

reviews

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Chronic Fatigue Syndrome (CFS/ME): The Facts

Michael Sharpe, Frankie Campling



Oxford University Press,
£9.99, pp 290
ISBN 0 19 263049 0

Rating: ★★★

The past decade has seen an outpouring of publicity, and more than a trickle of research, about chronic fatigue syndrome. Yet, despite all this activity, the subject remains a cause of frustration for doctors and patients alike. This is not for want of information, but rather the opposite, an internet-led flood of anecdotal evidence and advice.

Sharpe and Campling, the former a consultant psychiatrist and the latter a

“person with CFS/ME,” have endeavoured to give an evidence based approach to the subject, delivering known facts but also highlighting gaps in our knowledge. Their target audience is the sufferer.

They begin by outlining our current understanding of chronic fatigue syndrome. This is a condition with several names, some of which can mislead—such as the term “myalgic encephalomyelitis,” which implies a neurological inflammation that is not present. This uncertainty extends into diagnosis, which can be difficult because of overlap with many other symptom-defined conditions, ranging from fibromyalgia to depression. The authors are suitably non-committal about the aetiology of the syndrome, emphasising its multifactorial nature: infection, muscle dysfunction, stress, and brain abnormalities are just a few of the theories discussed.

While the authors admit there is no cure, they align chronic fatigue syndrome with other conditions that can be successfully managed without a clear idea of aetiology. They outline the current roles of drug and psychological treatments and how patients’ attitudes towards the illness can influence outcome.

The self help section offers sufferers practical steps towards making their lives easier, such as keeping a diary to monitor rest and activity. Relaxation, sensible pain control, a good sleep pattern, and a balanced diet all help manage symptoms. Good control of any concomitant psychiatric symptoms is recommended. Practical issues, such as approaching the medical profession and returning to work, receive appropriate attention.

There is no shortage of self help books dealing with chronic fatigue syndrome. So how does this one compare? The answer is, extremely well. This book assumes sufferers to be intelligent and inquiring and provides a list of research papers in place of the more usual personal testimonies. This means that, at times, it can read more like an undergraduate textbook, with explanations of the hypothalamic-pituitary axis and postural hypotension. Indeed, clinicians unfamiliar with chronic fatigue syndrome could learn a fair amount from this text. The pearls of wisdom may, however, be lost at times in the factual information, and a few more diagrams would have helped.

Gina Hossain *specialist registrar in liaison psychiatry, Maudsley Hospital, London*

Quacks: Fakers and Charlatans in English Medicine

Roy Porter



Tempus, £19.99, pp 256
ISBN: 0 7524 1776 2

Rating: ★★★★★

Quacks first appeared in 1989 with the more precise title *Health for Sale: Quackery in England 1650-1850*. This reissue of a classic work greatly benefits from being illustrated with an extensive series of monochrome and col-

oured contemporary prints. Quackery, after all, was a highly visual art.

The 17th century definition of a quack as someone who “pretends to have medical skill or knowledge” is pejorative and remains in common use. It conjures up an image of the pre-modern medical world as being neatly divided between physicians and surgeons practising their vocation and disreputable businessmen selling their proprietary pills to a gullible public. Porter, however, will have no truck with such an anachronistic reading of events. As he correctly points out, medicine in the early modern period should be seen as an occupation rather than a vocation, and both “regular” medical practitioner and quack were subjected to the vagaries of market forces. It is therefore not surprising that one of Porter’s chief findings is that there was a far greater convergence of attitudes and activities of “physicians” and “quacks” than has hitherto been acknowledged.

Robert James is a case in point. The fact that James was DM(Oxon) did not stop him marketing his highly popular (and lethal) “febrifuge” powders to such luminaries as Oliver Goldsmith and Laurence Sterne. Whether we like it or not, the portrayal of

medicine throughout the ages as a “noble profession” owes more to Victorian propaganda than to sound historical scholarship.

I particularly enjoyed Porter’s analysis of quack culture drawn from contemporary publicity material. Quackery was pure theatre. The quack would move from town to town and would often appear to the local populace on a raised stage, decked out in eye-catching garb. At his side would be a clown whose job was to draw up a crowd and amuse it with tomfoolery. Testimonials from “satisfied customers” would be hung up as proof of efficacy. The quack’s speech to the crowd would stir the emotions with its “damn’d unintelligible gybberish” (as one contemporary put it), promising a cure for all ills. Likely as not, the remedy would stir the bowels.

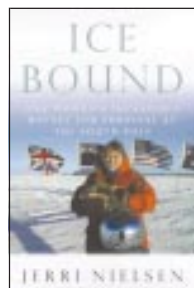
Porter presents a highly readable account of how regulars and quacks eked out a living—or, in some cases, got rich—over what historians call the “long 18th century.” It offers a reminder that the history of “medicine as business” needs just as much attention as the history of “medicine as profession.”

Tim Stokes *clinical lecturer in general practice, University of Leicester*

Items reviewed are rated on a 4 star scale (4=excellent)

Ice Bound: One Woman's Incredible Battle for Survival at the South Pole

Jerri Nielsen



Ebury Press, £16.99, pp 362
ISBN 0 09 185623 X

Rating: ★★★

Ice Bound is the story of a woman's survival during the long, dark, six month winter with 40 other people at the South Pole installation run by the National Science Foundation. As a tale of endurance, courage, patience, and boredom in the pursuit of knowledge, it is worth reading. However, it is also the story of a 47 year old emergency room doctor who goes to serve and to have an adventure but then finds her true self as

she battles against aggressive breast cancer. With these two themes intertwined, the book is hard to put down even though we may know the ending from news stories.

The book first tells the story of a year at the South Pole, from the preparations—the physical examinations and psychological testing, the travel and provisions—to the acclimatisation to the cold and adaptations to hypoxia when living at 11 000 feet above sea level. The adjustments humans must make to the extreme cold—the layers of clothing, changes in eating and living, and precautions—are explained as Nielsen approaches them in a state of wonder, as excited as a child preparing for backpacking for the first time. Then there are the perils of living at the South Pole—an adventure of its own. There are power failures, fires, frostbite, boredom, memory loss, nausea, and getting lost. Finally, Nielsen explains the relationships among the 41 people who together go through a hazardous, strenuous, challenging, and possibly deadly experience and must depend on each other and, in doing so, come to trust and care for each other.

As a doctor, Nielsen gives a unique insight into this process and its hazards and

benefits. The story of her life and her reasons for choosing an adventure in the most remote place on earth may be idiosyncratic, but they reflect the motivations of other explorers and workers to search, take risks, and expose themselves to danger. How these experiences change the individuals reflects on other events that we may share in spirit even if we have not spent a winter at the South Pole.

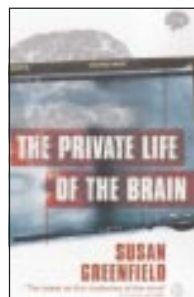
Finally, *Ice Bound* tells the story of a person fighting cancer horribly and completely alone, as all those who fight cancer are in essence alone, but made more extreme by her geographical isolation and inaccessibility. Nielsen's account is particularly compelling because she is a doctor—because she went to help others and then found that she needed to ask for help. While being alone, she finds a community.

This book may not be great literature, but it is a good read. It is an adventure tale in the true sense as Jerri Nielsen travels through more than just geography and finds herself at the end.

Jo Ann Rosenfeld *BMJ USA*

The Private Life of the Brain

Susan A Greenfield



Penguin, £18.99, pp 258
ISBN 0 713 99192 5

Rating: ★★★★★

The nature and seat of consciousness—the faculty that, above all, distinguishes humans from other animals—is at the forefront of brain research, attracting scientists of every persuasion, from geneticists to psychologists. Susan Greenfield, the internationally renowned director of the Royal Institution of Great Britain, is rightly acclaimed for the many years she has spent successfully chipping away at the coal-face of brain research. One of her most valuable achievements has been to include the wider public in her lucid explanations of neuronal networking while never ignoring her more technically advanced readers.

Her infectious smile, in contrast to the glum expression on the dust jacket of *The Private Life of the Brain*, shone out encouragingly during her television series last year. The book has the touch of a dedicated specialist steeped in up to the minute technical details, but is always humble (“I suggest,” “I have tried to show,” “I’ll stick my neck out and say”) and never forgets the wider humanitarian view.

Like Antonio Damasio, author of the recent *The Feeling of What Happens*, Greenfield believes that human consciousness emerged out of the development of emotion, in Anthony Clare's words, through the formation of the autobiographical self, identity, and personhood. Throughout the book, she nods towards the history of ideas in brain studies, referring to Euripides, Freud, and MacLean. However, she is largely concerned with the brain's geography, structure (“weighing only some three pounds with the consistency of a soft boiled egg”), and function. She discusses emotion, memory, will, and the many mental variations caused by depression, drugs, schizophrenia, and Alzheimer's disease. She concludes categorically that, for her, whether discussing fear or pleasure, she finds it impossible to distinguish the mind—the personalisation of the brain—from the concept of self.

She answers the many questions posed in her text with this stirring conclusion: “Consciousness will blossom into self-consciousness only when enough associations are in place ... to provide a common referent to myriad experiences ... The idea is that the young child is swamped with emotions that are gradually diluted by a growing retaliatory sense of Self and, most important, with a concomitant sense of inner control. I think this increasingly interactive and ever-changing dialogue between Self and outside world is important because it highlights the basic issues of how we see ourselves and, indeed, how we choose to live our lives.” (See *Personal view* p 937.)

Barbara Godlee *social anthropologist, Cambridge*

Hit parade

bmj.com

These articles scored the most hits on the *BMJ's* website in the week of publication

FEBRUARY

- ABC of diseases of liver, pancreas, and biliary system: Liver tumours**
2001;322:477-80 14 900 hits
- ABC of diseases of liver, pancreas, and biliary system: Other causes of parenchymal liver disease**
2001;322:290-2 11 452 hits
- ABC of diseases of liver, pancreas, and biliary system: Portal hypertension—2: Ascites, encephalopathy, and other conditions**
2001;322:416-8 10 081 hits
- ABC of diseases of liver, pancreas, and biliary system: Portal hypertension—1: varices**
2001;322:348-51 5 894 hits
- Recent advances: Management of patients in fast track surgery**
2001;322:473-6 5 534 hits
- Editorial: Not again!**
2001;322:247-8 5 395 hits
- Public standards and patients' control: how to keep electronic medical records accessible but private**
2001;322:283-7 4 623 hits
- Comparison of St John's wort and imipramine**
2001;322:493 4 301 hits
- Should depression be managed as a chronic disease?**
2001;322:419-21 3 864 hits
- Editorial: The fetal origins of adult disease**
2001;322:375-6 3 845 hits



New Labour, new matrons

At last, the government has revealed its secret plan to transform the NHS, make hospital wards sparkle, and ensure everyone eats up their greens, like it or not. After an absence of more than 30 years, matron is restarching her white hat ready to make a comeback.

Having regularly blamed almost every ill that has since afflicted the NHS on her disappearance, the media's response to the news was predictably suffused with triumphant excitement. "Back after 30 years to end the shame of shoddy care and dirty wards," exclaimed the *Daily Mail*. "Matron back on patrol—and she may be a man," the *Times* informed its readers. According to the *Daily Telegraph*, matron was being resurrected to "rule NHS wards."

Coverage of matron's second coming, and the inflated expectations vested in her by health secretary Alan Milburn, conjured up an icon for our times: a multitasking all-rounder—housekeeper, nanny, guardian angel, healer, disciplinarian all rolled into one—with whom the buck will stop.

But will reality bear any relation to the mythologising? Can her return really improve patients' wellbeing and boost nurses' morale and authority—or is it all a



KOBAL COLLECTION

Back by popular demand: matron, immortalised on screen by Hattie Jacques

shameless piece of electioneering by a government keen to counter a widespread feeling of betrayal among voters over its handling of the NHS?

The jury may not be out for too long. New Labour's new matrons will earn up to £31,000 a year and take charge of just a group of wards, unlike their predecessors who ran entire hospitals. There will be 500 of them within a year, and 2,000 in total by 2004. According to the Department of Health's press release (4 April), the new matrons' powers will be so wide-ranging as to be apparently supernatural. They will lead by example; make sure that patients get quality care; that the wards are clean and the food is

good; that elderly patients are treated with respect (what about the rest of us?); improve wards in some unspecified way; resolve problems for patients and relatives; and prevent and control hospital acquired infection.

Matron will wear a distinctive uniform, possibly one with stylish epaulettes. But close scrutiny of the DoH's press release also shows, somewhat confusingly, that matron will have influence, rather than control, over cleaning and catering budgets.

"There is an element of the government responding to a nostalgic longing for an individual who was trusted and respected—like the bobby on the beat," says Jane Salvage, a former World Health Organization nursing adviser, now nursing director at publishing group Emap Healthcare. "All the functions earmarked for these new matrons are already vested in other people. I'm not at all certain that having a new person flitting from one ward to another, dispensing advice, amounts to an effective and powerful new role."

Salvage is also concerned that indulging this longing for the archetypal matron figure—if indeed it exists beyond the headlines—is really rather unhealthy: "It's very backward looking, and plays up to a kind of infantile fantasy of having someone close at hand who will sort out all your problems, and make everything right."

Her concerns about the potential confusion of roles already seem justified. While Milburn emphasises that matron will provide "strong clinical leadership" on the wards, the NHS Confederation described the advent of matron as an "investment in management."

It could all turn out to be little more than a little pre-election April foolery, of course. Certainly, it would seem unwise to expect any notable changes at the bedside in the near future as a result of all this "matron-abilia." Meanwhile, carry on, nurse.

Judy Jones freelance journalist



WEBSITE OF THE WEEK

Body piercing Sexual enhancement, pain, aesthetics, mysticism, and shock value are some of the reasons for piercing everything from lobes to labia. It is a fashion promoted with relish on television, in magazines, and on the web. But Hanif and colleagues remind us that there are health risks (p 906). Piercing the ear, for example, is especially hazardous if it is through cartilage, as with "high" ear piercing. Endotoxic shock has been reported; antibiotic resistance is increasing in *Pseudomonas aeruginosa* (a common pathogen); and what begins as an aesthetic exercise can end with a cauliflower ear. And this before concerns about hepatitis and HIV infection.

With body piercing's sadomasochistic overtones and the glut of pornography on the web, it is easy to find out how to do it and where to get it done. Tribalectic magazine (www.tribalectic.com) is one of the many sites for the pierced community. Its piercer of the month slot emphasises the guru-like status of those wielding the hot needle. There is more of the same from Precision Body Piercing (www.ecsd.com/~casey/) which boasts that "It hurts to be beautiful." Steves (sic) Body Piercing Pages (www.tardis.ed.ac.uk/~skx/body/) tackle his personal experience "with the lovely world of body piercing." You get the picture.

For a more comprehensive overview go to www.bme.freeq.com/pierce/bme-pirc.html. Browse the body piercing dictionary to make sense of jargon, and learn fascinating facts about pocketing (ends of jewellery are hidden, the middle is exposed), and o-kee-pa suspension (Sioux torture administered to Richard Harris in the film *A Man Called Horse*). There is advice on good practice, as well as cautionary tales. And that is the heart of the problem with the body piercing phenomenon—it is poorly regulated, and there is little evidence about its adverse effects. Definitely pleasure at your peril.

Kamran Abbasi
BMJ
kabbasi@
bmj.com

PERSONAL VIEW

Time to abandon the term mental illness

When we use the term “mental illness,” not “brain illness,” do we put our patients in harm’s way? This is an appropriate time to ask, because it has become apparent in recent years that disorders of the brain and nervous system are among the most serious and prevalent health problems globally.

By 2020, diseases arising from nervous system disorders will make up 14.7% of all diseases worldwide (up from 10.5% in 1990), according to the Global Burden of Disease (GBD) Study recently carried out by the World Health Organization and other institutions (www.hsph.harvard.edu/organizations/bdu/gbdmain.html).

Although nervous system disorders comprise only 1.4% of all deaths, this study estimated that they account for a remarkable 28% of all years of life lived with a disability. Moreover, much of the burden of illness due to road traffic incidents, violence, war, and falls is a consequence of nervous system dysfunction. The president of the World Federation of Neurology, James F Toole, has highlighted brain dysfunction among world leaders as one of the greatest threats to global peace, and therefore the health of populations.

In making their estimates, the GBD researchers took into account that chronic illnesses differ in their impact on people, including the differential impact resulting from the way friends, coworkers, and society at large react and respond to each illness. For example, there is little doubt that people with nervous system disorders are more likely to be subjected to discrimination and stigmatisation than people with, say, disorders of the heart and lung. Employers try to avoid hiring people with a history of nervous system disorders, and otherwise compassionate people may avoid contact with such individuals in social settings. Health ministries or private insurance companies may deprive some people with serious brain disorders of the opportunity to consult with a psychiatrist or neurologist.

Our reflections upon the stigma and prejudice that apply differentially to people with nervous system disorders have led us to conclude that the mental health and mental illness labels traditionally and commonly used to characterise certain brain disorders contribute to these twin sources of unnecessary suffering. We propose that these terms be abandoned in favour of “brain health” and “brain illness.”

The concept of mind and mental effort is deeply woven within the western intellectual tradition as a fundamental concept of philosophy. Metaphysics is that branch of philos-

ophy that studies the nature of matter (ontology), of mind (philosophical psychology), and of the ways that matter and mind interact in sense perception and the acquisition of knowledge (epistemology). “That in the soul which is called mind,” Aristotle writes, is “that whereby the soul thinks and judges.” Philosophers, theologians, and children wonder whether mind is a uniquely human possession, whether other animals have minds, or whether there is a transcendent intelligence, an absolute mind, in the universe. However, in proposing that we replace the mental illness label with the brain label, we are arguing not from a philosophical position but within the domains of public

health and clinical medicine, as an essential step to promote the improvement of human health.

Last week’s World Health Day 2001 commendably highlighted nervous system disorders. Although the six disorders underscored in this project were all brain disorders (depressive

disorders, schizophrenia, dementia, alcohol dependence, epilepsy, and mental retardation), the event was widely known as World Health Day 2001 on Mental Health. Advances in neuroscience during the past 50 years have left us not knowing how or where to draw a line between brain and mental problems, or between psychiatric and neurological disorders, as is customarily done. From our angle of vision, there are only brain disorders that psychiatrists prefer to treat and other brain disorders that neurologists (and neurosurgeons) prefer to treat.

To be sure, there are many social problems and problems in living that most healthcare workers would agree do not reflect brain disorders. We frequently meet people with complex presentations, leaving us uncertain whether any brain disorder is present. We should honestly admit this uncertainty, and await the results of further research without retreating into the ambiguity of the “mental” paradigm.

We suggest that it is unscientific, misleading, and harmful to millions of people worldwide to declare that some brain disorders are not physical ailments. Neurology and psychiatry must end the 20th century schism that has divided their fields. There must be closer collaboration in neuroscience research and clinical practice. And we must build partnerships with our patients and with societies at large. Only then will we advance the prevention and treatment of brain and nervous system disorders.

Mary Baker *president of the European Parkinson’s Disease Association*

Matthew Menken *World Federation of Neurology liaison representative, World Health Organization*

It is harmful to millions of people to declare that some brain disorders are not physical ailments

SOUNDINGS

The European Leisure Time Directive

The European Working Time Directive, currently causing chaos in the NHS, puts a 48 hour limit on the working week. This is difficult for doctors as most of us warm up only after 48 hours. Indeed, we are starting to panic about how to fill the other 120. Fortunately, help is at hand in the form of the European Leisure Time Directive.

Research has shown that leisure is beneficial to health and therefore, like seat belts, it is being made compulsory. This is not as easy as it sounds. Academics, for example, are paid to think but if they do so beyond the limit, their employer will incur financial penalties. The traditional decerebrant, alcohol, is also unhealthy, so universities are introducing intensive tenpin bowling and snooker.

Unlike the Working Time Directive, which puts doctors on a par with shelf stackers, the European Leisure Time Directive (ELTD) treats medicine as a special case. It also acknowledges that Britain is not like other countries, leisuewise.

Britain’s favourite relaxation is watching television drama. Nowadays this consists entirely of psychologically damaged people being aggressive to one another. As doctors spend much of their time listening to psychologically damaged people being aggressive, soap operas—particularly *EastEnders*—will not count as medical leisure activity (MLA) under European law.

The country’s second leisure activity is eating out. This raises problems of definition as working meals become more common. The ELTD requires the buffet to be weighed before and after a meal and the difference divided by the number of doctors present. A working breakfast is defined as up to 75g of croissant, 100g of muesli or 50g of yoghurt per head.

Our third relaxation is sport. The gym is classed as MLA although it involves more calorific output than work. Boxing and taekwondo are acceptable MLA for geriatricians but not for casualty officers, for whom they are normal working activities. Coarse fishing involves sitting around for long periods staring into space and waiting for the chance to do something, so it does not count as MLA for NHS surgeons in winter.

Fourth is complaining about the state of the NHS. The ELTD recognises reality and allows this as leisure activity for doctors as for everyone else.

James Owen Drife *professor of obstetrics and gynaecology, Leeds*