

Assessment and diagnosis of chronic fatigue syndrome myalgic encephalomyelitis

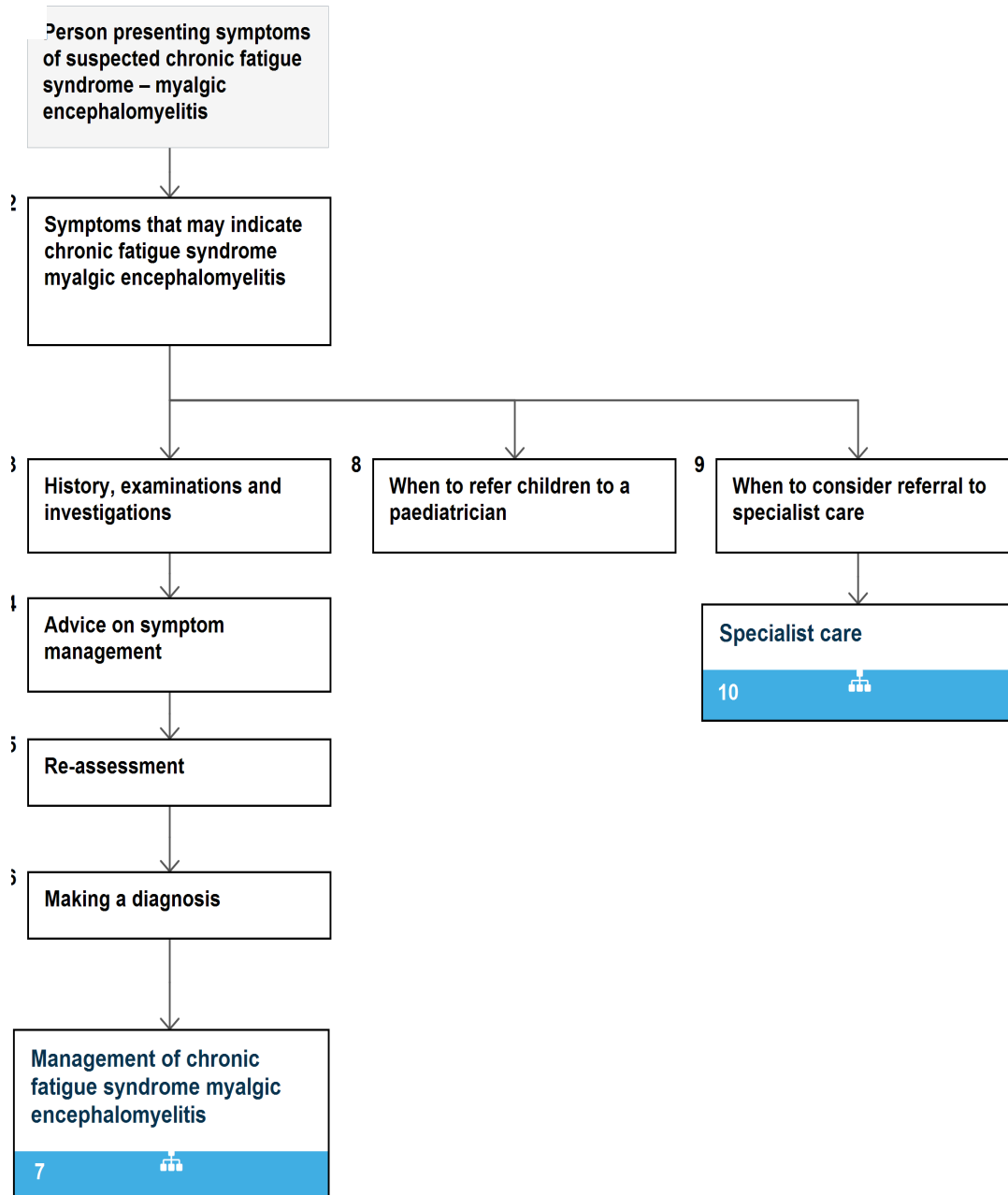
A NICE pathway brings together all NICE guidance, quality standards and materials to support implementation on a specific topic area. The pathways are interactive and designed to be used online. This pdf version gives you a single pathway diagram and uses numbering to link the boxes in the diagram to the associated recommendations.

To view the online version of this pathway visit:

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

Pathway last updated: 27 July 2015. To see details of any updates to this pathway since its launch, visit: [About this Pathway](#). For information on the NICE guidance used to create this path, see: [Sources](#).

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1 Person presenting symptoms of suspected chronic fatigue syndrome – myalgic encephalomyelitis

No additional information

2 Symptoms that may indicate chronic fatigue syndrome myalgic encephalomyelitis

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

Consider the possibility of CFS/ME if a person has:

- fatigue with all of the following features:
 - new or had a specific onset (that is, it is not lifelong)
 - persistent and/or recurrent
 - unexplained by other conditions
 - has resulted in a substantial reduction in activity level
 - characterised by post-exertional malaise and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over several days)

and

- one or more of the following symptoms:
 - difficulty with sleeping, such as insomnia, hypersomnia, unrefreshing sleep, a disturbed sleep-wake cycle
 - muscle and/or joint pain that is multi-site and without evidence of inflammation
 - headaches
 - painful lymph nodes without pathological enlargement
 - sore throat
 - cognitive dysfunction, such as difficulty thinking, inability to concentrate, impairment of short-term memory, and difficulties with word-finding, planning/organising thoughts and information processing
 - physical or mental exertion makes symptoms worse
 - general malaise or 'flu-like' symptoms
 - dizziness and/or nausea

- palpitations in the absence of identified cardiac pathology.

Be aware that the symptoms of CFS/ME fluctuate in severity and may change in nature over time.

Signs and symptoms that can be caused by other serious conditions ('red flags') should not be attributed to CFS/ME without consideration of alternative diagnoses or comorbidities. In particular, investigate the following features:

- localising/focal neurological signs
- signs and symptoms of inflammatory arthritis or connective tissue disease
- signs and symptoms of cardiorespiratory disease
- significant weight loss
- sleep apnoea
- clinically significant lymphadenopathy.

See also the NICE pathway on [suspected cancer recognition and referral](#).

3 History, examinations and investigations

Take a full history (including exacerbating and alleviating factors, sleep disturbance and intercurrent stressors), and carry out a physical examination and assessment of psychological wellbeing.

The following tests should usually be done:

- urinalysis for protein, blood and glucose
- full blood count
- urea and electrolytes
- liver function
- thyroid function
- erythrocyte sedimentation rate or plasma viscosity
- C-reactive protein
- random blood glucose
- serum creatinine
- screening blood tests for gluten sensitivity
- serum calcium

- creatine kinase
- assessment of serum ferritin levels (children and young people only).

Use clinical judgement when deciding on additional investigations to exclude other diagnoses.

Tests for serum ferritin in adults should not be carried out unless a full blood count and other haematological indices suggest iron deficiency.

Tests for vitamin B12 deficiency and folate levels should not be carried out unless a full blood count and mean cell volume show a macrocytosis.

Tests that should not be performed routinely

The following tests should not be done routinely to aid diagnosis:

- the head-up tilt test
- auditory brainstem responses
- electrodermal conductivity.

Serological testing should not be carried out unless the history is indicative of an infection.

Depending on the history, tests for the following infections may be appropriate:

- chronic bacterial infections, such as borreliosis
- chronic viral infections, such as HIV or hepatitis B or C
- acute viral infections, such as infectious mononucleosis (use heterophile antibody tests)
- latent infections, such as toxoplasmosis, Epstein-Barr virus or cytomegalovirus.

4 Advice on symptom management

Advice on symptom management should not be delayed until a diagnosis is established. Tailor this advice to the specific symptoms the person has, and aim to minimise the impact on daily life and activities.

5 Re-assessment

If symptoms do not resolve as expected in a person initially suspected of having a self-limiting condition, primary healthcare professionals should listen carefully to the person's and their family and/or carers' concerns and be prepared to reassess the initial opinion.

If considering the possibility of CFS/ME or another serious alternative condition, consider discussion with a specialist if there is uncertainty about the interpretation of signs and symptoms and whether a referral is needed. This may also enable the primary healthcare professional to communicate their concerns and a sense of urgency to secondary healthcare professionals if symptoms are unusual .

6 Making a diagnosis

Make a diagnosis after other possible diagnoses have been excluded and the symptoms have persisted for:

- 4 months in an adult
- 3 months in a child or young person; the diagnosis should be made or confirmed by a paediatrician.

When a diagnosis of CFS/ME is made, provide honest, realistic information about CFS/ME and encourage cautious optimism.

- Most people with CFS/ME will improve over time and some people will recover and be able to resume work and normal activities.
- However, others will continue to experience symptoms or relapse and some people with severe CFS/ME may remain housebound.
- The prognosis in children and young people is more optimistic.

Reconsider the diagnosis of CFS/ME if none of the following key features are present:

- post-exertional fatigue or malaise
- cognitive difficulties
- sleep disturbance
- chronic pain.

7 Management of chronic fatigue syndrome myalgic encephalomyelitis

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

8 When to refer children to a paediatrician

Refer a child or young person who has symptoms suggestive of CFS/ME to a paediatrician for assessment to exclude other diagnoses within 6 weeks of presentation.

9 When to consider referral to specialist care

Base any decision to refer a person to specialist CFS/ME care on their needs, the type, duration, complexity and severity of their symptoms, and the presence of comorbidities. Make the decision jointly with the person with CFS/ME.

Referral to specialist CFS/ME care should be offered:

- within 6 months of presentation to people with mild CFS/ME
- within 3-4 months of presentation to people with moderate CFS/ME symptoms
- immediately to people with severe CFS/ME symptoms.

10 Specialist care

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

Glossary

Activity

Any task or series of tasks that a person performs. A task may have physical, emotional, cognitive and social components.

Activity management

A person-centred approach to managing a person's symptoms by using activity. It is goal-directed and uses activity analysis and graded activity to enable people to improve, evaluate, restore and/or maintain their function and well-being in self-care, work and leisure.

Age

- Adult: aged 18 years and older.
- Young person: aged between 12 and 17 years.
- Child: aged between 5 and 11 years.

The age at which care is transferred between child and adult health services varies between 16 and 19 years, depending on the young person and their family's preferences and local circumstances.

'Boom and bust' cycles

Cycles of fluctuating activity levels and symptoms, which are a common feature of CFS/ME. Boom and bust cycles can happen when a person with CFS/ME is overactive when they are feeling better, which may lead to an increase in symptoms and a decrease in function.

Cognitive behavioural therapy (CBT)

An evidence-based psychological therapy that is used in many health settings, including cardiac rehabilitation and diabetes management. It is a collaborative treatment approach. When it is used for CFS/ME, the aim is to reduce the levels of symptoms, disability and distress associated with the condition. A course of CBT is usually 12–16 sessions. The use of CBT does not assume or imply that symptoms are psychological or 'made up'.

Deconditioning

Loss of physical fitness as the general physiological response to, for example, a prolonged period of inactivity.

Graded exercise therapy (GET)

An evidence-based approach to CFS/ME that involves physical assessment, mutually negotiated goal-setting and education. The first step is to set a sustainable baseline of physical activity, then the duration of the activity is gradually increased in a planned way that is tailored to the person. This is followed by an increase in intensity, when the person is able, taking into account their preferences and objectives, current activity and sleep patterns, setbacks/relapses and emotional factors. The objective is to improve the person's CFS/ME symptoms and functioning, aiming towards recovery.

Pacing

The report of the Chief Medical Officer's working group defined the principles of pacing, and these are supported by people with CFS/ME and patient groups. Many of the principles are included in this guideline's recommendations on CBT, GET and activity management. Examples include spreading activities over the week, breaking tasks down into small manageable parts, interspersing activity with rest and setting appropriate, realistic goals for increasing activity.

In this guideline, pacing is defined as energy management, with the aim of maximising cognitive and physical activity, while avoiding setbacks/relapses due to overexertion. The keys to pacing are knowing when to stop and rest by listening to and understanding one's own body, taking a flexible approach and staying within one's limits; different people use different techniques to do this.

However, in practice, the term pacing is used differently by different groups of people. One understanding of its meaning is as adaptive pacing therapy, which is facilitated by healthcare professionals, in which people with CFS/ME use an energy management strategy to monitor and plan their activity, with the aim of balancing rest and activity to avoid exacerbations of fatigue and other symptoms.

Another understanding is that pacing is a self-management strategy, without specific intervention from a healthcare professional. People with CFS/ME generally support this approach.

Rest periods

Short periods when a person is neither sleeping nor engaged in physical or mental activity. Rest periods are a core component of all management approaches for CFS/ME.

Setback/relapse

An increase in symptoms above the usual daily fluctuations, which may result in a reduction in function for a time.

Severity

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.

Specialist CFS/ME care

A service providing expertise in assessing, diagnosing and advising on the clinical management of CFS/ME, including symptom control and specific interventions. Ideally this is provided by a multidisciplinary team, which may include GPs with a special interest in the condition, neurologists, immunologists, specialists in infectious disease, paediatricians, nurses, clinical psychologists, liaison psychiatrists, dietitians, physiotherapists and occupational therapists.

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 (2007) NICE guideline CG53

Your responsibility

The guidance in this pathway represents the view of NICE, which was arrived at after careful consideration of the evidence available. Those working in the NHS, local authorities, the wider public, voluntary and community sectors and the private sector should take it into account when carrying out their professional, managerial or voluntary duties. Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way which would be inconsistent with compliance with those duties.

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