

Myalgic encephalomyelitis (or encephalopathy) / chronic fatigue syndrome: diagnosis and management

National Guideline 206 ♦ published 29 October 2021

Core extracts - Severely Affected Patients



ME/CFS is a complex (multifaceted, complicated and diverse), chronic medical condition affecting multiple body systems. [1.1.1; Table 2 of 2 page 984]

The quality of life of people with ME/CFS is lower than that of many people with other severe chronic conditions. [Context, page 84]

Medical assessment and diagnosis is a core element of care. This typically requires access to an ME/CFS specialist physician or a GP with a special interest in ME/CFS. [1.10.1; Rationale, page 68]

A strong theme in the evidence before the guideline committee was the lack of knowledge, understanding and up-to-date training that health and social care professionals have about ME/CFS. Health and social care providers should ensure that all staff delivering care to people with ME/CFS receive training relevant to their role so they can provide care in line with the guideline. [1.16.1; Rationale, pages 80-81]

Recognising the distinctive clinical picture of ME/CFS

People with ME/CFS need timely and accurate diagnosis. The diagnostic criteria are now stricter and the duration of symptoms before a firm diagnosis can take place has been reduced from six months to three.

It is the combination and interaction of the symptoms that is critical in distinguishing ME/CFS from other conditions and illness. Patients experience a disproportionate worsening following activity, often delayed in onset by hours or days, with prolonged recovery time. This may be described as 'post-exertional malaise' (PEM) or 'post-exertional symptom exacerbation'. Different activities combine and interact to cause a cumulative impact for the person.

Debilitating fatigue, neither caused by excessive exertion nor significantly relieved by rest, is among the core features. Fatigue in ME/CFS typically includes the following components:

- rapid loss of muscle strength or stamina, causing for example, sudden weakness, clumsiness, lack of coordination, and being unable to repeat physical effort consistently
- low energy or a lack of physical energy to start or finish activities of daily living and the sensation of being 'physically drained'
- feeling flu-like
- cognitive fatigue that worsens existing difficulties
- Restlessness or feeling 'wired but tired'

Comment: This description is important as it shows that 'fatigue' in ME/CFS differs from the sensation of 'fatigue' that a healthy person would experience.

Other core features are unrefreshing sleep and/or sleep disturbance, and cognitive difficulties. It is also essential that the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels.

[Box 2; 1.1.4; 1.2.2, Rationale page 60; 1.4.1, Rationale and Impact page 63; Terms used in this guideline- Activity pages 51-52, PEM page 55, Fatigue page 53]

Common features of ME/CFS

In addition to the core diagnostic criteria there are a several other features commonly associated with ME/CFS. These include:

Intolerance to alcohol

Intolerance to certain foods

Intolerance to chemicals

Pain, including myalgia and/or neuropathic pain. People with severe or very severe ME may experience severe and constant pain, which can have muscular, arthralgic or neuropathic features. Refer to [CG173 on Neuropathic Pain](#) and [CG150 on Headache, including migraine and cluster headache](#), as appropriate.

Gastrointestinal problems - such as nausea, incontinence, constipation and bloating and difficulty swallowing. Professionals should work with the person and their carers (as appropriate) find ways of minimising complications caused by gastrointestinal symptoms, nausea, changes to appetite, swallowing difficulties, sore throat or difficulties with buying, preparing or eating food.

Orthostatic intolerance and autonomic dysfunction - including dizziness, palpitations, fainting, nausea on standing or on sitting upright from a reclining position. This may take the form of **Postural Orthostatic Tachycardia Syndrome (POTS)**: a significant rise in pulse rate when moving from lying to standing [page 54]. ME/CFS patients with orthostatic intolerance should be referred to secondary care if their symptoms are severe, if their symptoms are worsening and / or if there are concerns that another condition may be the cause.

[1.2.4; 1.12.9; 1.12.11; 1.12.14; 1.12.20; 1.17.1; Terms used in this guideline - Orthostatic intolerance, page 54]

Comment: It has been found that patients who meet CFS criteria and also have POTS have a similar clinical, autonomic and neuro-humoral profile to other POTS patients. This research was among the papers which led NICE to decide that the previous guideline on 'CFS/ME' (CG53) required to be updated and replaced.

Prescribing

As people with ME/CFS may be more intolerant of drugs it is best to consider starting at a lower dose than usual, gradually increasing the dose if the medicine is tolerated

[1.12.14; 1.12.17, Rationale page 76]

Vitamin D deficiency There is a risk of vitamin D deficiency, especially in housebound or bedbound patients. Refer to [NICE Public Health Guideline 56](#). [1.12.23]

Differential diagnosis and co-morbidities

It is important that when a doctor suspects ME/CFS they should also consider alternative explanatory diagnoses or coexisting conditions: these should be investigated, with referral to an appropriate specialist in case of uncertainty.

After a diagnosis of ME/CFS is established, new symptoms or a change in symptoms should be evaluated and investigated, not assumed to be caused by their patient's ME/CFS. Consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether a referral is needed.

[1.14.4; 1.15.7; Rationale, page 61]

Energy must be carefully managed

From the time that ME/CFS is first suspected, professionals should advise patients not to use more energy than they perceive they have and to rest and convalesce as needed. Managing symptoms early may prevent them from getting worse and the person's health deteriorating [1.3.1; Rationale, page 62].

Energy management is one of the most important tools that people with ME/CFS have. However no approach to energy management is curative. [1.11.2; Rationale, page 70].

Although energy management is not a physical activity or exercise programme there is potential for harm through energy management being wrongly applied to people with ME/CFS. [Rationale, page 71]

If the person is experiencing a few days of worsening of their symptoms beyond any normal day-to-day variation then it is likely that they are having flare-up. This can lead to relapse if activity is not monitored and adjusted. A relapse can last for years, with the person moving to a more severe form of ME/CFS. [1.14.2; 1.14.7; Rationale, page 79]

Comment: Principles of management flow from the relationship between symptoms and activity. Inappropriate energy management can lead to lasting deterioration, so the right approach to energy management is crucial.

Physical activity programmes developed for people with other illnesses, or for healthy people, should not be offered to an ME/CFS patient.

People with ME/CFS should not be offered a programme of fixed incremental increases in activity or exercise, such as 'graded exercise therapy'. Nor should recommendations for

activity be based on theories of 'exercise avoidance' and physical deconditioning as perpetuating factors in the patient's ill health and/or the related notion that any such approach is potentially curative. [1.11.14 and Box 4]

Professionals should only consider a programme of physical activity or exercise for a person with ME/CFS *if* the patient feels ready to progress their physical activity beyond their current activities of daily living *and* would like to incorporate physical activity or exercise. [1.11.10]

Comment: These prohibitions apply regardless of the present stage of the patient's illness - whether stable, flared, relapsed or improving.

Cognitive Behavioural Therapy

Cognitive behavioural therapy (CBT) should only be offered to support people with ME/CFS to manage symptoms, improve their functioning and reduce distress associated with having a chronic illness.

CBT should not be based on the assumption that people have abnormal illness beliefs and behaviours as an underlying cause of their ME/CFS. It is not a 'treatment' (cure) for ME/CFS and should not be offered as such.

[Box 5; 1.12.32; Rationale, page 78]

Facilitating Aids & Adaptations

People with ME/CFS that is moderate or more severe may benefit from aids and adaptations (such as a wheelchair, blue parking badge or stairlift) but often have difficulty getting the equipment they need. Aids and adaptations identified in a social care needs assessment should be provided without delay. [1.8.8; 1.8.9; Rationale, page 67]

Professionals should also enable prompt assessment for funding for home adaptation and, if the person is not eligible for funding, offer information and support in arranging home adaptations. [1.8.7]

Supporting the most severely affected patients

Evidence relating to people with severe ME/CFS reinforced the committee's experience that this group of people are often neglected, and the severity of their symptoms misunderstood. [Rationale, page 81]

Assessing Risk Professionals should risk assess each interaction with a person with severe or very severe ME/CFS in advance, to ensure that potential benefits outweigh risks (notably worsening) posed by the impact of the interaction itself.

For the most severely affected patients, professionals should consider discussing this with family / informal carers, if appropriate, on the person's behalf. [1.17.4]

Comment: For practical guidance, please see next page.

Implications for Social Care Personal care and support for people with severe or very severe ME/CFS should be carried out by practitioners who are known to them, wherever possible, and aware of their needs. [1.17.3]

In people with ME/CFS, particularly those who are severely or very severely affected, there is a risk that the impact of their symptoms on ability to function may be confused with signs of abuse or of neglect. [1.7.1]

When a patient is experiencing prolonged periods of immobility, professionals should assess at every contact for:

- areas at risk of pressure sores ([CG179](#))
- deep vein thrombosis ([NG158](#))
- risk of contractures. [1.12.6]

Nutritional Support Severe ME/CFS may mean that the person is unable to chew food easily and some of the most severely affected people have reduced ability or inability to swallow.

Support with hydration and nutrition could include oral nutrition support and enteral feeding. Follow the recommendations on screening for malnutrition and indications for nutritional support in [CG32 'Nutrition Support in Adults'](#). [1.17.1; 1.17.2; 1.17.11; 1.17.12]

Access to care and support *environmental conditions, communication needs and reasonable adjustments to service delivery*

The guideline recognises that activity and sensory stimulus such as noise or light can adversely affect a person with ME/CFS and that this is particularly problematic for people with severe or very severe ME/CFS, who may be hypersensitive. [1.17.1]

Against this background, the guideline sets out ways in which health and social care professionals should act to ensure that people with ME/CFS can use their services:

- adapt the timing, length and frequency of all appointments to the person's needs
- take into account physical accessibility, such as: how far the person has to travel, whether there is suitable transport and parking, and where rooms are for appointments
- take into account sensitivities to light, sound, touch, pain, temperature extremes or smells
- provide care flexibly to the person's needs, such as by online or phone consultations or making home visits. [1.8.1]

Further guidance is provided concerning severe and very severely affected patients, who may:

- need a low-stimulus environment, for example a dark quiet room with interaction at a level of their choice (this may be little or no social interaction)
- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch
- be unable to communicate without support
- have problems accessing information, for example difficulty with screens, sound and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration. [1.17.2]

Hospital and care in a residential setting Discuss in advance of hospital admission or outpatient appointment whether any aspects of where care will be provided could cause problems for the patient, including:

- where a bed is situated on a ward (if possible, aim to provide a single room)
- the accessibility of toilets and washrooms
- environmental factors such as lighting, sound, heating and smells. [1.8.4]

***Comment:** An acute hospital may be unable to treat ME/CFS, however a person with ME/CFS may suffer from a co-morbid illness that does require hospital investigation and/or treatment. Also a person with severe ME/CFS may be admitted to a residential care facility, for example for care respite or to avoid noisy work being undertaken at their home.*

In addition, for severely and very severely affected ME/CFS patients professionals should:

- discuss the person's care and support plan with them in advance, including information on comorbidities, intolerances and sensitivities, in order to plan any reasonable adjustments that are needed
- when the time comes to travel to hospital, aim to minimise discomfort and post-transfer deterioration (PEM), for example planning the route in advance, avoiding noisy areas and admitting straight to the ward on arrival
- aim to provide a single room if possible
- keep stimuli to a minimum, for example by: seeing the patient one-to-one; using calm movements and gestures; not duplicating assessments; being cautious about the pressure of touch; keeping lights dimmed; reducing sound; keeping a stable temperature; and minimising smells. [1.17.7]

V2 November 2022