



Management: NICE Guidelines

Richard Baker



Improving care

- Care in the past has been patchy
- Too often, it has failed to meet patients' expectations and needs
- A new guideline:
 - Recognition of the importance of CFS/ME
 - For the first time, national recommendations health professionals are expected to take fully into account
 - A message for commissioners



Scope

- Set out by NICE before the guideline group is set up
- ‘The diagnosis, treatment and management of CFS/ME in children aged 5 years and upwards (including young people in transition to adulthood) and adults who are mildly, moderately or severely affected.’



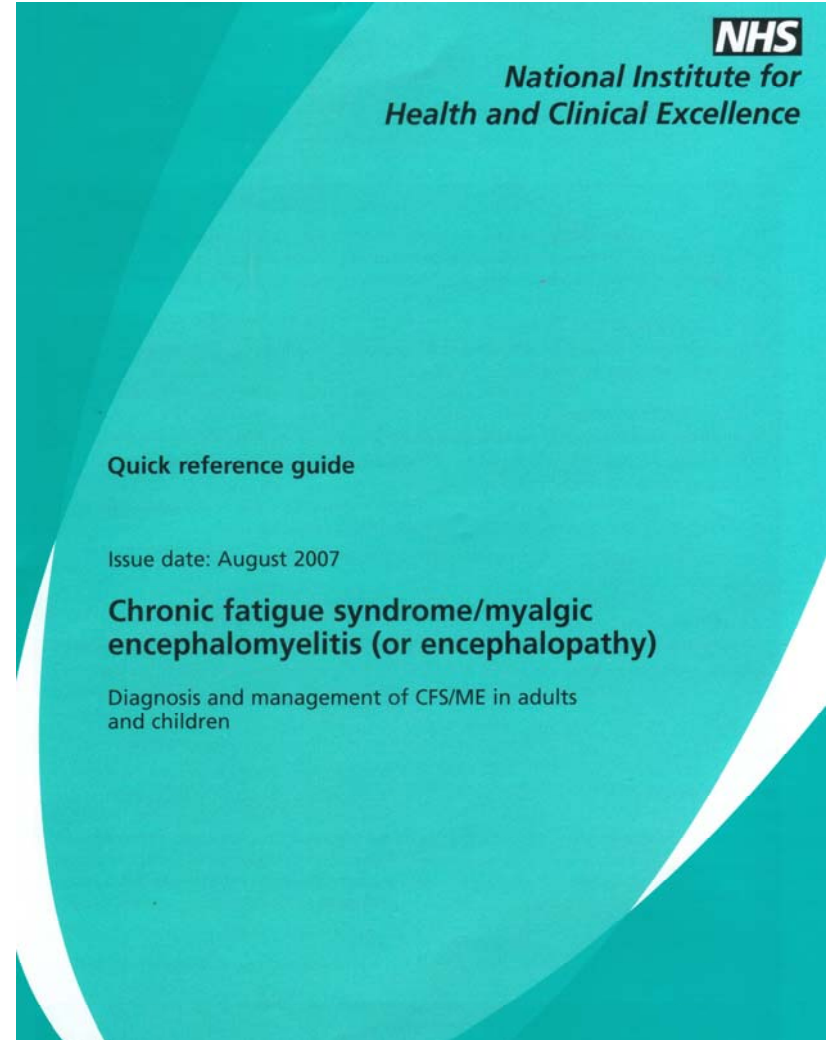
The guideline group

- 18 members
- 3 patient representatives
- Professionals – GPs, paediatricians, neurologist, psychologist, occupational health physician, infectious disease physician, physiotherapist, psychiatrist, nurse, occupational therapist, dietician, immunologist



Methods

- Evidence review
- Stakeholder evidence
- Health economist
- Consensus exercise





Accounting for different views

- Consensus rating of statements by the guideline group twice
- Consensus ratings by wider group (219 people - 119 patients, 29 carers)
- Consultation on draft guideline (many comments received)

Presentation, diagnosis and pathway of care

CFS/ME is recognised on clinical grounds alone. Primary healthcare professionals should be able to identify the characteristic features of CFS/ME.

Person presents with symptoms that may indicate CFS/ME (see box 1)

Do an initial assessment

- Take a full history (including exacerbating and alleviating factors, sleep disturbance, intercurrent stressors).
- Examine the person.
- Assess their psychological wellbeing.

Arrange investigations

- Investigate symptoms listed in box 2 before attributing them to CFS/ME.
- Consider other investigations according to symptoms (see box 3, page 8).

Manage symptoms

- Give tailored advice on managing symptoms, aiming to minimise their impact on daily life.
- Do not delay advice until diagnosis.

- If the person has severe CFS/ME symptoms, offer referral immediately.

Reassess and seek advice

- If symptoms of an apparently self-limiting condition do not resolve, listen to the concerns of the person and their family and/or carers and reassess.
- If CFS/ME or another serious condition is possible, discuss with a specialist any uncertainty about the interpretation of signs and symptoms, and the need for referral.

Refer

- Refer a child or young person to a paediatrician for assessment (as in boxes 2 and 3) within 6 weeks of presentation.

Follow general principles of care (see page 9)

Start general management (see page 11)

Plan for and manage setbacks/relapses (see page 15)

Arrange regular review (see page 16)

Make the diagnosis

- In adults: if symptoms have lasted 4 months and other diagnoses have been excluded.
- In children and young people: if symptoms have lasted 3 months and other diagnoses have been excluded; diagnosis is made or confirmed by a paediatrician.
- Reconsider if none of the features in box 4 (page 8) are present.

Consider referral to specialist CFS/ME care

- Offer referral:
 - within 6 months of presentation to people with mild CFS/ME
 - within 3–4 months of presentation to people with moderate CFS/ME symptoms.
- Make any decision to refer jointly with the person, depending on their symptoms and any comorbidities.
- Continue primary care involvement after referral.

Specialist CFS/ME care (see pages 17–20)



Three key elements

- General principles
- General management
- Specialist care



General principles

- Shared decision making
- The person is in charge of the overall aims of the plan, and mutually agrees pace of progression through any intervention



Key priorities 1

- Shared decision-making between the person with CFS/ME and health care professionals should take place during diagnosis and all phases of care.
 - Acknowledge reality & impact, provide information (interventions, management, causes, course, returning to work/education, local & national self-help and support groups)
 - Take account of age, severity, preferences and outcomes of previous treatments



General principles

- Establish a supportive relationship
- Suit care to the individual e.g. domiciliary services, email
- Provide information about the benefits and risks of management strategies
- Information in a variety of formats, on:
 - Possible causes, nature & course, returning to work/education, self-help & support groups



General principles

- The professional should have appropriate expertise
- An individualised management plan developed with the patient
- Review the plan at each contact



Key priorities 9

- An individualised, person-centred programme should be offered to people with CFS/ME. The objectives of the programme should be to
 - Sustain or gradually extend, if possible, the person's physical, emotional and cognitive capacity
 - Manage the physical and emotional impact of their symptoms



General management

- Don't delay symptom management until firm diagnosis
- Manage symptoms as in usual practice
- Paediatrician assessment of children
- Advice on
 - sleep management
 - diet
 - rest periods



General management

- Relaxation techniques
- Prolonged bed rest
- Fitness for work or education



General management

- Do not
 - Advise unstructured vigorous exercise
 - Management programmes by inexperienced practitioners
 - Certain drugs
 - MAOIs
 - gluco/mineralocorticoids
 - dexamphetamine
 - thyroxine



General management

Managing setbacks/relapses

- Advice that setbacks/relapses are to be expected, and develop a plan
- If possible, identify causes, manage triggers in the future
- Review management plan
- Additional strategies
- Gradual return to previous level, when possible



Specialist care

- Confirm diagnosis & continue the helpful general management strategies
- Individualised, person-centred programme
- Offer CBT and/or GET to mild or moderately affected
- Components of CBT and/or GET with activity management and relaxation techniques



Key priorities 10

- Cognitive behavioural therapy and/or graded exercise therapy should be offered to people with mild or moderate CFS/ME and provided to those who choose these approaches, because currently these are the interventions for which there is the clearest research evidence of benefit.



The severely affected

- Refer for specialist expertise
- A record of every consultation
- Coordination of care by a specific professional
- Explain risks of prolonged bed rest
- Equipment to maintain independence
- Tailored activity management programme
- Review regularly



Research recommendations

- Strategies for the severely affected
- Cost-effective delivery e.g. domiciliary care
- Measuring outcome in research studies



The goal

- Access to services delivered by skilled professionals, with patients driving decision-making