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NICE guidelines pave the way forward for patients and doctors

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The uncertainty inherent in making a diagnosis of chronic fatigue syndrome (CFS) is reflected by the variety of names (such as myalgic encephalomyelitis; ME) it has been given. The names reflect the hope that such labels can impose some certainty where little exists. Many doctors are reluctant to make a diagnosis of CFS, with half not even believing it exists.¹ The consequences of this uncertainty and reluctance

have been that patients hear mixed messages and often receive poor, if any, care.² It is therefore a welcome relief that the National Institute for Health and Clinical Excellence (NICE) has just published clinical guidelines on the diagnosis and management of this disease.³ In this week's *BMJ*, Baker and Shaw summarise the guidelines.⁴

How has the development of these guidelines

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Competing interests: PDW and MM work with a colleague who was a member of the guideline development group (GDG). PDW does consultancy work for the Department for Work and Pensions and Swiss Re, a re-insurance company. AYME's medical adviser was a member of the GDG.

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come about? Eleven years ago, three UK royal colleges agreed that CFS/ME existed as an independent diagnosis and that treatments were possible.⁵ Unfortunately, this had little effect on the provision of services. In 2002, an independent report was endorsed by the chief medical officer for England, which recommended that services should be routinely provided.⁶ The government responded positively by providing three years of ring fenced central funds to set up and support specific CFS/ME services, albeit only in England and with insufficient funds to cover the country. Some 50 services were created or enhanced, but they faced two fundamental problems—how to make an accurate diagnosis of CFS/ME and how then to treat it?

NICE has now come up with some answers,^{3,4} based on a recent systematic review,⁷ as well as using formal consensus techniques where no evidence exists. The guideline development group included members of all relevant healthcare professions and three patient representatives. The draft guidelines were circulated to numerous stakeholders, who provided more than 2000 pages of comments that helped to shape the final guidelines.

What are the main messages for doctors? CFS/ME exists and effective treatments are available. We remain unsure of its causes, pathophysiology, or how to classify it, but there are many other remediable conditions of which this is also true. It serves no purpose to disbelieve the patient, who may be severely disabled as a consequence of the illness and handicapped by the lack of medical support or understanding.

The diagnosis is a clinical one—no diagnostic tests are currently available, but prolonged malaise or fatigue after exertion are characteristic features. It is important to exclude alternative and common diagnoses, such as endocrine diseases, sleep apnoea, and mood disorders. Controversy has previously centred around management, and it is here that the NICE guidelines are particularly helpful. It may surprise doctors that the guidelines emphasise the need to negotiate management programmes with the patient and not to coerce them into specific treatments, but some patients have reported that this occurs.⁶

In primary care, early management of symptoms, advice on activities and occupation, and criteria for specialist referral are emphasised. In specialist care, cognitive behaviour therapy and graded exercise therapy should be available, because these treatments show “the clearest research evidence of benefit,”³ and the guidelines include the principles and practice of both treatments. Sufficient evidence was not available to recommend such treatments for severely disabled people and children. Instead, the consensus view recommended a watered down version of activity management based on the principles of these treatments. Patient groups prefer the term graded activity, which incorporates the diversity of such management programmes. Specific advice regarding children and young people included earlier diagnosis, referral criteria, and both advice and liaison over education.

Will the guidelines be useful and can they be implemented? The answers are yes and why not? The guidelines may seem too obvious to be useful, but this view underestimates the previous disagreement about how to help patients. A survey conducted by a national patient charity reported that half of patients found graded exercise therapy harmful,⁸ although a later survey showed that this was related to inappropriate advice or lack of therapeutic support.⁹ This guidance should remove arguments about whether to provide a service and what such a service should include. The implementation requires primary care trusts to ensure local provision of services in the large areas of the United Kingdom where no service exists. Existing services should ensure that their provision is consistent with the guidelines. General practitioners should be confident in making a diagnosis, providing initial management and referral.

Two large UK Medical Research Council funded trials of rehabilitation currently under way—one of which includes pacing developed in collaboration with a patient group—will provide better information about the most cost effective treatments.^{10,11} The history of this field has been littered with miscommunications and misunderstandings. NICE has forged a remarkable consensus and created a unique opportunity for us all to work together to provide the right care for the right patients at the right time.

- 1 Thomas MA, Smith AP. Primary healthcare provision and chronic fatigue syndrome: a survey of patients' and general practitioners' beliefs. *BMC Fam Pract* 2005;6:49.
- 2 Deale A, Wessely S. Patients' perceptions of medical care in chronic fatigue syndrome. *Soc Sci Med* 2001;52:1859-64.
- 3 National Institute for Health and Clinical Excellence. Clinical guideline CG53. *Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management*. London, NICE, 2007. <http://guidance.nice.org.uk/CG53>.
- 4 Baker R, Shaw EJ. Diagnosis and management of chronic fatigue syndrome or myalgic encephalomyelitis (or encephalopathy): summary of NICE guidance. *BMJ* 2007 doi: 10.1136/bmj.39302.509005.AE.
- 5 Royal Colleges. *Chronic fatigue syndrome: report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners*. London: Royal College of Physicians, 1996. www.rcplondon.ac.uk/pubs/brochure.aspx?e=60.
- 6 CFS/ME Working Group. *A report of the CFS/ME working group: report to the chief medical officer of an independent working group*. London: Department of Health, 2002. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4064840.
- 7 Chambers D, Bagnall A-M, Hempel S, Forbes C. Interventions for the treatment, management and rehabilitation of patients with chronic fatigue syndrome/myalgic encephalomyelitis: an updated systematic review. *J R Soc Med* 2006;99:506-20.
- 8 Action for ME. *Severely neglected: ME in the UK, membership survey*. 2001. www.afme.org.uk/res/img/resources/Severely%20Neglected.pdf.
- 9 Action for ME. *All about ME: an introduction*. 2004. www.afme.org.uk/res/img/resources/All%20about%20ME.pdf.
- 10 Wearden AJ, Riste L, Dowrick C, Chew-Graham C, Bental RP, Morriss RK, et al. Fatigue intervention by nurses evaluation—the FINE trial. A randomised controlled trial of nurse led self-help treatment for patients in primary care with chronic fatigue syndrome: study protocol. *BMC Med* 2006;4:9.
- 11 White PD, Sharpe MC, Chalder T, DeCesare JC, Walwyn R; on behalf of the PACE trial group. Protocol for the PACE trial: a randomised controlled trial of adaptive pacing, cognitive behaviour therapy, and graded exercise, as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome/myalgic encephalomyelitis or encephalopathy. *BMC Neurol* 2007;7:6.