, the very fear of stigma led them to 'pass' and 'cover'.

I didn't tell anyone for a long time and then just the ones that were closest to me (Rob, 60, 12).

(After eighteen months of having the symptoms) I had a friend who was in the next class to me and she actually came in ... And she asked if I was alright and I said, "No" and I told her how I felt and I said, "Don't say anything to any one". I don't know why but I didn't want anyone to know (Jill, 44, 10).

*The extent to which cultural expectations about illness impact on the experience of illness at its onset*

The extent to which ideas about illness influenced the actions of the respondents during the initial stages of their illness can be seen in the length of time that the respondents continued to by and large ignore and/or hide their symptoms. This ranged from 1 month after the onset of ME/CFS to 3 years and was on average 2 years. For the majority of the respondents, the point of reconsidering the meaning of their symptoms came when they could simply 'no longer carry on'. Importantly, 20% 'only gave up the

fight', because they were forced to. That is, through having a potentially fatal accident, or what Zola (1973) refers to as an interpersonal crisis (see chapter 3), they ended up in hospital:

I tried to go to (name of town) with Amy, 5 months old, fastened in the back of the car. I blacked out at the wheel, wrote the car off and ended up in hospital (Pauline, 52, 12).

I struggled on for so long that I can't remember ... feeling so ill and I was getting to the office at 8 0 clock in the morning and feeling so ill, so drained. I carried on for 18 months I wasn't the sort of person to stop work for illness but as I carried on it got worse. I just got worse and worse and one day I collapsed (Kevin, 51, 10).

### **ME/CFS and the experience of seeking a diagnosis**

At the onset of ME/CFS, the actions that individuals take appear to be similar to the actions taken by those individuals with conditions for which there is no immediately recognisable sign of serious illness. For example, as shown in chapter 3, writers such as Stewart and Sullivan (1982), Locker (1983) and Robinson (1988) argue that persons with multiple sclerosis and rheumatoid arthritis also, during the early stages of illness, interpret their symptoms as minor, 'carry on regardless' and experience 'meanings at risk'. These writers continue that, at the point of realising that perhaps the symptoms are more serious than originally thought, individuals seek advice from a GP or a hospital consultant.

With regards to seeking help, the actions that individuals with ME/CFS take, again, appear to be no different than the actions taken by other individuals with chronic illness. For example, all of the respondents, having reevaluated their symptoms, sought medical advice. This finding suggests that, as argued by Parsons (1951) and Freidson (1970) in



western culture, individuals tend to look to the authority of the medical profession in the defining of illness. In addition, it once again backs up the point made by Goffman (1968) that during the pre-patient phase of the moral career, individuals tend to hold the same beliefs regarding illness, as others.

Initially, the experience of seeking a diagnosis for the symptoms of ME/CFS appears to be similar to the experiences of individuals with other chronic illnesses as reported in the literature. However, as time progresses, the findings suggest that the experience of sufferers departs from the experiences of others. This is because, in ME/CFS, seeking a diagnosis appears to be marked essentially by a struggle rather than by broad consensus. These findings are the subject of the following section.

### *ME/CFS and the 'medical merry go round'*

For many of the respondents, the initial visit to the doctors marked the beginning of a long phase of testing for illness. This phase appears to mirror that of the 'medical merry go round' described by Robinson (1988). For example, during the initial period of seeking advice from medical professionals, it was argued that typically, blood samples would be taken and sent away for analysis. The results of such tests would come back showing no sign of physical illness. After initial testing, many of the interviewees reported that they were sent to a variety of NHS consultants in the hope that further investigations might lead to discovering what was wrong. However, as with the previous tests, it was maintained that the consultants could detect nothing. For many of these respondents, as argued by Robinson, the period of testing was a tense one, marked

with peaks and troughs caused by the anticipation of a definite explanation and despair when one was not found:

I went back to the doctors, nothing progressed from there. Then I went back again - another set of blood tests - nothing. And I'm back and forth to the doctors over a few weeks. I went back and I had another load of tests and I thought, "Oh great, this should finalise it, I can get back to square one, I can get back to racing" but the tests came back and there was nothing there at all (Richard, 29, 6).

As typical medical tests continued to show no sign of pathological illness and thus as the 'medical merry go round' slowed down, the unanimous decision made by GPs and hospital consultants was that the their patients were simply suffering from 'the stresses and strains of modern life'.

#### *Sufferers reactions to a 'non diagnosis'*

The framing of their illness by the medical profession as 'non serious' was met with horror by the respondents. First, it appears that their taken for granted expectations of a serious diagnosis were abruptly shattered. Second, in their interactions with the medical profession, they found themselves suddenly exposed to public judgement (a situation that they had previously taken great care to avoid).

The judgement implicit in their GP's deliverance of what constituted a 'non' diagnosis, can be seen to correspond with the cultural expectation about non-serious illness described above. Namely, that when symptoms are minor, individuals should not gain access to the sick role. Rather, they should be responsible for pulling themselves together. Moreover, according to the reports of the respondents, in their deliverance of a 'non' diagnosis, many GPs made reference to the moral status of the sufferer,

indicating that he or she 'did not know his or her own mind' (hypochondriasis), and/or that he/she was 'making it up' (malingering):

(The doctor) told me it was virtually all in the mind, he saw about 14 women of my age a year with this complaint. All I needed to do was just to go for all the things I really wanted to do but felt I couldn't at the time even though they would make me ill and I would be better in 6 months (Pip, 40, 10).

I went to my GP and to my horror he said, "I think you're in for an early retirement"(Simon, 70, 10).

It is at this stage during the illness career of the ME/CFS sufferer that the experience of conflict or struggle emerges. The respondents' reactions to their GP's 'non' diagnoses were such, that they simply 'did not' or 'could not' believe what they were hearing. Three related reasons were given for this. First, the respondents stated that because of the severity of the symptoms it was physically impossible for them to carry on (indeed, they had already tried this and failed). Second, the respondents saw it as inconceivable that their symptoms were indicative of minor illness (the aches and pains of everyday life are not physically disabling). Third, the respondents saw it as implausible that they were psychologically ill (they were as emotionally stable as anyone else):

I knew there was something wrong with me. I was looking in all the medical books at all the symptoms that I had and they kept pointing to the same thing; a brain tumour or MS (Joanne, 26, 8).

The specialist said that in his view I was suffering from depression and that if I didn't take antidepressants I would have a nervous breakdown. I told him I had a happy marriage, a lovely family, a great job. I'd never been so emotionally happy in my life. He said to trust him he knew what was best (Pauline, 52, 12).

It is clear from the quotes above that, rather than buying into medical ideas about the nature of psychosomatic illness, sufferers continued to draw on common ideas of



'serious' and 'non-serious' illness to make sense of their conditions. Further, the respondents picked up on the moral implications of a non-diagnosis and made attempts to defend their status. These findings suggest once again that by virtue of belonging to the wider culture, as suggested above, sufferers hold the same ideas about what constitutes the seriousness of illness as others. This extends to the notion that physical illness is socially acceptable and psychological illness is socially undesirable. It is the combination of these powerful ideas that appears to propel sufferers to dismiss the definitions of their symptoms, as provided by GPs and hospital consultants.

### *Disputing non-diagnosis: ME/CFS and the dialectic of control*

Whilst it may be the case that powerful ideas are used by ME/CFS sufferers to dispute the decisions of the medical profession, it does not follow that sufferers turn their backs on the idea that the medical profession hold authority when it comes to the defining of illness. Indeed, the reports of the respondents suggest that sufferers still invest power in the authority of the medical profession by continuing to seek, from GPs and consultants, a diagnosis of 'serious physical illness'. In taking this action, sufferers of ME/CFS can be said to embark on a power struggle with the medical profession. This can be seen in terms of Giddens' (1984) 'dialectic of control' and raises the question of 'who wins?'

The findings suggest that as a result of 'going back to their GPs for a diagnosis that fits their experiences of chronic illness', sufferers of ME/CFS step once again on to a 'medical merry go round'. Thus, they continue to experience the peaks and troughs of hope and despair, that the 'medical merry go round' engenders:

In November, the doctor decided I needed to see a consultant and I went to the hospital. In I trotted and got used as a pincushion and whatever else and he did all these tests and at the end decided that although most of his tests had come back negative. There were a few things - raised white blood cell count which showed I was fighting some sort of infection or virus or something, but that was really nothing that they could say one way or the other. Then I caught a cold and he decided this was it I'd had this sinus infection all along and this was what was causing the pain and that I needed to see an ENT specialist and get my sinuses washed out. Then he took an X-ray and gave me some antibiotics for the infection and I saw the ENT specialist about a week later and they'd lost my X-rays. It was quite fortunate in the end, because they said, "You'll have to have another set done". So, I had another test done and they were completely clear. It had just been a normal infection and the antibiotics had cleared it and he said well, "Nothing wrong with you love" patted me on the head and "Off you go back to the consultant" (Janine, 24, 10).

As time wears on, it appears that medical testing still fails to provide a physical explanation of illness. As this happens, it appears that the ideas held by medical practitioners regarding the mental status of the sufferer increasingly dominate explanations of their patients' conditions. These types of explanation are interpreted by sufferers as humiliating moral judgements that imply once again that he or she, 'does not know his or her own mind', and/or that he/she is 'making it up':

(At the neurologists) I saw his assistant to start with. One of the first questions he asked me was, "Do you have any friends?" I thought, "Hey up I know what this is going to be like, he basically thinks, "I'm screwy". He went next door and had a long, long discussion with the neurologist, who then came in and asked me the same question, "Have you got any friends?" Then he said, "Oh your parents are deaf! You must have had a hard time relating to them as a child". I sat there in my bra and knickers really angry, I couldn't walk out! I said, "Of course I had problems relating to them as a child wouldn't you? but I've had counselling and sorted that out" ... I gave him a right mouthful I was so fed up. I was beside myself with despair (Joanne, 26, 8).

Then they decided that I must be psychiatrically ill. So he suggested that I see an adolescent psychiatrist, he didn't say I had to but it was kind of inferred, "Well if you don't you're just making the case stronger for a mental illness" (Janine, 24, 10).

### *The dominance of medical ideas about illness*

The continued conviction of medical professionals that the symptoms experienced by the respondents were not indicative of serious illness suggests that, despite their attempts, initially sufferers fail to change the meaning attributed to their symptoms. This finding backs up Freidson's (1970) argument that ideas about illness espoused by the medical profession will dominate over ideas about illness espoused by the lay public. In addition, it lends weight to Freidson's observation, that the profession of medicine play a key role in the moral ordering of illness. This point is acknowledged by one respondent who states:

I wish that doctors would recognise that when you don't get diagnosed a whole chain of events is set off (Pip, 40, 10)

### *The impact of not obtaining a diagnosis: ME/CFS and the non-legitimate sick role*

As time progresses and the symptoms of ME/CFS become known to the public world of what Goffman (1963) refers to as 'normals', it appears that the intensity of the stigma of malingering and hypochondriasis, increases. Indeed, in the absence of a diagnosis, ideas about the illness status of the sufferer materialise to the extent that sufferers' claims to be seriously ill are met by family, friends and colleagues, for example, with disbelief:

My family didn't believe me, told me to pull myself together (Joanne, 26, 8).

My whole family doubted me. Everyone doubted me. On top of the massive symptoms I was having. It was horrible (David, 30, 6).



I was depressed. I was very depressed. I knew something was wrong but no one would believe me (Adam, 42, 11).

Because they did not diagnose me, no one took me seriously, my mother and my aunt refused to believe it and told me to pull myself together. My main social group was the church, but they could not tolerate the illness. They assumed that you had to be healed. They chucked me out because I didn't have any sins to confess. My friends were instructed to ignore me and I was ostracised. This doesn't happen in all churches, just when you get very powerful leaders. It was traumatic as my friends thought I'd obviously done something terribly wrong as you're not being healed, they had me in this tiny room three men and shouted at me for three hours. I was so ill and bewildered I had never heard of ME at that time, my brain was all foggy, speech slurred, I kept collapsing, I'd lost my job too. That night I curled up in a ball under the stairs and poured the sleeping tablets out. I had no support at the beginning of my illness. I was completely alone (Claire, 48, 18).

The reactions of others towards the respondents appeared to result in marked disadvantage. Thus, on top of the embodied experience of illness (as described in the previous chapter), it seems that they were denied access to the sick role with its' privileges of 'time out', 'medical support' and 'exemption from blame for illness'. Indeed, the findings suggest that sufferers of ME/CFS, during the initial pre-patient stage of the illness career, find themselves taking on the (opposite) non-legitimate sick role as described by Freidson (1970). For example, many of the respondents were forced, despite their condition, to continue in work or education:

I lost my job within a year, of course I couldn't get a medical certificate as the doctors didn't believe me. I had to get a job as a medical secretary. I kept falling asleep on the desk. The job was only part time but because I did it I had a terrible relapse (Claire, 48, 18).

I was forced back to school because we had a truancy officer come round our house ... the truancy officer said to my parents "If she's not back soon, you'll get taken to court and everything" which, you know, worried us. So I went back to school feeling awful (Anna, 21, 7).

Further, they were given little in the way of advice regarding how to treat and manage the symptoms. Thus they were left feeling none the wiser with regards to the aetiology, or prognosis of their condition:

It just became a matter of coping from day to day, not really understanding what was happening (Christine, 42, 6).

In addition to the practical consequences of the non-legitimate sick role, the feeling of 'not being believed' had a profound affect on the respondents' sense of meaning. Essentially, it appears that the sense of 'not being believed' exacerbated the loss of self that they already felt as a result of the losses caused by the symptoms of ME/CFS. For example, the respondents said that the stigma of malingering knocked their confidence in their sense of reality, causing them to question their own integrity:

The diagnoses (of depression) had a very bad effect on my self-esteem because I thought somehow that it was my fault and that the illness challenged my integrity (Pauline, 52, 12).

Further, the loss of self, was precipitated by the feeling that others too doubted their integrity to the extent that their claims to be ill were simply ignored:

'Cos (*sic*) he was saying, "I can't find nothing wrong with you". I even went to the lady doctor ... I burst out in tears in her surgery ... this is it, you see, you just couldn't understand it. I was getting annoyed with myself thinking, "This is stupid, why am I like this?" I must admit my family went through a lot of problems with me. I was getting so short tempered with them and accusing them of not understanding what I was going through and I said, "You don't understand. Nobody understands what I'm going through. I can't explain it to you." I said, "What I'm explaining nobody believes me" and I said, "This is the problem" I said, "Nobody will believe me, what I'm like" I said, "If somebody will only listen" (Jane, 54, 6).

All the time you are low, you're in a pit, no one listening anywhere and hasn't anyone else got this. I'm thinking, "Why can I be the only one?" You know, "Why isn't anyone listening?" (David, 30, 6).

Above all, the consequences of 'not being believed', appeared for the persons that took part in this study, to lead to a sense of being socially 'cast out', completely uncertain about the reality of illness and completely uncertain about the future:

It then became a big void of emptiness because previously I had been fighting to find out what was wrong and what to do etc. etc. Suddenly, you're being a void, you haven't got a name for it, how then do you get this over to friends and family, because it still sounds as if you're inventing something because you haven't got a name and also where you go from here. It's a world without an end as though you don't know whether this is for life or just for tomorrow. So I had a cross ... "You're on your own Buster", with this kind of open-ended thing. It's like stepping out of an aircraft that's flown away and you've stepped out into total void ... nothing (Wendy, 54, 21).

The sense of desperation felt by the interview respondents at this stage in the illness career was such that 5 individuals stated that they had wished that they had a fatal condition such as a brain tumour or cancer. The connection that the respondents made between their condition and what are considered culturally as 'the most serious illnesses' illustrates the respondents' ideas about the severity and chronicity of their condition. In addition, implicit in the respondent's accounts, is the notion that a medical diagnosis would provide a solution to the many problems that they were facing:

I began to wish that I had a brain tumour or MS just so that someone would acknowledge the fact that I was so ill. I thought that I was going nuts. ... Then the symptoms got neurological and they said I might have a brain tumour. I would have been pleased if I had have had one. In fact I was disappointed when they said I didn't have one as I desperately wanted someone to acknowledge that I was in a really bad way (Joanne, 26, 8).

Everything in life is so defined, there becomes this enormous yearning and longing to be one of these cancer patients to be told "You've got 3 months to live" because there's a definite point. There's a definite point in the next 3 months because you're going to cram it full of everything and there's a definite termination. There's a sudden realisation of how enormously lucky they are. It's almost perverse, but it isn't? (Wendy, 54, 21).



*Reacting to the non-legitimate sick role: taking the public view*

The above quotes imply, that rather than provide clarity and meaning to the bewildering symptoms, for those that were not diagnosed immediately after the onset of the symptoms, the initial journey along the pathway towards making sense of the symptoms was blocked. This led to circumstances of extreme distress. Indeed, the combination of the embodied experience of illness and the experience of the non-legitimate sick role, might account for why, as shown in the previous chapter, a high proportion of ME/CFS sufferers reported wanting to commit suicide during the early stages of their illness. However, again, as I have shown in the previous chapter, it appears that sufferers of ME/CFS somehow find a way of making sense of their conditions and thus regaining a sense of self. For many of the respondents, in the face of disbelief in their illness, the route to making sense of the symptoms involved, in the first instance, reassessing their original interpretation of their symptoms as physical and believing that perhaps their conditions were 'all in their mind'. This finding illustrates the power of cultural expectations about illness and backs up Goffman's (1968) argument cited in Chapter 3, that towards the end of the pre-patient phase, the stigmatised individual, in search of acceptance, feels as if he or she does fall short of what he or she ought to be:

By this time, it's been going on for so long that you are totally convinced that maybe the doctor was right. I mean my husband was totally convinced that I was off my head with some kind of Munchenhausen's Syndrome or whatever they call it. You know, when you invent this kind of scenario to gain attention or something. People convinced you. I didn't believe it, but I was beginning to feel I'd got to accept that this was perhaps the situation (Wendy, 54, 21).

I had no support at the beginning of my illness I was completely alone, within two months all this happened. I was so determined to get over what it was, I decided that I was mentally ill. I could not understand why though that I must be feeling so physically ill. I thought, "I must

pull myself together". I thought, "I know what I'll do, I must change my career", so out of 2000 people I got a place doing physiology. Even though I couldn't walk across the room, I worked through Gray's Anatomy. Got my uniform and books. In the end, I was so ill I couldn't turn up. All your self-confidence, credibility, friends, family job, lost (Claire, 48, 18).

Nobody understood. I felt, "Well, it must be me, it must be in my head" and it was an awful time actually it really was ... You go through all that business. I mean I had so many blood tests and they all come back, you know and they're fine and you do begin to feel like that nobody will ever find out what's wrong with you ... it was as if I was going round the twist (Viv, 65, 7).

Those respondents who considered taking the diagnosis of their GPs seriously, stated however, that, because of the continued incapacitating nature of their symptoms (as shown by the results of the SF - 36 in Chapter 5), they eventually became 'unstuck' with this way of thinking and arrived back at their original conclusion that their condition 'had' to be physical.

### *ME/CFS and the continued search for an explanation*

For all of the respondents, the antidote to the distressing circumstances of the non-legitimate sick role during the early stages of illness lay eventually in obtaining a professional diagnosis of 'serious illness'. Consequently, they started seeking an explanation for their symptoms elsewhere. For many, this involved 'starting on a long trail of different private doctors'. This finding suggests that once again the respondents entered the 'medical merry go round', but this time it was operated by a different set of experts. Despite this, rather than confirm the story of the patient, many private practitioners tended to corroborate the diagnoses of the NHS GPs and consultants. This

confirmation served to further impress onto the respondents the sense of futility, described above:

The first specialist said, in his view I was suffering from depression and that if I didn't have antidepressants I would end up with a nervous break down. The second specialist, I saw 6 months later, when I went a really yellow colour and felt desperately ill. I could hardly walk. I had to crawl upstairs. The doctor did a urine test, said, "you're depressed and you've been eating too many carrots". I said it was okay to tell me that he didn't understand the cause of my illness, but it wasn't okay to diagnose me with an illness just because he didn't understand it. That was the ultimate insult. I was so grieved by what he had said that that was the last time I went to the doctors about my ME (Pauline, 52, 12).

An added dimension to the 'private medical merry go round' appears to be that a number of individuals, in their desperation for an explanation, spent vast sums of money:

Next I went to this horrendous guy and his wife in (names town). They both did allergy tests and were from (names church). But you're so desperate and you'll clutch at straws. I went for about 4 weeks and he took £450 off me. They do this skin pricking and I had needles across the tops of both of my arms. I came up against everything. I was allergic to apple, barley beef, chicken, eggs, sugar, milk wheat, milk, yeast, carrot, cod, peanuts, peas, bacon, pork and tuna! He kept carping on about the illiocapel (?) valve. I hadn't heard of it. He'd lie you down, press your side and wave your leg up and down and then said, "You're okay now, that's 20 quid". That was that doctor (Pip, 40, 10).

### *Obtaining a diagnosis of ME/CFS: revisiting the dialectic of control*

The findings presented above suggest that the respondents eventually exhausted all of the conventional avenues that lead towards a diagnosis. At this point, it might be easy to assume that the respondents simply 'gave up' and 'accepted their lot'. However, this is not the case. Many of the interviewees eventually found out about the condition known as ME/CFS through other sources. This finding reinforces the finding of Robinson (1988) that when the 'medical merry go round' slows down, the discovery of a



diagnosis elsewhere might precede formal medical confirmation of illness. Further, it indicates that, despite the prevalence of certain ideas about the severity of illness amongst the public in general, alternative discourses also exist (particularly with regards to ME/CFS):

When I first heard of it my daughter said, "Oh my God, you've got ME" and I said, "What on earth's ME?" and so then of course, I took an interest and started trying to find out more details. It was very difficult at the time because there wasn't very much about and I can't remember when I first got an address from, but then I wrote to them and they sent me some literature and I read it and I thought, "That's me!" (Viv, 65, 7).

Of course they go through all the tests, but I actually realised what it was when two people came up to me in the office with an article they had read and said that it seemed to describe exactly what I was going through. At the time I hadn't heard of it (Bob, 50, 5).

For these individuals, the discovery of a label for the symptoms that fitted their interpretations of the illness as 'real', was a breakthrough. Having something to go on, many then went back to a medical practitioner to convince him or her that their illness was called ME/CFS. This finding, once again, highlights the importance of gaining a diagnosis. Further, it suggests that whilst as Freidson (1970) argued, medical ideas about illness tend to dominate, it is possible for individuals to change the minds of the medical profession with regards to the nature of illness.

I went and bought two books on ME and I read them through and I said, "That is me". All of it was me. So I went down to see the lady doctor and I said to her, "I've got this book" and I said, "That is me" and she said, "You've got ME" (Margaret, 63, 12).

Others, rather than go back to their GP, went to a private consultant to obtain an official diagnosis. This often involved travelling a long way and/or paying vast sums of money, as noted on the previous page by Pip:

In the end I had to go and see a consultant in Bristol (Rob, 60, 12).

But when it came out about ME, I paid to see someone in (names town). I didn't care what handle they put on it as long as they cured me (Bob, 50, 15).

I actually paid about 350 pounds for a private SPEC scan and went up there and had this and they proved that I've got a lack of blood flow to my, mainly to the frontal and priotal lobes which is consistent with having ME and A slight lack of blood flow to the brain stem as well (John, 55, 11).

Regardless of the time it took and through whatever means it was gained, all of the interviewees described their feeling on receiving an official diagnosis of ME/CFS as one of immense relief. In particular, it appears that the label of ME/CFS signified a way of solving the practical and psychological problems posed by the non-legitimate sick role and therefore a way into the legitimate sick role. For example, the respondents stated that a diagnosis served to confirm their own beliefs that the condition was more than just 'in the mind' and spoke of feeling that their 'integrity was restored' by 'being understood at last'.

It was such a relief especially to find someone who understood (Pip, 40, 10).

I was so relieved to find out, "Yes there was something", it wasn't in my head (Viv, 65, 7).

I come away from the doctors, it seems stupid and I've spoke to other people since and I come away happy, because he made me feel as though it wasn't in my mind ... But when he told me that I'd got it, you know, I came out and my husband was in the car park and he said "Oh you look happy what's happened?" And I said "They've diagnosed it, I have got an illness". I said, "I'm so relieved to think that there's somebody there that recognises you've got something that's not all in your mind" (Jane, 54, 6).

I was relieved ... I at last felt that through this lady that I actually had somebody on my side, which was good, it really was (Richard, 29, 6).

It was such a relief to have someone believe me (Joanne, 26, 8).

At least I had an excuse it sounds awful but I wasn't swinging the lead about it. People realised that I'm not well but it was diagnosed. (Geoff, 40, 10).

In addition to feeling believed, for those interviewees who had been searching for an explanation for a long time, the official diagnosis of ME/CFS provided a license to take legitimate 'time out' and rest:

I was diagnosed as having ME and told that I must rest immediately and well, I got into bed that evening and I'd never in my life experienced such terrible head pains which I hadn't had previous and I never got out of bed again for three months. It was almost as if I was told I could rest (Jill, 44, 10).

A further consequence of the diagnosis, again particularly for those who had waited a long time, was the feeling of finally 'having a lead to follow'. Thus, once they had obtained a name for their condition, the interviewees were able to conduct their own research in order to find out about its aetiology, prognosis, and treatment:

That's why I was pleased when the doctor told me the name of it as I had something to go on (Sarah, 24, 3).

I thought, "Right this is it", you know, "Now I can try and build my life" (Barry, 52, 3).

I said, "That's all right, you can tell me what it is" and that was that, I just started taking care of myself. You just, you can manage everything when you know what it is, when you have got the book and the information (Margaret, 63, 12).



## **Discussion**

The findings presented in this chapter indicate that during the initial stage of illness (the stage of seeking an explanation), in contrast to sufferers of other chronic conditions (as reported in the literature), sufferers of ME/CFS experience many problems in addition to the increasing incapacity brought about by their symptoms. This experience can be defined in terms of Goffman's pre-patient phase of the moral career. An understanding of the pre - patient phase of the moral career of ME/CFS sufferers provides an insight into three sociological issues.

First, the findings suggest that culturally ideas about illness are strongly bound up with ideas about the moral status of the sufferer. Thus, when a condition is seen as 'serious' the individual is granted access to the 'legitimate sick role' as described by Parsons (1952). In contrast, when a condition is seen as 'minor' the individual is not expected to gain access to the sick role. These ideas about illness, it appears, are held, not only by the public in general, but by ME/CFS sufferers themselves. Thus, at the onset of the symptoms of ME/CFS, sufferers go to great lengths to conceal their symptoms from others and 'carry on as normal'. Indeed, it appears that the power of cultural expectations about illness is such, that sufferers often attempt to carry on regardless for years until they are eventually forced to stop through collapsing or having a potentially fatal accident. The findings further indicate that culturally, much power is vested in the medical profession as an organisation that defines and categorises illness. Again, it appears that by virtue of belonging to the same culture, such ideas about the authority of the medical profession are held by sufferers of ME/CFS themselves. Thus as the symptoms persist, sufferers seek medical advice.

Second, the suggestion made by Freidson (1970) that the medical profession play a dominant role in the shaping of illness, appears to be borne out by the findings. For example, despite extensive medical testing, GPs and hospital consultants can find no pathological sign of illness. As a result, rather than diagnosing 'serious illness', sufferers report being told that their symptoms are related to the aches and pains of everyday life. Implicit in the non-diagnoses of serious illness made by GPs and hospital consultants appears to be the moral judgement that sufferers should, 'pull themselves together'. The 'non diagnosis' of serious illness as made by medical professionals has profound implications for sufferers of ME/CFS. Indeed, the findings suggest that when an individual is not accepted as ill, yet continues to make claims to being ill, he or she will experience illness in a way that can be described in terms of Freidson's non-legitimate sick role. A central feature of this role is that the individual becomes prone to accusations from others of not knowing his/her own mind and/or making illness up for personal gain. As a result, he or she is not granted the sick role privilege of 'being exempted from blame for illness'. In addition, he or she is less likely to be granted access to the sick role privilege of 'time off from work, education and other daily responsibilities'. Further he or she is given little access to medical advice or treatment. As such, it appears that rather than gaining an explanation for the symptoms and thus regaining a sense of self, sufferers are propelled further away from the reality that they are trying to hold on to. In sum the consequence of the non- legitimate sick role during the early stages of illness appears to be a feeling of being socially cast out and alone in one's suffering.

Finally, the findings suggest that during the early stages of illness, individuals with ME/CFS begin to believe that 'perhaps they are hypochondriacs and malingerers'. This

results in them taking drastic measures to make themselves well. However, the continued, incapacitating nature of the symptoms appears to be such that eventually, rather than accept the diagnosis of their condition as psychosomatic, sufferers begin to challenge the definition of their condition. In doing so they continue to seek a diagnosis of serious pathological illness through the medical profession. This action attests once again to the power of cultural expectations about illness. First, it suggests that sufferers drawing on ideas about what constitutes real illness 'cannot believe' that their symptoms are related to what they associate with minor illness. Second, it indicates that sufferers continue to see a medical diagnosis as the solution to their problems.

The fact that eventually sufferers do obtain an official diagnosis of ME/CFS (a condition that they consider to be a 'serious illness'), suggests that despite the initial dominance of medical ideas, there is room in medical/lay interactions for negotiation. Indeed, at the stage of obtaining a diagnosis it can be argued that sufferers succeed in their struggle with the medical profession. This apparent feeling of success can be seen in the finding that a diagnosis of ME/CFS is met with total relief as sufferers expect that they will be able to leave the non legitimate sick role and gain access the legitimate sick role.

In the following chapter, I consider the experience of ME/CFS 'after being diagnosed'. This experience corresponds with the second stage of the illness career as described by Charmaz: that of 'reconstructing order'.

## **Chapter 7**

### **The illness careers of ME/CFS sufferers: reconstructing order**

#### **Introduction**

In this chapter I consider the second stage in the illness career of the ME/CFS sufferer. As I have shown in Table 4 (page 110), Charmaz (2000) suggests that this stage follows being diagnosed with illness and involves 'reconstructing order'. In exploring how individuals with ME/CFS reconstruct order, I investigate the respondents' experiences of first, seeking 'explanations for' and 'ways of managing' the symptoms of ME/CFS, second, seeking support from family, friends and colleagues and third, seeking financial assistance.

The accounts of the respondents with regards to 'reconstructing order', bear a close resemblance to Goffman's (1968) description of the second stage of the moral career. Goffman implies that once an individual is labelled with a stigmatising condition, he or she is stripped of many accustomed affirmations and satisfactions and subjected to a new set of experiences. In the case of ME/CFS, it appears that, despite succeeding in gaining an official diagnosis of 'illness', the usual avenues of support available to persons with chronic illness remain blocked. Indeed, the reports of the respondents indicate that, sufferers of ME/CFS continue to experience (or, in the case of those who were diagnosed during the early stages of illness, experience for the first time) the conditions of the non-legitimate sick role. Thus, they continue to have their moral status questioned by GPs who are reluctant to give any advice with regards to the aetiology



and management of the condition and in many cases, continue to blame their patients for time wasting and malingering. In addition, friends, colleagues and family members often continue to treat sufferers' claims to be 'really ill' with cynicism, as do disability officers, whose job it is to assess the eligibility of the sufferer for financial support. Alongside the practical problems that these ideas about illness engender, such reactions are said to lead ultimately to a complete 'non acceptance' of who the sufferer is.

Goffman (1968) argues that in response to this kind of moral labelling, individuals take on new sets of identity beliefs and practices. Thus they single out and retrospectively elaborate experiences, which serve to account for their coming to the practices that they have adopted. In response to their situations, the respondents drew on alternative discourses of ME/CFS that confirmed their ideas that they were really ill. This finding backs up Giddens' (1984) assertion that, in late modernity, individuals utilise more than one source of expert knowledge to make sense of certain phenomena. The discourses drawn upon by sufferers of ME/CFS suggest (as demonstrated in chapter 1) that ME/CFS is a pathological condition caused by external agents such as a virus or organophosphate poisoning. Such discourses are often contextualised by the respondents within their own biographies and as such, serve to help them reconstruct order by providing what is seen as a plausible explanation for their condition. In addition, the alternative discourses of ME/CFS act to protect the moral integrity of the sufferer by providing a rationale that states that 'others' react the way they do because they are simply uneducated about the 'reality' of ME/CFS and have a 'limited understanding' of it. Despite being able to legitimate ME/CFS to themselves however, the findings suggest that sufferers fail to change the views of others and gain access to the legitimate sick role.

## **Reconstructing order: seeking ‘explanations for’ and ‘ways of managing’ the symptoms of ME/CFS**

As I have shown in the previous chapter, for those respondents who spent a long time in what I have termed ‘the pre-patient phase of the moral career’, a diagnosis of ME/CFS represented success in terms of changing the medical opinion of their illness from being ‘in the mind’ and ‘non serious’ to ‘real’ and ‘serious’. Further, a diagnosis signified the beginning of being able to ‘reconstruct order’. That is, many individuals assumed that others would believe, at last, that they were not ‘making their symptoms up’. This, it was stated, would lead to a situation of social acceptance and medical support, a situation that can be defined as ‘accessing the legitimate sick role’. The findings suggest however, that the feeling of success on obtaining an official diagnosis of ME/CFS is short lived. In the first instance, it appears that a diagnosis makes little difference with regards to seeking ‘explanations of’ and ‘ways of managing’ the symptoms of ME/CFS. The first indication of this can be seen in the finding that GPs were reluctant to provide medical advice about how to treat and manage the symptoms. Instead, the respondents were told simply that ‘nothing could be done’, to ‘go home and rest’ and to ‘seek help from the support groups’:

I didn’t really understand much about the illness, it was just that they said, “You’ve got ME.” They never said, “Well you know this is this and this is what its going to be like” or anything (Anna, 22, 6).

The reluctance on the part of the medical profession to provide medical information immediately after providing a diagnosis, was met with shock by the respondents. As such, it was seen to imply a lack of commitment to ME/CFS and the continued underlying belief that the moral status of the sufferer was questionable. Indeed, the

reaction of the medical profession having diagnosed ME/CFS demonstrates that, whilst sufferers succeed in obtaining a diagnosis for their condition, the medical profession continue to play a dominant role in the moral ordering of illness. The extent to which this reaction to ME/CFS impacted on the experience of 'all' of the respondents is shown below. However, first it is necessary to make a brief digression from an analysis of the illness careers of sufferers 'in general' to consider the initial experiences of those respondents who were diagnosed with ME/CFS during the early stages of their illness.

*The consequences of not being informed about ME/CFS for those individuals who were diagnosed with ME/CFS during the early stages of illness.*

The experiences of those individuals who were diagnosed close to the onset of their symptoms merits discussion at this stage of the analysis because they underwent an experience that appears to be similar to that of the pre-patient stage of the moral career as described in the previous chapter. Many of these individuals, at the time of being diagnosed, had heard about the condition known as ME/CFS and assumed, like the public in general (as I show later in this chapter) that the condition is a 'minor illness'. The diagnosis of ME/CFS and consequent lack of information served to reinforce this initial idea and thus led to the assumption that they had 'nothing of any significance'. Indeed, many of the individuals who were diagnosed 'early on' assumed that they would be well again in a short period of time:

I thought it was just going to be for a little amount of time (Anna, 22, 6).

I never thought of it as really severe compared to other illnesses (Dominic, 17, 3).

In particular, the male respondents associated ME/CFS with 'woman's problems'. That is, they saw their symptoms as indicative of 'not coping with the stress of everyday life' and related to 'emotional problems' similar to pre-menstrual tension or the menopause. This idea of ME/CFS was perpetuated, in many instances by their GPs:

The doctor said, "Do you read women's magazines? I believe you've got ME." He said, "Have you heard of ME?" and I said that I hadn't and he said, "That's what I think it is." So okay, great, no problem, we'll carry on bearing in mind I thought it was something like chickenpox (Dan, 26, 12).

The finding that the male respondents saw ME/CFS as a 'female problem', backs up the findings of Ettore and Riska (2002: 1187) that accounts of illness reflect gender specific psychological distinctions. Indeed, the actions taken by the 'early diagnosed' male respondents, indicates that as Ettore and Riska argue, for men, to admit to succumbing to a 'female illness' would indicate a 'loss' of their 'self regulatory power and autonomy'. For example, in the absence of much information about ME/CFS many of the male respondents attempted to carry on regardless:

ME, as far as I was concerned was all in the head anyway. I knew the only way round this was to believe there was nothing wrong with me so I carried on and on (Jim, 25, 5).

As with those individuals who during the pre-patient phase dismissed their symptoms as 'not serious', the continuing symptoms and their increasing severity led those persons who were diagnosed with ME/CFS during the early stages of illness to eventually 'rethink' their ME/CFS and assume that the condition might be more serious than they originally thought. Many of the male sufferers who were diagnosed early on rejected their interpretations of their GP's diagnosis and attempted to seek further proof from the medical profession that they had what they considered to be a 'real' or 'serious' illness.



I just carried on and on. But I just couldn't get everything together I was relying more and more on others ... I went back to the doctor again and said, "You know this ME business? I don't think it's that, I think it's a bit more serious." So I had another load of blood tests and I thought, "Great this'll finalise it, I can get back to square one" and the tests come back and there was nothing there, at all. I thought, "There's got to be something 'cos (*sic*) I'm so blimming tired and knackered" (Dan, 29, 6).

The data suggests however that like those who sought confirmation that their symptoms were indicative of pathological illness during the pre-patient phase, for both males and females, the seriousness of ME/CFS was often confirmed via other sources:

My mum said, "look there's this chap, he suffered from ME." (Eventually) I said, "Get hold of him, I need to speak to somebody." He sat the family down and I thought, "Here we go this is some hypochondriac telling me you know what it's all about." He said, "Okay Dan" and asked me what I did and every thing else and he said, "You're a classic case of ME" and I said, "Yeah, yeah right". I didn't really want to know. Then he started going through the symptoms and I thought "Christ, Yes that's what I've got!" and at that point I just wanted to break down and cry. Well I did break down and cry. A fully-grown man of 25, wanting to break down in tears. It just all came back. He said, "Look you've got to take it seriously and you're going to have to take time off work" (Dan, 29, 6).

The ultimate consequence of not being given much information about ME/CFS during the early stages of illness appears to be that many individuals who are diagnosed early on experience a 'delayed reaction' to their diagnosis. That is, initial relief is followed by grief and despair as patients learn, through other sources, that ME/CFS is experienced as severely disabling and can last for many years:

I just went ballistic because I knew it lasted for about a year and (my mum) contacted the ME Association for some literature and some books and anything that she could read up on. And she had to have it all sent to my Gran's house because if I saw anything with ME written on it or I heard her mention it or anything I just went, "No, no, no, no, no" (Janine, 24, 10).

*Becoming informed about ME/CFS: the experience of 'all' sufferers post diagnosis*

The findings suggest that, in spite of apparent disinterest from their GPs, regardless of the stage of illness at which they are diagnosed with ME/CFS, sufferers go back to their GPs in search of more information. This, it appears, leads to further problems. As such, often when the sufferer goes back to the GP for help, it becomes clear that whilst both parties agree on the diagnostic category for the condition, their ideas about ME/CFS differ. For many of the interview respondents, this position was made explicit by the GP, who suggested that the condition derived from psychological problems:

The bloke was no use what so ever he went off into a long spiel about how, "There are some of us that don't believe that it is an organic illness, there are some of us that feel that it is psychological" (Liz, 25, 10).

My first GP was the family doctor he was an absolute \*\*\*\*\*. He sent me to the psychiatrist, he asked me about my sex life, whether I liked the opposite sex – it was as if he was saying I had ME because I was homosexual. The whole attitude at that doctor's surgery was horrible. One day I lost my temper with the secretary and they told my doctor. And one day the locum saw me and he didn't believe me I was using Aloe Vera at the time and he said, "You've either got skin problems or you are a woman" (Dan, 26, 6).

When I went to the doctor I asked him out right "What are your views on ME?" and he said, "I'm very sceptical" (Adam, 42, 10).

*The consequence of not receiving any help from the medical profession post diagnosis*

In addition to experiencing continued judgements by GPs about their moral status, the continued lack of help from the medical profession appears to result in a feeling of

‘having no one to turn to’ and continued uncertainty. As such, it seems that the sufferer feels no closer to reconstructing order in terms of answering the questions of ‘Why me?’ and ‘How do I manage?’

You never know what happened. You can only piece together the jigsaw for yourself and that’s the perspective you have to take it from. You feel so alone and isolated when you’ve got it, as if you’re the only person in the world with anything wrong with you. I mean it’s the only way to keep sane. You ask, “Why did it happen to me?” (Pip, 40, 10).

### *Reconstructing order: ME/CFS and the continued search for meaning*

In the face of disbelief from GPs ‘post’ diagnosis, the respondents began to reconstruct order by drawing on the alternative explanations of ME/CFS that they read about in the literature. This backs up Giddens (1984) point that, in the conditions of late modernity, there are a range of expert discourses to draw on in making sense of certain phenomena. Indeed, as the respondents read more about ME/CFS it appears that their own perceptions of the condition as ‘serious’ and ‘real’ began to be confirmed. This new knowledge marked a shift in the way of thinking about doctors in general, who were consequently seen to possess a limited knowledge about the ‘reality’ of ME/CFS and as such ‘misunderstand’ the condition. These ideas about the ‘true nature’ of ME/CFS served to reinforce the notion that local GPs, by virtue of their ignorance about the condition, were actively discriminating against the sufferer:

Understanding was not replaced with “non understanding” but it was replaced with “misunderstanding”. And treatments were not replaced by “no treatments” they were replaced by “mistreatments” (Pauline, 52, 12).

Indeed, a number of the interview respondents stated that they felt angry and let down by the medical profession:

I feel betrayed by the apathy of doctors (Male, 40, 6, written response to the quality of life question).

I hated doctors (Scott, 18, 5)

As I have suggested above, despite their limited capabilities for mental and physical functioning, the respondents were compelled to reconstruct order by taking on the full responsibility for educating themselves about the medical debates surrounding the cause of and treatments for ME/CFS. This is put succinctly by Pip who states that the sufferer 'is left to piece together the jigsaw for him or her self'. Similarly Pete states:

I joined the National ME Association and I got the book by Charles Shepherd and learnt as much about it as I could that way (Pete, 51, 16).

The problem with becoming what might be termed 'a lay expert on ME/CFS' was said to be that, 'the more that was read, the more confusing things became'. For example, on starting to read up on the aetiology of ME/CFS, the respondents stated that they came across the mass of information that I have described in Chapter 1. This, it was reported, was confusing and often contradictory:

I eventually got some books on it but I was confused, because different books were saying different things (Jane, 54, 6).

Despite the initial confusion and uncertainty caused by the information available on ME/CFS, however, many of the sufferers arrived at some sort of explanation for the condition. These explanations, again, as I have suggested above, were based on the idea that ME/CFS is a physical or 'organic' illness. For example 84% of the questionnaire sample and all of the interview respondents, reported that they thought ME/CFS was a



physical disorder. Some of the interview respondents argued that ME/CFS is caused by a virus:

I think it's the virus of glandular fever. It lies dormant and when you get something like the flu, it comes back again (Dan, 26, 6).

I don't doubt that they will find the cause of it and I think it's a virus. One time I thought it's something in the food chain. God knows what goes in the food chain these days and I thought ... they are now saying that cervical cancer is due to a virus but they haven't found one for ME. But I do think that one day it will come out. What they can do about it I don't know, but it's amazing when you think that even Florence Nightingale had something very similar to ME. Then there's clusters of it isn't there? (Margaret, 63, 12).

I think the virus lays dormant in your muscles. When you use them, you reactivate the virus. You wake it up. (Bob, 50, 15)

Many favoured a chemical hypothesis:

I think Gulf war syndrome and organophosphate poisoning that's very similar, but it's not like every farmer who's been exposed to OPs isn't ill and similarly, whatever causes ME doesn't cause it in everybody, so what triggers it in some people and not in others? ... I think it's environmental, something you ate or something that's in the atmosphere. They had poison in the water at Camelford, it's like that. People don't make up the conditions for the fun of it what is the point of that? (Pete, 51, 16).

I believe that ME is caused by a build up of chemicals in the body. Once the chemicals reach a saturation point they start to leak into the system and poison it. Interestingly, psychologists say, "Depression". Depression is an American word; it used to be called melancholy. Melancholic is Greek for 'black bile', when the bile is black it is altered due to poisoning. The word may have originated because there was a lot of poisoning in Roman times. The Romans used to work with lead piping (Kevin, 51, 10).

Others considered their condition to be caused by a dysfunctional immune system:

I think it was just a little less than a year, that I first went to the doctor realising that something was wrong with my immune system ... I think at that stage all the doctor did was take some blood tests to see why my immune system seemed to have packed up (Christine, 42, 6).

Others stated that they thought their ME/CFS might be related to their genetic make up:

I wonder if I'm responsible for carrying a gene that precipitates cot death and ME. (Pip had a son who died from cot death) They've found a link between cot death and ME in New Zealand (Pip, 40, 10).

And some argued for a multifactorial aetiology:

It totally knackers (*sic*) up your immune system. Mine was totally wiped. I've been open to every cough, cold that's gone round. And it seems as though there's a virus in me that's in there, that flares up every few weeks really and it will flare up and then you will go into a relapse and then you'll go down again and you'll get over that and you'll have another (Esther, 34, 5).

As the quote from Pip above suggests, those respondents who felt they had some understanding of the aetiology of ME/CFS tried to make sense of their conditions by contextualising the various expert discourses on offer, into their own biographies. This finding backs up the observation made by Williams (1984) and Comaroff and Maguire (1981) cited in chapter 3, that questions relating to 'Why me?' are often worked out against the backdrop of the events that occur in one's own life:

At the beginning, I moved into a timber framed house sprayed with petrachloro ... organo phosphates and other solvents ... within a few years this Vagnasolve, as it was known, was banned as it was killing people. After I'd been in the house a few weeks I developed the flu. It wasn't flu. It was weird I couldn't breathe and it hit my brain (Claire, 48, 18).

I used Timber treatments, I was a builder you see, and I think that was the start of it (Kevin, 51, 10).

These findings indicate that, regardless of the reactions of local medical experts, ME/CFS sufferers do eventually find ‘something to go on’ and are thus able to arrive at an explanation for their condition. As such, rather than challenge conventional ideas surrounding psychological illness it appears that ME/CFS sufferers opt to find an explanation that is fitting with common cultural conceptions of what constitutes ‘real illness’. These explanations however, are vague in comparison to the explanations given by persons with other chronic illnesses. As such, implicit in them is a high degree of uncertainty. Indeed, Joanne admits:

I wouldn't mind not knowing what caused it - long as I knew what was happening inside me and how to treat it. I mean is it just the brain, the muscles or what? (Joanne, 26, 8)

#### *Reconstructing order: seeking treatment and management advice*

The search for a meaning behind ME/CFS is also accompanied by the search for a treatment and cure. In the absence of much help from their NHS GPs, a number of the respondents sought advice from private GPs, however, by far the most popular source of help was complementary therapists. This finding, again, backs up Giddens' (1984) suggestion, that individuals in contemporary society draw on a range of expert systems. 80% of the questionnaire sample had seen a complementary therapist at some point in their illness career. The types of therapist that were consulted are shown in Table 18 below. 49% of the sample had consulted a homeopath, 33% had seen a reflexologist, 32% had seen an acupuncturist, 29% had seen a nutritionist and 26% had seen a spiritual healer. A further 8% had seen a Naturopath, 5 % had seen an aromatherapist, 5% had seen a kinesiologist, 5% had seen a crystal healer and 4% had seen a chiropractor. In addition to the therapists shown in Table 18, other complementary

practitioners consulted were: hypnotherapists and specialists in either, colonic irrigation, reiki, bioenergy, Chinese herbal medicine and Alexander technique. According to the interviewees, as well as seeking help from private consultants and alternative practitioners, information about treatments was also found in support group magazines, health food shops, chemists, books and magazines and on the Internet. Many treatments were obtained through the post.

**Table 18:** Types of complementary therapist consulted by the questionnaire respondents (N=265)

	<i>Number of respondents who consulted</i>	<i>%</i>
<i>Homeopath</i>	131	49
<i>Reflexologist</i>	88	33
<i>Acupuncturist</i>	84	32
<i>Osteopath</i>	77	29
<i>Nutritionist</i>	67	25
<i>Spiritual healer</i>	69	26
<i>Naturopath</i>	22	8
<i>Aromatherapist</i>	14	5
<i>Kinesiologist</i>	13	5
<i>Crystal healer</i>	13	5
<i>Chiropractor</i>	11	4
<i>Shiatsu</i>	11	4

As with the availability of alternative discourses on the aetiology of ME/CFS, outside of the doctor's surgery there appears to be no end of treatment avenues to explore. Indeed, it seems that there are so many remedies available, that the quest to find a cure or treatment for ME/CFS may be endless:

I've tried most things that are going. A Tens Machine. It just makes my muscles go into spasms. I've taken loads of vitamins, oh this horrible Kombucha Culture urrh (*sic*). It made me feel so ill, you brew this tea, put vinegar and sugar in it. Then you put this culture in it. You sieve the culture out and drink it. I've been trying these things all along, homeopathic stuff. I take antidepressants to make me sleep, I've got



tablets for the nausea, tablets for the vertigo, tablets for the stomach ache. One person in my group said the other day, "This is so sad, I've resorted to eating grass". She'd been trying this remedy which you grow from seed. It looks like grass! The things we'll try; it's just ridiculous. I get a lot of stuff off the Internet, the ME BFF Network. She sends out a lot of stuff every month. There's constant research going on, with drugs etc. There's the cold water treatment. There's all these vitamins that you can take. There's loads of anti oxidants, carrot juice and stuff. My mate's just given me loads of bumf (*sic*). He got his ME when he had his wisdom teeth out. I've heard the one about having your fillings out and I keep thinking shall I or shan't I? (Joanne, 26, 8).

Implicit in the respondents' statements is the notion that sufferers of ME/CFS are so desperate for a cure, that they'll try anything. This desperation appears to make sufferers vulnerable to a range of hazards. First, the findings suggest that the desperate search for a cure may make them spend a vast amount of money (as noted earlier):

I think I have probably spent upwards of 8000 pounds (Geoff, 40,10).

Second, it appears that sufferers are exposed to the risk of being conned by persons eager to exploit the growing demand for treatments:

He said, "It's ME", I said, "What's the cure?" He said, "You've got it so bad you're never going to recover, I'm putting you to bed, go upstairs ... It's £200 a week." I replied that I didn't have any money and he asked me whether I had a house. He suggested that I sell it so that I could afford to live there, he said, "Really you've got no choice." They told me again to sell my house and put £7000 down. I discharged myself (Claire, 48, 18).

Third, the findings suggest that, the easy access to information about treatments and the lack of regulation can result in sufferers further risking their health by using untested or illegal substances:

So I am more on an even keel but that is basically through the Choloidal Silver I think. It's even beaten the homeopathy. Absolutely fantastic ... It's just silver particles suspended in water. I found it at an alternative

get together at (names venue), “Quest”, that’s what it’s called. So I went there and money back guarantee and I thought, “Can’t go wrong on this stuff”. So I tried it and by the time I got near to the bottom of the bottle I thought, “Yea (*sic*), I’ve been doing quite well lately”. So I liked it so much I got a machine that makes it. So now I have it basically on tap and I am just ... and that’s got rid of all the viruses in me. It says it kills hundreds and hundreds of viruses. My dad looked it all up on the Internet and found the sad cases that got poisoned by the stuff. But, no I like it, it suits me down to the ground ... Basically I want a cure (Esther, 34, 5).

Fourth, many of the treatments available appear to have the potential to worsen the already compromised quality of life of sufferers:

My mum’s friendly with the nutritionist. She’d treated several people with ME and apparently helped them and so I went to see her. So we went on a restriction diet and it was so boring and I didn’t feel any better for it and was just, like usual, missing my sugar, and by the end of the month, that was it. I just couldn’t hack it anymore. It was pate, rice cakes and oat biscuits, loads of veg and more veg and it was just dire. The thing is you weren’t eating any nice comfort food to cheer yourself up really so I decided the diet had to go (Esther, 34, 5).

Ultimately, the accounts given by the interviewees indicate that as they continue desperately to seek treatments, they experience a relentless cycle whereby hopes are raised and consequently dashed, as new treatments are tried and found to have little impact on their symptoms. This cycle as I have shown in chapter 3 has been defined by

Jobling (1988) as the Sysphus Syndrome:

I tried so many different strategies and each one I tried I was disappointed but I carried on saying, “What shall I try next?” (Pauline, 52, 12).

One respondent described this phenomenon as ‘chasing the end of the rainbow’:

Don’t look for false hopes because I’ve been there too many times. I’ve seen quite a lot of my pen friends who have chose what I call “at the end of the rainbow” and I’m not saying that you shouldn’t do that ‘cos (*sic*)

you should and it keeps you going. But don't think every single time "This is it" and put all your absolute soul in to this being it. Because you say to yourself, "Next time this happens I am not going to let this happen and you do it every time" (Janine, 24, 10).

As with sufferers of other chronic illness, the majority of the interviewees eventually reached a point in their illness careers where they realised that most of the treatments on offer had little impact and that going desperately from treatment to treatment was actually detrimental to their health, finances and quality of life in general. For some, this stage was reached early on in their illness career as financial management and coping with everyday life took precedence:

Actually it takes a lot of energy going along those lines and I just can't afford the energy at the moment. With having to run a family I can't afford to do things that are going to make me worse (Christine, 42, 6).

This stage of slowing down the search for treatments, appeared to be marked by a shift in perspective, whereby the desperate hope for a 'fix' was replaced by the gradual resignation that despite being physical, perhaps their condition was after all, untreatable and more importantly, incurable. The realisation that little could be done signalled the beginning of accepting or coming to terms with ME/CFS:

The first thing that I had to do was come to terms with the fact that this was the situation and no matter how much I hated it and wanted it to be different at this moment in time there was nothing I could do. I couldn't take a pill. I couldn't have an operation. So I had to learn that this was the situation and fighting it aggressively and in the wrong way was not going to help the situation, it was going to make things worse. The way that I learnt to look at it was, "I can't beat this illness physically but mentally, if I don't give it the things to feed on to beat me then I'm beating it" (Janine, 24, 10).

The findings presented in this section suggest that the process of understanding ME/CFS is, like the process of making sense of illness in the pre-diagnosis stage, beset with



obstacles that derive from the idea that ME/CFS is all in the mind. Despite these obstacles, it appears that sufferers find ways of reconstructing order by drawing, in the main, on information deriving from alternative sources. The sufferer of ME/CFS uses these alternative sources, in the same way sufferers of other chronic illness use conventional sources of information: to justify physical illness. This it appears, enables him or her to make sense of what his/her condition and legitimate his or her illness and hence his or her moral status to him or herself.

*Reconstructing order: seeking support from others*

Whilst sufferers of ME/CFS appear to get round the problems posed by the medical profession by 'cutting out the middle man' and becoming experts in their own right, the findings suggest that they continue to experience the non-legitimate sick role. This experience is perpetuated by friends, family, colleagues and other associates who, despite a diagnosis of ME/CFS, continue to see the sufferer's condition as indicative of 'non serious' illness. Thus, rather than obtaining support from others, others, in many cases, continue to compound the experience of illness by imputing on the individual, moral judgement in the form of the stigma of 'hypochondriasis' or 'malingering'.

Evidence of the stigma associated with ME/CFS can be seen in the response to the question posed on the questionnaire: 'What would most improve your quality of life?' For example, 13% of the sample said that their quality of life would be improved if there were a change in the attitude of the general public towards ME/CFS. In their written statements, the questionnaire group defined the general public as 'everyday people', 'strangers', 'colleagues', 'friends' and 'family members'. This finding suggests



that as Goffman (1963) argues, the pervasiveness of stigma is such that it permeates most encounters that individuals have with 'normals' and 'the wise'.

Within their statements the questionnaire group suggested that the reaction of others in general often tended to be to that of disbelief that ME/CFS exists. As one person put it:

(My quality of life would be improved) if people believed that what I said was true (Female, 45, 8, written response to quality of life question).

In addition, the interview respondents stated that when they were not believed, others often implied that they were 'malingerers', 'lazy', 'not pulling their weight', 'skiving', 'being wet', 'pathetic', or 'moaning':

Because there is so little known about it we are open to abuse, to allegations of malingering, to mistrust (Trevor, 62, 8).

The "It's all in your head" philosophy prevails (Male, 39, 4, written response to quality of life question).

The interview respondents stated that the reasons why they continue to experience the stigma of hypochondriasis after being diagnosed with ME/CFS is that the public are simply unaware of the reality of the condition. Indeed, as Table 19 shows below, 43% of the questionnaire respondents stated that the public did not know what ME/CFS is. 21% reported that the public did not know whether ME/CFS is physical or psychological and 21% reported that in their view the public thought that ME/CFS is a psychological condition. Only 3% reported that in their view the public thought that ME/CFS is a physical illness.

**Table 19:** What the public think about ME/CFS according to the questionnaire respondents (N=226)

	n	%
<i>The public do not know</i>	115	43
<i>Not sure if it is physical or psychological</i>	55	21
<i>It is a psychological disorder</i>	56	21
<i>Total</i>	226	85

The interview respondents stated that the public is confused and thus sceptical about ME/CFS for four reasons. First ME/CFS is equated with Yuppie flu and therefore seen as ‘made up’:

Well, I suppose its so annoying because everybody understands other illnesses like MS and cancer. But ME, it’s still got that stigma of being Yuppie flu and “Pull yourself together, nothing wrong with you” (Esther, 34, 5).

Second, the symptoms are equated with trivial health problems:

People that don’t know me don’t really understand, even though I take in all the leaflets, for them to see what it was actually I had. At one stage I said, “I would never wish this on anybody.” But I’ve gone beyond that now I now think people ought to, really, really ought to, have it for a good few months and then they might actually realise what 5 years is like. Because I got really fed up. Because somebody had flu and they said, “Ooh I really know how you feel.” I thought, “You’ve only had it for two weeks.” They said, “I was sat in bed and I couldn’t do any thing.” I thought, “Yes, two weeks.” (Esther, 34, 5).

Third, persons with ME/CFS rarely look ill. For example one respondent said:

People say, “Well you look okay”, well, so what like, most people who are dying from cancer look okay but you wouldn’t dare say it to one of them would you? You wouldn’t dare be so insensitive as to say, “You look alright” to somebody who had cancer. But most people think its perfectly alright to say something like that to me, like that means I must be okay, you know I look okay, so I must be okay (Martine, 30, 6).

And finally, the respondents stated that there has been a lack of public awareness about the 'reality' of the symptoms:

I think they think heart disease is more serious and that ME is nothing you're tired that's all. There's so much about heart disease when you see open heart surgery on the TV you see it quite frequently these days, yes, "Oh that's a big one", people understand that you've had your chest opened (Jane, 54, 6).

This latter findings reflects, once again, the general cultural idea that ME/CFS is a minor illness and as such, warrants little in the way of a publicity campaign to educate persons to think about the condition in any other way. Further, implicit in the quotes above is the notion that illness is ordered according to a moral hierarchy, whereby conditions such as cancer and heart disease are at the top of the hierarchy and conditions associated with tiredness such as ME/CFS are at the bottom. Moreover, the above statements demonstrate the continued belief amongst sufferers that their condition is misunderstood and wrongly placed at the bottom end of the moral hierarchy.

#### *The consequence of being stigmatised by others*

The main consequence of the stigma of hypochondriasis appears to be that sufferers of ME/CFS continue to experience what Bury (1988) describes as 'meanings at risk'. As I have argued in Chapters 3 and 6, 'meanings at risk' refers to the experience of never being sure whether, during social interactions, that others share the same meaning of illness as you. Indeed, the persons that took part in this study spoke of having to 'continually explain themselves' or being 'under constant pressure to explain themselves' or being 'faced with sceptical people all the time'. Many felt pressured or challenged by the attitudes of others and maintained that they regularly had to 'convince

others' and 'defend' or 'justify' their condition. Challenging encounters appeared to occur frequently on the daily round of the individual. For example, many of the respondents stated that they were judged by friends, family and acquaintances:

My friends really have not got any understanding, none of my friends have got any understanding of it at all they think that I'm putting on them to ask them to come round ... There's not one of my friends that I had before that understands (Martine, 30, 6).

I know that I'm going to be hearing from my father any minute he still has no understanding and will come down here (for Christmas) and expect me to put his breakfast on the table which I can't do, I can barely get my own breakfast (Jill, 44, 10).

At the time I really didn't want to get up. My father laughed at this, I mean he literally didn't understand, he couldn't comprehend any of this. My old man would say, "Come on then boy, we'll go out and do this and I'd say, "I can't dad" and he couldn't relate to the fact that this was his son who was 20 years younger than him (Richard, 29, 6).

As the above quotes suggest, the second consequence of having ME/CFS in terms of reconstructing order is that, in the absence of understanding from others regarding the severity of the condition, sufferers are expected by others to continue in their previous roles. Because of this, attempts to gain control of the activities of social life become more difficult. As such, it is harder to delegate the responsibility for chores to others. These findings, as I have suggested above, are indicative of the non-legitimate sick role as described by Freidson (1970). That is, sufferers do not gain exemption from blame for illness, but take on the extra burden of stigma. Further, they do not gain full access to the sick role privilege of 'exemption from daily responsibilities'.

The reactions of others towards the ME/CFS sufferer has implications for how individuals learn to live with the condition. Indeed, it can be argued that, because of the



stigma of hypochondriasis, the lost self that Charmaz (1983) refers to is perpetuated. For example, one respondent stated that the attitudes of others amounts to 'a complete non acceptance of who I am'. Indeed, the findings suggest that, whilst sufferers of ME/CFS appear to be able to reconstruct order by drawing on alternative sources to legitimate their conditions to themselves, it is impossible to change the opinions of others with regards the moral status of ME/CFS. Rather, they attempt to protect themselves from the stigmatising attitudes of others by, where possible 'passing' and/or covering:

All through my illness, I've never found it that easy to talk about having ME. I'd rather kind of ignore it and hope that other people would too (Liz, 25, 10).

I tend not to tell people. I'm quite a private person. I don't want people to know. ME still has that hangover from the 80's of Yuppie Flu (Scott, 18, 5).

It's different having it if you're male because men naturally bottle things up about their illnesses whereas females talk to each other. Men have to be seen as hard and macho (John, 22, 3).

I'm careful about who I tell as some people don't understand and they think you're a bit "doo lally" (*sic*) anyway. If someone come up to you and said they had cancer you'd understand. I used to sometimes wish that I had something like cancer 'cos (*sic*) people can understand it 'cos (*sic*) as far as I was concerned my life was restricted enough that it might as well be cancer. But nobody understood it and I didn't want sympathy. I just wanted understanding. I didn't want anybody to say "Poor Richard", I just wanted people to understand the reason why I wasn't jumping up and down and doing things I used to was because I was genuinely ill. I go up to racing now and I see my old mates and there's some people that know but I don't tell most of them and people keep asking when I'm coming back because they see a healthy person. I used to go up there and they'd say, "Come on we'll get a cart ready for you" and I know that I'm still struggling, but I hate to tell anybody (Richard, 29, 6).

If it is just a brief social contact, I just act well and don't mention it. I can cope like that for a little while, but obviously if it's more of a prolonged contact, it's going to need a different approach (Christine, 42, 6).

In sum, the accounts of the respondents suggest that sufferers do not manage to gain access to the legitimate sick role through persuading others to believe them. Rather, they have to learn ways of adapting to the non-legitimate sick role. This finding is also borne out in the data on 'seeking financial assistance'.

### *Reconstructing order: seeking financial assistance*

Many of the respondents, unable to work, had to seek financial assistance from the Department of Social Security. The benefits system is a complicated one and in order to understand peoples' experiences of it, it is first necessary to outline how it works. The Department of Social Security provides two main kinds of benefit for persons with an illness or disability. These are outlined in Table 20 below. In Table 20, I have defined these two benefit types as 'unemployment benefits' and 'illness or disability benefits'. As their name suggests, unemployment benefits are designed to cover the cost of not being able to work. Illness or disability benefits are designed to cover any additional costs engendered by a person's condition. These are the cost incurred through being physically immobile and/or unable to look after oneself.

There are four types of unemployment benefit available. These are: incapacity benefit, income support, statutory sick pay or the retirement pension. The type of unemployment benefit for which a person is eligible to apply depends on factors such as previous employment, age, household income and payment of National Insurance

contributions. Similarly, there are three types of illness or disability benefits. These are disability allowance, attendance allowance and severe disablement allowance. A person's entitlement to each illness or disability allowance is dependent in the first instance on age and National Insurance Contributions. The basic details of each benefit are summarised below.

**Table 20.** Disability benefits: a guide to the main benefits available to ill or disabled people over the age of 16 years

<i>Name of benefit</i>	<i>Details of persons eligible to claim</i>
<i>Unemployment benefits</i>	
Statutory Sick Pay (SSP)	Proven illness or disability, aged < 65 years and employed at illness onset
Short Term Incapacity Benefit	Ill or disabled for < 1 year, < 65 years, unable to get SSP, N.I. contributions.
Long Term Incapacity Benefit	Ill or disabled for > 1 year, < 65 years, N.I. contributions.
Income Support Pension	Ill or disabled, < 65 years, low income, no N.I. contributions. 65 years +
<i>Illness/Disability benefits</i>	
Disability Living Allowance: Care component Mobility component	< 65 years.
Attendance Allowance	65 years +
Severe Disablement Allowance	25 years or over, no NI contributions. Used to be available instead of income support

Source: leaflet number SD1 April, 2000

A person with an illness or disability may submit a claim for both unemployment benefit and for an illness or disability benefit. As all these categories are separate, the procedures for assessing whether a person is entitled to benefits from each category are also separate. For example, if an individual attempts to claim incapacity benefit and disability living allowance (DLA), he or she is required to fill in two sets of forms and gain two sets of sick notes from his or her GP. In addition, for each benefit, he or she will be required to have a medical examination by a physician employed by the

Department of Social Security (DSS). The medical examination for unemployment benefit is based on a standard test, which assesses a person's fitness for work. The medical examination for disability benefit is based on a standard test that assesses a person's ability to look after him or her self.

If an individual is successful in his or her claim for a benefit, he or she will be allocated an amount of time for which that benefit is allowed. The decision regarding the length of time an individual is entitled to claim for varies depending on the circumstances of each person. When the time allocated for a benefit runs out, a person's entitlement to financial assistance is reviewed. Thus he or she is required to repeat the assessment procedure for that benefit once again. For example, after 6 months of claiming incapacity benefit and disability living allowance a person might be asked to reapply for both allowances. In addition to being required to repeat both assessment processes on a regular basis, individuals whose claims are rejected initially may also appeal against decisions made and reapply by repeating the assessment process.

#### *The types of benefit received by persons with ME/CFS*

The types of benefits that the respondents received at the time of the survey are shown in Table 21 below. 73% of the questionnaire respondents were claiming an unemployment benefit at the time of the survey. For example, 8% of the sample were in receipt of severe disablement allowance, and 6% were in receipt of statutory sick pay. 1% were working part time and claiming disability working allowance. 1% of the sample were claiming unemployment benefit and 2% received a state pension. The



benefits claimed most frequently were incapacity benefit (38%) and income support (16%).

In contrast to the number of individuals claiming an unemployment benefit, very few respondents were claiming an illness or disability benefit. For example, whilst 73% of the sample were deemed eligible for one form of unemployment benefit, only 29% of the sample were claiming some form of disability or illness benefit. 23% were claiming the mobility component of disability living allowance and only 6% were claiming the care component of disability living allowance.

**Table 21: Types of benefit received by the questionnaire sample (N= 265)**

<i>Type of benefit claimed</i>	<i>Number of persons claiming</i>	<i>% of sample</i>
<b><i>Unemployment benefits</i></b>		
<i>Incapacity benefit</i>	104	38
<i>Severe disablement allowance:</i>	22	8
<i>Statutory sick pay</i>	16	6
<i>Disability working allowance:</i>	2	1
<i>Income support</i>	43	16
<i>Unemployment benefit:</i>	3	1
<i>Pension</i>	6	2
<i>Total</i>	196	73
<b><i>Illness/disability benefits</i></b>		
+DLA (mobility)	61	23
+DLA (care)	16	6
<i>Total*</i>	77	29

\*Both benefits can be claimed by one person, therefore the total number does not represent the total number of persons in the sample on disability benefits, the total number is more likely to be 61 people (23%).

As with persons with ME/CFS and their local GPs, these figures imply that there is a tension between how individuals with the condition perceive the severity of their illness and how those persons assessing disability benefits perceive the severity of ME/CFS. In short, it appears that, whilst many persons with ME/CFS see their condition as almost totally incapacitating, thus rendering them severely limited in terms of mobility and in need of help with personal care, DSS examiners perceive the condition to have less of an impact. Evidence for this is borne out in Table 22 below, which shows that, whereas only 7% of the respondents were refused one of the unemployment benefits at least 33% of the questionnaire sample had been refused a ‘disability or illness benefit’. Indeed, 27% of the questionnaire sample had applied for the mobility component of disability living allowance and had had their claims rejected and 11% of the sample had been refused DLA care allowance.

**Table 22.** Numbers of individuals deemed by the DSS to be unsuitable for Disability Living Allowance (N= 265)

<i>Type of benefit refused</i>	<i>Number of people refused</i>	<i>% of sample</i>
<i>DLA mobility</i>	73	27
<i>DLA care</i>	17	6
<i>Total</i>	90	33

It was argued by the respondents, that one reason why persons with ME/CFS are often denied access to a disability benefit, is that the criteria for disability used in the independent assessments does not adequately test how incapacitated they are. Tests for disability living allowance assess a person’s mobility (or functional ability) by, for example, seeing whether he or she can climb a flight of stairs, or lift objects of a certain

weight. The respondents said that such tests are inappropriate for assessing the mobility of persons with ME/CFS because, whilst a person might be able to do each activity once, the lack of energy available to them means that they will not be able to do that activity again. They maintain that, if an individual demonstrates that he or she can climb 5 stairs for example, it does not mean that he or she will be able to go up and down the stairs whenever he or she pleases. In fact, as the SF-36 data in Chapter 5 demonstrates, for many persons with ME/CFS, simply climbing up stairs once, takes a large percentage of the daily energy quota and doing it twice is out of the question:

They still think as long as you can put something in the microwave and get to the bathroom you can cope on your own (Viv, 65, 7).

Medicals are a bit of a farce because what you can do on the day is in no way representative of your disabilities (Geoff, 40, 10).

In addition to fundamental problems with the disability assessments, the respondents suggested that, because ME/CFS is defined in the disability benefits literature as a psychological disorder, independent disability assessors are more likely to 'disbelieve' patients when they say that their problems are physical:

The Benefits Agency think that ME is a psychological illness as its guideline books show (Female, 35, 8, written answer to quality of life question)

(My quality of life would improve by) being accepted by the benefits system that it's an illness (Female 46, 3, written answer to quality of life question).

Indeed, many of the interview respondents, in seeking financial assistance from the DSS, once again, experienced accusations of malingering. This led, once again, to extreme distress:

Then we started to claim for DLA (disability living allowance) benefit because obviously my mum had had to give up work and things were getting fairly tight and I had to see a doctor for a medical assessment. This was around February and we went in and it was just unbelievable. We sat there and he did not speak one civil word to me the whole time. I'd started to put on weight, I'd never been small, but with the exercise (tennis) I'd always managed to keep slim. He said things like, "Oh, you're a big girl", in a nasty way and then he started to say about my illness and then he tried to imply that I was ill because I didn't get on at school. "I'd fallen out with my friends perhaps!" And then he asked a bit about my background. I said I did the sports. Then he turned round and said, "If you've got the guts and determination to play your sport for the county and for your country and all that, you've got the guts and determination to get up out of that wheel chair now and walk out of here." I was dumbstruck and the way he said it, it was so aggressive and absolute hatred and venom. I just burst in to tears and he said, "Oh, stop blubbing now." He said, "Right I want you to get out of your wheelchair and walk up these steps." I said, "I can't do it". He said, "You will do it, get out of that chair and walk up the steps". And I got up and I did, I think, about two steps and I just stopped and I said, "I can't do any more". He went off again in some tirade and I was still crying my eyes out and we just got out of that surgery and all the way home in the car I just cried and cried and cried (Janine, 24, 10).

It's been a nightmare claiming benefits, I don't like going to the DSS at the best of times, I hate visiting. There's been a doctor that I went to see, the first time that I went it was awful and I came out in buckets of tears because he made you almost feel like you were lying. Because he didn't understand what you had you think you're mad and I just thought, "he doesn't believe me". I've got turned down twice (Sarah, 24, 3).

In desperate need for financial help, the interviewees said that, just as they tried to battle with GPs in order to 'prove' their illness, so they used the appeal system to try and prove the severity of their condition to the DSS. However, in many cases, after dragging themselves to tribunals, negotiating with their local GPs for written confirmation of the severity of their disability, filling in countless lengthy forms and undergoing numerous disability tests, appeals were frequently turned down.

I did appeal, but I think it was probably the toughest interview panel I've ever been in front of. I mean, I realise that you are dealing with other people's money when you are on benefit ... I expect them to be thorough



and objective. But I wasn't prepared for the intensity of the questioning. I went through all this but I failed to get my claim accepted (Rob, 60, 12).

Whether an individual is appealing against a benefits' decision or having their existing claims reviewed, it appears that, for persons with ME/CFS on low incomes, the process of disability assessment is ongoing. In addition to the energy that this process appears to take up, the majority of the respondents who were on benefits said that they experience regular anxiety. Anxiety appears to be caused by the fear of going through disability tests and the fear of either having benefits withdrawn or not being granted benefits at all. The anxiety that the process of 'form filling' and 'physical testing' provokes, is articulated by the respondents below who write:

More than anything else (my quality of life would be improved if I could get) Disability Living Allowance for Life and not to be stressed to death with the horrendous forms and visits and to feel continually unbelievably – its criminal' (Female, 48, 9, written response to quality of life question).

(My quality of life would be improved by) not being harassed by the DSS on a yearly basis (Male, 45, 13, written response to quality of life question).

The fear of having benefits taken away is demonstrated in the quotes below:

My quality of life would be improved by not being constantly concerned that my disability benefits could be stopped because someone doesn't believe in M.E. Its not like I can say, "okay fine, I'll go and get a job". I could lose my home, get into serious debt and probably get iller (*sic*) from stress and worry (Female, 52, 10, written response to quality of life question).

(My quality of life would be improved) by not worrying about having my benefits stopped. I am having to reapply and attend medicals on an annual basis and find it increasingly stressful and distressing (Female, 38, 6, written response to quality of life question).

My quality of life would be improved by stability in the benefits system. The threat or perceived threat of benefits reducing or being removed altogether is a constant concern and makes budgeting for the future difficult (Female, 42, 8, written response to quality of life question).

These findings suggest that the reaction to ME/CFS by the DSS is no different than the reactions of GPs and, to borrow from Goffman (1963), 'normals' and 'the wise'. In short, sufferers continue after diagnosis to find their moral status judged and thus experience 'meanings at risk'. This reaction of others serves to keep sufferers in the 'non-legitimate sick role' as they are denied exemption from the blame for illness and attempts to gain justified time off, through seeking support from others and financial assistance fail.

## **Discussion**

The accounts of the respondents with regards 'reconstructing order' bear a close resemblance to Goffman's description of the second stage of the moral career. Goffman implies that once an individual is labelled with a stigmatising condition, he or she is stripped of many accustomed affirmations and satisfactions and subjected to a new set of experiences. In the case of ME/CFS, it appears that, despite succeeding in gaining an official diagnosis of 'illness', the usual avenues of support available to persons with chronic illness remain blocked. Indeed, the reports of the respondents suggest that many sufferers of ME/CFS continue to experience, (or, in the case of those who were diagnosed during the early stages of illness, experience for the first time), the conditions of the non-legitimate sick role. Thus, they continue to have their moral status questioned by GPs' who are reluctant to give any advice with regards to the aetiology and management of the condition and in many cases continue to blame their patients for

time wasting and malingering. In addition, friends, colleagues and family members often continue to treat sufferers' claims to be 'really ill' with cynicism, as do disability officers, whose job it is to assess the eligibility of the sufferer for financial support. Alongside the practical problems that these ideas about illness engender, such reactions are said to lead ultimately to a complete 'non acceptance' of who the sufferer is.

These findings, once again, suggest that cultural ideas about serious and non serious illness exist and that when an illness is seen as non-serious yet the individuals claims that it is serious, his or her moral status is judged. Further, these findings suggest that, as argued by Freidson (1970), dominant medical ideas about illness conditions hold sway when it comes to the cultural categorising of illness. Finally, the findings indicate that such cultural ideas have a profound impact on the lived experience of illness. In the case of ME/CFS the sufferer finds him or herself propelled into marked disadvantage.

Goffman (1968) argues that in response to the kind of moral labelling described above, individuals take on new sets of identity beliefs and practices. Thus they single out and retrospectively elaborate experiences, which serve to account for their coming to the practices that they have adopted. In response to their situations, the individuals that took part in this study drew on alternative discourses of ME/CFS that confirmed their ideas that they were really ill. This finding backs up the point made by Giddens (1984) that individuals draw on more than one source of expert knowledge to make sense of things. The discourses drawn upon by sufferers of ME/CFS suggest (as demonstrated in Chapter 1) that ME/CFS is a pathological condition caused by external agents such as a virus or organophosphate poisoning. Such discourses were often contextualised by the respondents within their own biographies and as such, served to help them reconstruct

order by providing what was seen as a plausible explanation for their condition. In addition, the alternative discourses of ME/CFS act to protect the moral integrity of the sufferer by providing a rationale that states that 'others' react the way they do because they are simply uneducated about the 'reality' of ME/CFS and have a 'limited understanding' of it. Despite being able to legitimate ME/CFS to themselves, however, the findings suggest that sufferers fail to change the views of others and gain access to the legitimate sick role. The experience of managing daily life within the confines of the non-legitimate sick role is the subject of the final findings chapter: maintaining control over life.



## Chapter 8

### **The illness careers of ME/CFS sufferers: maintaining control**

In this final findings' chapter, I consider how individuals with ME/CFS maintain control (Charmaz 2000). Section one is entitled, 'Maintaining control: accepting chronicity'. In this section, I focus briefly on the point at which the respondents' came to realise that their condition was 'long term but not life threatening'. In section two, I consider the strategies that the respondents developed to help them live with ME/CFS on a daily basis. In the third section, 'Embodying ME/CFS', I discuss the respondents' illness narratives. That is, I consider the respondents' accounts of how they saw themselves and their lives, in the light of 'having ME/CFS'. In the final section of this chapter, I focus on the relationship between the strategies used by the respondents, their illness narratives and their actual lifestyles.

The findings suggest that, if the social conditions are right, for many sufferers of ME/CFS there might well be an end stage to the moral career, whereby, in addition to accepting that they 'have' a chronic illness, sufferers also accept their changed bodies and their place in the social world (Goffman 1968). However, for the majority of individuals with ME/CFS, the social conditions do not appear to be right. Thus, despite accepting that they 'have' ME/CFS and that it is a chronic condition and despite developing strategies that help lessen the affect of ME/CFS, the majority of the respondents do not accept their altered situations. These findings indicate that the notion that individuals 'maintain control' and that they somehow, 'reach a way of reconciling the losses bought about by chronic illness', is flawed. A more fitting

premise appears to be that, in ME/CFS at least, fully accepting chronic illness into one's life often becomes part of an ongoing struggle.

### **Maintaining control: accepting chronicity**

It is argued in the literature that the stage of 'maintaining control' begins at the point at which sufferers' accept that they have a chronic illness (Charmaz 2000). The process by which the respondents' reached this stage has been outlined in the previous chapter. For example, as I have stated, having struggled to obtain an explanation for their symptoms, many of the respondents began eventually to draw on alternative discourses of ME/CFS to legitimate to themselves the fact that they had a 'real' and therefore 'serious' illness. Further, having tried to seek a cure for their ME/CFS by drawing on, by and large, complementary medicine, the respondents reached a point where their desperate hope for a 'quick fix' was replaced by the idea that their condition was not life threatening, rather, it was long lasting and to a large extent, untreatable. This realisation thus marked a point of acceptance in the mind of the sufferer that his or her life would go on and that he or she would have to learn to live with his/her ME/CFS:

In my case, for the first two years I was trying to get well, fighting back. Now there is no point trying to find a cure for it, or to think about what triggered it, because that is just a reminder, its like the death thing, you grieve, it is just better to carry on as best you can (Bob, 50,15).

At this point, as the above quote implies, many of the respondents said that, rather than 'fight their illness' they began to realise that they had to 'accommodate their changed bodies' or 'listen to their bodies' and start to shape their lives according to the demands it made. Indeed, as suggested by Charmaz (2000), the respondents realised that they had to maintain control over their ME/CFS:

You try all sorts if you can but the only way is to learn to adapt, to live with it (Jane, 54, 6).

I felt well it was no good trying to fight it, but I had to learn to live with it and to do the best I could in those circumstances (Viv, 65, 7).

So now my life revolves around adapting to it (Claire, 48, 28).

It disrupts everything it disrupts your whole way of life you change your way of life to accommodate the illness (Richard, 29, 6).

### **Maintaining control: developing strategies**

#### *'Cutting corners'*

Consistent with the findings of writers that have written about the experience of other chronic illnesses (see for example, Williams, 1993) the main way of maintaining control over ME/CFS was said to be through careful illness management. The data suggests that one strategy in the management of ME/CFS is 'cutting corners'. This management strategy is similar to that described by Kelleher (1988, see chapter 3), whereby individuals change their practices so as to reduce the significance of the symptoms. Kelleher maintains that by doing this, it is possible to see oneself as more healthy than one perhaps is. The successful use of 'cutting corners' is described below:

I only feel about 20% disabled in the world that I live in because I've reorganised my real world. For example I make sure I have clothes without buttons on because they are impossible to do up or undo, I wear socks instead of tights. I don't eat non-cut up food, like steaks, pizzas, they're impossible. I eat the food with my fingers. The ice cream man comes to my door every Wednesday. If you were to take me away from my own world and transpose me in to another one I'd be 80% disabled. My car has electric windows and electric mirrors. People don't notice I'm disabled 'til (*sic*) it comes to walking somewhere. Then I get the

wheel chair. I actually couldn't walk from this front door to the garden (Adrienne, 54, 21).

### *'Pacing'*

The interviewee accounts indicate that whilst 'cutting corners' is one way through which to maximise the amount of activities that a person can do, the key management strategy used by sufferers of ME/CFS is 'pacing'. 'Pacing' was said to be the most effective way of keeping on 'an even keel' and capitalising on the small amount of energy available. In order to 'pace' oneself, it was maintained that an individual with ME/CFS has to be aware of the limits posed on his/her energy. Once an individual defines his/her energy limits he/she has to discipline him/herself to stop tasks and rest before the point that energy drains from the body. If energy is allowed to drain completely from the body, the result is often 'a relapse'. However, if an individual stops using his or her energy before it runs out completely, then he or she will have a shorter time to wait before levels are topped up again (perhaps only having to rest for hours or days). By carefully controlling the amount of energy used and the amount of rest needed, it becomes possible to have a fairly consistent lifestyle where one can sustain a daily routine of 'a lot of rest' and 'a very small amount of activity'. This is in contrast to having a lifestyle, which tends to peak and trough as individuals overdo it and have to spend weeks doing nothing in order to 'recharge their batteries':

ME lets you know as soon as you have overstepped the mark that you have overdone it and it takes you days and months to get back to where you were before. *Pacing's the key* (Bob, 50, 15, my emphasis).



According to the data, 'pacing' often means that tasks have to be broken down into a series of minute stages. Thus, a person might spend 20 minutes doing an activity, stop the activity, rest for two hours, spend another twenty minutes doing it and so on:

Sometimes if I try to do jobs around the house I try to do half an hour and back to bed, half an hour and back to bed, you know, it's all that. It's a staccato type of thing (Barry, 52, 3).

So what I have to do is do things in very, very small bites. You know, stupidly so for other people. At the moment I've got to empty my flat of rubbish and stuff and I'm doing that I feel I'm moving forward if I pick up a pile of magazines and put them in the bin. That's it for the day and I'll do it again the next day just slowly. If I'm going away I start packing about 4 days before and just have a pile in the corner of the room and you know, as I go from room to room, I pick up a pile and put it next to it. So you have to break things down into the smallest component (Geoff, 40, 10).

It's just a case of taking things steadily. Some things have to get done and you have to nibble away at them and it can take months and months (Graham, 52, 7).

A number of the respondents said that rather than doing things in short bursts throughout the day, an alternative use of 'pacing' was to rest for longer periods of time and then use their whole energy quota up in one go. For example, an individual might rest all day in order to spend two hours doing an activity during the evening:

You've got to work things out. You gradually get to know your symptoms and what you can do. Just for example, if you wanted to go out anywhere ... now next week I'm going to my husband's works do. So that means that that day, I won't do nothing, just rest the whole day so I build up the energy to go in the evening (Christine, 42, 6).

### *'Being responsible for treating the symptoms of ME/CFS'*

In addition to 'cutting corners' and 'pacing', the respondents also developed strategies for 'treating' the symptoms of ME/CFS. First, many came to recognise that they had to carry the responsibility for their own treatments. Consequently, they began to see themselves less as 'patients' and more as 'experts':

Another change that has come about is the realisation that my health is my concern. I used to think that the doctor would fix it. My doctor can't fix it. Can't give you a magic pill to take it away ... I realise that I am the expert on my own body. I will choose whether to go to the doctors or to WESTCARE, to take vitamin supplements, to see a support group (Trevor, 39, 3).

### *'Consuming treatments'*

As the above quotation suggests, in becoming experts on their own illness, the findings indicate that, with regards to treating ME/CFS, there is a tendency for individuals to become empowered consumers of treatments rather than desperate patients. The majority of the respondents, for example, were inclined to tailor care packages to suit their own individual needs. This consisted of isolating each symptom and, where possible, 'buying in' or obtaining the treatments and support that had been found to work. Thus an individual might go to a GP for painkillers, to a health food shop for vitamins and to a patient support group for guidance and empathy:

I like everything to be in compartments so that I can understand it and that's what I found I had to do, try and understand as much as possible why I might have it, and what the symptoms are. Then you can isolate the symptoms you can treat each one individually and watch how they interact with each other, it helps you keep on top of it. Keeping a diary is helpful in this respect. The most important people who helped me were: Dr Sanden for my body, Ivor for my spiritual and Jane did the rest (Pip, 40,10).

I just manage it myself. If I need say painkillers or a calcium supplement I go to the doctor. I can't remember going in the past year except for a hospital appointment for statementing (Daniel, 16,3).

### **Maintaining control: embodying ME/CFS**

It is frequently assumed in the experience of illness literature that, because they develop strategies that afford some degree of control over the body, sufferers of chronic illness arrive at a stage of learning to live with illness (see for example, Bury, 1991). However, Frank (1995) points out that learning to live with illness involves a substantial amount of work at the deeper level of personal meaning. As I have shown in chapter 3, Frank (1995) states that the ways that individuals think about their altered situations can be seen in the types of narratives that they use. Frank suggests that there are three types of illness narrative. These are: the restitution narrative, the chaos narrative and the quest narrative. Within the accounts of the respondents two types of narratives can be seen. These are the quest narrative and the chaos narrative. Each narrative is discussed below.

#### *The quest narrative*

According to Frank, the quest narrative 'meets suffering on the head ... accepts illness and uses it' (1995: 115). In other words, through illness, the quest narrative suggests, the individual has realised a new sense of purpose. The quest story is thus often presented as a journey via which the individual undergoes a positive transformation. Through this transformation the individual gains special insights that can be passed on to others.

Only 4 of the interview respondents used the quest narrative, two males and two females. Interestingly, gender made a difference to the type of quest narrative that was presented. For example, the quest narratives of the men revolved around coming to terms with not being workers. As such, these narratives were drawn from discourses that critique the social meaning of work and suggest that members of western culture sufferer from a false consciousness that keeps them bound to a treadmill. The onset of illness it is implied, acts as a revelation of this phenomenon and signifies that there is 'another way':

I'm better now than I was in many ways. I'm the little boy who's seen the king with no clothes. I've seen it, I know what a load of old crap has been drummed into people's heads. And I don't want to know it. I don't want to know about the next company car. I think, "You're fooling yourselves". I know that that is the world and there's an inevitability about it and you can't do much about it and you've got to have a job, but I don't want it. I've had years of it. I feel, even with the restrictions on my abilities it's a better life now ... I mean what is life what is truth? It can only be what you feel you are happy doing. Existentialism isn't it? Where you make your choices and you do what you want to do, not in a hedonistic way but you make the choices where you don't accept other people. I had the choice made for me of leaving work and I hadn't realised when I turned left out of work I didn't realise there was a turn right as well (Barry, 52, 3).

I'm quite grateful I've had it in a way. I look back at life. I was like a hamster, so busy getting on. I never stopped to think about it. But I was forced to get off and now I've resumed life I'm a lot more reflective and spiritual, more compassionate, less materialistic and see every day as a gift from God (Pete, 51, 16).

Whilst, for the men the quest narrative was bound up with their 'coming to terms with not being workers', for the females the quest narrative appeared to be bound up with 'having a lucky escape from the typical female role':

I'm quite glad I've got it. That sounds strange doesn't it. You almost, you're quite pleased really because like with Lee (my boyfriend that left me because I was ill). We could have been married and I could



have been ill and all that could have happened so you're quite glad you found out now (Sarah, 24, 3).

Basically I have quite actively disconnected a load of negatives ... I've let my sense of humour rip so I sometimes say all sorts of extremely cheeky things to people, which I would never have done before. I would have been far too reserved and I thought, "No, damn it! If I want to have a cynical dry sense of humour, then I shall have it." And if somebody takes offence, then it's up to them. I don't care anymore. I used to play a game of like, sort of holding myself back and being very diplomatic. I don't care anymore. All sorts of things like that, whereas before I would have been a bit sort of uptight and pussy-footed and not wanted to offend (Adrienne, 54, 21).

### *The chaos narrative*

As I have stated above, those individuals who used the quest narrative were in a minority. Indeed, 75% of the interview respondents spoke about their situations in a way that matched Frank's (1995) concept of the chaos narrative. Frank maintains that the plot of the chaos narrative is one that imagines life never getting better. He maintains that the chaos narrative, feeds the sense that the body is swept along by the contingencies of illness and every day life and suggests that there is no way out. For Frank, the chaos narrative does not reconcile the body and the self and the individual remains passive in the face of illness. The respondents who used the chaos narrative used the words, 'desperate', 'chaotic', 'confused', 'depressed', 'isolated' and 'struggle' in their descriptions of everyday life with ME/CFS. Rather than indicating that the sufferer has 'reconstructed order' and is 'maintaining control', the chaos narrative, used by the respondents conveyed the sense that for many sufferers of ME/CFS 'life is beyond control':

This is what I've lived with all these years. I mean it does become part of a life. You try to cope with it and you try to get on with it. I think

the hardest part is the adjustment and not being able to cope with it to being able live with it and accepting it. Because people often say to me 'how do you manage?' and I say 'well you have a choice, you either live or you don't'. And if you live you've got to sort of do the best you can and I try (Jill, 44, 10).

I was already on medication for depression at that time, I had been since Christmas. I'd just try and deal with it by distancing myself from normal life, like sitting at the Internet. It's good because it gives me a little bit of time out, time to forget that I can only walk across the room from bed to my chair. The other day I wrote on there, I'm really, really depressed with the meaning of life, I'm not coming back, bye bye (John, 17, 2).

### *Strategies, narratives and lifestyles*

Two questions emerge from the findings presented above. The first is, 'Why is it that some individuals use the quest narrative yet the majority don't?' The second, related question is, 'Are there any differences between the lifestyles of the individuals who used the quest narratives and those who used the chaos narrative?' Those individuals who used the quest narrative had two things in common. The first was that they had the resources to delegate the mundane chores of daily life to another individual (thus they had a home help or a relative that acted as a carer). Secondly, those respondents who used the chaos narrative had little, if any, responsibility for anyone else. The consequence of these two factors appeared to be that they could use the precious energy that they saved through the activities of 'pacing' and 'cutting corners', to take part in 'life affirming activities'. By taking part in 'life affirming activities', the burden of being trapped in the body (as described in Chapter 5) appeared to be easier to bear. The sense of place that being able to take part in life affirming activities engendered is illustrated in the quotes below.

I don't have a dull time, I go to the pub, I have a boyfriend. There are a lot of reasons for being, like going to the sea, seeing the birds and the

flowers (what is real the sea crashing on the rocks or a bank balance?), having a good sex life. You've always got a role to play and personal worth, people say why pay out all that money to have home help, it means I don't have to keep struggling and I can do the things that are important. *I can keep my sense of place in the world* (Adrienne, 54, 21, emphasis my own).

I'm not *letting myself go completely* in fact I've gone to night school to do navigation, that's done me so much good. I'm absolutely slaughtered the next day and I sleep as much as I can the day before it but it's done a lot for my head because I can now look at problems and know that I can solve that problem whereas before I felt unconfident and I didn't have any esteem about myself and I just thought "I can't do anything" and what's the point I might as well just go and jump off a cliff because I'm useless but that has done me some good (Barry, 52, 3, emphasis my own).

Through being able to take part in 'life affirming activities', the respondents were able to derive a meaning for their life. Indeed, their situations had much in common with Goffman's (1968) description of 'the final stage of the moral career'. Goffman argues that the final stage in the moral career is where the individual comes to feel that she should be 'above passing'. At this stage, Goffman argued, the individual feels that if he/she accepts his/her stigma, he/she will respect him or herself. In short, Goffman argued that the final stage of the moral career signifies 'a state of grace'. Evidence that individuals who used the quest narrative reached a stage that resembled Goffman's final stage of the moral career can be seen in the quotes below. These quotes demonstrate, for example, that the sufferer no longer feels an outsider and as if he/she should hide his condition:

I'm fairly pragmatic about it in that I think that most people you ever meet will not accept that that's what you've got. If you come from that sort of point of view you can cope with it. I couldn't care less what they think. It's me I have to do what I'm doing and I don't care I'm not out to prove anything to them (Barry, 52, 3).



You have to start enjoying doing nothing. I make a big point of making it special doing nothing. I listen to ambient music and I burn candles and incense and make a big thing of it. I'm way into chilling out, I listen to stuff people crash to after a dance club. In summer it's great I spend all my time lying outside which to many people looks like a perfect lifestyle. It has its compensations, I'm the first to admit that as well, which makes people awfully suspicious when you admit that. But I wouldn't choose to be a teacher full time if I got better. I don't know that I'd rush back in to work. I would like to travel and things like that but you know when other people are rushing off to work and getting depressed and all that you think "Well yep, this is okay, my work is resting". But if I were working full time and fit I'd get more done on the hobby front than I do now when I've got 24 hours a day to myself to spend as I wish (Geoff, 40,10).

The lifestyles of the individuals that used the quest narrative stood in stark contrast to the lifestyles of those individuals who used the chaos narrative. As I have stated, the majority of the respondents spoke about their situations in terms of the chaos narrative. This included both the younger and older persons that were interviewed. It is important to distinguish between these two groups of respondents because the reasons for the chaos narrative appeared to differ according to age.

For the older respondents the reason for feeling as if they were swept along by their illness and not in control, appeared to stem from the fact that they were unable to take part in the 'reaffirming activities' described above. Indeed, those older respondents who used the chaos narrative had the following in common: first, due in the main, to not being granted access to Disability Living Allowance, they were unable to mobilise any financial support for help in the home. Second, they had a number of responsibilities towards other individuals. As a result, the limited energy that they could accumulate, through 'pacing', had to be spent carrying out personal and domestic chores, such as washing, cleaning, shopping, preparing food, and looking after the children.



More often than not, because of the lack of energy that these respondents had, many of the necessary chores of everyday life went undone. This resulted in a constant accumulation of chores and an increasingly chaotic home life. For some, especially those who could not mobilise any support from friends or family, the inability to keep up with basic domestic and personal tasks resulted in living in conditions that were deteriorating around them. Indeed, a number of the respondents in this study asked to be interviewed over the phone because they did not want anyone to see the state of their houses. The problems posed by 'not being able to keep on top of things' resulted in many individuals not being able to 'pace themselves', but literally having to 'carry on regardless', through necessity and the guilt engendered by not being able to keep life in order.

The perceived lack of financial and social support and its impact on 'maintaining control' was not only mentioned by the older interview respondents. It was by far the most relevant issue for the older persons that took part in the questionnaire study. Indeed, the need for 'help with daily living' was contained in the statements of 27% of the respondents:

(My quality of life would be improved) if I had a lot more money to buy care and help (that is) personal care, housework, childcare, driver, respite (Female, 39, 7, written response to quality of life question).

(My quality of life would be improved) if I had a home help, childminder, shopper (Female, 32, 3, written response to quality of life question).

(My quality of life would be improved if I had) Someone to Hoover and clean, to do the washing up, do my washing at the laundry, to drive me around in a car (Female 52, 14, written response to quality of life question).

These respondents recognised that if they were able to take part in 'life affirming' activities their lives would be transformed. Thus, contained in the answers to the question posed on the questionnaire, 'What would most improve your quality of life at this present moment in time?' was the desperate need to be released from the 'treadmill' of daily life and the idea that financial assistance would allow them to regain a sense of self:

(My quality of life would be improved by) – a little more money to enable me to pay someone to do the housework, *thus freeing my mind and energy to pursue more enjoyable and rewarding activities* (Female, 47, 7, written response to quality of life question, my emphasis).

I would like to be in a position *where I can use the little energy that I have on enjoyable things and not only on domestic chores* (Female 37, 4, written response to quality of life question, my emphasis).

I desperately *need total rest* as I am acutely ill. i.e. someone washing, ironing gardening. The house and garden have gone to rack and ruin after 2 years severe illness. My husband can only do so much work and run our sons around. This makes me feel guilty – *we all desperately need a family holiday* as the pressure of the illness falls on to the whole family. *Some relief from financial pressure caused by my loss of job and prospects would help dramatically* (Female 42, 2, written response to quality of life question, my emphasis).

The sense of chaos that derived from a lack of social support, appeared to exacerbate the feeling of being trapped in one's own body because, as such, the respondents continued to blame their bodies for not letting them do what they wanted. The respondents lamented the fact, for example, that the dominance of the body in ME/CFS is such that they constantly have to discipline their 'selves' to 'pace' every activity:

As far as lifestyle within the home goes, I suppose, for me, it's a matter of quite rigid disciplining of my mind. I try to limit myself to one major task a day, like a major household task that I really want to do. I really have to try and minimise that and maybe do half today and half

tomorrow and make sure I stop, even before I'm even beginning to feel tired, which is really, really hard. It's very difficult to break off even before it's affecting my body. (Christine, 42, 6).

Moreover, the respondents spoke of the 'torture' of being rendered incapacitated for the best part of the day and left to do nothing but 'think' in surroundings that reminded them of the lack of control in their lives:

You're sitting here and the place is an absolute tip, you're really stressed. I didn't know the meaning of stress until I got ME/CFS. I stand at the sink and try and peel the vegetables so at least the food is prepared for cooking. My husband is out all day working and to think that I haven't even cooked him a meal is crucifying (Denise, 43, 3).

I mean the problem I find is killing time. Because I can't expend a lot of energy and therefore I spend a lot of time sitting and resting I find it very difficult to take my mind off things (Bob, 50, 15).

In sum, the continuing situation of many of the older respondents was portrayed as one of futility. Indeed, the findings suggest that as sufferers are reminded of their incapacity to prevent the practical problems of daily life from spiralling out of control, the losses engendered by ME/CFS are constantly reinforced. Rather than learning to live with their ME/CFS, as time progresses, many older sufferers appear to make little headway when it comes to 'regaining a sense of self worth' (Charmaz 2000).

Whilst for the older respondents the chaos narrative derived from being in receipt of little help and social support, for the younger respondents the chaos narrative derived from seeing their peers move on in life whilst like the older respondents described above they felt 'trapped in their bodies'. As I have shown in chapter 5, this situation of being reminded of 'missing out on life', appears to be never ending. Indeed, it appears that as life goes on, the more losses there are to mourn. Hannah aged 24, who lived

with her parents and had suffered from ME/CFS for 6 years at the time of the interview, spoke about missing out on a university education when she first had ME/CFS, she then went on to talk about 'missing out on starting a family':

Having babies, getting married. It's a time in life when you want independence. It's horrible, I get wound up and crochety, I cry. I think, "What is going to become of me ... will I be like this forever?" ... At times I think there is no point (Hannah, 24, 6).

Sarah too, states how past plans had been dashed and future plans are impossible to make:

Before this I was working, I had a normal social life, a boyfriend. I had planned maybe to stay working at the council and save up and get my own place. Now I have to live from day to day. I have had to move home and now rely completely on my mum and dad. Mum, runs my bath, washes my hair and cooks for me (Sarah, 24, 3).

These findings suggest that, whilst the reasons for using the chaos narrative might be different, for the younger respondents too, it is often difficult to learn to live with ME/CFS. For many of the younger respondents, feelings of loss, isolation, depression and guilt permeated the everyday experience of illness.

## **Discussion**

In this final findings chapter I have considered how individuals with ME/CFS maintain control (Charmaz 2000). First I considered the point at which the respondents accepted that their condition was chronic. Second, I discussed the strategies that the respondents developed to help them live with ME/CFS on a daily basis. In the third section, I considered the respondents' illness narratives, that is, the respondents' accounts of how they see themselves and their lives, in the light of having ME/CFS. In the final section



of this chapter, I have considered the relationship between the strategies used by sufferers, their illness narratives and their actual lifestyles.

The findings suggest that, despite the complex pathway through ME/CFS that appears to characterise the illness career, sufferers of ME/CFS eventually reach a stage of accepting that they have a long term, chronic illness with which they will receive little medical or social support. At this stage they start to develop strategies for maintaining a degree of control over their bodies and hence their lives. Indeed, many sufferers appear to develop ways of coping with their illness, using similar management strategies to persons with other chronic illnesses. However, whilst sufferers might develop strategies for maintaining a degree of control over their bodies it does not necessarily mean that they have reached a stage of accepting their altered situations. Indeed, a closer look at the illness narratives of the respondents demonstrates that only a few individuals reached a point of finding positive meaning in everyday life. This can be seen in the quest narrative, which suggested that particular respondents felt as if, through illness, they had learnt a new 'more realistic' way of looking at the world. As such, this way of looking at the world enabled them to feel alive and valuable.

In contrast to this small group of respondents, for the majority, 'accepting' ME/CFS as part of their everyday lives appeared to be part of a personal, ongoing daily struggle. This is reflected in the chaos narratives. At best the sufferers who used the chaos narrative can be said to reach a stage of 'barely tolerating the illness'. That many sufferers do not fully accept their ME/CFS appears to be due to the unrelenting demands that the condition makes on the body and social action. For many older sufferers, these demands are compounded by the fact that due to the non-legitimate sick

role, many do not obtain the financial assistance necessary for 'help with mundane daily chores'. Because of this they are unable to use their limited energy to engage in activities that reaffirm the self and life in general. Rather they are compelled to use the time available to them to try and ensure that the very basic conditions for existence are met. For many this situation is one of perpetual chaos as they see their previous standards of living fall away and worry about the future. For younger individuals the demands made by ME/CFS are compounded by the fact that they are reminded constantly of 'what they are missing out on'.

The findings suggest then, that if the social conditions are right, there might well, for many sufferers of chronic illness, be an end stage to the moral career, whereby as Goffman (1968) argued, sufferers accept the social idea of who they are and move 'beyond passing and covering'. However, for the majority of individuals with ME/CFS, the social conditions do not appear to be right. Thus, despite accepting that they have ME/CFS and that it is a chronic condition and despite developing strategies that help lessen the affect of ME/CFS, the majority of the respondents do not accept their altered situations. These findings indicate that the notion that individuals 'maintain control' and that they somehow 'reach a way of reconciling the losses bought about by chronic illness', is flawed. A more fitting premise appears to be that, in ME/CFS at least, fully accepting chronic illness into one's life often becomes part of an ongoing struggle. As such, there might never be an end to the moral career. That is many sufferers do not reach what Goffman (1968) refers to as 'a stage of grace'. These findings have implications for some of the key concepts that are presented in the literature. In the final chapter I draw together the empirical data and the literature and discuss the general implications of this thesis.

## **Chapter 9: Concluding discussion**

### **Introduction**

Through an empirical study of 'what it is like to suffer from ME/CFS', I have set out in this thesis to explore sufferers' experiences of illness that is contested. In addition, my aim has been to consider first, the extent to which the sociological literature explains the experience of ME/CFS and contested illness and second, the contribution that an understanding of the experience of contested illness might make to the sociology of health and illness.

At the end of chapter 3 (page 111), I developed a summative model of the literature that related to my research aims. The purpose of developing such a model was to provide a loose theoretical framework, which I could use to organise my empirical findings. In addition, the model provided a manageable way of using my findings to explore the main concepts provided by the literature. In this final chapter, I draw together the literature and the findings of my study. First, I discuss the value of Freidson's (1970) expanded version of Parson's (1951) sick role. Second, I consider the contribution that the experience of illness literature makes to an understanding of contested illness. Third, I discuss Goffman's (1968) idea of the 'moral career'. Finally, I consider the application of my findings to the sociological understanding of the experience of chronic illness in general.

## **The value of Freidson's (1970) expanded version of Parson's (1951) sick role**

In this section, I argue that Freidson's (1970) classification of legitimate and non-legitimate illness is of value. This is because it demonstrates that ideas about illness are bound up with ideas about the moral status of the individual. However, Freidson's analysis is limited because, first, he does not discuss the moral discourses that accompany certain disease labels. Second, his conception of the non-legitimate and legitimate illnesses are 'ideal types' that represent opposite ends of a continuum of the experience of legitimacy. Third, Freidson does not acknowledge that ideas about moral status extend beyond notions of the responsibility for 'the cause of illness', to ideas about the responsibility for 'dealing with illness'.

The findings of this study into the experience of sufferers of ME/CFS suggest that, as argued by Freidson (1970), ideas about illness are strongly bound up with ideas about the moral status of the individual. These ideas, it appears, are related to the social meaning attributed to the diagnostic label. In particular, it seems that certain conditions carry with them the moral assumption that the individual is to blame for illness because he or she is making it up. That is, his or her claims to be really ill are seen by others to be based on an over exaggerated interpretation of symptoms that, in reality, signify nothing more than the 'aches and pains, or stresses and strains of every day life'. The case of ME/CFS suggests that when an individual complains about such symptoms his or her reason for complaining can often be attributed to a personality defect. He or she is either seen as, 'neurotic', 'obsessive', 'attention seeking', 'hormonal', 'depressed' or 'unmotivated'. Such defects are frequently attributed to events in the life of the



individual that have led to his or her state. These events might be for example, an unhappy marriage or 'not getting out enough'.

Whilst this study can only account for the experiences of one group of ME/CFS sufferers, I venture that the diagnostic labels of illness that are often socially equated with this type of moral judgement also include depression, the menopause, pre-menstrual tension, allergies and low back pain. The conditions of Gulf war syndrome, organophosphate poisoning, repetitive strain injury and multiple chemical sensitivity are also included. This premise is based on the findings of writers such as Cornwell (1984) on ideas about 'health problems that are not illnesses', Bendelow (2000) on back pain, and Ewan, Lowry and Reid (1991) on repetitive strain injury and further, on anecdotal accounts of Gulf war veterans that can be seen in the popular press<sup>1</sup>.

I also propose that, as argued by Freidson (1970), a distinction can be made amongst the conditions described above, between those that are seen as 'minor deviations' and those that are seen as 'major deviations'. The conditions that are seen as minor deviations often include depression, the menopause, pre-menstrual tension, low back pain and allergies. These conditions are seen as minor deviations because, whilst the individual might be 'overly' complaining about illness, he or she continues to take part in the activities of daily life. The conditions of Gulf war syndrome, organophosphate poisoning, repetitive strain injury, multiple chemical sensitivity and ME/CFS are often seen as major deviations because the individual both complains and often ceases taking part in the activities of daily life. The distinction between minor or major deviant non-legitimate illness is an important one because the severity of illness has a bearing on the

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<sup>1</sup> It has been beyond the scope of this study to incorporate all of the literature that I have read.

extent to which sufferers experience moral judgement and the extent to which they contest the moral status with which they are accorded.

In addition to moral ideas surrounding the 'authenticity' of illness, Freidson suggests that another type of moral assumption exists with regards to the cause of illness. This assumption is that the individual has brought illness onto him or her self because he or she has indulged in 'unhealthy behaviour'. For Freidson, the diagnostic labels of illness that are often equated with this type of moral judgement are those that are associated with religious discourses of good and evil. Such conditions include 'stammer' and 'epilepsy'. Whilst these conditions are no longer seen as constituting a form of deviance, one condition that might be included in this moral category is AIDS. For example writers such as Sontag (1988) have pointed out that gay and bisexual sufferers often experience the accusation that their condition is self inflicted and/or the outcome of divine punishment. The notion of self infliction also extends today, to conditions such as heart disease and cancer where the cause of illness might be blamed on unhealthy practices such as smoking. (See for example, Blaxter 1983.)

The observation that an amount of blame can be attributed to individuals with chronic illness for indulging in 'unhealthy behaviour' indicates that ideas about the legitimacy of illness are not, as Freidson (1970) suggested, based solely on the broad social meaning of the diagnostic label. As the case of AIDS suggests, it appears that the extent to which an individual is held responsible for his or her illness depends on other factors. These include the background of the individual, whether or not he or she is known to others and whether or not others have had experience of the illness in question. Further, Locker (1991) and Williams (1993) both demonstrate that ideas

about the moral status of the individual with chronic illness can be influenced by the meaning attributed by others, to the symptoms that they observe. Individuals with rheumatoid arthritis and chronic obstructive airways disorder, for example, experience what Bury (1988) defines as 'meanings at risk', because others associate the severely disabling symptoms of both conditions with the symptoms of 'run of the mill aches and pains', or 'self inflicted illness'. Similarly, Robinson (1988) demonstrates how the credibility of a medical diagnosis may well be undermined for those who, only mildly affected by MS, are in remission and thus appear well.

The observation that moral ideas about illness are influenced by more than just the diagnostic label can also be seen in the fact that ideas about responsibility extend beyond the responsibility for the 'cause' of illness to the responsibility for 'dealing with' illness. Indeed, the experience of illness literature indicates that, as originally suggested by Parsons (1951), there is a pressure on the chronically ill to be 'successful copers', or to present themselves as 'bearing up' in the face of illness. As such, ideas about the responsibility for dealing with illness are similar to ideas about the responsibility for the cause of illness. That is, 'unsuccessful copers' are in danger of being seen as 'whingers' or, of not taking the correct actions to minimise the impact of illness. This point is illustrated by Cornwell (1984) who argues that public accounts of illness differ from private accounts because public accounts express a resolve to do what is seen as 'right', whereas private accounts express the extent to which the individual feels that he or she is really suffering. Similarly, one respondent in this study stated 'no one likes a moaner'. The expectation that sufferers should be seen to be 'coping well' in the face of illness can also be seen in some of the sociological accounts of the experience of illness. For example, Radley (1989) argues that those who do not

come to terms with illness can be said to be in 'active denial'. This concept suggests an underlying assumption that the individual who is not coping has a psychological (non-legitimate) problem.

In summary, the observation that ideas about the moral status of individuals with chronic illness are based on more than the social meaning attributed to the diagnostic label suggests that it is not the case that there are simply those conditions that are legitimate and those that are not. Indeed, it appears that moral ideas about illness permeate the experience of illness to a much greater degree than Freidson (1970) indicated. As such, Freidson's categories of 'non-legitimate' and 'legitimate' illness might be seen as ideal types that represent the opposite ends of a 'continuum of legitimacy'. The degree to which a condition is experienced as non-legitimate depends, in many instances, not only on the diagnostic label and also on the factors mentioned above (for example, the background of the sufferer and how others interpret the symptoms). In addition, whilst ideas about the degree of legitimacy of illness are important, any consideration of the moral dimension of illness must also take into account the extent to which individuals are held responsible for dealing with their illness.

The point that ideas about the moral status of the individual are part of 'living with chronic illness' is made by Annandale (1998: 258) who argues that:

Health is seen as moral virtue and illness is a fall from grace. In such a context illness calls for a good deal of work on the part of the individual to reclaim a sense of place in the world.



If there is a continuum of legitimacy then it follows that the amount of 'work' that the sufferer has to do in order to regain his or her sense of place in the world will vary in its intensity. In the following section I discuss the extent to which the 'experience of illness' literature explains the 'work' undertaken by sufferers of ME/CFS and hence by individuals who experience a high degree of non-legitimation.

### **The value of the 'experience of illness' literature**

According to Freidson's (1970) model, the consequence of having a non-legitimate illness is that the individual is first, held responsible for illness and second, denied access to the sick role privileges of 'time out from daily responsibilities' and 'medical support'. The problem with this interpretation of the experience of illness is that it does not explain the experience of ME/CFS sufferers as documented in this thesis. Indeed, Freidson's category of the non-legitimate sick role leaves little room for an understanding of the interplay between public and private ideas about illness and the consequent actions that result from these ideas.

Whilst it introduces into the equation a valuable understanding of the embodied experience of illness and the illness career, the problem of describing the complexity of ME/CFS is not resolved by taking into account the experience of illness literature. The main reason for this, it appears, rests on the fact that the experience of illness writers do not consider in enough depth how ideas about illness change when a person becomes ill. The findings of this study suggest that when an individual becomes ill, he or she begins to see his or her condition, less in terms of the categories of illness drawn from the lay version of the biomedical model and more in terms of the lived experience of the

symptoms. In many cases, the onset of illness appears to bring about feelings of ambivalence. For example, when the body 'dys-appears' (Leder 1990, Williams 1996b), the sufferer begins to question how much his or her pain constitutes 'real' or 'legitimate' pain. In order to answer these questions, he or she starts to gauge his or her ideas about the severity of illness on the extent to which they impact on the activities of daily life.

Whilst the observation that ideas about illness change at the onset of illness is not new (see for example, Zola 1973, Robinson 1988), the ongoing tension between public and private ideas about illness that can occur when illness strikes is rarely identified as the subject of focus. Indeed, sociological accounts of the difference between ideas held by ill persons and others tend to fix their attention on disagreements that take place between doctors and their patients (see for example Annandale and Hunt 1998). As such, it is generally assumed that, as illness progresses, there emerges a consensus between private and public ideas about illness. This, the literature indicates, occurs as the result of either the ability of the medical profession to change lay ideas about illness (as suggested by Freidson) or as the result of a natural agreement amongst patients and others (as suggested by Parsons and implied in much of the experience of illness literature).

The neglect of any possible ongoing tension between private and public ideas about illness has led to a sociological understanding of the experience of illness that tends towards a homeostatic model of illness. This model indicates that individuals with chronic illness embark at the onset of illness on a relatively unproblematic, linear route 'through illness' that is marked by events such as obtaining a diagnosis and finding

information and treatments. This route through illness is portrayed as enabling the sufferer to 'reconstruct order', 'maintain control' and thus 'accept' or 'accommodate' illness.

The example of ME/CFS shows however that the illness career can be far from linear and in many cases does not lead to the 'accommodation of illness'. Rather, it is characterised by the tension caused when ideas about illness clash. Indeed, individuals can be said to embark on a journey through illness that follows a twisting pathway, beset with problems caused by the combination of incapacity and a lack of social support and acceptance. As time progresses, this struggle tends to shift in the main, from the public world into the private world.

### **The value of Goffman's (1968) concept of the moral career**

The findings of this study suggest that the complexity of non-legitimation, as experienced by many ME/CFS sufferers, can be understood more clearly in terms of Goffman's (1968), 'moral career'. The value of the concept of the moral career is that it brings to the subject of the illness experience an understanding of first, the moral ideas surrounding illness, second the tension between public and private ideas about illness and third, how this tension plays itself out over time. In short, the moral career highlights the finding that, in general, sufferers' embodied experiences are viewed and treated by others in terms of moral categories over which they have no control. Consequently sufferers are compelled to try and navigate their ways around the problems that this moral categorising imposes. The moral career of the ME/CFS sufferer is described as follows.

In the first instance, general ideas about illness, are held by sufferers of ME/CFS themselves. As a result, at the onset of illness, many sufferers dismiss their symptoms as trivial and carry on with the duties of everyday life. When, because of the incapacitating nature of the symptoms, sufferers eventually seek medical advice, despite extensive medical testing, GPs and hospital consultants find no pathological sign of illness. Consequently, medical practitioners do not diagnose sufferers. The dominance of medical ideas about their illness is such that sufferers find themselves propelled into a situation of 'not being seen as ill'. This experience is characterised by the expectation from others that the sufferer should not gain any of the privileges of the sick role. This situation suggests that a moral category of illness exists independently of Freidson's non-legitimate sick role. This category is the category of non diagnosed illness. The stigma of 'no diagnosis' appears to be disbelief that the individual is ill. A consequence of being disbelieved appears to be a lack of practical social support and further, humiliation, uncertainty and a sense of social isolation. This experience contradicts sufferers' expectations. As such, in seeking help, they assume that they will be able to find a way of making sense of the losses that are brought about by their changing bodies and start to regain a sense of who they are.

As a result of finding themselves undiagnosed, many individuals begin to consider that their condition is, after all, 'in the mind'. However, eventually, rather than accepting the cultural view of their (non-) illness, many sufferers of ME/CFS opt to struggle against it. In doing so, they continue to draw on widely held ideas about what constitutes authentic illness in their own interpretations of their symptoms. Further sufferers' continue to seek a label for illness and thus confirmation from the medical profession that they have an illness. The finding that eventually sufferers do obtain an official



diagnosis of ME/CFS, suggests that, despite the initial dominance of medical ideas, there is room in medical/lay interactions for negotiation. Indeed, at the stage of obtaining a diagnosis, sufferers appear to succeed in their struggle with the medical profession. This success can be seen in the finding that a diagnosis of ME/CFS is met with relief, because, as such, sufferers expect that their claims to be 'really ill' will, at last, be socially accepted.

The accounts of the respondents with regards to the stage of illness that occurs after being diagnosed (the stage that Charmaz 2000, refers to as 'reconstructing order') continues to bear a close resemblance to Goffman's (1968) description of the moral career. Goffman implies that once an individual is labelled with a stigmatising condition, he or she is stripped of many accustomed affirmations and satisfactions and subjected to a new set of experiences. That the condition known as ME/CFS is a stigmatising condition can be seen in the finding that, despite succeeding in gaining an official diagnosis of 'illness', the usual avenues of support available to persons with chronic illness remain blocked. Indeed, the reports of the respondents suggest that sufferers of ME/CFS experience the conditions of the non-legitimate sick role as described by Freidson. This can be seen in the finding that their moral status continues to be questioned by GPs who, in many cases, continue to blame their patients for time wasting and malingering and are reluctant to give any advice with regards to the aetiology and management of the condition. In addition, friends, colleagues and family members often continue to treat sufferers' claims to be 'really ill' with scepticism, as do disability officers, whose job it is to assess the eligibility of the sufferer for financial support. Alongside the continued practical problems that these ideas about illness engender, such reactions are said again, to lead ultimately to a complete 'non

acceptance' of who the sufferer is. As such, many sufferers experience a situation whereby not only do they experience the loss of self but their 'self' is blamed for causing it's own loss.

Goffman argues that, in response to this kind of moral labelling, individuals take on new sets of identity beliefs and practices. Thus they single out and retrospectively elaborate experiences that serve to account for their coming to the practices which they have adopted. In response to their situations, the individuals that took part in this study eventually drew on alternative discourses of ME/CFS that confirmed their ideas that they were really ill. This finding backs up Giddens' (1984) assertion that in late modernity individuals utilise more than one source of expert knowledge to make sense of certain phenomena. The discourses drawn upon by sufferers of ME/CFS suggest (as demonstrated in chapter 1) that ME/CFS is a pathological condition caused by external agents such as a virus or organophosphate poisoning. Such discourses were often contextualised by the respondents within their own biographies and, as such, served to help them reconstruct order by providing what was seen as a plausible explanation for their condition. In addition, the alternative discourses of ME/CFS acted to protect the moral integrity of the sufferer by providing a rationale that stated that 'others' react the way they do because they are simply uneducated about the reality of ME/CFS and have a 'limited understanding' of it. Despite being able to legitimate ME/CFS to themselves however, the findings suggest that sufferers fail to change the views of others.

It can be argued that, in finding explanations of their illness elsewhere, sufferers of non-legitimate illnesses develop a 'revised lay version' of the cultural view of illness that suggests that the social meaning of the diagnostic label can be found outside of

mainstream medicine. Whilst these discourses serve to legitimate the condition to the sufferer and shield against the moral judgements of others, they do not appear to change the dominant public view of ME/CFS as 'in the mind'. Thus, alternative discourses of ME/CFS appear to pose little threat to conventional ideas about illness at present. However, in taking the actions that they do, sufferers can be said to contribute towards the development of a discourse of illness that might in the future be drawn upon by sufferers of other contested or little recognised illnesses. As this new lay discourse of illness becomes popular it might, in turn, become part of wider mainstream thinking.

An exploration of how individuals with ME/CFS manage eventually their embodied experiences, having legitimised illness to themselves, suggests that many sufferers develop ways of coping with their illness, using similar management strategies to persons with other chronic illnesses. However, 'accepting' ME/CFS as part of their everyday lives appears to be part of a personal, ongoing daily struggle. At best, many sufferers can be said to reach a stage of 'barely tolerating illness'. That sufferers do not fully accept their ME/CFS appears to be due to the unrelenting demands that the condition makes on the body and social action. These demands are compounded by the fact that due to the non-legitimate sick role, many sufferers do not obtain the financial assistance necessary for 'help with mundane daily chores'. Because of this, sufferers are unable to use their limited energy to engage in activities that reaffirm the self and life in general. Instead, they are compelled to use the time available to them, to try and ensure that the very basic conditions for existence are met. For many, this situation is one of perpetual chaos as they see their previous standards of living fall away and worry about the future.

The findings suggest that if the social conditions are right, there might well, for many sufferers of chronic illness, be an end stage to the moral career, whereby as Goffman argued, sufferers accept the social idea of 'who they are' and move 'beyond passing and covering'. This is embodied in the quest narratives of those sufferers who were able to obtain a relatively high level of social support. However, it appears that for many, the notion that somehow the losses caused by the experience of illness are reconciled is a myth or, to put it another way another 'moral assumption' held by culture in general. A more fitting premise appears to be that for individuals labelled with 'non legitimate chronic illness', acceptance becomes part of an ongoing daily struggle, which, because of the myth of acceptance, takes place in the private world of the individual and becomes increasingly invisible in the public world.

### **Legitimation, embodied experience and the moral career: the case of all chronic illnesses?**

I have argued above that it is not simply the case that some illness are more legitimate than other illnesses. Rather, ideas about the moral status of individuals with chronic illness might be seen in terms of a continuum of legitimacy, which is marked by non-legitimacy at one end and unconditional legitimacy at the other end. I have also suggested that the degree of legitimacy imputed to the individual will have a bearing on the amount of work that the individual has to do to regain his or her sense of place in the world. Whilst ME/CFS provides a clear example of the work that sufferers of highly non-legitimate illnesses might have to do, the question arises as to the 'type of' and 'amount of' work that individuals with less legitimate conditions have to do.



In order to understand this it might be useful to apply the concept of the moral career to all conditions, in addition to looking at the embodied experience of illness. This would highlight the tensions experienced along the illness career and the ways, if any, that individuals deal with them. Indeed, an application of the moral career to the embodied experience of all illness would demonstrate, for example, the tensions often experienced in illnesses that are often seen as less severe and non-legitimate. Sufferers of back pain for example, often report having to manage the tension between 'not being seen as moaners' and experiencing profound disability. Similarly, an application of the moral career to an understanding of the experience of Rheumatoid arthritis would show that, whilst there is a general agreement about the aetiology of illness amongst patients and the medical profession, sufferers often experience tension because their symptoms are seen by others as 'the aches and pains of daily life'. In contrast, an application of the moral career to medicalised conditions such as pregnancy might demonstrate that sufferers experience a high degree of conditional legitimation from others which results in a pregnancy career that is marked by less tension.

Further to considering the interplay between moral ideas about the cause of illness an understanding of the moral career might also take into account moral ideas about the responsibility for dealing with illness. As I have suggested above, the sociological literature tends to indicate that individuals eventually reach a stage of accommodating illness (Radley, 1989). The findings of this study suggest, however, that many individuals with ME/CFS do not reach a stage of accepting illness, rather the embodied experience of illness is such that they continue to struggle with living with illness on a daily basis. Indeed, it appears that because of the public emphasis on the acceptance of illness, much of this struggle takes place in private. This point is noted by Vranken

(1989) who argues that the lived experience of extreme back pain tends to be invisible in the public world: it is something that the sufferer has to put up with in private. The danger of assuming that individuals suffering from chronic illness reach a point of accommodation is that the ongoing experience of chronic illness is not seen as worthy of sociological study. Indeed, with the exception of writers such as Frank (1991), Kleinman (1988), Vranken (1989) and Bendelow (2000), little consideration is given in the mainstream literature to the ongoing embodied experience of illness and the tensions that occur when an individual interacts with others.

Finally, in addition to drawing attention to the tension that might occur in chronic illness due to moral judgement, an understanding of the moral career is of particular relevance to the present day. This is because, as the chronically ill population expands, ideas about what causes illness and who is responsible for dealing with illness are taking on an increasingly moral tone. This can be seen for example, in current scientific and lay literature which emphasises the fact that personality factors can cause illness. Stress, anxiety and 'unhealthy habits', such as smoking and over eating are being increasingly held up as predisposing persons to diseases such as coronary heart disease or cancer. Similarly, individual behaviour is becoming increasingly medicalised. Attention deficit disorder, anorexia and obsessive compulsive disorder, are to name but a few of the new illness categories that have emerged in recent years (<http://mentalhelp.net> 20<sup>th</sup> September 2002). Alongside the increasing popularity of discourses surrounding the relationship between the cause of illness and human behaviour, there are similar moral discourses about 'good coping strategies'. This can be seen in the prevalence of self-help literature and the growing popularity within the medical profession of cognitive behavioural therapy as a strategy for changing the

negative thought patterns of individuals and thus creating a way of dealing with distressful life events.

**Revisiting the extent to which moral ideas permeate the lives of all individuals with chronic illness.**

In conclusion I suggest that all individuals with chronic illness experience a form of the moral career. It is not simply the case that those individuals with non-legitimate illnesses take on the non-legitimate sick role and thus experience the moral career and those individuals who take on the legitimate sick role will not experience any problems. I propose that further research into the interplay between both public and private ideas about illness and their impact will throw up a number of interesting sociological insights. However, I argue that sociological studies of the moral careers of sufferers should not take precedence over studies into the embodied nature of chronic illness. Rather, an understanding of both aspects of illness is of equal importance when it comes to making sense of the complex subject that is 'the illness experience'.

## **Appendices**



## Appendix 1

### The medical criteria that has been used in the diagnosis of ME/CFS

**TABLE 1**

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**Oxford criteria for diagnosing ME/CFS**

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**Chronic fatigue syndrome (CFS)**

- (a) A syndrome characterized by fatigue as the principal symptom.
- (b) A syndrome of definite onset that is not life long.
- (c) The fatigue is severe, disabling, and affects physical and mental functioning.
- (d) The symptom of fatigue should have been present for a minimum of 6 months during which it was present for more than 50% of the time.
- (e) Other symptoms may be present, particularly myalgia, mood and sleep disturbance.
- (f) Certain patients should be excluded from the definition.

**They include:**

- (i) Patients with established medical conditions known to produce chronic fatigue (eg severe anaemia). Such patients should be excluded whether the medical condition is diagnosed at presentation or only subsequently. All patients should have a history and physical examination performed by a competent physician.
- (ii) Patients with a current diagnosis of schizophrenia, manic depressive illness, substance abuse, eating disorder or proven organic brain disease. Other psychiatric disorders (including depressive illness, anxiety disorders, and hyperventilation syndrome) are not necessarily reasons for exclusion.

**Post-infectious fatigue syndrome (PIFS)**

This is a subtype of CFS which either follows an infection or is associated with a current infection (although whether such associated infection is of aetiological significance is a topic for research).

To meet research criteria for PIFS patients must:

- (i) fulfil criteria for CFS as defined above and
- (ii) should also fulfil the following additional criteria:
  - (a) There is definite evidence of infection at onset or presentation (a patient's self-report is unlikely to be sufficiently reliable).
  - (b) The syndrome is present for a minimum of 6 months after onset of infection.
  - (c) The infection has been corroborated by laboratory evidence.

**TABLE 2**

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**Centre for Disease Control criteria for diagnosing ME/CFS**

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- (1) Clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially relieved by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities; and
- (2) the concurrent occurrence of **four or more** of the following symptoms, all of which must have persisted or recurred during six or more consecutive months of illness and must not have predated the fatigue:
  - self-reported impairment in short-term memory or concentration severe enough to cause a substantial reduction in previous levels of occupational, educational, social or personal activities.
  - sore throat
  - tender cervical or axillary lymph nodes
  - muscle pain
  - headaches of a new type, pattern or severity
  - unrefreshing sleep
  - post-exertional malaise lasting more than twenty four hours
  - multijoint pain without joint swelling or redness

**TABLE 3**

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**Australian Criteria for diagnosing ME/CFS**

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- (1) Disabling and prolonged feelings of physical tiredness or fatigue, exacerbated by physical activity.
- (2) Present for at least 6 months.
- (3) Unexplained by an alternative diagnosis reached by history, laboratory, or physical examinations.
- (4) Accompanied by the new onset of neuropsychological symptoms including impaired short-term memory and concentration, decreased libido, and depressed mood. These symptoms usually have their onset at the same time as the physical fatigue, but are typically less severe, and less persistent than those seen in classic depressive illness.

Patients are excluded if:

1. They have a chronic medical condition that may result in fatigue.
2. There is a history of schizophrenia, other psychotic illnesses, or bipolar affective disorder.

In addition, drug or alcohol dependence makes CFS very unlikely.

## Appendix 2

### The cover letter and questionnaires



**IMPORTANT: BEFORE READING THIS LETTER, PLEASE READ THE ARTICLE ABOUT THE M.E. / C.F.S. / P.V.F.S. SURVEY WHICH IS IN YOUR NEWSLETTER**

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**David Mason** BA MSc  
Professor of Sociology and  
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14.12.99

Dear Reader

#### **M.E. / C. F.S. / P.V.F.S. Survey**

Thank you very much for agreeing to take part in this survey which is part of a PhD research project. The aims are: 1) to explore sufferer's experiences of living with a fatigue related illness of an apparent unknown cause and 2) to compare the quality of life of people who have a fatigue related illness of an apparent unknown cause with those suffering from other long term illnesses. This PhD is based on my earlier MSc. research.

I have defined these fatigue related illnesses of an apparent unknown cause as either M.E., Chronic Fatigue Syndrome or Post Viral Fatigue Syndrome and represented them on the questionnaire as 'ME/CFS/PVFS'.

Enclosed are two questionnaires. Each one should take approximately 10 to 15 minutes to complete. I am interested in information from both children and adults as well as those whose conditions range from mild to severe. I would request that you kindly ask someone else to fill in the questionnaires on your behalf if you are feeling too ill to complete them yourself.

It is hoped that the findings will be published nationally thereby bringing attention to the situation of people with ME/CFS/PVFS. In addition it is anticipated that the results will be reported in the October 2000 editions of Action for M.E. and Perspectives. All replies will be treated in the strictest confidence and your anonymity will be protected.

When you have completed the questionnaires, please return them both in the envelope enclosed.  
Thank you again for your help

Yours Sincerely

Tracey Collett

**Questionnaire 1**  
**(General information and quality of life measure)**  
**Thank you for taking the time to fill in this questionnaire**

**About your ME/CFS/PVFS**

1 Do you currently have either M.E., Chronic Fatigue Syndrome (C.F.S.), or Post Viral Fatigue Syndrome (P.V.F.S.)?

(PLEASE CIRCLE ONE NUMBER ONLY)

Yes ..... 1  
 No ..... 2

2 What name do you call this illness?

(PLEASE CIRCLE ONE NUMBER ONLY)

M.E. .... 1  
 C.F.S. .... 2  
 P.V.F.S. .... 3

3 How long have you had ME/CFS/PVFS?

(PLEASE STATE IN BOX OPPOSITE)

Years  Months

4 Are you diagnosed with any other illness at present?

(PLEASE CIRCLE ONE NUMBER ONLY)

Yes ..... 1  
 No (go to question 6)..... 2

5 Which other illness (es) are you diagnosed with at present?

(PLEASE STATE ON LINES OPPOSITE)

.....  
 .....  
 .....

**About you in general**

6 Are you male or female?

(PLEASE CIRCLE ONE NUMBER ONLY)

Male ..... 1  
 Female ..... 2

7 What age were you on your last birthday?

(PLEASE STATE IN BOX OPPOSITE)

Years

8 Which ethnic group do you belong to?

(PLEASE CIRCLE ONE NUMBER ONLY)

Bangladeshi ..... 1  
 Black African ..... 2  
 Black Caribbean ..... 3  
 Chinese ..... 4  
 Indian ..... 5  
 Pakistani ..... 6  
 White ..... 7  
 Other (please state) ..... 8



<p>9 What is the current annual income for your household?</p> <p>(PLEASE CIRCLE <u>ONE NUMBER ONLY</u>)</p>	<p>Less than £5000 ..... 1</p> <p>Between £5001 and £10 000 ..... 2</p> <p>Between £10 001 and £20 000 ..... 3</p> <p>Between £20 001 and £30 000 ..... 4</p> <p>Between £30 001 and £40 000 ..... 5</p> <p>Between £40 001 and £50 000 ..... 6</p> <p>More than £50 000 ..... 7</p>
<p>10 Has your annual household income been reduced as a result of your having ME/CFS/PVFS?</p> <p>(PLEASE CIRCLE <u>ONE NUMBER ONLY</u>)</p>	<p>Yes ..... 1</p> <p>No ..... 2</p>
<p>11 Are you married / living with a partner?</p> <p>(PLEASE CIRCLE <u>ONE NUMBER ONLY</u>)</p>	<p>Yes ..... 1</p> <p>No ..... 2</p>
<p>12 How many individuals, including you, live in your house?</p> <p>(PLEASE STATE ON LINE OPPOSITE)</p>	<p>.....</p>
<p><b>About the impact of ME/CFS/PVFS on work</b></p>	
<p>13 Do you have any extra paid or unpaid help in your home?</p> <p>(PLEASE CIRCLE <u>ONE NUMBER ONLY</u>)</p>	<p>Yes ..... 1</p> <p>No (go to question 15 ) ..... 2</p>
<p>14 Who provides this help?</p> <p>(PLEASE STATE ON LINES OPPOSITE)</p>	<p>.....</p> <p>.....</p>
<p>15 Before you had ME/CFS/PVFS which statement best described your working situation?</p> <p>(PLEASE CIRCLE <u>ONE NUMBER ONLY</u>)</p>	<p>In full time education ..... 1</p> <p>In part time education ..... 2</p> <p>Looking after the home or family ..... 3</p> <p>Working full time (for an employer) ..... 4</p> <p>Working part time (for an employer) ..... 5</p> <p>Self employed ..... 6</p> <p>On a government training scheme ..... 7</p> <p>Unemployed ..... 8</p> <p>Retired ..... 9</p> <p>Unable to work due to a long term illness/disability ..... 10</p> <p>Other (please state) .....</p>

<p><b>16 Which statement best describes your current working situation?</b></p> <p><b>(PLEASE CIRCLE ONE NUMBER ONLY)</b></p>	<p>In full time education ..... 1</p> <p>In part time education ..... 2</p> <p>Looking after the home or family..... 3</p> <p>Working full time (for an employer) ..... 4</p> <p>Working part time (for an employer) ..... 5</p> <p>Self employed ..... 6</p> <p>On a government training scheme ..... 7</p> <p>Unemployed ..... 8</p> <p>Retired ..... 9</p> <p>Unable to work due to along term illness/disability ..... 10</p> <p>Other (please state) ..... 11</p>
<p><b>17 Has your work situation changed because of your ME/CFS/PVFS?</b></p> <p><b>(PLEASE CIRCLE ONE NUMBER ONLY)</b></p>	<p>Yes ..... 1</p> <p>No ..... 2</p>
<p><b>18 Why did your work situation change?</b></p> <p><b>(PLEASE STATE ON THE LINES OPPOSITE)</b></p>	<p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

**PLEASE TURN TO THE NEXT PAGE**

The last section of this questionnaire is a standard quality of life measure, the results from this measure can be used to compare your quality of life with the quality of life of people suffering from other chronic illnesses.

## Overall Health

The following questions ask for your views about your health and how you feel about life in general. If you are unsure about how to answer any question, try and think about your overall health and give the best answer you can. Do not spend too much time answering as your immediate response is likely to be the most accurate.

<p>1 <u>In general</u>, would you say your health is:</p> <p>(PLEASE CIRCLE ONE NUMBER ONLY)</p>	<p>Excellent ..... 1</p> <p>Very good ..... 2</p> <p>Good ..... 3</p> <p>Fair ..... 4</p> <p>Poor ..... 5</p>
<p>2 Compared to <u>one year ago</u> how would you rate your health in general now?</p> <p>(PLEASE CIRCLE ONE NUMBER ONLY)</p>	<p>Much better than one year ago ..... 1</p> <p>Somewhat better than one year ago ..... 2</p> <p>About the same ..... 3</p> <p>Somewhat worse than one year ago ..... 4</p> <p>Much worse than one year ago ..... 5</p>

## Health and Daily Activities

3 The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much?	(PLEASE CIRCLE ONE NUMBER ON EACH LINE)		
	Yes, limited a lot	Yes, limited a little	No, not limited at all
a) Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b) Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
c) Lifting or carrying groceries	1	2	3
d) Climbing several flights of stairs	1	2	3
e) Climbing one flight of stairs	1	2	3
f) Bending, kneeling or stooping	1	2	3
g) Walking more than a mile	1	2	3
h) Walking half a mile	1	2	3
i) Walking 100 yards	1	2	3
j) Bathing and dressing	1	2	3

**Health and Daily Activities (continued)**

During the past 4 weeks, how much time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	(PLEASE CIRCLE <u>ONE NUMBER ON EACH LINE</u> )				
	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a) Cut down on the amount of time you spent on work and other activities	1	2	3	4	5
b) Accomplished less than you would like	1	2	3	4	5
c) Were limited in the kind of work or other activities	1	2	3	4	5
d) Had difficulty performing the work or other activities (eg it took more effort)	1	2	3	4	5
5 During the past 4 weeks, how much time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?	(PLEASE CIRCLE <u>ONE NUMBER ON EACH LINE</u> )				
	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a) Cut down on the amount of time you spent on work and other activities	1	2	3	4	5
b) Accomplished less than you would like	1	2	3	4	5
c) Did work or other activities less carefully than usual	1	2	3	4	5
6 During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?	Not at all ..... 1				
	Slightly ..... 2				
	Moderately..... 3				
	Quite a bit ..... 4				
	Extremely ..... 5				
7 How much bodily pain have you had during the past 4 weeks?	None ..... 1				
	Very mild ..... 2				
	Mild ..... 3				
	Moderate .. ..... 4				
	Severe ..... 5				
	Very severe .... ..... 6				



**Health and Daily activities (continued)**

8	During the past 4 weeks, how much did pain interfere with your normal work (both outside the home and housework)?	Not at all .....	1
		A little bit .....	2
		Moderately .....	3
		Quite a bit .....	4
		Extremely .....	5

**Your feelings**

9	<p>These questions are about how you feel and how things have been with you during the past month. For each question please give the one answer that comes closest to the way you have been feeling.</p> <p>How much time during the last month:</p>	(PLEASE CIRCLE <u>ONE</u> NUMBER ON EACH LINE)					
		All of the time	Most of the time	Some of the time	A little of the time	None of the time	
		a) Did you feel full of life?	1	2	3	4	5
		b) Have you been very nervous?	1	2	3	4	5
		c) Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5
		d) Have you felt calm and peaceful?	1	2	3	4	5
		e) Did you have a lot of energy?	1	2	3	4	5
		f) Have you felt downhearted and low?	1	2	3	4	5
		g) Did you feel worn out?	1	2	3	4	5
		h) Have you been happy?	1	2	3	4	5
i) Did you feel tired?	1	2	3	4	5		
10	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc.)?	All of the time .....	1				
		Most of the time .....	2				
		Some of the time .....	3				
		A little of the time .....	4				
		None of the time .....	5				

**Health in General**

11	How TRUE or FALSE is each of the following statements for you?	(PLEASE CIRCLE ONE NUMBER ON EACH LINE)				
		Definitely true	Mostly true	Not sure	Mostly false	Definitely false
a)	I seem to get ill more easily than other people	1	2	3	4	5
b)	I am as healthy as anybody I know	1	2	3	4	5
c)	I expect my health to get worse	1	2	3	4	5
d)	My health is excellent	1	2	3	4	5

**THANK YOU FOR COMPLETING QUESTIONNAIRE ONE, PLEASE-FILL-IN QUESTIONNAIRE TWO AND RETURN BOTH QUESTIONNAIRES TO THE ADDRESS BELOW IN THE FREEPOST ENVELOPE PROVIDED.**

**IT IS HOPED THAT THE RESULTS WILL CONTRIBUTE TOWARDS HIGHLIGHTING SOME OF THE DIFFICULTIES THAT PEOPLE WITH M.E. / C.F.S. / P.V.F.S. FIND THEMSELVES IN.**

**If you have any enquiries please contact**

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**Email. TCollett@plymouth.ac.uk**

## Questionnaire 2

**Thank you for agreeing to do the second questionnaire.  
The results will highlight some of the difficulties faced by people suffering from ME/CFS/PVFS**

<b>Experience of diagnosis</b>	
<p><b>1 Has your ME/CFS/PVFS been diagnosed formally?</b></p> <p><b>(PLEASE CIRCLE ONE NUMBER ONLY)</b></p>	<p>Yes..... 1</p> <p>No (go to question 4 )..... 2</p>
<p><b>2 Who first formally diagnosed you with ME/CFS/PVFS?</b></p> <p><b>(PLEASE CIRCLE ONE NUMBER ONLY)</b></p>	<p>Your local GP..... 1</p> <p>An N.H.S consultant ..... 2</p> <p>A private consultant ..... 3</p> <p>An alternative practitioner..... 4</p> <p>Other (please state)..... 5</p>
<p><b>3 How long after your first visit to a GP about the ME/CFS/PVFS symptoms did you get formally diagnosed?</b></p> <p><b>(PLEASE STATE IN BOXES OPPOSITE)</b></p>	<p>Years <input style="width: 40px; height: 20px;" type="text"/> Months <input style="width: 40px; height: 20px;" type="text"/> I did not see a GP <input style="width: 40px; height: 20px;" type="checkbox"/></p>
<b>Experience of the N.H.S.</b>	
<p><b>4 How many times have you consulted your GP about your ME/CFS/PVFS in the last six months?</b></p> <p><b>(PLEASE STATE ON LINE OPPOSITE)</b></p>	<p>.....</p>
<p><b>5 Have you ever changed your GP because you were not satisfied with his/her approach to your ME/CFS/PVFS?</b></p> <p><b>(PLEASE CIRCLE ONE NUMBER ONLY)</b></p>	<p>Yes..... 1</p> <p>No..... 2</p>
<p><b>6 How satisfied are you with your current GP?</b></p> <p><b>(PLEASE CIRCLE ONE NUMBER ONLY)</b></p>	<p>Very satisfied..... 1</p> <p>Satisfied..... 2</p> <p>Neither satisfied or dissatisfied..... 3</p> <p>Dissatisfied..... 4</p> <p>Very dissatisfied..... 5</p>

<p><b>8 Which, if any, of the following medical consultants have you been referred to on the N.H.S. specifically because of your ME/CFS/PVFS?</b></p> <p><b>(PLEASE CIRCLE ALL THAT APPLY)</b></p>	<table style="width: 100%; border-collapse: collapse;"> <tr><td>Consultant Physician .....</td><td style="text-align: right;">1</td></tr> <tr><td>Psychiatrist .....</td><td style="text-align: right;">2</td></tr> <tr><td>Neurologist .....</td><td style="text-align: right;">3</td></tr> <tr><td>Rheumatologist .....</td><td style="text-align: right;">4</td></tr> <tr><td>Paediatrician .....</td><td style="text-align: right;">5</td></tr> <tr><td>Immunologist .....</td><td style="text-align: right;">6</td></tr> <tr><td>ME/CFS/PVFS consultant .....</td><td style="text-align: right;">7</td></tr> <tr><td>Psychologist .....</td><td style="text-align: right;">8</td></tr> <tr><td>Other (s) (please state) .....</td><td style="text-align: right;">9</td></tr> <tr><td>I have not seen any N.H.S. consultants.....</td><td style="text-align: right;">10</td></tr> </table>	Consultant Physician .....	1	Psychiatrist .....	2	Neurologist .....	3	Rheumatologist .....	4	Paediatrician .....	5	Immunologist .....	6	ME/CFS/PVFS consultant .....	7	Psychologist .....	8	Other (s) (please state) .....	9	I have not seen any N.H.S. consultants.....	10
Consultant Physician .....	1																				
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Other (s) (please state) .....	9																				
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<p><b>9 The following questions are about how satisfied you have been with the consultants that you have seen through the N.H.S. How satisfied were you with the following consultants?</b></p>	<p><b>(PLEASE CIRCLE 1 NUMBER ON EACH LINE)</b></p> <table style="width: 100%; border-collapse: collapse; text-align: center;"> <thead> <tr> <th style="width: 15%;"></th> <th style="width: 10%;">Very satisfied</th> <th style="width: 10%;">Satisfied</th> <th style="width: 10%;">Neither satisfied nor dissatisfied</th> <th style="width: 10%;">Dissatisfied</th> <th style="width: 10%;">Very dissatisfied</th> <th style="width: 10%;">*n/a</th> </tr> </thead> <tbody> <tr> <td>a) Consultant Physician</td> <td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td> </tr> <tr> <td>b) Psychiatrist</td> <td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td> </tr> <tr> <td>c) Neurologist</td> <td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td> </tr> <tr> <td>d) Rheumatologist</td> <td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td> </tr> <tr> <td>e) Paediatrician</td> <td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td> </tr> <tr> <td>f) Immunologist</td> <td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td> </tr> <tr> <td>g) Psychologist</td> <td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td> </tr> <tr> <td>h) ME/CFS/PVFS Consultant</td> <td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td> </tr> <tr> <td>i) Other (please state which)</td> <td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td></td> </tr> </tbody> </table>		Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	*n/a	a) Consultant Physician	1	2	3	4	5	6	b) Psychiatrist	1	2	3	4	5	6	c) Neurologist	1	2	3	4	5	6	d) Rheumatologist	1	2	3	4	5	6	e) Paediatrician	1	2	3	4	5	6	f) Immunologist	1	2	3	4	5	6	g) Psychologist	1	2	3	4	5	6	h) ME/CFS/PVFS Consultant	1	2	3	4	5	6	i) Other (please state which)	1	2	3	4	5	
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\*Not applicable as I have not seen this consultant through the N.H.S.





**Experience of alternative practitioners**

12 Which, if any, of the following alternative practitioners have you consulted because of your ME/CFS/PVFS?  
  
(PLEASE CIRCLE ALL THAT APPLY)

- Crystal Healer ..... 1
- Nutritionist ..... 2
- Homeopath ..... 3
- Osteopath ..... 4
- Acupuncturist ..... 5
- Reflexologist ..... 6
- Naturopath ..... 7
- Spiritual healer ..... 8
- Other (s) please state ..... 9
- I have not seen any alternative practitioners..... 10

13 The following questions are about how satisfied you have been with the alternative practitioners that you have consulted because of your ME/CFS/PVFS. How satisfied were you with the following alternative practitioners?

(PLEASE CIRCLE 1 NUMBER ON EACH LINE)

	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	*n/a
a) Crystal healer	1	2	3	4	5	6
b) Nutritionist	1	2	3	4	5	6
c) Homeopath	1	2	3	4	5	6
d) Osteopath	1	2	3	4	5	6
e) Acupuncturist	1	2	3	4	5	6
f) Reflexologist	1	2	3	4	5	6
g) Naturopath	1	2	3	4	5	6
h) Spiritual Healer	1	2	3	4	5	6
i) Other (please state which) .....	1	2	3	4	5	6

\*Not applicable as I have not consulted any alternative practitioners

**Experience of obtaining benefits**

14 What financial assistance, if any, do you currently receive from Social Security Benefits Agency).

(PLEASE CIRCLE ALL THAT APPLY)

- Mobility Allowance ..... 1
- Attendance/ Carers Allowance ..... 2
- DLA Mobility Allowance ..... 3
- DLA Attendance Allowance ..... 4
- Disability Working Allowance ..... 5
- Income Support ..... 6
- Sickness Benefit / Statutory Sick Pay ..... 7
- Invalidity Benefit ..... 8
- Severe Disablement Allowance ..... 9
- Unemployment Benefit ..... 10
- Other (s) (please state) ..... 11
- I do not receive any financial assistance ..... 12

15 Have you ever been refused financial assistance from Social Security (Benefits Agency)?

(PLEASE CIRCLE ONE NUMBER ONLY)

- Yes ..... 1
- No (go to question 18 ) ..... 2

16 How many times have you been refused financial assistance?

(PLEASE WRITE IN BOX OPPOSITE)

TIMES

17 Please state which benefit was refused most recently and write why.

(PLEASE WRITE ON THE LINES OPPOSITE)

.....  
 .....  
 .....

**Understanding about ME/CFS/PVFS**

18 Which of the statements opposite best describes your understanding of ME/CFS/PVFS?

(PLEASE CIRCLE ONE NUMBER ONLY)

- It is a physical disorder ..... 1
- It is a psychological disorder ..... 2
- Not sure whether it is physical or psychological ..... 3
- It is both physical and psychological ..... 4
- I Do not know what it is ..... 5
- Other (please state below)  
 ..... 6



19 Which of the statements opposite do you think best describes the understanding that the general public have of ME/CFS/PVFS?

(PLEASE CIRCLE ONE NUMBER ONLY)

- It is a physical disorder ..... 1
- It is a psychological disorder ..... 2
- Not sure whether it is physical or psychological ..... 3
- It is both physical and psychological ..... 4
- They do not know ..... 5
- Other (please state below) ..... 6

**Experience of immediate support**

20 About how many close friends and close relatives do you have (people you feel at ease with and can talk about what is on your mind)

(PLEASE WRITE NUMBER IN BOX)

= Number of close friends and relatives

21 People often look to others for companionship, assistance or other types of support. How often is each of the following kinds of support available to you if you need it?

(PLEASE CIRCLE 1 NUMBER ON EACH LINE)

	None of the Time	A little of the Time	Some of the Time	Most of the Time	All of the Time
a) Someone to help you if you were confined to bed	1	2	3	4	5
b) Someone you can count on to listen to when you need to talk	1	2	3	4	5
c) Someone to give you good advice about a crisis	1	2	3	4	5
d) Someone to take you to the doctor if you needed it	1	2	3	4	5
e) Someone who shows you love and affection	1	2	3	4	5
f) Someone to have a good time with	1	2	3	4	5
g) Someone to give you information to help you understand a situation	1	2	3	4	5
h) Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
i) Someone who hugs you	1	2	3	4	5



Question 21 continued: How often is each of the following kinds of support available to you when you need it?	(PLEASE CIRCLE 1 NUMBER ON EACH LINE)				
	None of the Time	A little of the Time	Some of the Time	Most of the Time	All of the Time
j) Someone to get together with for relaxation	1	2	3	4	5
k) Someone to prepare your meals if you were unable to do it for yourself	1	2	3	4	5
l) Someone whose advice you really want	1	2	3	4	5
m) Someone to do things with to help you get your mind off things	1	2	3	4	5
n) Someone to help you with the daily chores if you were sick	1	2	3	4	5
o) Someone to share your most private worries and fears with	1	2	3	4	5
p) Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
q) Someone to do something enjoyable with	1	2	3	4	5
r) Someone who understands your problems	1	2	3	4	5
s) Someone to love you and make you feel wanted	1	2	3	4	5
22 Which, if any, of the support groups listed opposite do you belong to?  (PLEASE CIRCLE ALL THAT APPLY)	Action for M.E. .... 1 The M.E. Association ..... 2 AYME ..... 3 Local ME/CFS/CFIDS/PVFS support groups ..... 4 International ME/CFS/PVFS/CFIDS support groups .. 5 Other (s) (please state which) ..... 6				

23 If you still have the energy to complete this question please state what would most improve your quality of life at present.

(PLEASE WRITE ON THE LINES OPPOSITE)

.....  
.....  
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**THANK YOU FOR YOUR HELP. PLEASE POST BOTH QUESTIONNAIRES TO THE ADDRESS BELOW IN THE FREEPOST ENVELOPE PROVIDED**

Phase two of this research also involves interviewing people about their 'social' experience of ME/CFS/PVFS. The interviews will be conducted by a sensitive researcher who has worked and lived with ME/CFS/PVFS sufferers. Interviews will be conducted with the welfare of respondents in mind. All interviews will be treated in the strictest confidence and anonymity will be protected. It is intended that the interviews will take place in respondent's homes or by phone. If you would be kind enough to take part in the interviews or would like further details, please write your name, address and telephone number in the box below and you will be contacted in the near future. Thank you.

Yes I am willing to take part in the interviews for phase two of this research project <input type="checkbox"/>	
Name	
Address	
Phone number: Day	Evening
E mail address	

If you have any enquiries please contact:

T. Collett, Dept. of Sociology, University of Plymouth, Drake Circus, Plymouth, Devon, PL4 8AA  
Email: TCollett@plymouth.ac.uk

## Recruitment letters placed in support group magazines

Dear Theresa

Thanks for e mailing me regarding the survey that I am doing, I have enclosed two copies of the letter for the magazine, along with a photograph (just in case you feel this is necessary)- I hope that you feel that the content of the letter is okay- I have tried to make it brief, but if it is not brief enough I could just do a small add:

**Wanted: People with ME / CFS to take part in national questionnaire survey.**

**The more respondents the bigger the impact of the survey!**

The survey is part of a PhD project. It is funded by the ESRC and aims to investigate the quality of life of people who have ME and compare it with the quality of life of people suffering from other illnesses. If you would be kind enough to take part please leave your name and address on the answer machine at this number (01752) 673637 and I will send you the questionnaire. Thank you.

**WANTED: PEOPLE WITH ME / CFS TO TAKE  
PART IN NATIONAL QUESTIONNAIRE  
SURVEY.**

**The more respondents the bigger the impact of the  
survey!**

The survey is part of a PhD project. It is funded by the ESRC and aims to investigate the quality of life of people who have ME and compare it with the quality of life of people suffering from other illnesses. If you would be kind enough to take part please leave your name and address on the answer machine at this number (01752) 673637 and I will send you the questionnaire. Thank you.

I hope that one of these is okay, if I need to change anything, please contact me and I will do it straight away. Thank you again



Tracey Collett



Dear Readers

I am writing to ask whether you would be kind enough to take part in a survey that I am doing. The survey is part of a larger PhD project that I have managed to secure funding for. The funding is from the Economic and Social research Council.

The PhD aims to build on previous work that I have done at masters level which investigated the experience of ME//CFS from the point of view of the person who actually has it. In order to start this research off I need to conduct a questionnaire survey on a large number of people who have ME/CFS as possible. The respondents can be of any age, in fact the bigger the age range the better. In addition, if it is appropriate, where a respondent is unfortunately too ill to complete the questionnaire, a third party can do it on his or her behalf, this will ensure that all levels of severity are covered.

As I am aware that surveys consume precious energy i have tried to minimize the impact by splitting one long questionnaire into two short ones. This way each questionnaire can be filled in separately, thus allowing time for a rest in between. The questionnaires are based mainly on circling numbers, and although they may appear long, my pilot study found that each one takes about ten minutes to fill in. The questionnaires contain questions about how ME/CFS has affected work, study, ability to get benefits, experience of GP's etc. They also include a short quality of life measure which can be used to compare the quality of life of the ME/CFS sufferers with the quality of life of people with other chronic illnesses.

I think the findings will really highlight the situation that many people with ME/CFS find themselves in and as someone with a sister and a mother who both have ME/CFS I know how urgent this is.

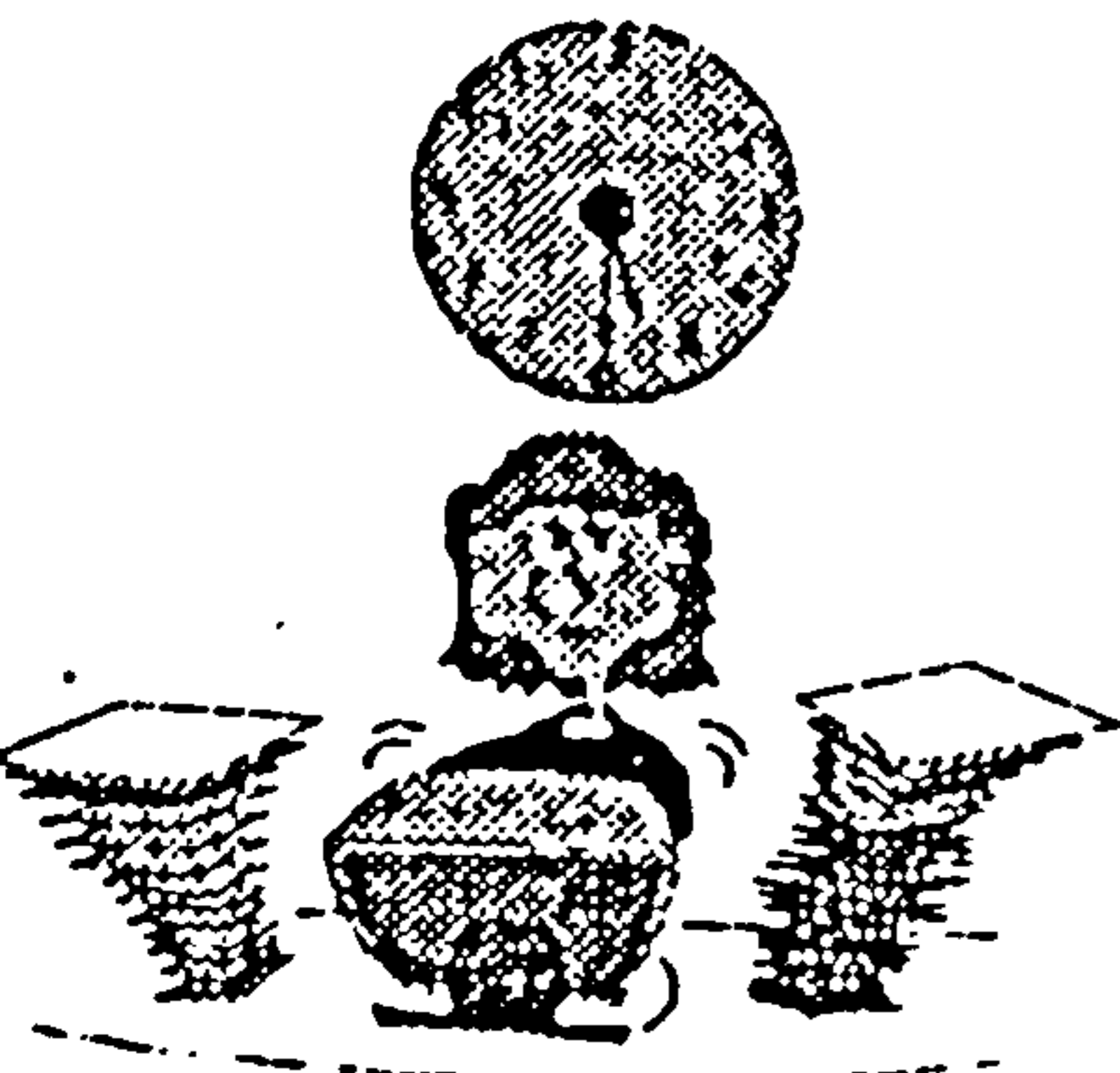
If you think this research is worth while and are willing to participated, the questionnaires can be found along with a freepost envelope in the envelope with this newsletter. For further enquiries, please contact me at the address/e-mail printed below, or phone 01752 673637 leaving a message on the answer phone.

My thanks to you all.

Tracey Collett (MSc)

Dept. of Sociology  
Portland Villas  
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## Tracey's PhD so far!

M.E. quality of life and pathways through illness

## Structure of presentation

- Findings of quality of life survey
- Key themes from interview data
- Questions

## The SF - 36 Health survey

- Physical functioning
- role limitations (physical)
- social functioning
- role limitations (emotional)
- bodily pain
- vitality
- general health perceptions
- mental health

## Research methods

- The M.E. Sample
  - taken from support groups (n = 268)
- General population and disease groups
  - population - Jenkinson et al (n = 8889)
  - low back pain - Garrat et al (n = 558)
  - ms - Rothwell et al (n = 47)
  - depression - CAPC (n = 250)

## Summary of findings

- M.E. Patients:
  - are as ltd in physical functioning and role physical as ms and low back pain patients
  - have only slightly less body pain than back pain
  - have worse social functioning than all groups
- M.E. Does not appear to affect mental or emotional as much as physical functioning
- Like the other conditions M.E. Sufferers have a unique pattern of functional impairment

## Discussion

- Policy
  - contributes to a greater understanding of the severity of M.E. (med prof, DSS)
  - shows areas which are most affected and where there is most need for support

## The interviews

- **Illness influenced by social factors**
- **Parsons and the sick role**
  - pathways through illness
  - get sick, visit G.P. access to sick role
  - sick role = exemption from responsibility for illness, exemption from work, obligation to follow docs orders and get do best to get better

## Experience of GPs

- Disillusioned
- Seeking a cure for ME/CFS
- From patient to expert
- Economic impact of ME/CFS

## Discussion

- **Access to the sick role is denied**
- **As a result:**
  - people still held responsible for being ill
  - not always let off responsibility from normal roles
  - responsible for illness management
  - In addition to being severely impaired many pathways through illness appear to be blocked

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