

NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE

SCOPE

1 Guideline title

Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy):
diagnosis and management of chronic fatigue syndrome/myalgic
encephalomyelitis (or encephalopathy) 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 chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) (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.
- c) NICE clinical guidelines support the role of healthcare professionals in providing care in partnership with patients, taking account of their

individual needs and preferences, and ensuring that patients (and their carers and families, where appropriate) can make informed decisions about their care and treatment.

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. Symptoms may fluctuate in intensity and severity. It is characterised by debilitating fatigue that is unlike everyday fatigue and can be triggered by minimal activity. It raises especially complex issues in severely affected children and adults.
- 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. However, there is a lack of epidemiological data for the UK, which means that population estimates are based on extrapolations from other countries. 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 patients and their families. Uncertainties about diagnosis and management, and lack of clinical guidance for health professionals exacerbate this impact.
- d) 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.

- c) Where good evidence exists, the guideline will make recommendations on different approaches to management for different groups of patients (for example, according to age, gender, ethnicity, or severity or duration of symptoms).

4.1.2 Groups that will not be covered

- a) The guideline will not address the 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 about, the care of people with CFS/ME.
- b) The guideline will address care provided in primary and secondary care and in specialist centres/teams.
- 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.

4.3 Clinical management

- a) The guideline will cover the clinical management of patients given a diagnosis of myalgic encephalomyelitis (or encephalopathy) and/or chronic fatigue syndrome.
- b) As the management of CFS/ME depends on a correct diagnosis, the guideline will include recommendations about the process of assessment leading to a diagnosis. This will include:

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- clinical case definition
 - appropriate timing for diagnosis
 - the appropriate use of laboratory tests, imaging or other tests.
- c) The guideline will address the following types of intervention, including, where good evidence exists, different approaches applicable to different groups (for example, according to age, gender, ethnicity, or the severity or duration of symptoms), and respecting the patient's (and where appropriate carer's) views:
- symptom-management strategies
 - rehabilitation strategies
 - support for patients and carers.
- d) Specific interventions covered by the guideline will include:
- self-care strategies
 - return to education and/or employment
 - pharmacological therapies
 - physical therapies (including graded exercise therapy)
 - life-style management (including pacing, graded activity)
 - psychological therapies (including cognitive behaviour therapy)
 - nutrition
 - complementary therapies.

- e) The guideline will make recommendations on:
- criteria for referral to appropriate specialist services for children, young people and adults
 - the provision of advice by healthcare professionals on home tuition or return to school
 - the provision of advice by healthcare professionals on return to work
 - information needs of healthcare professionals, patients and carers and other professions involved in care.
- f) The guideline will not address:
- the management of co-morbidities
 - highly specialised procedures and procedures that are pilot/exploratory studies
 - service provision or models of care.

4.4 Status

4.4.1 Scope

This is the final draft of the scope.

4.4.2 Guideline

The development of the guideline recommendations will begin in March 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*

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- *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.'