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Simon Wessely

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Neurasthenia and Chronic Fatigue: Theory and Practice in Britain and America

SIMON WESSELY

The symptoms that make up the construct of neurasthenia, including fatigue and exhaustion, are dimensionally distributed in the community. The decision to create a category called neurasthenia is an arbitrary one, influenced by issues of severity and morbidity. The prevalence and nature of the resulting concept are also substantially influenced by the decision on how to classify the close relationships among excessive fatigue, depression and anxiety. Superimposed upon this classification is a second, parallel structure of illness beliefs. The original construct of neurasthenia as a physical disease that resulted from overwork, was of considerable utility to both doctors and patients. This early concept of neurasthenia can be recognized in the modern revival of interest in chronic fatigue syndrome (CFS) in Western cultures. The current highly charged atmosphere surrounding these diagnoses reflects the issues of legitimacy and non-legitimacy in illness, usually expressed in competing physical and psychological explanations of ill health.

INTRODUCTION

“The first difficulty felt by anybody who enters on the study of neurasthenia is caused by the wide divergence of views held by the medical authorities both as to its nature and causation” (Cobb, 1920).

This paper addresses two aspects of the problem of neurasthenia. The first is the epidemiology of neurasthenia as an operationally defined condition, and its relationship to psychological distress. This is, in theory at least, a relatively straightforward problem to which one can apply the techniques of psychiatric epidemiology. However, it will be argued that such research will not shed light on a second

problem of neurasthenia: This is the belief, whether self or doctor generated, that one is suffering from a specific neurasthenic syndrome. In particular, I shall draw attention to the social meaning of one concept of illness becoming increasingly popular in the English speaking world, chronic fatigue syndrome (CFS).¹

CONVENTIONAL EPIDEMIOLOGY OF NEURASTHENIA

It is a truism to state that the epidemiology of a condition depends upon its definition. Fortunately the number of definitions of neurasthenia far outweighs the number of population based studies, so it is necessary only to introduce such definitions as are relevant to the data presented.

On a simple level, subjects fulfilling various criteria for neurasthenia or neurasthenic syndromes are common. In the Zurich Longitudinal survey, Angst and Koch (1991) reported that 29% of women and 17% of men met criteria for a neurasthenia syndrome, whilst in the Swedish longitudinal study on the Island of Lundby, the lifetime prevalence of fatigue syndrome (defined again as excessive fatigue in the absence of clear cut features of anxiety or depression) was 33% for women and 21% for men (Hagnell, Grasbeck, Ojesjo & Otterbeck, 1993).

Neurasthenia is thus common, but many of those cases will equally fulfil criteria for psychological disorders, especially depression and anxiety. Easy fatigability, poor concentration, irritability and the sense of increased mental effort appear in many of the criteria for both neurasthenia and common neurotic disorders and community studies confirm the close association between the two. For example, Angst and Koch (1991) found that neurasthenia increased the odds of a diagnosis of depression or anxiety by 4.6 times. When Angst excluded patients with depression and anxiety, the prevalence of neurasthenia decreased from 29% to 10% in women and 17% to 10% in men. A subsequent analysis by Merikangas & Angst (*in press*) using the ICD-10 criteria found prevalences for ICD-10 neurasthenia of 6% for men and 10% for women. In our community study, we found a similar relationship (Pawlikowska, Chalder, Hirsch, Wallace, Wright & Wessely, 1994). Depending upon the exact criteria used, between 60 and 80% of cases of CFS were also cases of psychiatric disorder when interviewed using a standardized psychiatric assessment.

So far, I have been assuming that there exists in nature a condition with certain characteristics called neurasthenia. At some stage researchers will discover a pathological marker which will enable the clinical boundaries of the syndrome to be delineated. This assumption underlies much of the current research in CFS. Alternatively, the good and the great who decide such things will in time agree on the definitions of neurasthenia to be used, perhaps in DSM-V or ICD-11. This is the basis of much of the current epidemiological approaches to neurasthenia. But how valid is each position?

The dichotomous approach, that one either has or doesn't have neurasthenia, is an essential prerequisite for determining conventional epidemiological measures such as incidence and prevalence. This is in line with conventional medical practice. Doctors treat cases of illness, administrators and epidemiologists count cases, and insurers pay for cases. However, just how accurate is such a dichotomous view as regards neurasthenia? Is there a qualitative difference between "normal" fatigue and "abnormal" fatigue? Is there a division between those with, and those without, neurasthenia?

There is considerable evidence to support a dimensional, rather than a categorical, view of the core symptom of fatigue. To quote the late Geoffrey Rose, "the real question in population studies is not 'Has he got it?', but 'How much of it has he got?'" (Rose & Barker, 1978). Considering symptoms in the community Goldberg and Huxley (1971) wrote, "it would be tedious to enumerate the surveys which have shown that symptoms are continuously distributed in the population: rather than attempt to do this, we will observe that we are unaware of a single survey that shows anything else." So it is with fatigue. A survey of general practice attenders in South London found that the number of fatigue items endorsed was best described along a continuous distribution (David, McDonald, Mann, Pelosi, Stephens, Ledger & Rathbone, 1990). In a population study using a fatigue scale that incorporated a range of fatigue symptoms, and also allowed for a measure of severity, we also showed a continuous distribution of risk (Pawlikowska *et al.*, 1994). Another population based study, this time from the United States, grouped together ten items on tiredness, weakness, slow recovery from viral infections and need to rest, termed "asthenia." Once again plotting the number of items endorsed against the number of persons with each score yielded a continuous distribution (see: Lewis & Wessely, 1992).

It appears, therefore that no sharp distinction can be drawn between the normal and abnormal fatigue. Hence if we are to use only severity to define when fatigue becomes abnormal the precise point must be arbitrary. This observation is not new. Wells (1908) advocated "shifting the viewpoint from the measurement of discrete states of fatigue to continuous determinants of susceptibility." How can a dimensional model of fatigue be reconciled with fatigue as illness? It may be helpful to consider the example of blood pressure and the definition of hypertension. During the 1960s there was a famous debate between Platt and Pickering on the nature of high blood pressure, with the former maintaining that a discrete disease ("hypertension") existed, the latter that there was a continuous distribution of blood pressure across the community. It is now held that the evidence supports the dimensional view, and that no discrete disease called "high blood pressure" exists.

Epidemiology, thus, shows that fatigue is a dimensional, not a categorical variable. As the experience of fatigue increases in severity, a person is more likely to view him or herself as ill and to present to a doctor with the complaint. Whether increasing severity of fatigue is also associated with an increased risk of fatigue being associated with a discrete entity such as neurasthenia remains a moot point. Most current writing and research into fatigue syndromes assumes that this is so, but often on flimsy evidence.

Continuing the analogy with hypertension, it remains true that although population studies do not find much evidence of a categorical syndrome of excessive fatigue, nor of a disease called hypertension, discrete causes do exist for both. In specialist practice, cardiologists are always alert to the possibility of renal artery stenosis or phæochromocytoma, although their public health impact is slight. Similarly, discrete diseases associated with severe fatigue are known and no doubt others remain to be identified. Nevertheless, the epidemiology of fatigue serves to put such diagnoses as CFS or neurasthenia into a population perspective. Until proven otherwise, I will argue that fatigue syndromes such as CFS and neurasthenia are arbitrarily created syndromes that lie at the extreme end of the spectrum of fatigue.

The example of hypertension has other lessons for those concerned with the study of neurasthenia. First, although fatigue is a dimensional variable that cannot be easily separated from the normal sensation and experience of tiredness, it still requires understanding

and treatment. Hypertension, even if labelled “essential,” is not benign. So it is with neurasthenia. The fact that one cannot detect a clear-cut division between “normal” fatigue and the devastating illness so vividly detailed in the numerous first person accounts of neurasthenic or CFS sufferers, no more invalidates the latter than the dimensional view of blood pressure invalidates the medical importance of severe hypertension.

Until a convincing marker for fatigue syndromes is found or refuted, what other possible factors might differentiate between a case of fatigue and one of neurasthenia? For example, the current criteria used for chronic fatigue syndrome introduce a number of restrictions on the diagnosis to create an arbitrary division between symptom and syndrome. These include duration of illness, functional disability and the requirement for additional symptoms. Something similar is attempted by the many different criteria for neurasthenia that have been well described by various contributors to this symposium. But how valid are these classifications and divisions?

Many defining variables are themselves confounded by the issue of illness behaviour and sample. For example, by requiring the syndrome to include fatigue of longer than six months, and associated with a level of functional disability, the new syndrome will inevitably be associated with illness behaviour, presentation to a doctor and ultimately referral to a hospital specialist. Variables such as duration, severity and disability must also be dimensionally distributed. There is no *a priori* reason for insisting on six months of illness, or 50% functional disability. Most criteria also specify that fatigue syndrome of whatever shape or form is not solely fatigue, but also involves other symptoms as well. For example, one somatic symptom, myalgia (or muscle pain) is incorporated into the name given one particular fatigue syndrome, myalgic encephalomyelitis. Other criteria require symptoms of subjective neuropsychological impairment, such as poor memory or concentration. The concept of neurasthenia put forward by Jules Angst in Zurich insists upon “nervous irritable weakness.”

These, and other symptoms, have already been studied in the context of the epidemiology of fatigue. Myalgia is a common somatic symptom. In a population study, 14% of subjects aged 18 to 45 complained of muscle pain at rest, and 22% complained of muscle pain after exercise (Pawlikowska *et al.*, 1994). However, myalgia was closely associated with fatigue. This is not surprising—

many people find it difficult to distinguish between the two experiences, since the experience of painful muscles merges with the sense of painful weariness that is one expression of fatigue. Similar criticisms to those of the arbitrary nature of definitions of CFS can also be encountered in the context of the fibromyalgia syndrome, also associated with fatigue and myalgia (see: Croft, Rigby, Boswell, Schollum & Silman, 1993; Makela & Heliovaara, 1991).

It is not just fatigue and myalgia, but many other symptoms such as headache, chest pain and dizziness, that cluster together. Patients who complain of fatigue are more likely to complain of other somatic symptoms (Cathébras, Robbins, Kirmayer & Hayton, 1992; Nelson, Kirk, McHugo, Douglass, Ohler, Wason & Zubkoff, 1987). This association becomes stronger as one moves from the community to specialist care, since one characteristic of fatigued patients seen in specialist care is the remarkable number of other somatic symptoms experienced (Lane, Manu & Matthews, 1991; Wessely & Powell, 1989). This has been enshrined in the first of the operational criteria for CFS, the CDC criteria (Holmes, Kaplan, Gantz, *et al.*, 1988). Since one of the most robust findings in psychiatric epidemiology is that the greater the number of somatic symptoms, the greater is also the risk of fulfilling criteria for psychiatric disorder (Goldberg & Huxley, 1991) and the greater the number of pain symptoms, the greater the risk of depression (Dworkin, Von Korff & LeResche, 1990), such criteria inevitably lead to a greater proportion of psychiatric disorder among CFS subjects (Katon & Russo, 1992).

More restrictive diagnostic criteria will also reduce the prevalence of fatigue syndrome. For example, in our population study we noted that 38% of the sample complained of excessive fatigue, but in only 1% had this lasted for more than six months, been experienced all the time, and been associated with myalgia. This group was distinguished from the rest by a female predominance, and a closer association with psychological distress. We found a linear relationship between the number of somatic symptoms (either all those recorded, or just those required by the CDC for the diagnosis of CFS) and both the score on a depression inventory and the risk of psychiatric disorder determined by direct interview.

I conclude that using epidemiological techniques to establish the boundaries of any division between normal and abnormal fatigue is fraught with difficulties, and may result in the arbitrary creation of

a distinction where there is none in nature. Epidemiology is unable to assist us in understanding the meaning and symbolic importance of neurasthenia. For this we need to look elsewhere.

Despite these caveats, neurasthenia continues to be frequently encountered in medical practice and classification. In Germany, a systematic community survey gave a point prevalence of ICD-9 neurasthenia of 0.3% (Schepank *et al.*, 1987). Neurasthenia is a frequent diagnosis in Dutch primary care (Ormel, Van Den Brink, Koeter, Giel, Van Der Meer, Van De Willige & Wilmink, 1990).

Going East, neurasthenia becomes increasingly common. It is a well recognized diagnosis in both the former Yugoslavia (Starcevic, 1991) and Soviet Union (Calloway, 1992), where neurasthenia is considered to be the most widespread form of neurosis. The Russians recognize three types of neurasthenia—the hypersthenic (corresponding to nervous irritability), hyposthenic or asthenic (with fatigue and inability to work), and a transitional category. They also distinguish between brief, reactive states and prolonged states lasting years. In up to half, there is evidence of asthenic personality. Finally, the Soviet school of psychiatry, like some Western observers, considers these disorders to be increasing in prevalence (see: Calloway, 1992).

However, it is in China that neurasthenia retains its firmest grip (see: Sartorius, 1992). It was the most common non-psychotic diagnosis in one Chinese centre (Kleinman, 1982), where it was viewed as a physical illness, without stigma, describing what Western observers label as depression (Kleinman, 1982). This is not, however, typical of all of Asia, since only 1% of psychiatric contacts in either Nagasaki or Seoul receive the same diagnosis (Nakane *et al.*, 1991). Although it had been a frequent diagnosis in Japan, by the 1980s it no longer occupied a prominent place in psychiatric classification (Lin, 1989), being used instead largely as a euphemism for schizophrenia (Munakata, 1989).

In contrast neurasthenia is rarely encountered in the English speaking world. In the United Kingdom Morbidity Survey of general practitioner consultations, not only was neurasthenia rarely diagnosed, but there was an eighteen fold variation in the use of the term among general practitioners (Dunn & Smeeton, 1988). The diagnosis is not used with any degree of consistency, and such figures simply indicate that it is a rare and idiosyncratic diagnostic label. A similar degree of inconsistency is noted for the diagnosis of CFS. Clements

(1991), in Scotland, found that a diagnosis of CFS was made in between 1 and 60 and 1 in 10,000 general practice patients.

NEURASTHENIA REVISITED

The rise and fall of neurasthenia is by now a well known piece of psychiatric and social history. From its pre-eminence at the close of the last century, it had to all intents and purposes vanished from Western countries by the Second World War. Norma Ware (1992) has written that in consequence "chronic fatigue had become invisible," with "no name, no known etiology, no case illustrations or clinical accounts in the medical textbook, no ongoing research activity—nothing to relate it to current medical knowledge." Of course, exhausted patients continued to be seen in medical settings. Subsequent papers on chronic fatigue bore labels such as "tired, weak and toxic" (Alvarez, 1935), "chronic nervous exhaustion" (Macy & Allen, 1933), "fatigue and weakness" (Allan, 1945) or "fatigue and nervousness" (Wilbur, 1949). All of them had a generally psychological emphasis.

The rise of the psychogenic school was thus one reason for the change in the meaning of neurasthenia, and hence its decline. What then happened to the physical paradigm of Beard, Mitchell and others? There was a second line of descent from neurasthenia, traced in a series of illnesses embodying the concept of physical fatigue, due to external factors, allegedly easily and unfairly confused with psychological disorders, and usually regarded with academic scepticism. Thus we encounter chronic brucellosis in the 1940s and 1950s (Imboden, Canter & Cluff, 1959), reactive hypoglycæmia in the 1960s (Singer, Arnold, Fitzgerald, Madden & Von Legat, 1984), premenstrual syndrome in the 1970s (King, 1989) and later total allergy syndrome, multiple chemical sensitivity and chronic candidiasis (Howard & Wessely, 1993). Clinically, these conditions overlap with severe forms of both CFS and neurasthenia (Stewart, 1990a; 1990b), although none have the professional acceptance once accorded neurasthenia and now appearing for CFS.

These conditions represent a small, but important part, of the neurasthenia heritage. However, the true successor to neurasthenia only appeared in the 1980s, with the arrival of chronic fatigue syndrome (CFS). It has been argued that the clinical condition known to us as chronic fatigue syndrome represents in part (but by

no means entirely) the illness known to the Victorians as neurasthenia (Abbey & Garfinkel, 1991; Greenberg, 1990; Shorter, 1992; Wessely, 1990). This claim is based first on the symptomatic parallels between the conditions. These parallels do not stop at symptoms, but also include progress to aetiological theories, social class, culture and treatment (see: Shorter, 1992; Wessely, 1994). It is to CFS that one must turn to understand the significance of neurasthenia in contemporary Western society.

The equation of neurasthenia then with CFS now does not mean that neurasthenia as used in current practice should be equated with CFS. Indeed, the opposite is true. The reasons for this caution will become clear, but are largely because of the change that has happened in the meaning and usage of the term neurasthenia. It is neurasthenia in its heyday that is the parallel (contemporary advocates of CFS react with considerable disfavour to any analogy with neurasthenia, which they usually assume to be synonymous with psychogenesis, unaware of its rich organic heritage), and not neurasthenia of current psychiatric classifications, or neurasthenia as used at present in Holland, Switzerland or Eastern Europe.

Leaving behind the prevalence of an operationally defined neurasthenic syndrome, in practice how common is the label of neurasthenia? In Germany, 26.2% of a population survey in Mannheim complained of "states of fatigue and exhaustion" over a seven day period (Schepank *et al.*, 1987). Similar figures are encountered in other Western countries (see: Lewis & Wessely, 1992). Most of these fatigued people neither consider themselves ill, nor consult a doctor (Morrell, 1976; Zola, 1966). Of those that do consider themselves as ill, at present few would attribute their symptoms to any neurasthenic syndrome. The self diagnosis of neurasthenia is unknown in British population surveys. However, that of CFS/ME is not common either. Of the 15,283 people surveyed in a community sample, only 38 (0.2%) stated they suffered from CFS/ME (Pawlikowska *et al.*, 1994).

Although no longitudinal data is available, it is reasonable to assume that this figure will rise. There is some evidence that fatigue itself is increasing in prevalence—for example in the Lundby study (Hagnell *et al.*, 1993)—but the rapid appearance of the label of CFS must owe more to social and cultural factors. It is, however, worth observing that CFS has a long way to go before it equals the popularity of neurasthenia at the turn of the last century. Neuras-

thenia spread with remarkable alacrity across Europe and America. In France “the name of neurasthenia was on everybody’s lips, the fashionable disease” (Dubois, 1909), the “maladie a la mode” (Certhoux, 1961). It was as successful in Germany—Bumke (1925) later wrote that there was probably no instance in the history of medicine of a label having the impact of neurasthenia.

NEURASTHENIA AND PSYCHIATRIC DISORDER:
A USEFUL DISTINCTION?

I have already suggested that the decision as to whether or not to separate out neurasthenia from psychiatric disorder using operational criteria is arbitrary. It may also be of little practical relevance. Returning to the example of CFS, the oft cited case definition of CFS (Holmes *et al.*, 1988) explicitly states that psychiatric exclusion criteria be applied. If this were to be adhered to, most cases of CFS referred to specialist clinics would be excluded on this basis. There is little evidence to suggest that this has been carried out in any centre. Furthermore, would it actually be of use? In our clinic, and in our studies, we find that the presence or absence of sufficient evidence to make an operational diagnosis of depressive syndrome is not particularly relevant as regards effective management or prognosis, unlike knowledge of illness beliefs, background and coping strategies.

The current acrimonious debate over the relationship between CFS and psychiatric disorder based solely on comparisons of operational criteria is unhelpful. CFS and psychiatric disorder show considerable overlap. There is a close correlation between the severity of fatigue and the severity of emotional distress (Pawlikowska *et al.*, 1994), between the diagnosis of chronic fatigue and psychiatric disorder in primary care (McDonald, David, Pelosi & Mann, 1993), and between CFS and psychiatric disorder in specialist care (Katon *et al.*, 1992; Wessely & Powell, 1989). It is inevitable because of the way in both concepts have been constructed, the similarities of the criteria and the measures used to define them. This does not imply that one causes the other (although this argument is frequently used by both supporters and opponents of psychological causation), nor that psychiatric disorders and neurasthenia/CFS are the same. It does, however, imply that operational criteria, the tool of epidemiologists and taxonomists, will be of little assistance in making the distinction between neurasthenia/CFS and psychiatric disorders.

OVERVIEW

If scientific evidence has failed to provide what is needed—a simple method of separating out the neurasthenic wheat from the psychiatric chaff, then how can this separation be achieved? One answer is via social and cultural factors. An example of this in practice comes from the early literature on myalgic encephalomyelitis, a British variant of CFS, that arose in the aftermath of a famous outbreak of the condition at the Royal Free Hospital in 1955. A bitter debate developed concerning the nature of this illness. At the heart of the controversy was the belief that this was an organic, infective condition, contrasted with the opposite view of its hysterical nature. Symptoms alone did not suffice, since, in the view of the doctor who first described the condition, and became the champion of the organic school, “the symptoms of hysteria are present, although not the diagnosis” (Ramsay, 1986). Another strong supporter wrote that “it would have been easy to concur that the illness is entirely a manifestation of mass hysteria” (Behan & Behan, 1980), and instead relied on immunological abnormalities of questionable significance to make the distinction. Another adherent of the organic school wrote that “rather than ME being a psychoneurosis, all cases of psychoneurosis were sporadic ME” (Poskanzer, 1970). By simply redefining one in terms of the other this again acknowledged that both lay claim to the same clinical territory. As symptoms alone could not differentiate between the two, and tests continue to fail to live up to their promise, social factors were needed to make the distinction. The next three sections consider how this was applied in practice.

DIFFERENCES BETWEEN NEURASTHENIA AND PSYCHIATRIC DISORDERS

THE TYPICAL PATIENT

The distinction between neurasthenia/CFS and psychiatric disorders depends upon a number of factors. The first of these is the character and personality of those afflicted with either condition. In the debate about the nature of the paradigmatic outbreak of ME at the Royal Free Hospital advocates of the condition claimed it affected professionals of impeccable moral stature, “level headed” (Howells, 1970), in whom “illness was alien to their nature” (Judge, 1970), and who were “extravert types of stable personality” (Ramsay, 1973). As ME spread to other settings these arguments grew in

intensity. Sufferers are more likely to “have a good premorbid personality and work record” (Dowsett & Welsby, 1992). CFS sufferers are “do-ers” (Maros, 1991), all of them “active, energetic, capable, competent.”²

Another way of minimising psychological influences on CFS is to link the illness with famous sufferers—“as for the accusation that it is a malingerer’s complaint, well, I think the number of high achievers who’ve got ME...shows that to be a nonsense.”³ Many historical figures, such as Florence Nightingale and Charles Darwin have been labelled as early cases of ME. Sports people seem to be well represented amongst sufferers, for a number of reasons, both physical and psychological (Eichner, 1989). However, their prominence in media coverage, which includes professional footballers, olympic athletes, champion squash players and golfers,⁴ also serves once again to emphasize the physical and psychological stature of those afflicted.

Also prominent among the ranks of sufferers are member of the professions. In 1893 Erb gave an address entitled “On the Increasing Nervousness of our Time,” which echoed Beard’s view that neurasthenia was on the increase, especially in “brain workers.” French neurologist Paul Blocq considered that “certain occupations predispose to neurasthenia, because they demand sustained and considerable intellectual efforts, or because they entail excessive and permanent emotional activity. Thus doctors, whose occupation combines those two troublesome conditions, speculators, engineers, literary men contribute a striking contingent to the neurasthenical class” (Blocq, 1891). Neurasthenia was more likely to affect “teachers, students and nurses...than domestic servants or factory hands” (Edes, 1895). Ballet (1911) noted the illness’ “excessive rarity among the labouring classes, and its almost exclusive limitation to the cultivated classes.” George Beard had no doubt whatever that neurasthenia only occurred in the upper echelons of advanced civilizations, in the “civilized, refined and educated, rather than the barbarous and low born and untrained” (Beard, 1881). A Canadian physician wrote in 1905 that “it is a disease of bright intellects; its victims are leaders and masters of men, each one a Captain of Industry,” and continued “it is axiomatic that neurasthenia does not develop in a fool” (Pritchard, 1905).

Turning to the modern era, one nurse writes that “there is epidemiological evidence that well over 60% of sufferers were in

health care, teaching or sport...ME is not so common in sedentary workers" (Kedzierski, 1991). One survey of general practitioners' knowledge of CFS also showed that teachers or students were over represented amongst those recognized as having CFS (Ho-Yen & McNamara, 1991), and teachers are often claimed to be at higher risk.⁵ Health workers remain at risk of CFS both in its sporadic and epidemic forms (Bell, McCartney & Riding, 1988; Feiden, 1990; Ramsay, 1986). In one ME clinic, 41% of the patients were either teachers or health service workers (Dowsett, Ramsay, McCartney & Bell, 1990); the same pattern was found in Belfast (McCluskey, 1993).

Just as Beard, Mitchell and Putnam willingly conceded their own histories of neurasthenia, many of the doctors now involved in CFS, either as writers or clinicians, are themselves sufferers. Some recount their own personal experiences of illness during newspaper interviews about their clinical practice.⁶ Self acknowledged sufferers are not infrequent amongst medical writers on the condition, and several have contributed personal views of their illness to the medical journals. Doctors as sufferers are frequently used in newspaper and magazine articles as examples of typical sufferers.⁷ Of the 3,000 individuals who phone the Center for Disease Control CFS Information Line every month, a quarter are medical or paramedical (Gunn, 1993).

There are two possible explanations for the excess of health professionals: (1) selection bias—the apparent high visibility of health service staff may have nothing to do with the risk of CFS, but instead reflect illness behaviour and access to specialists; (2) legitimacy—the status of the doctor in society is such that their willing admission to the illness itself lessens the possibility of psychological origins to symptoms. In a speech to the American Neurological Association Weir Mitchell (1908) referred to his own neurasthenia, and pointed out how depression could not be an explanation for his condition, since he had "no depression that was abnormal or unreasonable." He used his own example, and that of "an eminent president of the college" to reaffirm that it was impossible that neurasthenia could be "a malady of the mind alone."

The typical Victorian neurasthenic was an active member of society, in contrast to those suffering from disorders with which neurasthenic could easily be confused, such as hysteria. Ernest Reynolds, Professor of Medicine in Manchester, wrote that hysteria

was “purely a mental condition, whose basis is a morbid craving for sympathy and notoriety,” whereas neurasthenia was “entirely different,” a “functional disorder of chronic overuse of neurones” due to “gross overwork and worry” (Reynolds, 1923). Sir Frederick Mott (1919), in his classic contribution on shellshock, wrote that “neurasthenia...was more likely to be acquired in *officers of a sound mental constitution than men of the ranks*, because in the former the prolonged stress of responsibility which, in the officer worn out by the prolonged stress of war and want of sleep, causes anxiety less he should fail in his critical duties” [italics in the original]. The notion of an officer class is now less prevalent, but it is not fanciful to argue that the same role is played by the citation of athletic, medical or professional sufferers which serves to dispel any suggestion that CFS sufferers are anything other than active members of society.

CFS/ME sufferers are often characterized as perfectionists and overachievers. One sufferer told a journalist that “until my symptoms started I gave 120% to every aspect of my life.” Hence when she picked up an infection “instead of resting I just carried on.”⁸ Such descriptions are one strategy for countering suggestions of psychological aetiology, but can also be viewed in the same light as the examples quoted in the Victorian literature—as cautionary tales. Sufferers are particularly prone to be overactive, unlikely to take things easy, “the last people to take time of work for no good reason” (Shepherd, 1989). “It seemed like a bad bout of flu from which (as usual) I did not allow myself proper time to recover.”⁹ Sufferers “work until they drop, whilst everyone else creeps to bed with the slightest headache or snuffle...lazy people don’t get ME.”¹⁰ In a piece on women and fox hunting, one woman is shown using a portable telephone whilst riding her horse to hounds. The text notes that both she and another female rider have “ME from trying to do too much.”¹¹ Even children are “enthusiastic, energetic, positive-minded people who try too hard when they are ill,”¹² or “bright, bubbly, energetic...competitive, sports loving.”¹³

These stories serve several purposes, related to the purpose of the diagnosis of neurasthenia or CFS itself. Sufferers from neurasthenia or CFS, who acquire their illnesses through praiseworthy means such as overwork, have a legitimate right to be sick (Gosling & Ray, 1986). However, the stereotype of overachievement also leads to other less flattering labels, such as the current sobriquet of “Yuppie flu.” Some CFS advocates are aware of this contradiction—one notes

that it has been necessary to steer doctors away from the stereotype of the neurotic woman, in order to “convince the medical community that the disease is legitimate,” but to do so has to portray patients as “successful super achievers” (Jessop, cited in Feiden, 1990).

THE NATURE OF PSYCHIATRIC DISORDERS

If psychiatric illness is so stigmatizing and threatening to the neurasthenic patient, how is this threat to be neutralized? That this is necessary is rarely in doubt. One sufferer articulated the purpose of such an approach—“In order to qualify as a ‘real’ illness any connection between mind, body and environment must be severed”¹⁴—but in most writings this is implicit rather explicit. If depression, hysteria and so on occur in malingerers, shirkers and those with low moral fibre, than the CFS sufferer must have none of these characteristics. Another strategy is to create distinctions between ‘ME depression’ and psychiatric depression. For example, psychiatric depression is “suffering from life” (Franklin & Sullivan, 1989). In psychiatric depression there is a loss of interest, in CFS depression a loss of performance; unlike those with psychiatric depression, CFS patients are “terribly concerned about what their symptoms mean.”¹⁵ Writers on ME note that “psychiatric” depression does not have lymph nodes, fevers, etc.—a chapter in a recent book on CFS was headed by the quote “you don’t get a temperature with a nervous breakdown” (Stone, 1991)—although both chills and fevers are in fact, not uncommon presentations of psychiatric disorder (Harding, Arango, Baltazar, Climent, Ibrahim, Ladrado-Ignacio, Murthy & Wig, 1980; Wilson, Widmer, Cadoret & Judiesch, 1983).

When sufferers from CFS become depressed they know it to be a physical condition. One sufferer told a journalist that “I accept that there was an element of depression but it didn’t feel like depression: I knew there was something wrong with my body.”¹⁶ A California internist noted that CFS depression is thus not exogenous depression, provoked by external factors—instead CFS depression is “a different form of depression. It’s not something patients have control over, it’s not something they did to themselves and they can’t wish it away” (Jacobson, cited in Feiden, 1990). If depression is construed in those terms, it is not surprising that “CFS depression,” whatever that may be, is something different.

CFS depression may also be a reaction to physical illness. One correspondent to a national newspaper expressed it succinctly: “why

do some doctors still insist on telling us that the illness is caused by depression rather than depression being caused by the illness?"¹⁷ A sufferer admitted that she was "depressed and unhappy, but only because I had been ill for so long."¹⁸ Another "was depressed because I was ill—not ill because I was depressed."¹⁹ This contrasts the popular view of depression as an understandable reaction to life stress (an aetiological view) with the medical usage of depression as a syndrome (a symptomatic description).

Depression is also acceptable as an organic consequence of the physical illness—"an effect of the virus burrowing through the brain and directly interfering with its operation."²⁰ One article included quotes from a doctor that viruses could create a "similar chemical reaction to depression, mimicking its symptoms...this can at times resemble depression."²¹

DOES IT MATTER IF NEURASTHENIA IS A PSYCHIATRIC DISORDER?

Why is it so important to emphasize the nonpsychiatric nature of neurasthenia/CFS? First, psychiatry is equated with madness. The President of the Institute of Actuaries reported that in the early stages of his illness "I thought I was mad. I thought I was going to be locked up."²² "Psychiatrists decided that ME is a psychiatric illness—i.e. we are mad" (MacIntyre, 1989). For many, madness is the only concern of psychiatry.

Second, psychiatric illnesses are not seen as legitimate, but are instead viewed as imaginary or non-existent. In consequence, sufferers have a "hard time convincing doctors, friends and relatives that what they are suffering, physically and mentally, is real—and not malingers' malaise."²³ If unsuccessful, they are "accused of malingering or given a psychiatric referral,"²⁴ or of being "a malingerer and a neurotic" (Feiden, 1990). "The medical profession dismissed ME as the malingerer's complaint,"²⁵ so that "normal, well balanced adults hit by M.E. are often diagnosed as hysterical, work shy and in need of psychiatric help"²⁶—implying that psychiatric treatment is only applicable to the work shy and hysterical. The Observer subtitled an early article on ME: "New medical research should prove 100,000 'neurotic' people are genuinely ill."²⁷ This research will prove "once and for all that sufferers are not malingerers." There seems to be no end to the succession of articles

describing new evidence that will prove that “ME is a genuine physical disorder and not a psychiatric condition.”²⁸

Just as psychological illness in general means disbelief, so does depression in particular. Those “affected are not depressive or ‘shirker’ types.”²⁹ The current President of the ME Association stated that one of the distinctive differences between ME sufferers and depressives is that those with ME are highly motivated achievers — “they almost have too much will power, whereas depressives have virtually none.”³⁰

The fear of being labelled as psychological distressed and its untoward consequences is realistic. One sufferer was originally refused sickness insurance benefit because his policy excluded depression, of which he had a past history. His subsequent claim to be suffering from ME was rejected, although he was informed that this decision would be changed if a test for ME were to be developed and he tested positive.³¹ It is not surprising that sufferers constantly hope for a diagnostic test for ME, and rejoice with each such claim. “All ME sufferers must have been elated by the news in January 1988 that a specific blood test for ME had been perfected” (Franklin & Sullivan, 1989). A newspaper greeted this announcement with the memorable headline “Virus research doctors finally prove shirkers really are sick.”³² The same test, now seen as of little value, was “an enormous boon for sufferers from ME, even when it proved negative” (Merry, 1991).

These views are understandable, since in the absence of acceptable tests or physical signs, onlookers find it harder to accept the reality of distress. The patient rarely looks sick. Sufferer after sufferer note how outsiders make comments such as “well, you don’t look sick—you look great” (Cited in Ware, 1993). “My skin is clear and tanned. I don’t have a plaster cast on a broken leg...people say ‘you look so well’.”³³ For sufferers, looking healthy has been identified as a major obstacle in their interactions with the medical profession.³⁴

Similar observations have been made concerning chronic pain, an area with considerable overlap to chronic fatigue (Blakely, Howard, Sosich, Murdoch, Menkes & Spears, 1991). Both are private experiences to which no one else has access. Baszanger (1992) argues that in chronic pain the absence of objective evidence is a fundamental barrier to the normal organization of relationships between sufferer and doctor.

Given the commonly held views concerning the nature of psychiatric illness, it is inevitable that sufferers feel denigrated and shamed by any hint of a psychological component of their complaints. Norma Ware (1993) used transcripts of interviews with CFS patients in Boston to show how disconfirmation, either by comparing the patient's symptoms to those we all experience ("everyone gets tired now and then") or by attributing them to psychological causes, leads to further distress and self-doubt. Time after time articles written by sufferers contain descriptions of the devastating effect of receiving a psychological explanation for their illness from a doctor. During a House of Commons debate on ME, this was claimed to be the single worst cause of suffering in the illness.³⁵ "Go to your GP with ME, and you will be met by disbelief, condescension, and possibly given antidepressants or sent to a psychiatrist" said the Director of the ME Action Campaign.³⁶ The suggestion of any psychological or psychiatric aspects to disability is interpreted by the patient as dismissive, even when it is not intended as such. What to the doctor may be a reasonable and caring attempt to look for psychosocial causes of distress may appear differently to the sufferer—"My forays to the doctors were a nightmare. My GP muttered about depression and over doing it, asking, completely unprompted, if I was having problems with my boyfriend."³⁷ A medical sufferer wrote that "the psychospeculation of physicians was only frightening and infuriating—not reassuring" (English, 1991).

Popular or professional papers that highlight psychological aspects of the condition are customarily greeted with varying combinations of anger or contempt. The current patient organization publications usually contain summaries of the current literature, interpreted not so much on their merits, but how they help the cause (Aronowitz, 1992). Psychiatric papers are given a particularly rough ride. Papers arguing for social and cultural models are seen as "ridiculing CFS" and "belittling the sufferer" (Bell, 1992).

It is sad to note that the reluctance to accept mental suffering as genuine, is shared, and often initiated, by the medical profession. Writing about the rise, and subsequent fall, of psychosomatic explanations for ulcerative colitis, Aronowitz and Spiro (1988) note that an uncomfortable attribute of the psychosomatic concept is the potential it has for blaming the patient for the disease. A consultant physician told a reporter that "certainly there are neurotic people who will present the same symptoms but a doctor...could distinguish

whether they are genuine sufferers or not.”³⁸ A doctor agreed that it is important that psychiatric patients are separated from ME because “some neurotic patients devalue the tales of genuine sufferers.”³⁹ Another is quoted as telling a medical conference that “ME is an imaginary disease...for which the best treatment is psychiatric.”⁴⁰ Doctors thus share many of the prejudices of the CFS sufferer—psychiatrists treat imaginary, malingered or nonexistent diseases.

It seems regrettably true that the poor treatment, condescension and frank rudeness to CFS patients so often described in the self-help literature has both a firm basis in reality, and a long tradition. English neurasthenics were “always ailing, seldom ill” (Clark, 1886). American neurasthenics were described by a neurologist as “purely mental cases. Laziness, indifference, weakness of mind and supersensitiveness characterize them all. They are .. ill because of lack of moral courage” (Jelliffe, 1905). Patients were “occupied by their symptoms beyond reason” going from physician to physician where they “write down their sensations in long memoranda which they hasten to read and to explain” (Blocq, 1891). Such views were echoed in the popular press—“The majority of sufferers have better reason to complain of the weakening of their moral fibres than of either their mental or physical ones” (Anon, 1894).

A contemporary paediatrician who received publicity for an anti-ME stance also admitted that “his views were a lot more moderate than many of his colleagues who believed that ME was nonsense.”⁴¹ Journalists frequent comment on similar reactions from doctors whom they approach for their stories about CFS, although the doctors usually prefer to remain anonymous.⁴² Occasionally such views surface—one article in a medical magazine calls ME an “escape route for the middle classes,” and that those affected “suffer triumphantly, and their claim that the disease has ruined their lives is not to be believed.”⁴³

The problem of dismissal and discourtesy from doctors is such that each generation of doctors interested in fatigue has seen fit to warn their colleagues against levity in their treatment of fatigue patients. Charles Beevor (1898) at the National Hospital for Nervous Disease reminded his colleagues that “on no account should the patient’s symptoms be laughed at,” whilst John Mitchell (1908) at the Johns Hopkins Hospital complained that his medical colleagues treated the neurasthenic patient “with ridicule or a contemptuous summing up of his case in the phrase ‘there is nothing the matter, he is only

nervous.’” Paul Cheney, one of the leaders of the CFS movement in the United States, told a journalist that “there are doctors who leave the room after speaking to one of these [CFS] patients and can’t stop laughing.”⁴⁴

The tension between ME/CFS and psychiatry is a fundamental one—it is, as a sufferer observed—the division between “imaginary illness or legitimate disease.”⁴⁵ One doctor gave an illustration in a recent article in the Scotsman, writing that “there are four causes of profound debilitation and tiredness all the time. Some patients will have a diagnosable medical condition, some will be people who cannot cope with their life situation, some will have a mental illness such as depression or anxiety and some (in my opinion probably most) will have M.E....patients with any of these four cases seek a label of ME to legitimise their debility, so that they are not regarded as inadequate, workshy or neurotic. This is a perfectly logical approach which should of course only be successful if the patient has M.E..”⁴⁶ The message is simple—only if one has ME does one escape the label inadequate, workshy or neurotic. A medical sufferer expressed a similar dichotomy—“Royal Free Disease really does exist—it may not be a psychiatric problem after all.”⁴⁷

THE USES OF NEURASTHENIA

The purpose of neurasthenia is thus to give legitimacy to distress that would otherwise be unacceptable to the patient, and to society. This has many benefits. I have pointed out how badly doctors can treat the patient perceived to have a psychological origin to their distress. This can be avoided when the label of neurasthenia/CFS is seen to indicate a physical, and hence blameless, aetiology.

The second purpose may be to allow the sufferer to make necessary changes in their life without stigma. The doctors who treated neurasthenia considered themselves able to offer advice about many aspects of life, often moving from the strictly medical, to the social and indeed moral. Virtually any aspect of “faulty living” (Craig, 1905) could cause neurasthenia, and therefore, was the legitimate concern of the doctor. The prevention of neurasthenia was a frequent topic, and many books included lengthy discussions on the role of education and schools in the prevention of the disorder.

Nowadays the self-help literature on neurasthenia and CFS is equally full of wide-ranging suggestions for changes in lifestyle. A

typical book (Dawes & Downing, 1989) included not only the usual advice on diet, rest, exercise, candida infection, stress and work, but also sections on the power of prayer, attitudes, the need to love oneself, and a section discussing the relative merits of holidays in the mountains or the Mediterranean—just as the older neurasthenia texts discussed the merits of the different European spas.

Sufferers are urged to alter their lifestyle by placing their own personal well-being, comfort and happiness at the centre of their concern. A sufferer must accept an inability to live at the same pace as previously, but, as with the Victorians, this can lead to moral and spiritual benefits. Self-worth is “not measured by being busy, earning money or even being good at anything” (MacIntyre, 1989). Of the patients studied by Norma Ware in Boston, nearly half had undergone a transformation of lifestyles as a result of CFS, which they declared to be painful, but ultimately positive (Ware, 1993). In this country, an actor told a newspaper that ME had “been like a gift, as though it was sent to sort my life out...My life has taken a completely different direction.”⁴⁸ One American sufferer found that CFS led her to consider “better ways to feel, think and relate” and to address the chronic stresses of her life, which were responsible for the depletion of her immune system.⁴⁹ Another sufferer wrote that as a result of ME “I have tried to use the time positively to make changes I accept were overdue,” going on to describe reassessment of work, relationships and so on.⁵⁰ A doctor with ME became a changed woman, seeing “a value in going for a walk on her own. She feels no guilt about enjoying herself or taking time off to relax.”⁵¹

As well as permitting changes in lifestyle, neurasthenia/CFS serves as a conduit for social concerns, in which sickness can be expressed in metaphoric terms familiar to the sufferer. Neurasthenia was frequently blamed on the unwelcome features of contemporary life, and indeed historians have not been slow to ascribe its emergence as a reaction to the rapid pace of industrialization at the end of the nineteenth century (Gilbert, 1977). Contemporaries such as George Beard blamed the arrival of the wireless telegraph, steam-power, the new sciences and others (Beard, 1881). He even used algebraic formulas to demonstrate how these features interacted with others, such as overwork, to create neurasthenia. Others blamed neurasthenia on the “dust, and whistling, noisy pandemonium, smoke and bad air of the city” (Ely, 1906). Beard had a gift for expressing

social concerns in a scientific idiom, striking a balance between the language of the current scientific discourse, and the concerns and language that were meaningful to the lay reader. Much of this was conveyed by metaphors drawn from business life—"The strenuous man of business knows well the significance of an overdraft in his bank account, and does not treat it so lightly as an overdraft on his nerve center balance" (Hughes, 1906). The writings of Beard and many others are replete with expressions such as nervous capital, overspent nervous resources and so on. Metaphors from the world of electricity have not lost their popularity. In neurasthenia "the storage battery has been discharged rapidly or for too long a time" (Pershing, 1904). Modern ME sufferers must have batteries that are either flat,⁵² unable to hold their charge (MacIntyre, 1989), or in need of recharging.⁵³ In consequence the "sufferer should treat her energy resources as if they were money in the bank, and be careful not to overdraw."⁵⁴

An individual's responsibility for neurasthenia or CFS is thus restricted to the relatively blameless (and indeed praiseworthy) habit of overwork, of struggling on beyond the limits of what is physiologically tolerable (Dercum, 1917; Nixon, 1991). Overwork thus summarizes the individual's role in acquiring CFS, that of society is summarized by "overload." According to Beard (1881) the unwelcome features of contemporary life which caused neurasthenia did so by creating an "overload" or "overloaded system." The same concepts have surfaced in the context of CFS/ME. Articles are frequently entitled "the ME Generation"—one began with the question "What is modern life doing to us?"⁵⁵ The answer is that it is causing CFS, since "ME is very much a disease of our time—an attack on the immune system exacerbated by stress, pressure and the demands of twentieth century life."⁵⁶ ME is "an overload disease unique to this century" (Steincamp, 1989), since "the body can tolerate so much stress from whatever source, but at some point the bucket gets full" (Jacobs, 1990). Nowadays the overload is due to pesticides, allergies, chemicals, neurotoxins, antibiotics, over-refined diet, pollution, electromagnetic radiation, candida and so on. CFS is due to the "sickness of the planet."⁵⁷ It would tedious to list all the references in the popular literature making links between these factors and CFS/ME—it is an exceptional account that fails to do so.

Neurasthenia was thus described using a modernistic idiom that would be familiar to the lay audience, but also had the necessary

scientific overtones. In our own time the language used to describe CFS has a similar quality. Although some modern descriptions can only be evocative to a modern audience, for example, CFS can “come in like a Stealth bomber,”⁵⁸ others, such as the use of metaphors from the world of business and technology, are direct echoes of neurasthenia. Commonest of all, as Abbey and Garfinkel (1991) have elegantly shown, are metaphors and analogies drawn from those great current contemporary concerns, virology and immunology. Beard might not have recognized the jargon, but he would have understood the use of contemporary scientific discourse to underline essentially social metaphors. Those social stressors which, in Beard’s day, acted to deplete nervous capital and nervous energy, now decrease immune function and impair the body’s defences against infection.

The same metaphors reappear not only in ideas about aetiology, but also concerning treatment. The familiar Victorian metaphor of the supply and demand of energy reappears frequently. In one contemporary book there is a passage that catches the tone familiar to the previous generation. Dawes and Downing (1989) tell sufferers to always do “seventy five percent of what you are capable of...unless you want to plummet down with another relapse soon, you really must follow the rule of doing less than you think you can.” As a result those afflicted must “live life in slow motion”⁵⁹ or “pace myself carefully, nurturing my fragile energy like a delicate plant”⁶⁰ and “use energy at a slower rate than you make it.”⁶¹ The treatment comes back to that mainstay of the Victorian approach to neurasthenia, the rest cure. An American self-help book (Feiden, 1990) heads a section with the title “Rest, Rest and More Rest,” and discusses “aggressive rest therapy,” as does an English self-help title (Franklin & Sullivan, 1989).

Neurasthenia and CFS diagnoses serve a useful purpose. Neurasthenia did not disappear because of academic dissatisfaction—that was nothing new (see: Wessely, 1994). It disappeared because it has ceased to be “useful to the doctor” (Lancet, 1912)—when it failed to allow sufferers to receive sympathetic treatment without the stigma of psychiatry. As in modern Japan, neurasthenia served as a code for non-psychotic illnesses for which the only effective treatments were psychologically based. The diagnosis was made “for the comfort of the relatives and peace of mind of the patient” (Risien Russell, 1913) since it avoided the stigma of psychiatric

illness and the necessity to seek treatment in an asylum, where the neurasthenic would “soon be subject of the usual stigma attached to the abode of mental patients” (Hallock, 1911). Others commented that even if the symptoms were psychological, it was better to talk about nervous diseases and neurasthenia since “the patient and the patients’ friends usually have a horror of mental disease” (Barker & Byrnes, 1913). Neurasthenia disappeared once Freud, Janet, Dana and others began to break these codes. The doctor ceased to believe in the simple organic model, and inevitably the patients themselves gradually learnt that neurasthenia was no longer the passport to trouble free medical care that it had been.

THE DISADVANTAGES OF NEURASTHENIA

The previous sections have outlined how the concept of a physical chronic fatigue or neurasthenia syndrome is both an attractive and useful one for doctor and patient. Unfortunately, as Mrs. Thatcher was fond of saying, there is no such thing as a free lunch. In order to understand the complex legacy of neurasthenia/CFS, it is now necessary to turn to the disadvantages of the current formulations of CFS. The climate of opinion and controversy surrounding CFS means that the sufferer is frequently caught in a trap. The treatments suggested by a model of CFS as a unitary condition, the sole consequence of a single physical agent, are straightforward, simple to explain, free of stigma and moral implications. As yet few appear to work. On the other hand, other strategies, based on a more complex model, involving either psychological or behavioural interventions, are far from value free. All of this is magnified in the light of the controversy surrounding CFS. In this climate accepting any treatment other than those based on the single disease/external agent model is fraught with difficulty. For many it is better to have an incurable disease such as CFS than a psychological disorder even if that might be treatable—“The day Nomi Antelman learned she had an incurable disease, she rejoiced.”⁶²

The hostility towards psychological distress, perceived as it is as synonymous with low moral fibre and blame, permeates treatment and outcome. Psychiatrists are seen as having little or no role in the management of CFS. In the CFS literature often the good psychiatrist is the one who finds nothing wrong and declares the sufferer psychologically normal. This character surfaced in a popular

television series, "Golden Girls," which, in September 1989 addressed the subject of CFS. We first see the image of the bad doctor, who is rude to the patient, keeps her waiting, finds all her tests normal and tells her to pull herself together, before finally diagnosing her condition as one of loneliness—a functional or mental problem. Another neurologist pronounces her well, and recommends that she see a psychiatrist. However, she has already done so, and produces two letters saying her problems are physical, not psychological. A non-fictional sufferer in this country told a popular newspaper that he had seen a neurologist who failed to find anything physically wrong, became "beside himself with wrath, and suggested that I see a psychiatrist, who told me that I was no madder than the rest of the population and sent me back to the by now quivering and speechless neurologist."⁶³ Pleas are often made for a multidisciplinary approach to CFS. One distinguished epidemiologist appeared to answer these requests when he told a journalist that "there is need for multidisciplinary approaches. We are talking about a disease, the investigation of which requires epidemiologists, virologists, psychologists." However, "Why the psychologist? To prove you're not all crazy" (Grufferman, cited in Feiden, 1990).

The consequences of these views are not in doubt. "Sufferers often reject psychiatric treatment for fear of being told it is all the mind."⁶⁴ Accepting any form of psychiatric treatment is seen as stigmatizing CFS. "I don't know anyone who has been for psychiatric treatment, because CFS is a physical illness. I'm not crazy, I'm sick."⁶⁵ Being referred to a psychiatrist is "being blackballed" (Conant, 1990). The image of being on trial is common⁶⁶—"For me being a psychiatric patient was a little like being imprisoned for a crime I didn't do."⁶⁷ Such views do little for the self-esteem of the average psychiatrist, but they have more serious consequences. Many CFS patients are denied what may be simple but effective treatments. The rejection of any social or psychological intervention may set in motion a series of maladaptive behavioural patterns.

If this is so, then one would expect the prognosis for neurasthenia/CFS to be poor. There is considerable evidence that this is so. Behan and Behan (1988), who have perhaps the most extensive experience of CFS in this country, wrote that "most cases do not improve, give up their work and become permanent invalids, incapacitated by excessive fatigue and myalgia." There is evidence to support this gloomy outlook. Hellinger and colleagues (1988) and

Gold and his colleagues (1990) reported that half the patients referred had not improved after one year, and only 6% were symptom free. Hinds and McCluskey (1993) found that only 18% of those referred to an immunology clinic improved. Only 13% of those referred with post-viral fatigue to the Oxford infectious disease clinic considered themselves fully recovered (Sharpe, Hawton, Seagroatt & Pasvol, 1992). Poor prognosis was independently associated with a belief in a viral cause for illness, membership of a self-help organization, current emotional disorder and alcohol avoidance. According to an Australian study the strongest association of poor outcome in CFS was again the strength of belief in an exclusively physical cause for symptoms (Wilson, Hickie, Lloyd, Hadzi-Pavlovic, Boughton, Dwyer & Wakefield, 1994).

Much of the current information on CFS may also adversely influence prognosis. Current literature on CFS is frequently gloomy in tone, with a tendency to use "worst case" examples for publicity purposes. The first President of the ME Association and its first Medical Advisor used the same words—the disease has "an alarming tendency to chronicity" (Ramsay, 1989; Smith, 1989). The current President of the ME Association states that an essential clinical feature of the disease is "a prolonged relapsing course lasting years or decades" (Dowsett & Welsby, 1992). Sufferers must make "very significant changes in their life style" (Shepherd, 1989). Newspapers and magazines frequently call the disease incurable. How much is this perception based on clinical reality, and how much does it influence that reality?

CONCLUSION: THE POLITICS OF FATIGUE

Any understanding of neurasthenia and CFS must take into account what a recent letter to a journal called the "highly charged, medical, social and political atmosphere" surrounding the subject (Reeves, Pellett & Gary, 1992). A journalist has written that "there is no middle ground when it comes to CFS" (Lechky, 1990). Paul Cheney, one of the most prominent doctors on the American CFS scene, has written that "we who believe that this is a real disease are almost in a death grip with those forces who would stifle debate, trivialize this problem, and banish patients who suffer from it beyond the edges of traditional medicine."⁶⁸ CFS "cannot be debated dispassionately" (Brodsky, 1991). Many will have had similar experience to one medical journalist, who, when writing about

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possible psychological contributions to CFS, observed that “at any dinner party you will find the friends of sufferers, who will either support or hotly dispute this view” usually with “ferocity.”⁶⁹

CFS is associated with a flourishing network of consumerism and political action, with support groups active in fund raising and political lobbying (Charatan, 1990). Patient organizations in this country have started advertising campaigns in the cinema and the popular press.⁷⁰ CFS is now accompanied by a rhetoric of struggle and injustice—a typical headline is “Justice for the neglected and maligned sufferers of ME.”⁷¹ ME sufferers in the United Kingdom “looked to the House of Commons for justice,”⁷² and have been rewarded by one Member of Parliament’s promise that they would mount “an aggressive programme of action.”⁷³ Passions are high. One activist chose to describe her involvement in this cause—“this issue chose me...if you were in Germany during the war, you didn’t get to pick your issue, yet there was no greater test of leadership” (Montgomery, cited in Feiden, 1990).

The reasons for these passions have been outlined in this paper. At the heart is the simple division into legitimate illness and illegitimate complaints, all too often equated with the distinctions that continue to be made between physical and psychological causes of distress.

NOTES

1. I shall use endnotes to reference all newspaper and magazine articles by title and publication. Professional publications will be referenced in the normal fashion in the text and listed at the end.
2. ME—not a middle class disease. (Mar. 24, 1988). *Social Work Today*.
3. ME: The Mystery Disease. (Nov. 1988). *Women’s Journal*.
4. Living Death of Fergie’s Rising Star. (Apr. 3, 1990). *Sun*; Athletes left fit to drop by spreading virus. (Feb. 10, 1993). *Times*; Eichner (1989); The ME Generation. (Jan. 22, 1989). *Sunday Telegraph Magazine*; Physical overload forces elite to breaking point. (Aug. 7, 1993). *Independent*; Young talents tired out. (Feb. 5, 1989). *Observer*; Viral fatigue which afflicts the young may affect patients long after initial infection. (July 20, 1991). *Times*.
5. ME. (Sept. 1989). *Report of the Assistant Masters and Mistresses Association*, p. 12-13; Passengers will not be carried. (Oct. 24, 1989). *Guardian*.

6. See: Dawes & Downing (1989); The ME Generation. (Jan. 22, 1989). *Observer*; ME and You. (June 1988). *Cosmopolitan*; (Sept. 3, 1993). *Sheffield Telegraph*.
7. See: The victims of a disease that is still baffling the medical men. (June 29, 1987). *Belfast Telegraph*; All in the mind—or in the body too. (July 19, 1988). *Daily Telegraph*; Postviral Fatigue Syndrome. (Aug. 1991). *Marie Claire*; When the drive band snaps. (Aug. 5, 1988). *Hampstead & Highgate Gazette*; ME: The Mystery Illness. (Mar. 1989). *Woman and Home*; ME: Still Raising Doubts. (Sept. 1993). *Top Santé*; (Nov. 12, 1990). *Newsweek*; (Apr. 22-25, 1993). *European*.
8. Why perfectionists are most at risk from ME. (Sept. 28, 1993). *Daily Mail*.
9. Industry of Anxiety. (Aug. 1989). *Vogue*, 178-179.
10. Kilroy was here. (Autumn 1989). *Interaction* 3, 503.
11. Women who hold the reins. (Oct. 13, 1993). *Sunday Telegraph*.
12. When it is time for a child to be ill. (June 27, 1989). *Independent*.
13. I beat the disease of the 90s. (Apr. 11, 1990). *Daily Express*.
14. ME: in mind or body? (Apr. 14, 1989). *New Statesman & Society*.
15. Cheney P. cited in: Is CFS a real disease? (Aug. 22, 1992). *Awake*.
16. M.E. The Mystery Illness; (Mar. 1989). *Woman & Home*. op. cit.
17. That old psychosomatic blues again. (Sept. 8, 1991). *Observer*.
18. Postviral Fatigue Syndrome. (Aug. 1991). *Marie Claire*.
19. Let's Talk about M.E. (July/Aug. 1993). *Esquire*.
20. Francis C. (Winter 1988). *Interaction*, 1.
21. Am I Sick or Just Tired? (Aug. 24, 1991). *New Woman*.
22. (Sept. 13, 1990). *Money Marketing*.
23. M.E. and You. (June 1988). *Cosmopolitan*.
24. Post-viral does exist. (Sept. 18, 1987). *GP Magazine*.
25. ME: The Mystery Disease, (Nov. 1988). *Woman's Journal*.
26. Take M.E. Seriously. (Undated Factsheet). *M.E. Action Campaign*.
27. Postviral puzzle. (Aug. 2, 1987). *Observer*.
28. Brainwaves suggest ME is physical illness, not a psychiatric condition. (Aug. 29, 1992). *Guardian*.
29. Tired and Alone: My Mind Reduced to Porridge. (Feb. 21, 1987). *Sunday Times*.
30. Dowsett E. quoted in "Tired and Tested." (Oct. 1990). *Harpers & Queen*.
31. ME sufferers forced to battle with insurers. (June 27, 1993). *Independent*.
32. Virus research doctors finally prove shirkers really are sick. (Jan. 25, 1987). *Sunday Times*.
33. Condemned to live a lonely life. (July 6, 1991). *Guardian*.

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34. Don't listen if your GP says it's 'just nerves.' (Aug. 18, 1986). *Scotsman*.
35. 10 Minute Rule Bill on Myalgic Encephalomyelitis. (Feb. 23, 1988). *Hansard*.
36. The ME Generation. (Jan. 2, 1989). *Observer*.
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