

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

Core elements from National Guideline 206

This short paper has been produced to accompany the on-line module on ME/CFS at:

www.studyprn.com/p/chronic-fatigue-syndrome

It presents core extracts from the guideline published by the UK's National Institute for Health and Care Excellence (NICE) in October 2021, selected to give an overview of some key points that are valid in any country or healthcare context. Comments have been kept to a minimum and are presented *in italicised text* to differentiate them from guideline content.

ME/CFS is a complex chronic medical condition affecting multiple body systems. (1.1.1)

The quality of life of people with ME/CFS is lower than that of many people with other severe chronic conditions, including multiple sclerosis and some forms of cancer. (Context)

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 and Impact)

Recognising the distinctive clinical picture of ME/CFS

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.

People with ME/CFS need timely and accurate diagnosis. 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, that is neither caused by excessive exertion nor significantly relieved by rest, is among the core features. *The description of 'fatigue' in ME/CFS is important as it shows that 'fatigue' in ME/CFS differs greatly from what a healthy person experiences when fatigued.* 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'

Other core features are unrefreshing sleep and/or sleep disturbance, and cognitive difficulties.

The final essential criterion is 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; 1.4.1; Rationale and Impact; Terms used in this guideline - Activity, PEM, Fatigue)

Common features of ME/CFS

In addition to the core diagnostic criteria several other features are commonly associated with ME/CFS:

Temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold.

Neuromuscular symptoms including twitching (fasciculation) and myoclonic jerks.

Flu-like symptoms including sore throat, tender glands, nausea, chills or muscle aches.

Intolerance to alcohol, to certain foods, to chemicals.

Heightened sensory sensitivities including to light, sound, touch, taste and smell; people who are severely or very severely affected can be hypersensitive.

Pain including pain on touch, myalgia and/or neuropathic pain; pain may be in the eyes, abdomen or joints (without acute redness, swelling or effusion of joints); also head pain which can be in the form of migraine; in severe and very severe cases, pain can be severe and constant.

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. ME/CFS patients with orthostatic intolerance should be referred to secondary care if their symptoms are severe or worsening, or if there are concerns that another condition may be the cause.

(1.2.4; 1.12.9; 1.12.11; 1.12.14; 1.17.1; Terms used in this guideline - Orthostatic intolerance)

POTS patients who meet CFS criteria were found to have a similar clinical, autonomic and neurohumoral profile to other POTS patients ([Okamoto et al. 2012](#) Pubmed ID 21906029). Because there were no distinguishing features between POTS patients with and those without CFS, the researchers propose that CFS–POTS is not a separate clinical entity distinct from POTS without CFS. Rather, CFS seems to be part of the spectrum of POTS, associated with greater sympathetic activation and/or a more severe form of this condition.

Gastrointestinal problems may include nausea, incontinence, constipation, bloating and difficulty swallowing. Professionals should work with the person and their carers (as appropriate) find ways of minimising complications caused by gastrointestinal symptoms, or by difficulties with buying, preparing or eating food. (1.12.20)

Differential diagnosis and co-morbidities

ME/CFS is no longer a diagnosis of exclusion, nor is it an exclusive diagnosis.

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 the 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 and Impact)

Energy must be carefully managed from the outset

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

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, but no approach to energy management is curative. (1.11.2; Rationale, page 70)

Energy management is not a physical activity or exercise programme. Nonetheless, 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. A flare-up 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 and Impact)

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, nor the related notion that any such approach is potentially curative. (1.11.14; Box 4)

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 is not a 'treatment' (cure) for ME/CFS and should not be offered as such. Nor should it be based on the assumption that people have abnormal illness beliefs and behaviours as an underlying cause of their ME/CFS.

(Box 5; 1.12.32; Rationale and Impact)

These prohibitions relating to graded exercise and CBT apply regardless of the present stage of the patient's illness - whether stable, flared, relapsed or improving.

Prescribing

Medicines can be useful to manage symptoms. For example, regarding pain, refer to [CG173 on Neuropathic Pain](#) and [CG150 on Headache, including migraine and cluster headache](#), as appropriate.

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 and Impact)

Facilitating Aids & Adaptations

People with moderate or more severe ME/CFS 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 and Impact)

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 and Impact)

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)

For practical guidance from NICE on minimising risk, see next page.

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)

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 who are aware of their needs.

(1.17.3)

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)

Nutritional Support Severe ME/CFS may mean that the person is unable to chew food easily. Some of the most severely affected patients 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)

See also 'Gastrointestinal problems', above.

Facilitating access to care and support

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. (1.2.4; 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

While an acute hospital is unlikely to be offering treatment for ME/CFS, a patient with ME/CFS can suffer from a co-morbid illness that does require hospital investigation and/or treatment. The guidance provided in this regard would also be relevant when a person with severe ME/CFS will be spending time at a care of nursing home, for example for family carer respite or to avoid exposure to noise from work being undertaken at or near their home.

Professionals should discuss in advance with people who need inpatient or outpatient care whether any aspects of where care will be provided could cause problems for them, 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)

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)

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