

SCOPE

1 Guideline title

Chronic fatigue syndrome/myalgic encephalomyelitis: diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis in adults and children.

1.1 Short title

CFS/ME: diagnosis and management

2 Background

- a) The National Institute for Clinical Excellence ('NICE' or 'the Institute') has commissioned the National Collaborating Centre for Primary Care to develop a clinical guideline on CFS/ME for use in the NHS in England and Wales. This follows referral of the topic by the Department of Health and Welsh Assembly Government (see Appendix). The guideline will provide recommendations for good practice that are based on the best available evidence of clinical and cost effectiveness.
- b) The Institute's clinical guidelines will support the implementation of National Service Frameworks (NSFs) in those aspects of care where a Framework has been published. The statements in each NSF reflect the evidence that was used at the time the Framework was prepared. The clinical guidelines and technology appraisals published by the Institute after an NSF has been issued will have the effect of updating the Framework.

3 Clinical need for the guideline

- a) CFS/ME is a relatively common illness that places a substantial burden on patients, carers and families, and hence on society. It comprises a range of pervasive symptoms including fatigue, malaise, headaches,

sleep disturbances, difficulties with concentration and muscle pain. The defining characteristic is debilitating fatigue quite unlike everyday fatigue, and often triggered by minimal activity.

- b) Overall, the evidence suggests a population prevalence of at least 0.2%–0.4%, which means that a general practice with a population of 10,000 patients is likely to have at least 20–40 patients with CFS/ME, half of whom will need input from specialist services. There is a lack of epidemiological data about incidence and prevalence which means that population estimates are based on extrapolations of results from other populations. The estimated annual prevalence is approximately 4,000 cases per million of the population.
- c) CFS/ME, like other chronic illnesses with no certain disease process, poses real problems for healthcare professionals. CFS/ME can cause profound, prolonged illness and disability, which has a substantial impact on the individual and their family. Uncertainties about diagnosis and management, and lack of clinical guidance to health professionals exacerbate this impact.

In 1998, the Chief Medical Officer convened an Independent Working Group which reported in 2002. In the report, the Working Group acknowledged that CFS/ME is a chronic illness and that health and social care professionals should recognise it as such. As a result of the report, the Medical Research Council was commissioned to develop a research strategy, and has made research on CFS/ME a priority.

4 The guideline

- a) The guideline development process is described in detail in two publications which are available from the NICE website (see 'Further information'). *The Guideline Development Process – An Overview for Stakeholders, the Public and the NHS* describes how organisations can become involved in the development of a guideline. *Guideline Development Methods – Information for National Collaborating Centres*

and Guideline Developers provides advice on the technical aspects of guideline development.

- b) This document is the scope. It defines exactly what this guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health and Welsh Assembly Government (see Appendix).
- c) The areas that will be addressed by the guideline are described in the following sections.

4.1 Population

4.1.1 Groups that will be covered

- a) The guideline will address the diagnosis, treatment and management of CFS/ME in children aged 5 years and upwards (including young people in transition to adulthood) who are mildly, moderately or severely affected by the condition.
- b) The guideline will address the diagnosis, treatment and management of CFS/ME in adults who are mildly, moderately or severely affected by the condition.

4.1.2 Groups that will not be covered

- a) The treatment and management of people for whom CFS/ME has been excluded as a diagnosis.

4.2 Healthcare setting

- a) The guideline will cover the care provided by healthcare professionals who have direct contact with, and make decisions concerning, the care of people with CFS/ME.
- b) The guideline will address care in primary and secondary centres, but will not address the delivery of tertiary procedures.
- c) The guideline will also be relevant to the work, but will not cover the practice, of those working in:

- occupational health services
- social services
- educational services
- the voluntary sector
- the Department for Work and Pensions
- the Driver and Vehicle Licensing Agency

4.3 Clinical management

- a) The guideline will cover the clinical management of patients given a diagnosis of myalgic encephalomyelitis and/or chronic fatigue syndrome.
- b) As the management of CFS/ME depends on an accurate diagnosis, the guideline will include recommendations about the process of assessment leading to a diagnosis.
- c) The recommendations will also cover the interventions where good evidence is available. These will include:
 - graded activity
 - complementary therapies
 - rehabilitation strategies
 - psychological therapies.
- d) The guideline will include recommendations on:
 - on symptom management
 - criteria for referral to secondary and tertiary care for children, young people and adults

- issues relating to self-care, adjustment, support and self-medication, including, where evidence exists of effectiveness, different approaches for different age, ethnic and cultural groups
- information needs of healthcare professionals, patients and carers.

e) The guideline will not address service provision or models of care.

4.4 Status

4.4.1 Scope

This is the first draft of the scope.

4.4.2 Guideline

The development of the guideline recommendations will begin in early 2005.

5 Further information

Information on the guideline development process is provided in:

- *The Guideline Development Process – An overview for Stakeholders, the public and the NHS*
- *Guideline Development Methods – Information for National Collaborating Centres and Guideline Developers*

These booklets are available as PDF files from the NICE website (www.nice.org.uk). Information on the progress of the guideline will also be available from the website.

Appendix – Referral from the Department of Health and the Welsh Assembly Government

The Department of Health and Welsh Assembly Government asked the Institute:

Title: Clinical guideline for the investigation and management of chronic fatigue syndrome

Remit: 'To prepare for the NHS in England and Wales, guidance on the assessment, diagnosis, management of adjustment and coping, symptom management, and the use of rehabilitation strategies geared towards optimising functioning and achieving greater independence for adults and children of CFS/ME.'