Nursing Practice

5 minute briefing

Chronic fatigue syndrome/ME

Managing CFS/ME promptly reduces the possibility of lasting impairment and disability

How to care for patients with chronic fatigue syndrome/ME

Patients with chronic fatigue syndrome/ME have both physical and cognitive symptoms. They may demonstrate signs of exhaustion and fatigue (even after minimal exertion); disturbed sleep; temperature disturbances; headaches; nausea; muscle/joint pain and stiffness; and sore, swollen throat. Cognitive symptoms include an inability to concentrate, understand or retain information, and difficulty with problem solving. CFS/ME is often under or misdiagnosed, resulting in patients’ referral to other specialties for investigation.

There is no diagnostic test for CFS/ME and no known cure. Management centres on balancing gentle activity, exercise and relaxation with the recognition of individual signs of overexertion. Patients need to understand their patterns of activity, recognise when they may be in a cycle of overactivity and learn to spot early warning signs of fatigue to avoid further overexertion.

Simple symptom control, such as pain relief and gentle exercise, can be beneficial. Individual patients must be helped to find their own baseline level of activity. They should be encouraged to gradually increase activity, reviewing their health as their rehabilitation progresses.

Rehabilitation is more likely to be successful if patients work toward a specific goal. Sharing patient success stories can also help. Patients can feel isolated and have difficulties in other areas of their lives so may need specialist help from CFS/ME charities, Welfare Rights or Citizen’s Advice Bureaux.

Those who are mildly affected can be managed in primary care, whereas those who are moderately or severely affected may benefit from specialist referral. Diagnosis can be made within four to six months of symptom onset; prompt management will increase the likelihood of successful rehabilitation and reduce the possibility of long-term impairment and disability.

Amanda McGough is specialist nurse chronic fatigue syndrome/ME, South Tees Hospitals Foundation Trust

5 key points

1. Diagnosis is based on clinical history, physical examination and routine blood screening to exclude any other causes of fatigue
2. Patients should be given simple information on the illness and symptom management so they understand how to recognise signs of physical and mental fatigue
3. An individualised management plan with a clear rehabilitation goal should be used to manage activity
4. Patients should be encouraged to become responsible for their own management plan
5. Patients should be given a copy of the management plan to help with memory recall and to develop their confidence in health management and wellbeing

When to contact the nurse specialist

- If you are unsure about a patient’s suitability for rehabilitation and/or referral to a specialist team
- If there are other health issues affecting the patient, for example co-existing illnesses, mental health issues, alcohol misuse or obesity
- If the patient’s health has changed or deteriorated and/or rehabilitation has slowed or ceased
- If further advice is needed on symptom management or activity management
- Upon discharge or transfer to community services to ensure patients’ records and management plan are up to date and the patient knows how to seek further advice if needed

Guidance and resources

- The NHS Choices website has a helpful guide to understanding the condition, with video clips of patients talking about living with chronic fatigue syndrome/ME. Go to www.nhs.uk and click on Health A-Z
- Action for ME provides help, advice and support for professionals and patients dealing with CFS/ME. www.afme.org.uk
- Fighting Fatigue is a practical guide written by the Leeds CFS/ME team and a patient with CFS/ME, for understanding the condition, its impact and help with symptom management
- The National Institute for Health and Clinical Excellence provides recommendations on diagnosis and long-term management of CFS/ME. www.nice.org/CG053