

# Chronic fatigue syndrome myalgic encephalomyelitis overview

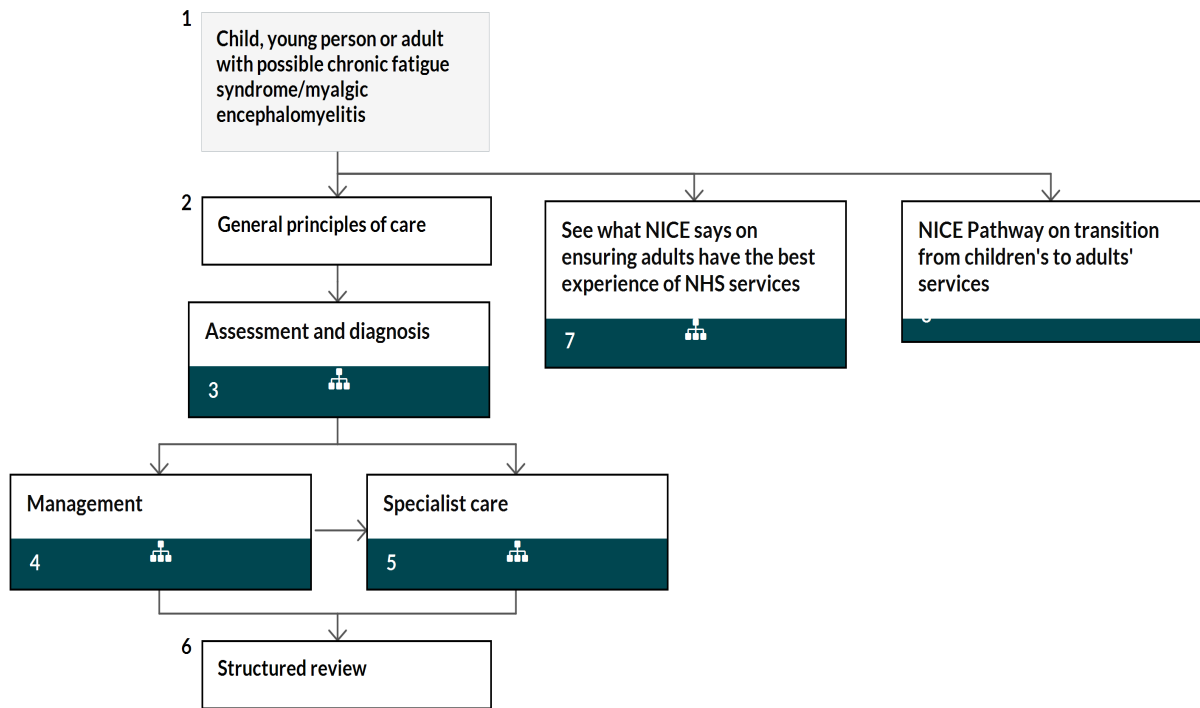
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

<http://pathways.nice.org.uk/pathways/chronic-fatigue-syndrome-myalgic-encephalomyelitis>

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This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



## 1 Child, young person or adult with possible chronic fatigue syndrome/ myalgic encephalomyelitis

No additional information

## 2 Principles of care

### Shared decision-making

Shared decision-making should take place during diagnosis and all phases of care.

- Acknowledge the reality and impact of the condition and the symptoms.
- Provide information about the range of interventions and management strategies as detailed in this interactive flowchart (such as the benefits, risks and likely side effects).
- Provide information on the possible causes, nature and course of CFS/ME.
- Provide information on returning to work or education.
- Take account of the person's age (particularly for children younger than 12 years), the [severity \[See page 8\]](#) of their CFS/ME, their preferences and experiences, and the outcome of previous treatment(s).
- Offer information about local and national self-help groups and support groups for people with CFS/ME and their carers (see also the [NHS Expert Patients Programme](#) or [Education Programme for Patients Wales](#)).

When providing care for children and young people, follow best practice as described in the [national service frameworks for children for England](#) or [for Wales](#).

Be aware that – like all people receiving care in the NHS – people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting other aspects of their care, or future choices about care.

Recognise that the person with CFS/ME is in charge of the aims and goals of the overall management plan. The pace of progression throughout the course of any intervention should be mutually agreed.

Provide diagnostic and therapeutic options to people with CFS/ME in ways that are suitable for the individual person. This may include providing domiciliary services (including specialist assessment) or using methods such as telephone or email.

## Support and information

To facilitate effective management of the condition, aim to establish a supportive and collaborative relationship with the person with CFS/ME and their carers. Engagement with the family is particularly important for children and young people, and for people with severe CFS/ME.

A named healthcare professional should be responsible for coordinating care for each person with CFS/ME.

Provide accurate information to people at all stages of CFS/ME, starting from when a diagnosis is first being considered. This should be tailored to the person's circumstances, including the stage and duration of the condition, symptoms experienced and relevant personal and social factors.

Provide information in a variety of formats if appropriate (printed copy, electronic and audio), which people with CFS/ME and their carers can refer to at home and in the clinical setting.

NICE has written information for the public on [chronic fatigue syndrome/myalgic encephalomyelitis](#).

## Provision of care

Healthcare professionals responsible for caring for people with CFS/ME should have appropriate skills and expertise in the condition.

Offer every person diagnosed with CFS/ME:

- information about the illness (see support and information)
- acceptance and understanding
- assistance negotiating the healthcare, benefits and social care systems
- assistance with occupational activities including work and education if appropriate (see [education and employment](#)).

Develop an individualised management plan with the person with CFS/ME, and their carers if appropriate. Review and document changes to the plan at each contact. Include:

- relevant symptoms and history
- plans for care and treatment, including managing setbacks/relapses (see [plan for and manage setbacks and relapses](#))
- information and support needs

- any education, training or employment support needs
- details of the healthcare professionals involved in care and their contact details.

See what NICE says on [transition from children's to adults' services](#).

### People with severe CFS/ME

Management of severe CFS/ME is difficult and complex and healthcare professionals should recognise that specialist expertise is needed when planning and providing care for people with severe CFS/ME.

Diagnosis, investigations, management and follow-up care for people with severe CFS/ME should be supervised or supported by a specialist in CFS/ME.

People with severe CFS/ME may need to use community services at times. These services may include nursing, occupational therapy, dietetics, respite care, psychology and physiotherapy (see the 'National service framework for long-term conditions'). The input of different professionals should be coordinated by a named professional.

Offer people with severe CFS/ME a summary record of every consultation because of their cognitive difficulties.

Most people with CFS/ME will not need hospital admission. However, there may be circumstances when a planned admission should be considered. The decision to admit should be made with the person with CFS/ME and their family, and be based on an informed consideration of the benefits and disadvantages. For example, a planned admission may be useful if assessment of a management plan and investigations would require frequent visits to the hospital.

For information on prolonged bed rest for people with severe CFS/ME, see [sleep, rest and relaxation](#). For information on activity management programmes for people with severe CFS/ME, see [activity management in specialist care](#).

## 3 Assessment and diagnosis

See [Chronic fatigue syndrome myalgic encephalomyelitis / Assessment and diagnosis of chronic fatigue syndrome myalgic encephalomyelitis](#)

## 4 Management

[See Chronic fatigue syndrome myalgic encephalomyelitis / Management of chronic fatigue syndrome myalgic encephalomyelitis](#)

## 5 Specialist care

[See Chronic fatigue syndrome myalgic encephalomyelitis / Specialist care for chronic fatigue syndrome myalgic encephalomyelitis](#)

## 6 Structured review

Undertake regular, structured review for all people with CFS/ME. If appropriate, include:

- Assessing improvement or deterioration in symptoms.
- Assessing any adverse or unwanted effects of therapy.
- Ongoing investigations.
- Considering the need to repeat investigations (for children and young people, repeating investigations should be considered if there is no improvement after 1 year).
- Reviewing the diagnosis, especially if signs and symptoms change (see [symptoms that may indicate CFS/ME](#)).
- Considering referral to specialist CFS/ME care.
- Reviewing equipment needs.
- Assessing any additional support needs (see general principles of care and the [management of CFS/ME](#)).

The timing of the reviews should depend on the severity and complexity of symptoms, the effectiveness of any interventions, and the needs of the person with CFS/ME.

## 7 See what NICE says on ensuring adults have the best experience of NHS services

[See Patient experience in adult NHS services](#)

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**8 NICE Pathway on transition from children's to adults' services**

[See Transition from children's to adults' services](#)

The degree to which CFS/ME affects a person's functioning and daily life.

- People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.
- People with moderate CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.
- People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise.

## Glossary

### CFS/ME

(chronic fatigue syndrome/myalgic encephalomyelitis)

### Stage

(there are different stages in the natural course of CFS/ME: acute illness, maintenance or stabilisation, and recovery)

## Sources

[Chronic fatigue syndrome/myalgic encephalomyelitis \(or encephalopathy\): diagnosis and management](#) (2007) NICE guideline CG53

## Your responsibility

### Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful



consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

## Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of

implementing NICE recommendations wherever possible.

### **Medical technologies guidance, diagnostics guidance and interventional procedures guidance**

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.