

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

Guidance for Social Care Professionals

National Guideline 206 ♦ published 29 October 2021

www.nice.org.uk/guidance/ng206

Knowledge and understanding are essential

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 able to provide care in line with recommendations contained in the guideline.

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. 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.

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.

[Recommendations 1.7.1, 1.16.1, 1.17.3; Rationale, pages 80-81]

Energy must be carefully managed and conserved

Professionals should advise people with ME/CFS not to use more energy than they perceive they have.

People with ME/CFS experience a worsening of symptoms following activity, even relatively trivial activity. Symptoms typically begin to get worse 12 to 48 hours afterwards. This distinctive feature of ME/CFS is commonly known as 'post-exertional malaise' (PEM) or 'post-exertional symptom exacerbation'.

The deterioration can last for days or weeks and, if activity is not adjusted, what might otherwise be a shorter term flare may lead to a relapse. Relapse can last for years and may mean that the person moves to a more severe form of ME/CFS.

'Fatigue' in a person with ME/CFS is not the same as the sensation of 'fatigue' that a healthy but tired person would experience. People with ME/CFS are likely to have:

- 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 energy and the sensation of being 'physically drained'
- feeling flu-like.

[Box 2 - Symptoms for suspecting ME/CFS; Rationale pages 60 & 79; 1.3.1; 1.4.1, 1.14.7; Terms used in this guideline - PEM page 55, Fatigue page 53]

Social Care and Support

Approach to Care Both 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 hyper-sensitive. [1.17.1]

Against this background, the guideline sets out ways in which professionals, including 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 sensitivities to light, sound, touch, pain, temperature extremes or smells
- provide care flexibly to the person's needs. [1.8.1]

Social care professionals should also be aware that clients with severe and very severe ME/CFS 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]

In the light of the above, professionals assessing for or providing social care to severely and very severely affected clients should minimize risk of provoking a deterioration by keeping sensory stimulus to a minimum, for example by:

- using calm movements and gestures
- not duplicating assessments
- being cautious about the pressure of touch
- keeping lights dimmed
- reducing sound
- keeping a stable temperature
- minimising smells. [1.17.7]

Mere interaction can lead to deterioration in a severely affected person. For the most severely affected clients, care professionals should consider discussing requirements with family or a nominated advocate, with the permission of the client, on the client's behalf. [1.17.4]

Nutrition and Gastrointestinal Problems Gastrointestinal difficulties - such as nausea, incontinence, constipation and bloating - may be experienced in severe or very severe ME/CFS. Some people have reduced ability or inability to chew and/or swallow.

These manifestations of ME/CFS may result in the person being unable to eat and digest food easily and requiring support with hydration and nutrition.

People with ME/CFS may also experience intolerance to certain foods and to chemicals. (NOTE: Processed foods may contain 'chemical' ingredients.)

Professionals should work with the person 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.

This could mean food with softer texture, modified eating aids, or oral nutrition support, for example. Some people with very severe ME require enteral feeding.

[1.2.4; 1.12.20; 1.17.1; 1.17.2; 1.17.11; 1.17.12]

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]

Regarding funding, 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]

NG206 on Social Care presented by:

The 25% M.E. Group

Support Group For The Severely Affected

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See our range of supporting material to assist professionals in providing appropriate care to a person with severe or very severe ME here:

<https://25megroup.org/social-care>

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