

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

National Guideline 206 ♦ published 29 October 2021

www.nice.org.uk/guidance/ng206

ME/CFS is a medical condition: patients require a medically led service

Professionals should be aware that 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 with other severe chronic conditions. [Context, page 84]

Medical assessment and diagnosis is a core element of care and support. 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 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 are can provide care in line with the guideline. [1.16.1; Rationale, pages 80-81]

How to recognise the distinctive clinical picture of ME/CFS

People with ME/CFS need accurate and timely 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. This should improve diagnostic accuracy while enabling prompter access to appropriate management advice (see next page), potentially improving longer-term outcomes.

The combination of symptoms and their interaction with activity is key in distinguishing ME/CFS. 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.

Debilitating 'fatigue', that is neither caused by excessive exertion nor significantly relieved by rest, is among the core features. However this differs from the sensation of 'fatigue' that a healthy person would experience. It typically includes:

- 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.

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

[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]

Energy must be carefully managed from the outset

Principles of management flow from the relationship between symptoms and activity.

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 to convalesce as needed. Managing symptoms early may prevent them getting worse and the person's health deteriorating [1.3.1; Rationale, page 62].

While appropriate energy management is crucial, no approach to energy management is curative. [1.11.2; Rationale, page 70].

Energy management is not a physical activity or exercise programme. Still, there is potential for harm through energy management being wrongly applied. If energy management strategies are inappropriately applied in people with severe or very severe ME/CFS, this will increase the potential for harm. [Rationale, page 71; Rationale, page 82]

Deterioration can be long lasting. What might otherwise be a shorter term flare-up may lead to relapse if activity is not monitored and adjusted. A relapse may lead to someone moving to a more severe form of ME/CFS. Relapse can last for years. [1.14.7; Rationale, page 79]

Physical Activity and Exercise

It is not acceptable to recommend a programme of fixed incremental exercise, such as 'graded exercise therapy' to an ME/CFS patient. Nor should any form of physical activity or exercise be presented as a cure: for example, as addressing imputed 'exercise avoidance' and/or physical deconditioning as a perpetuating factor in the patient's ill health. Programmes developed for people with other illnesses, or for healthy people, should not be offered to an ME/CFS patient. [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 *and* would like to incorporate physical activity or exercise. [1.11.10]

Similarly, cognitive behavioural therapy (CBT) should only be offered to support people with ME/CFS to manage symptoms, improve their functioning and reduce the dis-

stress associated with having a chronic illness. CBT should not be offered based on the assumption that people have 'abnormal' illness beliefs and behaviours as an underlying cause of their ME/CFS. CBT is not a cure for ME/CFS and should not be offered as such. [1.12.28; Box 5; 1.12.32; Rationale, page 78]

Medical Ethics: Informed Consent and Duty of Care

For a patient to give informed consent to any treatment, therapy, or management approach, it is essential that they are provided with adequate information on material risks as well as potential benefits. The doctor has a duty to avoid exposing their patient to a risk of injury that the patient would otherwise have avoided. The patient is entitled to decide whether or not to incur that risk.

It follows that healthcare professionals must be cognisant of the potential risks of any approach - whether a medication for treatment or for symptomatic relief, or an activity or exercise programme - to their specific patient, in order to provide the necessary information.

General Medical Council (GMC) guidance states: "You must give patients clear, accurate and up-to-date information, based on the best available evidence, about the potential benefits and risks of harm of each option, including the option to take no action" and advises that in doing so the doctor should usually include:

- Recognised risks of harm that you believe anyone in the patient's position would want to know.
- The effect of the patient's individual clinical circumstances on the probability of a benefit or harm occurring.
- Risks of harm and potential benefits that the patient would consider significant for any reason.
- Any risk of serious harm, however unlikely.
- Expected harms.

REFERENCES:

Guidance on professional standards and ethics for doctors: Decision Making and Consent General Medical Council, Nov. 6464
www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors

Judgment in *Montgomery v Lanarkshire Health Board*; UK Supreme Court 11; Judgment given 11 March 2015
www.supremecourt.uk/cases/docs/uksc-2013-0136-judgment.pdf

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 As mere interaction can lead to deterioration, professionals should risk assess each interaction with a person with severe or very severe ME/CFS in advance, to ensure that potential benefits outweigh the risk posed by the impact of the interaction itself. (For practical guidance on how to minimise this risk, please see next page.) For the most severely affected patients, professionals should consider discussing this with family / informal carers, if available, on the person's behalf. [1.17.4]

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. Professionals should guard against this confusion. [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]

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]

Nutritional Support Severe and very severe ME/CFS may mean that the patient is unable to eat and digest food easily and/or may 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]

There is a risk of vitamin D deficiency in housebound or bedbound patients: refer to PH56 'Vitamin D: supplement use in specific population groups'. [1.12.23]

Gastrointestinal Problems

Some ME/CFS patients experience gastrointestinal problems - such as nausea, incontinence, constipation and bloating - and/or difficulty swallowing. Professionals should aim to find ways of minimising complications, whether caused by gastrointestinal symptoms, changes to appetite, swallowing difficulties, sore throat or difficulties with buying, preparing or eating food. [1.12.20; 1.17.1]

People with ME/CFS may also experience intolerance to certain foods and to chemicals. [1.2.4]

Co-morbid Illness

Doctors should be alert to the possibility of co-morbid disorders. 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. Similarly, after the 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]

Facilitating Aids & Adaptations

People with ME/CFS that is moderate or severe may benefit from aids and adaptations but often have difficulty getting the equipment they need to support activities of daily living and maintain their quality of life. [1.8.8; Rationale, page 67]

Aids and adaptations identified in a social care needs assessment should be provided without delay. [1.8.9]

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

Prescribing

Medicines can be useful to manage symptoms. For 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 page 76]

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. 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 and need to choose someone to be their advocate and communicate for them
- 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 Care While an acute hospital may be unable to treat or ameliorate ME/CFS, 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 respite care facility.

It is recommended that professionals discuss in advance in admission 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. [1.8.5]

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]

The 25% M.E. Group Support Group For The Severely Affected

March 2022