

Bedfordshire and Hertfordshire Priorities Forum Statement

Number: 49
SUBJECT: Chronic Fatigue Syndrome/ Myalgic Encephalitis (CFS/ ME)
Date: September 2008
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Guidance

Treatment of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) in units out of the local area or for inpatient care is considered a low priority treatment and will only be provided in exceptional circumstances following involvement of appropriate local services.

Chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME) is now generally accepted as being a discrete disorder or spectrum of disorders. This condition may also be known as post-viral or post-infectious fatigue syndrome. Some believe that ME is separate from CFS, but little evidence currently exists to support this division.

CFS/ME is a debilitating disorder characterised by profound tiredness or fatigue. Patients may become exhausted with only light physical exertion. They most often function at a level of activity substantially lower than their capacity before the onset of illness. In addition to these key defining characteristics, patients generally report various non-specific symptoms, including weakness, muscle aches and pains, excessive sleep, malaise, fever, sore throat, tender lymph nodes, impaired memory and/or mental concentration, insomnia and depression.

The PCTs follow the NICE clinical guideline for the management of CFS¹. The majority of the treatment and care of people with CFS/ME should be undertaken by primary and community services, with referral through to local secondary care specialist services when appropriate. **There is an advantage to the management of patients in their local area – for the provision of domiciliary services as well as links to social services, schools and other support services.** The development of a local skilled multi-disciplinary team to support rehabilitation programmes and adjustment to the disease and disability is cost-effective in terms of reducing referrals to secondary care.

There is evidence of effectiveness from randomised controlled trials for cognitive behavioural therapy (CBT) and graded exercise therapy (GET). Guidance on the management of patients is provided in the latest clinical guideline from NICE¹. A summary of other treatments is summarised below which is taken from this guideline:

1. Cognitive behavioural therapy, graded exercise therapy, activity management – see NICE guideline.
2. Encouraging maintenance of activity levels at substantially less than full capacity to reserve energy for the body to heal itself (The 'envelope theory'), or encouraging complete rest (cognitive, physical and emotional) during a setback/ relapse – there is considerable support for these approaches among people with CFS/ME, particularly when symptoms are severe. There is no evidence of benefit from controlled trials.
3. Prolonged or complete rest or extended periods of daytime rest in response to a slight increase in symptoms, or an imposed rigid schedule of activity and rest – these strategies should not be used.
4. Pacing – People with CFS/ME have reported pacing to be helpful in self-management, but there is not enough research evidence on the benefits or harm of pacing.

5. Complementary therapies – Not recommended: there is not enough evidence they are effective.
6. Supplements such as vit B12, vit C, co-enzyme Q10, magnesium, NADH or multivitamins and minerals – Do not prescribe for symptoms, as there is not enough evidence they are effective. See further notes in guideline.

Priority: Clinicians should be aware of the NICE clinical guideline on the effective management of patients with CFS. Referrals to out of area units for CFS are considered a low priority, and will only be considered in exceptional circumstances, as effective management should be available locally. Treatments of unproven effectiveness will not normally be provided under the NHS.

REFERENCES:

1. Chronic fatigue syndrome / Myalgic encephalomyelitis (or encephalopathy); diagnosis and management. **CG53 August 2007. National Institute for Health and Clinical Excellence.**

The Human Rights Act has been considered in the development of this guidance