Chronic Fatigue Syndrome

Rona Moss-Morris
and Keith J. Petrie

The Experience of Illness

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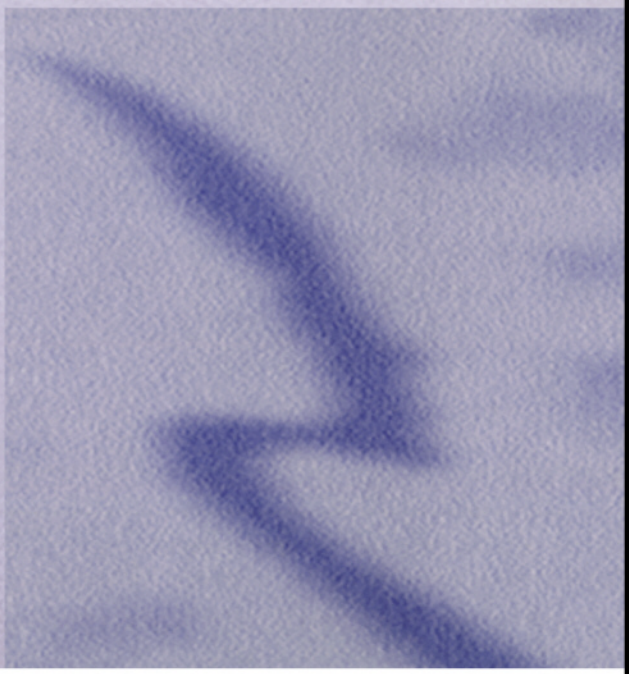

Chronic Fatigue Syndrome

Chronic Fatigue Syndrome is one of the most enigmatic medical disorders of our time, striking people often in their most productive years. With the controversial debate over cause and treatment of the illness in mind the authors seek to unravel many of the questions surrounding the disorder and its features and characteristics.

Integrating an overview of the latest research with patients' personal experiences and findings, they look at CFS in relation to:

- clinical features
- personal and economic implications
- biological and psychosocial factors
- experiencing symptoms
- coping with the illness.

This book will provide information for people with chronic fatigue syndrome and will assist health professionals in working with people with CFS to improve their quality of life

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The Experience of Illness

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Chronic Fatigue Syndrome

Rona Moss-Morris and
Keith J. Petrie

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Series editor's preface

Illnesses where the organic basis has yet to be established are always controversial. This is certainly true for chronic fatigue syndrome, which is tackled in this book by Rhona Ross-Morris and Keith Petrie. They deal with the controversy in a systematic fashion, starting off with the historical roots of other diagnoses and conditions that may relate to chronic fatigue syndrome. The nature of the condition involves mental and physical fatigue as well as some pain and muscle weakness, all or some of which most of us have experienced to some degree. The focus of the definition of the illness, as Moss-Morris and Petrie describe, involves a distinct symptom profile and is often used to exclude other psychiatric and medical conditions which may mimic the symptoms of chronic fatigue syndrome. The key area is that of fatigue which has been present for a significant amount of time and does not resolve easily. Although there are differences in the diagnoses used, there has been a development of a new consensus definition which they outline.

The psychological difficulties for patients in dealing with an illness which is not easily attributed to an organic condition, and the different experiences that they have in approaching healthcare professionals, are well described in this book. Petrie and Moss-Morris discuss and analyse the question of whether chronic fatigue syndrome is a unique, specific entity, and how the search for the biological basis of chronic fatigue syndrome has impacted on patients' understanding of the problem that they are experiencing.

The most controversial area concerns the relationship between chronic fatigue syndrome and psychiatric illness. Specifically, chronic fatigue syndrome has been related to anxiety or depression and a disorder where patients have these conditions but relate them to physical complaints. How patients relate their symptoms to a consideration of these having a

psychological basis, and the potential stigma associated with a diagnosis of a psychiatric disorder, is well analysed in Chapter 4.

Perhaps the most important issue is that of how patients make sense of their symptoms, and how they think of their condition. Using the illness representations model, Ross-Morris and Petrie carefully analyse the factors that influence patients' representations of chronic fatigue syndrome and how these influence their well-being and behaviour. The most important aspect of this is how patients' cope with their condition. This is outlined in Chapter 7, the final chapter of the volume.

In this volume Ross-Morris and Petrie have made a significant contribution to our understanding of what individuals with chronic fatigue syndrome experience, and how they try to make sense of their symptoms. It will be of interest not only to individuals involved in the treatment of people with chronic fatigue syndrome, but also to individual sufferers themselves. The way in which health care professionals approach the topic, and how this interacts with individuals with chronic fatigue syndrome, will be of particular interest.

Chapter 1

Chronic fatigue syndrome

Then and now

Most of us have felt unduly tired at some time or another. While this sensation is often unpleasant, the impact on our lives is seldom profound. We may cut down on certain commitments, but in most instances we can continue to perform our day-to-day tasks. However, for some people, like Judy, the experience of fatigue is devastating and ongoing. In describing her nine-year battle with fatigue, Judy explains:

> I had no energy or drive whatsoever. I used to feel that I had fifty-pound weights on each foot and about thirty-pound weights on each wrist. I had this terrible dragging feeling in both the physical and mental sense. Writing out a few cheques would be too much. Getting the rubbish bags organised and put out on Tuesday mornings was a dreaded chore. It was as though I had seized up.
>
> (Judy 1991:39)

Another sufferer of chronic fatigue, Dr Robbie Lopis, a general practitioner, describes how after a viral illness and six weeks rest he returned to work part time only to find that:

> 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.
>
> (Lopis 1995:16)

In many cases of profound fatigue a psychiatric or medical diagnosis

can account for these symptoms. However, for some patients, as in Dr Lopis's case where a 'barrage of medical tests came back normal', such fatigue cannot be explained by any single diagnosis. In these cases fatigue is usually accompanied by a range of other unpleasant symptoms such as mental confusion, muscle and joint pains and severe headaches. Over the past two decades special attention has been given to these patients and the causes of this debilitating fatigue have been hotly debated.

Early reports in the 1980s regarded persistent unexplained fatigue as a psychosomatic reaction to the stressors of modern society. Because the illness appeared largely to afflict young up-and-coming professionals, it became unkindly referred to as 'yuppie flu'. Advocates and sufferers of the illness concurred that the disease was a reaction to the overload of the twentieth century, but strongly rejected the notion that the illness might be psychological in origin (Wessely 1997). Rather, they favoured explanations which included twentieth-century pollutants, toxins, diets, viruses, and weakening of the immune system. A plethora of names for the condition arose, such as chronic immune deficiency syndrome, postviral fatigue syndrome, and myalgic encephalomyelitis (ME), each reflecting assumptions about the possible organic nature of the illness (Steincamp 1989). In response to the nomenclature controversy and in an attempt to define a homogeneous group of patients for research purposes, the Center for Disease Control and Prevention (CDC) in Atlanta renamed the condition chronic fatigue syndrome or CFS (Holmes *et al.* 1988). Despite claims that CFS is a malady of the past couple of decades, it does in fact have historical predecessors. This chapter reviews the history behind CFS to provide a framework for understanding both the contemporary definitions of the illness and some of the complex sociocultural issues which beset the disorder.

Neurasthenia

Chronic fatigue-like illnesses were described as long ago as the eighteenth century, but the origins of CFS have generally been traced back to the end of the nineteenth century in a condition known as neurasthenia (Shorter 1993; Wessely 1990; White 1989). Neurasthenia was a term coined by an American neurologist, George Beard, to describe a condition of profound nervous exhaustion (Beard 1869). The illness was characterised by mental and physical fatigue which could be exacerbated on the slightest exertion. A French doctor in the 1880s explained how even simple activities such as standing, talking or walking were problematic for his patient:

> Her head was continually heavy [*alourdie*], the only thing she wants is to remain in bed. Any activity causes her the greatest fatigue. In the months preceding my first visit she had renounced all activity, and normally did not leave her bed at all. She said that her illness had begun with a great sense of weariness in the head, followed almost immediately by great muscular fatigue.
>
> (Cheron 1893 cited in Shorter 1994)

Recent doctors' accounts of CFS are almost indistinguishable from such descriptions of neurasthenic patients. In his book *The Body at War*, John Dwyer (1988) provides a detailed account of Carol's battle with fatigue:

> Her body was that of a very old woman she thought. It protested that it did not want to move; it was exhausted. More than that, it ached from head to toe. She could feel each muscle protesting even as she lay immobile in bed. Many of the muscles felt tender to her touch. With the maximum amount of will power she dragged her new self to the bathroom, then collapsed back on her bed, utterly exhausted from this effort. She had been tired before but never had she felt anything approaching this sensation. Her head was pounding and she recalls how confused she was.
>
> (Dwyer 1988:192)

Like CFS, neurasthenia was associated with numerous other somatic complaints including headaches, general weakness, heart palpitations, gastrointestinal discomfort and muscle pain (Wessely 1990). As any form of exertion was seen to exacerbate the condition, rest was the advocated cure. In advising how to deal with neurasthenia it was stressed that 'any unnecessary expenditure of energy, must be averted, any super-fluous task, any wasting of force' (Hartenberg cited in Shorter 1992:226). This advice is not dissimilar to the 'aggressive rest therapy' frequently prescribed for CFS sufferers in self-help manuals.

The controversy raised by neurasthenia was remarkably similar to that of the 1980s' 'yuppie flu' debate. Despite affirming that there were no physical signs of the disorder and that neurasthenia was compatible with the appearance of good health, Beard was adamant about the organic nature of the condition. He observed that the illness was most prevalent in the upper echelons of the community and concluded that neurasthenia was a physical response to the demands of industrialised society. In his

view, over-exertion resulted in loss of nerve strength from nerves losing their natural charge. However, as with modern-day CFS, not everyone wholeheartedly accepted neurasthenia as an organic disorder. Indeed, many neurasthenics complained that they were treated with indifference by the medical profession (Wessely 1990). Despite this early scepticism, neurasthenia acquired credibility as a neurological condition and was a popular diagnosis in the early part of the twentieth century not only in the US, but as far afield as Europe and East Asia (Ware and Kleinman 1992).

In fact neurasthenia became so popular for a while that it was used to describe almost any complaint that included subjective symptoms (Shorter 1992). However, the early part of the twentieth century brought about a new sophistication in psychiatric classification or nosology. With this came the realisation that many patients previously labelled as neurasthenic were suffering from any of a wide range of disorders. Henri Feuillade in 1924 described how under the label of neurasthenia 'one finds melancholics, patients with compulsive thoughts [*des scrupeleux*], the anxious, the obsessed, the phobic, the impulsive, the degenerate, even some cases of neurosyphilis in remission' (cited in Shorter 1992:231).

This increasing recognition of distinct psychiatric disorders, together with the advent of Freudian ideology and psychodynamic theories of emotion, meant that ideas about neurasthenia began to shift from neurology to psychology (Greenberg 1990; Wessely 1990). Physicians began to focus on the analysis of unconscious conflict in chronically fatigued patients. Chronic fatigue was seen as misdirected neurotic energy or the unconscious expression of underlying emotional conflict (Greenberg 1990). People with neurasthenic symptoms became known as neurotic or hysterical and neurasthenia as originally described by Beard was rarely diagnosed. Today, neurasthenia no longer appears in recent editions of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). While it is retained in the section on Mental and Behavioural Disorders in the tenth revision of the *International Classification of Diseases* (ICD-10), it is classified under 'other neurotic disorders' and is largely regarded as a 'waste basket category' that can result in the missed diagnosis of depression or other medical conditions (David and Wessely 1993; Lee 1994). Thus, until the re-emergence of CFS as a unique disease of the 1980s, chronic fatigue became an 'invisible' diagnosis for the greater part of this century (Ware 1992).

War-related fatigue syndromes

Fatigue syndromes occurring during or after active combat also attracted attention at the turn of the century (Greenberg 1990; Hyams, Wignall and Roswell 1996). At the same time that ideas about neurasthenia were being formulated, another American physician described a very similar disease episode afflicting soldiers of the American Civil War, which he labelled 'irritable heart' (Da Costa 1871). The illness usually began with gastrointestinal upset followed by functional impairment aggravated by symptoms of exertional fatigue, disturbed sleep, dizziness, shortness of breath and sudden palpitations. Da Costa's emphasis on the last three symptoms suggests a substantial overlap with contemporary descriptions of panic and anxiety disorders. It is possible that some of the other symptoms reflected malnutrition, infections, stress or exhaustion. However, like neurasthenia, there were no consistent biological signs of disease and most irritable heart patients appeared to be in reasonable health. Da Costa believed the illness to be either of infectious origin or related to strenuous military duties. Treatment involved removal from active service and administration of a variety of tonics and medications for the heart (Demitrack and Abbey 1996).

A similar syndrome was common during World War I. This illness, referred to as the Da Costa syndrome, effort syndrome, and soldier's heart, incorporated most of the somatic symptoms described by Da Costa as well as a range of neuropsychological symptoms, such as forgetfulness and poor concentration (Greenberg 1990; Hyams *et al.* 1996). In many cases the symptoms were deemed serious enough to evacuate soldiers back to England. Effort syndrome was initially attributed to cardiac hypertrophy caused by over-exertion, but as the war progressed the illness was linked to a number of causes, including a past history of nervousness or physical weakness, infections and exhaustion. Cardiac medication was found to be ineffective for these patients and attributing their illness to heart disease appeared to hinder recovery and return to the trenches (Hyams *et al*. 1996). However, structured rehabilitation programmes incorporating a gradual return to exercise were found to be effective. By the end of the war it became accepted that effort syndrome was not caused exclusively by wartime exposure, but whether the illness was primarily physiological or psychological in origin was still uncertain (Hyams *et al.* 1996).

Effort syndrome remained a popular diagnosis at the beginning of World War II. However, attitudes towards the illness changed during the 1940s