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Faculty of Occupational Medicine

NHS Plus

Occupational aspects of the management of chronic fatigue syndrome/myalgic encephalomyelitis: evidence-based guidance for healthcare professionals

INTRODUCTION

This leaflet summarises the findings of a review of the scientific evidence on the occupational aspects of the management of chronic fatigue syndrome (CFS*)/ myalgic encephalomyelitis (ME). It is intended for healthcare practitioners and summarises the current evidence on how to support individuals back into, and to remain in, work. The research base for the guidance is limited by a lack of primary research on work outcomes.

WHAT IS CFS/ME?

CFS/ME is an illness characterised by severe, disabling post-exertional fatigue and other symptoms, which may include poor concentration, sleep disturbance, headaches, and musculoskeletal pain. These symptoms need to have been present for at least six months, although a presumptive diagnosis may be made much earlier.

Most people with prolonged fatigue do not have CFS/ME and practitioners should refer to clinical diagnostic criteria. Importantly, practitioners should look to exclude other conditions that may cause fatigue, such as thyroid disorders, anaemia and coeliac disease. While the six month threshold may be important in confirming diagnosis, the possibility of CFS/ME should be considered much earlier so that appropriate management is not delayed unnecessarily.

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* *Occupational aspects of the management of chronic fatigue syndrome: a national guideline*. NHS Plus. London 2006.

WHAT CAUSES CFS/ME?

There are many uncertainties and controversies surrounding the cause of CFS/ME.

As with other chronic illnesses, some people with CFS/ME go on to suffer from depression and anxiety. Where these occur, they should also be treated. Most people who develop CFS/ME are previously healthy individuals with no significant medical or psychiatric history.

As CFS/ME is poorly understood, the definition encompasses a heterogeneous group of clinical presentations and not all patients will respond to the management strategies mentioned here.

PREVALENCE AND PROGNOSIS

Around 0.4% of the adult population is thought to have CFS/ME, with prevalence higher in women than in men. It tends to be more common in people of working age, particularly those in their 20s, 30s, and 40s. Around 40% of individuals improve over time. As with many other chronic illnesses, co-existing psychiatric symptoms reduces the chances of recovery.

MANAGEMENT STRATEGIES

Interventions should aim to address not just the biological aspects of CFS/ME but also the various psychological, social and occupational factors that may delay the recovery process. There are currently two interventions, CBT and GET, which have been the subject of trials, a third intervention, Pacing, is the subject of a continuing large randomised controlled trial (RCT).

COGNITIVE BEHAVIOURAL THERAPY (CBT)

Cognitive behavioural therapy (CBT) has been shown to be helpful in enabling some individuals in returning to work, but it is not always effective. CBT is a structured form of psychotherapy. The duration of treatment with CBT varies between individuals and is generally undertaken over a period of six to 12 months. CBT is used to assist people to cope with the emotional impact of a variety of illnesses, including cancer.

There is evidence on the effectiveness of CBT in assisting individuals in returning to work. One RCT found that the benefits of CBT persist, even after five years, with 25% of individuals regarding themselves as ‘cured’ after this time. It found that CBT was significantly more likely to lead to full recovery, with fewer relapses, than was a programme of relaxation. [A] It should also be noted that the research studies on CBT excluded those patients who were too ill to attend or to continue attending CBT sessions.

Not everyone responds well to CBT, however, and a number of factors may limit its effectiveness. CBT does not work well where the patient still shows signs of a current infection or where there was poor social and work functioning before becoming ill; where there are signs of low sense of control over the CFS/ME symptoms; passive activity patterns; excessive focus on bodily symptoms; and taking medical retirement or disability-related benefit during the treatment.

GRADED EXERCISE THERAPY (GET)

GET also involves carefully structured and gradually increasing activity. Patients 'negotiate' an aerobic exercise programme tailored to their physical capacity and are advised against exercising beyond what has been agreed. Activities can include walking, swimming and everyday tasks.

Although some RCTs show evidence of improved functional capacity for work and reduced fatigue, some patients experience a significant deterioration in symptoms with this intervention. Poor outcomes are predicted by co-existing depression. [A]

PACING

Pacing is a lifestyle programme that requires individuals to determine and manage their energy levels within an 'envelope' at which they can function without relapse. The aim is to gradually increase physical and mental activity within their limitations at the time. Patient feedback indicates that pacing is an acceptable and very helpful form of activity management. As with CBT and GET, pacing is essentially a coping strategy, pacing assumes that individuals can work towards recovery by careful management of their activity, while avoiding 'boom and bust' cycles. It requires individuals to be positive about their recovery but also to learn and recognise their limitations.

There is no research evidence available, but results of a large RCT are expected in 2009.

OTHER INTERVENTIONS

No pharmacological interventions for CFS/ME are supported by consistent evidence of efficacy. There is no evidence that prolonged rest ie many months in bed after the acute stage of the illness is a suitable treatment for CFS/ME; indeed, a systematic research review found that such prolonged rest following viral illness might actually perpetuate fatigue. Unstructured exercise is also unhelpful.

As with many other chronic illnesses concurrent psychiatric conditions, especially depression, may occur. Where present they should be identified and treated. [B]

PREDICTING WORK OUTCOMES

The following factors have been identified as predictors of poorer work outcomes in individuals with CFS/ME:

concurrent depression [B]

- current psychiatric diagnosis [C]
- older age [C]

higher number of physical complaints [C]

higher number of physical signs, such as lymphadenopathy [C]

ADVISING PATIENTS

Patients who are still working should be advised to stay at work provided that this does not aggravate their symptoms. Each patient should be treated as an individual case because of the difficult nature of this illness. Those returning to work should discuss with their employer - and preferably with an occupational health professional in consultation with their GP or other treating practitioner - how to gradually build up their working hours and workload over time. Patients should be advised against seeking early medical retirement until all appropriate management strategies have been discussed and agreed with their medical professional. [D]

Disability Discrimination Act

The Disability Discrimination Act 1995 gives an employee certain rights where an illness such as CFS/ME is likely to last for 12 months or more. This Act requires their employer to make reasonable adaptations to an employee's work in accordance with their disability.

Individuals with CFS/ME should be advised that they may experience relapses in their recovery but should try to focus on their longer-term improvement rather than any relapses.

PREVENTION

Patients recovering from a viral illness should be advised to avoid both prolonged resting and over-exertion once the acute illness has passed. Inappropriate advice given to patients in the early stages of fatigue may adversely affect their long-term outcome. [D]

FUTURE DEVELOPMENTS

The Medical Research Council is funding two large-scale trials on the management of CFS/ME.

GRADING SYSTEM FOR RECOMMENDATIONS

[A] At least one high-quality meta-analysis, systematic review or RCT directly applicable to the target population or a body of high-quality evidence demonstrating overall consistency of results.

[B] A body of evidence including good-quality studies directly applicable to the target population and demonstrating overall consistency of results.

[C] A body of evidence including reasonable quality studies directly applicable to the target population and demonstrating overall consistency of results.

[D] Evidence from non-analytical studies or expert opinion.

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