

Action for M.E. summary of the National Institute for Health Excellence (NICE) guideline for M.E./CFS, draft for consultation, November 2020

Summary of guidance relating to severe and very severe M.E./CFS

Most sections of the draft NICE guideline for M.E. give specific guidance relating to severe or very severe M.E./CFS, which we summarise below, and share in full on pages 3 to 9. Please note this should be considered in the context of the overall guideline.

Severe or very severe ME/CFS are defined in the guideline as follows:

- People with **severe** ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may 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.
- People with **very severe** ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

Key messages around the impact of severe and very severe M.E./CFS

- In its most severe form, M.E./CFS can lead to substantial incapacity, and symptoms may include:
 - severe and constant pain
 - hypersensitivity to light, noise, touch, movement, temperature, and smells
 - extreme weakness with severely reduced movement
 - reduced ability or inability to speak or swallow
 - cognitive difficulties
 - sleep disturbance
 - gastrointestinal difficulties
 - postural orthostatic tachycardia syndrome (POTS) and postural hypotension.

These symptoms can significantly affect emotional wellbeing, communication, and the ability to interact with others and care for themselves.

- People with severe or very severe M.E./CFS may need:
 - a low stimulus environment (dark room, limited interaction)
 - assistance with all activities of daily living if bed-bound or housebound.
 - aids, such as wheelchairs
 - support with communication and advocacy
 - support with hydration and nutrition
 - alternative means of accessing and sending information, due to issues like difficulties with screens and light sensitivity, brain fog, etc.

Key messages around healthcare and services

- Personal care should come from health and social care practitioners who are known to the person/person's family/person's carer, and are aware of the person's needs.
- Health and social care practitioners should risk assess each interaction to ensure benefits will outweigh risks to the person.
- Specialist M.E./CFS teams should offer home visits to carry out holistic assessments and develop management plans.
- Medical professionals should recognise that symptoms, particularly with severe or very severe M.E., can often be confused with signs of abuse or neglect.
- When planning hospital care for people, healthcare professionals should discuss with the person what to expect, aim to minimise discomfort and symptom exacerbation, discuss the management plan with the person, aim to provide a single room, and keep stimuli to a minimum.
- Service providers should be proactive and flexible in delivering services. This could include home visits, online consultations, written communication, and supporting applications for aids and appliances that can maintain their independence and quality of life.
- People should be referred to a specialist M.E./CFS physiotherapy or occupational therapy service for support on developing energy management plans. When agreeing energy management plans, service providers should be aware that changes in activity should be small and any possible increases should be slow.
- People should be assessed at every contact for areas at risk of pressure ulcers, deep vein thrombosis, and risk of contractures.
- People should be referred for a dietetic assessment by a dietitian specialising in M.E./CFS. People who are at risk of malnutrition and unintentional weight loss (due to restrictive diets, poor appetite, intolerances, nausea/difficulty swallowing) should be monitored.
- Advice to support people's diets includes eating little and often, choosing nourishing foods and drink, choosing easy to eat foods (eg. soft foods), using eating aids, and oral nutrition support + enteral feeding.
- Healthcare professionals delivering CBT should adjust the process and pace to meet the person's needs.

Copied and pasted from each section of the draft NICE guideline, for ease of reference

From section 1.1 Principles of care for people with ME/CFS

Awareness of ME/CFS and its impact

1.1.1 Be aware that ME/CFS:

- affects each person differently and varies widely in severity – in its most severe form it can lead to substantial incapacity.
- is a fluctuating condition in which symptoms can change unpredictably in nature and severity over days, weeks or longer – ranging from being able to carry out most daily activities to severe debilitation.

Awareness of severe or very severe ME/CFS and its impact

1.1.8 Be aware that people with severe or very severe ME/CFS may experience some of the following symptoms that significantly affect their emotional wellbeing, communication, mobility and ability to interact with others and care for themselves:

- severe and constant pain, which can have muscular, arthralgic or neuropathic features
- hypersensitivity to light, noise, touch, movement, temperature extremes and smells
- extreme weakness, with severely reduced movement
- reduced ability or inability to speak or swallow
- cognitive difficulties, causing a limited ability to communicate and take in written or verbal communication
- sleep disturbance such as unrefreshing sleep, hypersomnia, altered sleep pattern
- gastrointestinal difficulties such as nausea, incontinence, constipation and bloating
- neurological symptoms such as double vision and other visual disorders, dizziness
- postural orthostatic tachycardia syndrome (POTS) and postural hypotension.

1.1.9 Recognise that symptoms of severe or very severe ME/CFS may mean that people:

- 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)
- are housebound or bed-bound and may need support with all activities of daily living
- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch
- need aids such as wheelchairs
- cannot communicate without support and may need someone else they have chosen to be their advocate and communicate for them
- are unable to eat and digest food easily and may need support with hydration and nutrition (see the section on dietary management and strategies)

- have problems accessing information, for example because of difficulty with screens, noise and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration.

1.1.10 Personal care and support for people with severe or very severe ME/CFS should be carried out by health and social care practitioners who are:

- known to the person and their family members or carers wherever possible
- aware of the person's needs.

1.1.11 Risk assess each interaction with a person with severe or very severe ME/CFS in advance to ensure its benefits will outweigh the risks to the person (for example, worsening their symptoms). For people with very severe ME/CFS, think about discussing this with the person's family or carer on their behalf.

From section 1.5 Assessment and care planning by a specialist ME/CFS team

People with severe or very severe ME/CFS

1.5.5 Offer home visits to people with severe or very severe ME/CFS to carry out their holistic assessment and develop their management plan.

From section 1.6 Information and support

Social care

1.6.10 Advise children and young people with moderate ME/CFS to severe or very severe ME/CFS and their parents or carers that they may be entitled to support from children's social care as children in need because of their disability.

From section 1.7 Safeguarding

1.7.2 Recognise that people with ME/CFS, particularly those with severe or very severe ME/CFS, are at risk of their symptoms being confused with signs of abuse or neglect.

From section 1.8 Access to care

People with severe or very severe ME/CFS

1.8.4 Service providers should be proactive and flexible in delivering services to people with severe or very severe ME/CFS, who may have particular difficulty accessing services and articulating their needs. This could include home visits, online consultations, written communication, and supporting their applications for aids and appliances.

Hospital care for people with severe or very severe ME/CFS

- 1.8.6 When planning hospital care for people with severe or very severe ME/CFS:
- discuss with the person (and their family members or carers, as appropriate) what to expect when they come into hospital
 - aim to minimise discomfort and post-exertional symptom exacerbation during transfer to hospital, for example by planning the route in advance, avoiding noisy areas and admitting them straight to the ward on arrival.
 - discuss the person's management plan with them, including information on comorbidities, intolerances and sensitivities, to plan any reasonable adjustments that are needed.
 - aim to provide a single room if possible
 - keep stimuli to a minimum, for example by:
 - seeing them one-to-one
 - using calm movements and gestures
 - not duplicating assessments
 - being cautious about the pressure of touch
 - keeping lights dimmed
 - reducing noise
 - keeping a stable temperature
 - minimising strong smells.

Aids and adaptations

- 1.8.11 For people with moderate ME/CFS or severe or very severe ME/CFS, consider providing or recommending aids and adaptations (such as a wheelchair, blue badge or stairlift) that could help them maintain their independence and improve their quality of life, taking into account the risks and benefits. Include these in the person's management plan.

From section 1.11 Managing ME/CFS

Physical activity for people with severe or very severe ME/CFS

- 1.11.9 Refer people with severe or very severe ME/CFS to a specialist ME/CFS physiotherapy or occupational therapy service for support on developing energy management plans.
- 1.11.10 Be aware when agreeing energy management plans with people with severe or very severe ME/CFS (and their families and carers as appropriate) that changes in activity should be smaller and any increases (if possible) much slower.
- 1.11.12 Assess people with severe or very severe ME/CFS at every contact for:
- areas at risk of pressure ulcers (see the NICE guideline on pressure ulcers)
 - deep vein thrombosis
 - risk of contractures.

Dietary management and strategies for people with severe or very severe ME/CFS

- 1.11.40 Refer people with severe or very severe ME/CFS for a dietetic assessment by a dietitian who specialises in ME/CFS.
- 1.11.41 Monitor people with severe or very severe ME/CFS who are at risk of malnutrition or unintentional weight loss because of:
- restrictive diets
 - poor appetite linked with altered taste and smell
 - food intolerances
 - nausea or difficulty swallowing and chewing. Follow the recommendations on screening for malnutrition, indications for nutrition support, and education and training of staff and carers related to nutrition, in the NICE guideline on nutrition support for adults.
- 1.11.42 Consider advice to support people with severe or very severe ME/CFS, which could include:
- eating little and often
 - having nourishing drinks and snacks, including food fortification
 - finding easier ways of eating to conserve energy, such as food with softer textures
 - using modified eating aids, particularly if someone has difficulty chewing or swallowing
 - oral nutrition support and enteral feeding.

Psychological support: cognitive behavioural therapy for people with severe or very severe ME/CFS

- 1.11.50 Healthcare professionals delivering CBT to a person with severe or very severe ME/CFS should adjust the process and pace of CBT to meet the person's needs. This might include shorter, less frequent sessions and longer-term goals.

Terms used in this guideline

p44 Physical maintenance

Physical maintenance is the process of incorporating into daily activity a level of movement that does not exacerbate symptoms and ensures that joint and muscle flexibility does not deteriorate further than that caused by the condition so far. For many people with ME/CFS, this will be to ensure as much independence as possible in activities ranging from personal hygiene to daily living, working and social interactions. For the most severely affected, it may only be passive movements, which aim to maintain joint flexibility and gently stretch muscle groups to avoid contractures developing. For some people with ME/CFS it can include physical activity which additionally assists bone health, posture and muscle strength. Such activity is undertaken within the person's energy envelope and avoids pushing through boundaries of tolerance.

Rationale and impact

p 47/48 (Principles of care for people with ME/CFS) Why the committee made the recommendations

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. The committee made recommendations on the symptoms experienced by people with severe or very severe ME/CFS and what this means when providing care.

p53 (Assessment and care planning by a specialist ME/CFS team) Why the committee made the recommendations

The committee outlined key areas to assess what support might be needed, based on their experience. The committee noted that the key areas to assess and the support needed will depend on the person's severity of ME/CFS, the impact of their symptoms and their needs. Someone with mild ME/CFS will not need as much support as someone with severe or very severe ME/CFS. Once the overall management plan is agreed, it then provides a basis for the more detailed assessments and plans outlined in specific interventions in the guideline, such as social care assessments, energy management, physical maintenance, CBT and dietary management. Each of these assessments and plans outlines the important considerations for each person in these areas of care.

Based on the evidence about problems with accessing services, the committee made a recommendation for home visits to people with severe and very severe ME/CFS to carry out the assessment.

p54 How the recommendations might affect practice

There may be an increased number of home visits for people with severe or very severe ME/CFS. However, this will provide equity of access to care for this group who are usually housebound. The emphasis in this guideline on early diagnosis and referral to a specialist team for a personalised care plan has the aim of minimising the number of people who may progress to severe ME/CFS.

p56 (Access to care) Why the committee made the recommendations

The committee was aware that difficulties accessing care are intensified in people with severe or very severe ME/CFS, particularly when they need hospital care. The evidence showed that, as a result of this, some people with severe or very severe ME/CFS have little contact with and support from health and social care services. To address this, the committee highlighted the flexibility and specific support needed by people with severe or very severe ME/CFS.

p60/61 (Energy management) Why the committee made the recommendations

The committee agreed that if energy management strategies are inappropriately applied in people with severe or very severe ME/CFS this will increase the potential for harm. To reflect this, they recommended specialist advice and additional care in this group.

p65 (Managing pain - recommendation 1.11.27) Why the committee made the recommendation

The committee agreed that if energy management strategies are inappropriately applied in people with severe or very severe ME/CFS this will increase the potential for harm. To reflect this, they recommended specialist advice and additional care in this group.

p66/67 (Dietary management and strategies - recommendations 1.11.33 to 1.11.42) Why the committee made the recommendations

The committee considered that people with severe or very severe ME/CFS are particularly at risk of problems associated with eating and are likely to need additional support and referral to a dietitian who specialises in ME/CFS. The committee also used their own experience to recommend some general dietary advice that could be helpful for people with severe or very severe ME/CFS.

p67/68 (Psychological support: cognitive behavioural therapy - recommendations 1.11.43 to 1.11.50) Why the committee made the recommendations

None of the clinical evidence included or reflected the needs of people with severe ME/CFS, and the qualitative evidence was mixed, with some people reporting benefit and others harm. The committee recognised that CBT could be supportive for people with severe ME/CFS but because of the severity of their symptoms it is important to be more flexible and adapt the delivery of CBT to accommodate people's limitations.

p69 (Managing flares and relapse - recommendations 1.13.1 to 1.13.7) Why the committee made the recommendations

The committee discussed the importance of recognising when a flare has moved to a relapse and that it needs to prompt a review of the person's management plan. It is also possible that a relapse may lead to someone moving to a more severe form of ME/CFS. Part of the review of the management plan is to consider what the causes of relapse might have been and to consider this when revising the plan.

p69/70 (Review - recommendations 1.14.1 to 1.14.8) How the recommendations might affect practice

There is variation in practice and some people with ME/CFS, including those with severe and very severe ME/CFS, do not get a clinical review routinely, so for some this will be a change in practice. These recommendations are in line with other long term conditions and support equity of access to care for people with ME/CFS. Routine follow-up might not be present everywhere but most people with ME/CFS already have regular contact with their primary

care teams, so there is not expected to be a large resource impact.

p71 (Context)

Everyday life for people with ME/CFS, their family and carers is disrupted and unpredictable. Many people with the condition are unemployed, and less than a fifth work full-time. Approximately 25% have severe disease and are housebound or bed bound. 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.