Reading about

EDITED BY SIDNEY CROWN and ALAN LEE

Chronic fatigue syndrome

SIMON WESSELY

Chronic fatigue and its syndromes are not new, yet every generation thinks they are. For that reason alone an understanding of history remains an essential starting point, as well as a humbling exercise. This reviewer has contributed some amateur accounts of the history of chronic fatigue syndrome (CFS), but for real guidance it is best to turn to the professionals. Edward Shorter in *From Paralysis to Fatigue* has attracted the most attention (1992). A marvellous read, it is strong on the narrative history of doctors and their patients as they wander through the nervous clinics, spas and out-patient departments of Europe and America. If it has a weakness, it only appears towards the end when the author's own interpretations become clear. Professor Shorter makes little secret of his own views – that these are fundamentally psychiatric illnesses – which has led some reviewers to see this as a partisan account. Perhaps so, but it is required reading. Anton Rabinbach's *The Human Motor* is less accessible to the medical reader; however, his discussion on the way in which scientific and technological changes impacted on the popular conceptions of fatigue remain relevant today (Rabinbach, 1990). For those in a hurry, the recent *History of Clinical Psychiatry* contains two essays on neurasthenia and chronic fatigue (Lutz & Wessely, 1996).

The professionals

For those blind to the past, the more conventional approach to a subject is that well known product – the multi-author textbook. Like any 'new' subject these have started to appear. Jenkins & Mowbray's was the first. It marks the golden age of the viral hypothesis, and much is now outdated (Jenkins & Mowbray, 1991). The next title was also an uneasy alliance of several competing forces. An unusual editorial team of Goldberg, Behan and Mowbray (their editorial conferences, if any ever took place, must have been entertaining) followed (Behan *et al*, 1991). Again, the emphasis on virology (that was the year of the persistent virus) is now dated, but good essays start to emerge on physiology, psychiatry and management. Probably the most informative is the account of the three day CIBA Foundation meeting that took place in 1992 (Bock & Wheelan, 1993). Anthropologists, social scientists and historians now join the fray, as they should. The beauty of the CIBA format is that not only do you get the essays themselves (this time of a uniformly high standard), but you also get the discussions as well. Sadly, much of the wit of the two chairmen, Stephen Straus for the laboratory scientists and Arthur Kleinman for just about everything else, has not survived the editorial clean up. Stephen Straus went on to edit another book, which, as one would expect from that pedigree, is again of high standard (Straus, 1993). Andrew Lloyd from Australia and Warren Strober from the National Institutes of Health contribute particularly informative chapters on immunology. Both are clearly aficionados of their discipline, but remain critical and informative.

The Americans have never been particularly sold on the idea of a persistent viral cause for chronic fatigue, but instead are enthusiastic for the concept of an immunological deficit. This was enshrined in a slender book published by the American Psychiatric Association, whose title – *Chronic Fatigue and Related Immune Deficiency Syndromes* – did not bode well (Goodnick & Klimas, 1993). The title itself is a deliberate echo of AIDS, and indeed is adopted by the most active of the US patient organisations. Unfortunately (or perhaps fortunately) CFS is not an immune deficiency syndrome. This gives the book a somewhat limited perspective. In contrast, what must soon be called the 'Oxford school' have taken a broader view, and extend the frame to include chronic fatigue within the spectrum of other medically unexplained syndromes (Mayou *et al*, 1995).

The most recent serious title also reflects the weakening of exclusively immunological or virological theories. Edited by two psychiatrists, Mark Demitrack and Susan Abbey, it concentrates on psychological and neurobiological aspects of the condition, and also provides much-needed practical reviews on sensible management (Demitrack & Abbey, 1996). Finally, I would be failing my co-authors if I did not mention the first non-edited book, written by myself, Matthew Hotopf and Michael Sharpe. We attempt a comprehensive review of chronic fatigue and its syndromes, from its origin, through its mechanisms, to its treatment. Our royalty payments will tell us how successful we were (Wessely *et al*, 1997).

The view from W. H. Smith

But there is more. The above books take, with varying degrees of success, the conventional approach to the problem – definition, epidemiology, aetiology, treatment. All follow the conventions of professional publication – experts quoting evidence backed up with references, although again with varying degrees of rigour. Nevertheless, all are recognised members of that genre: the professional book. Hence, all will tell you little about what is really happening.

To understand that we have to go down to W. H. Smith's. It is in the paperback self-help books that we find a completely different discourse. When I reviewed this literature in 1989 I counted six titles (Wessely, 1989). My shelves now contain 29, and I certainly missed some. They come and go, but most follow a similar format. First, the confessional. Most are written by people drawing on their own experiences. This gives them the energy to get their message across, and the required credibility. Next the polemic. What the professional literature fails to convey is the passion associated with this subject. The bitterness of being misunderstood, of being denied a label, or even worse given the wrong one. One can empathise with the hurt of being told there is nothing wrong when you are suffering, unable to work, unable even to get out of bed. Rather more often, the sufferer is told there is something

https://doi.org/10.1192/S0007125000147397 Published online by Cambridge University Press

wrong, but the diagnosis is not to their liking. In fact the anger and shame from being told the problem may be psychological is even more intense. It is harder for a practising psychiatrist to empathise with that pain, since it calls into question our own role and value, but empathise we must, since until we understand that bitterness and sense of rejection we have failed to understand anything about the subject. Let's face it, when sufferers protest about being asked to see one of us, they are right. Modern psychiatry has little to offer those who do not hear voices.

The purpose of these chapters is twofold. First, so that the reader experiences the conversion experience ("at last – those are my symptoms – that is what is wrong – now I understand") and the empathy ("I am not alone, someone else understands me – other people have been treated as badly"). These are the crucial messages conveyed by these books, and the fact that they strike such an immediate chord in so many should give us pause for thought.

After that, all turn to treatment. What is surprising is just how similar these are. What follows will be some permutation of diet, allergy treatments and candida regimes. This will be accompanied by a long list of things to avoid (chemicals, toxins, certain foods, exercise, radiation and so on), and finally some soft psychology (counselling, relaxation, meditation), all interspersed with advice to rest, look after yourself and so on. The exact permutation varies but the basic menu remains unchanging. What is fascinating is that the same advice can be found under a host of other labels. If you pick up a book on candida, electromagnetic sensitivity, food allergy, hypoglycaemia and so on, much remains unchanged. What we are seeing is the rise of modern illnesses, based in equal parts on the fears raised by our changing environment and a reaction to the excesses of the 1980s and the accompanying drive to success. What is striking is their paradoxical attitude to medicine. All are pro-science in that all take a rigid biomedical approach to the aetiology of symptoms. Nearly all include a guide to the current *Zeitgeist*, the immune system. It is an unusual book that does not include a quick account of T cells, B cells and killer cells. On the other hand all are also anti-medicine. Doctors are no longer any good. They do not have time for you anymore, they do not listen, are blinkered by new technology, and are particularly nasty if all your tests are normal. All thus combine a passionate attack on modern medicine with a fervent faith that somewhere the boffin of the month is slaving over his test tube and everything will be all right. What is at stake is not an attack on science, but on doctors. We as doctors are being told to get our act together to convert the sufferer's incontrovertible experience of illness into the legitimacy of disease. We as psychiatrists are the prime obstacle to this endeavour.

Emotion versus evidence

My personal favourites. One (Johnson, 1996) is written by Hilary Johnson, a journalist whose 1987 article about her mystery illness was one of the factors that led to the explosion of interest in the USA. She has now written an extraordinary account of the rise of CFS in the United States, and in particular, the efforts made to prove it is caused by a retrovirus. It is opinionated, often nasty and occasionally libellous. The word partisan is totally inadequate to convey its particular flavour. But that is why it is also unwittingly a vital document of our time – an account of the rise of the consumer, the politicisation of medicine, and the power of the media. It is a warning of the coming clash between our desire for decision-making on the basis of evidence, and the often equal and opposite demands of consumers and lobbyists. Finally, it is also a Greek tragedy of a decent scientist who could not face the possibility she might be mistaken. An alternative is to watch a video of the recent 'Rantzen report' on myalgic encephalomyelitis, but only for those with strong nerves. They give you the emotion, but if you want the facts, turn to the recent report produced by the three Royal Colleges (Anonymous, 1996). It is brief, evidence-based, cautious but practical. That is what I think, but I was a member of the committee. What do others think? The *British Medical Journal* called it "authoritative", but the *Lancet* said it was "biased and rigged". One thing we can all agree on – this is a subject on which we have never agreed, and probably never will. That is why it is so interesting.

REFERENCES

Anonymous (1996) *Chronic Fatigue Syndrome: Report of a Committee of the Royal Colleges of Physicians, Psychiatrists and General Practitioners*. London: Royal College of Physicians.

Behan, P., Goldberg, D. & Mowbray, J. (eds) (1991) *Postviral Fatigue Syndrome*. British Medical Bulletin, vol. 47, no. 4. Edinburgh: Churchill Livingstone.

Bock, G. R. & Wheelan, J. (eds) (1993) *Chronic Fatigue Syndrome* (CIBA Foundation Symposium 173). Chichester: John Wiley.

Demitrack, M. & Abbey, S. (eds) (1996) *Chronic Fatigue Syndrome: An Integrative Approach to Evaluation and Treatment*, pp. 72–112. New York. Guilford.

Goodnick, P. & Klimas, N. (1993). *Chronic Fatigue and Related Immune Deficiency Syndromes*. Washington, DC: American Psychiatric Association.

Jenkins R. & Mowbray, J. (eds) (1991) *Post-viral Fatigue Syndrome*, pp. 1–39. Chichester: John Wiley.

Johnson, H. (1996) *Osler's Web*.

Lutz, T. & Wessely, S. (1996) Neurasthenia and Fatigue Syndromes. In *A History of Clinical Psychiatry: The Origin and History of Psychiatric Disorders* (eds G. Berrios & R. Porter), pp. 509–544. London: Athlone.

Mayou, R., Bass, C. & Sharpe, M. (eds) (1995) *The Treatment of Functional Somatic Symptoms*. Oxford: Oxford University Press.

Rabinbach, A. (1990) *The Human Motor: Energy, Fatigue and the Origins of Modernity*. New York: Basic Books.

Shorter, E. (1992) *From Paralysis to Fatigue: A History of Psychosomatic Illness in the Modern Era*. New York: Free Press.

Straus, S. (ed.) (1994) *Chronic Fatigue Syndrome*. New York: Mark Dekker.

Wessely, S. (1989) What your patients may be reading: ME. *British Medical Journal*, **298**, 1532–1533.

—, Hotopf, M. & Sharpe, M. (1997) *Chronic Fatigue and Chronic Fatigue Syndromes*. Oxford: Oxford University Press.

Simon Wessely Reader in Psychological Medicine at King's College School of Medicine, 103 Denmark Hill, London SE5 9RS

https://doi.org/10.1192/S0007125000147397 Published online by Cambridge University Press