

Peter May reports on clashes between consumers and scientists

Chronic Fatigue Syndrome

A report to the Chief Medical Officer by an independent working party has considered best practice in managing Chronic Fatigue.¹ But the working party's conclusions caused six resignations from its committee. The four medical specialists who resigned constituted the majority of the expert medical members. The working party had used a 'trident' approach to evaluating the medical evidence: trying to find consensus from research findings, considered clinical opinion and patients' anecdotal stories.

What is in a name?

The report adopts the name CFS/ME as an interim title for the condition, while an international USA-based group is currently looking for a more acceptable title. The term 'fatigue', according to the report, provokes 'strong loathing' from sufferers, who do not consider it to be their main problem. Many consider it demeaning yet it is the *sine qua non* of the illness. 'Myalgic' is inappropriate, as muscle pain is not a significant feature for many patients. 'Encephalomyelitis', implying inflammation of the brain and spinal cord, is plainly incorrect. There is no evidence for it. An acceptable title would remove unnecessary conflict that is present at the beginning of the important doctor/patient relationship.

Approaches to management

The working party identified three successful approaches to modifying the condition that are offered on equal terms. These are Cognitive Behavioural Therapy (CBT), Graded Exercise Programmes and Pacing. There is now good documented trial evidence for the first two but none at all for the third.^{2,3} A number of clinicians advocate pacing as part of a 'common sense' approach to fatigue. Patients and patient self-help groups also advocate it strongly.

Cognitive Behavioural Therapy (CBT)

Evidence is accumulating that CBT helps most patients. The core components of this approach to CFS/ME include energy/activity management, establishing a sleep routine, goal setting and psychological support. Three out of four randomised, controlled trials found positive benefits. Few patients felt worse though only a few reported complete recovery. However, some patients refuse what they see to be a psychological treatment for what they perceive to be a physical illness. They need to be encouraged to take a holistic view of their illness, open to both physical and psychological interventions. The lack of general availability of CBT is a cause for concern.

Graded Exercise

Based on the belief that CFS/ME is maintained, though not caused, by inactivity, graded exercise seeks to offer a structured and supervised programme of gradual and increasing aerobic activities such as swimming or walking. This is initially based on the patient's current physical capacity. All three randomised controlled trials published so far have found varying degrees of improvement. Very few participants reported feeling worse, though patient surveys revealed more negative feedback for this than any other form of treatment, including drug treatments.

Pacing

The principles and practice of pacing are described in the 1994 task force report.⁴ While some clinicians advocate pacing within a framework of graded exercise, there lies within this approach an

internal contradiction. The theory behind pacing holds that the sufferer only has a certain amount of available energy (physical, mental and emotional) that is limited and finite. There is held to be a 'glass ceiling' that the patient cannot go beyond. Therefore, energy expenditure must be kept within budget throughout the day, maintaining a careful balance between expenditure and rest.

Critics maintain that if the patient is encouraged to believe that there is only so much energy available, there is no scope for increasing the amount of exercise. Bound by the conviction that their illness is essentially a physical condition, patients with strongly held beliefs about pacing are trapped into a lifestyle of persisting inactivity; this itself perpetuates the fatigue.

Inactivity is held by many clinicians to be a root cause of continued symptoms. Physical deconditioning has physiological consequences: muscle wasting, sleep disturbance, balance problems, autonomic dysfunction and loss of confidence may all result from it.

The Expert Patient?

Underlying the philosophy of the report is the view that patients should be encouraged to be experts in their own right and should become key decision makers in their own care.⁵ Patients' fixed beliefs, not open to evidence or discussion, are not addressed in the report. However worthy it is, the approach of regarding the patient as an expert clearly would have limited usefulness in various other conditions. Patients are not always in the best position to evaluate treatments objectively.

The report advocates the various ME self-help groups without drawing attention to the dangers of prejudice and fixed beliefs propagated by some of these organisations; not least in denying psychological factors, denigrating psychotropic medications and promoting a rigid view of pacing.⁶

Christians will welcome the working party's approach of getting alongside and listening to a group of patients who often feel alienated from orthodox medical care and is vulnerable to alternative therapists' claims. They will be less welcoming of recommendations that are not soundly based in objective evidence, are undergirded by a new 'political correctness' and may leave patients trapped in their illness by their own false perceptions.

Peter May is a General Practitioner in Southampton

References

1. CFS/ME Working Group. *Report to the Chief Medical Officer of an independent working group*. London: Department of Health, 2001 www.doh.gov.uk/cmof/cBound/bysmreport/index.htm.
2. Bagnall AM, Whiting P, Sowden A, Wright K. *Systematic review on the effectiveness of interventions used in the treatment and management of chronic fatigue syndrome/myalgic encephalomyelitis (ME) among adults and children*. University of York: The NHS Centre for Reviews and Dissemination, 2001 <http://www.york.ac.uk/inst/crd/cfs.htm>.
3. Whiting P, Bagnall AM, Sowden AJ, Cornell JE, Mulrow CD, Ramirez G. Interventions for the treatment and management of chronic fatigue syndrome. *JAMA* 2001; 286(11):1360-68.
4. *National Task Force on Chronic Fatigue Syndrome, Post Viral Fatigue Syndrome, Myalgic Encephalomyelitis*. Bristol: Westcare, 1994.
5. *The Expert Patient – A new approach to chronic disease management for the 21st Century*. London: Department of Health, 2001
6. CFS/ME Working Group. *Op cit*: section 4.3.2