**DHSC: Very Severe ME/CFS**

**Epidemiology, clinical definition and assessment of people with very severe ME/CFS: Implications for the development of a national specialist referral service**

## 1 Background

ME/CFS is classified by the WHO as a disease of the central nervous system in section G93.3 of ICD-10.

Research evidence indicates that ME/CFS may involve a convergence of immune, neurological, metabolic and genetic influences following an initial insult – which is often a viral infection. Proposed pathophysiological mechanisms include immune and metabolic dysregulation, neuroendocrine abnormalities, central nervous system and circulatory system dysfunction, cardiovascular defects and disturbances of the gut microbiome (1). People with ME/CFS have significant genetic differences in their DNA compared to the general population (2).

It has been estimated that around 25% of people with ME/CFS have a severe form of the disease (3). A small but significant number in this group have a very severe form of ME/CFS. However, there is no reliable epidemiological information or NHS data collection on the number of adults, young people and children with either severe or very severe ME/CFS (see addendum 1 re SNOMED classification).

Those with very severe ME/CFS will be totally housebound, confined to bed all day and night, unable to stand, have significant cognitive impairment and are reliant on 24-hour personal care.

The DHSC Delivery Plan on ME/CFS (4) highlighted the need for medical education on all aspects of ME/CFS. Two NHS overlapping e-learning modules are now available on severe ME/CFS – *Supporting people with Severe ME/CFS* and *Support and Clinical Management of Severe ME/CFS* (5).

A Prevention of Future Deaths Report (6) following the 2024 inquest into the death of Maeve Boothby O'Neill heard that provision of care for people with very severe ME/CFS was non-existent and that being placed on a ward that did not have expertise in their condition made admission to hospital very difficult for people to endure. It also became clear during the inquest that there was extremely limited training for doctors on ME/CFS and how to manage it – especially in relation to those with very severe ME/CFS. Concerns were expressed that future deaths could occur unless action is taken.

The DHSC Delivery Plan contained an action point for the DHSC and NHS England to explore whether a specialised referral service should be prescribed by the Secretary of State for people with very severe ME/CFS. To assist this

process Forward ME has been asked to prepare some information on the clinical definition of very severe ME/CFS.
In response, this briefing note contains information on epidemiology, clinical definition, symptoms and the clinical assessment of people with very severe ME/CFS.

## 2 Symptoms

In addition to debilitating fatigue and post-exertional malaise/symptom exacerbation – which is likely to be exacerbated or triggered by minimal amounts of physical or mental exertion - people with very severe ME/CFS are likely to experience most of the following symptoms:

- extreme weakness, with severely reduced movement which may extend to episodes of paralysis
- severe and constant pain, which can have muscular, arthralgic or neuropathic features
- cognitive difficulties involving memory, concentration, information processing and word finding difficulties which limit the person's ability to communicate and take in written or verbal communication
- reduced ability or inability to speak
- hypersensitivity to light, sound, touch, movement, temperature extremes and smells
- sleep disturbances which include unrefreshing sleep, hypersomnia, reversal of normal sleep rhythms and altered sleep pattern
- gastrointestinal difficulties such as problems with chewing and swallowing, nausea and vomiting, incontinence and constipation
- neurological symptoms such as visual disorders, paraesthesiae, dizziness
- autonomic nervous system dysfunction/dysautonomia – including orthostatic intolerance, orthostatic hypotension, postural orthostatic tachycardia syndrome (POTS) and postural hypotension
- temperature regulation problems

Section 1.17.1 of the NICE guideline on ME/CFS contains a list of symptoms in severe and very severe ME/CFS that affect all aspects of their lives (7).

The presence of numerous disabling symptoms has a very significant effect on all aspects of their lives, especially in relation to mobility, cognitive functioning, emotional wellbeing and the ability to interact with others and care for themselves.

Overall, several research studies have now found that ME/CFS causes a profound and severe reduction in quality of life, often worse than in many other long-term medical conditions to which it has been compared, including heart failure and cancer (8,9,10).

## 3 Complications associated with immobility and nutrition

People with very severe ME/CFS are at risk of developing well-recognised complications associated with prolonged immobility:

- electrolyte disturbances – hypercalcaemia, hyponatraemia and potassium imbalance
- muscle wasting
- osteoporosis
- pressure sores
- venous thrombosis
- vitamin D deficiency

People with very severe ME/CFS are also at risk of malnutrition (11) or **unintentional weight loss** because of:

- inability to tolerate certain foods
- poor appetite, which may be linked to altered taste, smell and texture
- nausea
- difficulty with swallowing and chewing.

Medical complications of malnutrition include**:**

- immune system - reduced ability to fight infection
- muscles - reduced ability to cough may predispose to chest infections and pneumonia
- impaired wound healing
- kidney function - inability to regulate salt and fluid can lead to over-hydration or dehydration
- impaired temperature regulation - can lead to hypothermia
- anaemia (iron and vitamin B12) and vitamin/nutrient deficiencies

A key concern in defining and managing very severe ME/CFS is the risk that nutritional compromise, gastrointestinal dysfunction, weight loss and reduced oral intake are misinterpreted as evidence of a primary eating disorder, particularly anorexia nervosa (AN), without adequate contextual assessment. Current screening approaches such as the SCOFF questionnaire may generate false positives if used rigidly or without understanding the multisystem manifestations of very severe ME/CFS. This can contribute to diagnostic

overshadowing, inappropriate psychologisation, delayed medical care for malnutrition, avoidable trauma, and loss of trust in healthcare services.

**4 Co-morbidities which may complicate the clinical picture include:**

- dysautonomia/autonomic nervous system dysfunction
- fibromyalgia
- hypermobility
- mast call activation syndrome
- migraine-type headaches

**5 Practical consequences of assessing people with very severe ME/CFS:**

- They operate within a severely constrained energy envelope, allocating limited capacity to essential tasks.

- Their condition may have a degree of fluctuation and unpredictability whereby brief functional capacity may be followed by prolonged worsening. This variability is often mistaken for inconsistency or preference, rather than a recognised feature of the disease.

- Communication is limited or absent. Cognitive exertion itself can trigger deterioration. Speech is often rationed accordingly. There is no loss of mental capacity – handling mental activity is the problem. They may therefore need to choose someone to be their advocate and communicate for them.

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

- The aims and benefits of an assessment should therefore be carefully organized to give them time to listen, understand, consider and respond where they can.

- They require a low stimulus, low stress and darkened environment. The NICE guideline on ME/CFS (NG 206) recognises hypersensitivity to light and sound as core features. In severe disease, sensory input itself can trigger symptom escalation.

- Recognising hypersensitivity symptoms, appreciating that sensitivity to touch can cause problems with physical examination and practical procedures, and reducing light and sound is therefore a clinical necessity, not a preference.

- They require a great deal of supervision and practical support, which may include various disability aids and appliances such as a bed hoist, and continued assistance with all aspects of personal care and daily living – changing bed clothes, washing, toileting and feeding.

- Difficulties with chewing, swallowing and digesting food mean that some people will require tube-feeding or parenteral nutrition.

Kingdon et al have published a comprehensive guide to visiting people at home with very severe ME/CFS (12)

**6 Clinical assessment of people with severe ME/CFS**

In addition to assessing symptoms and possible complications the **clinical history** should include, as noted in section 5, an assessment of nutritional status. Section 1.17.10 in the NICE guideline on ME/CFS recommends that people with severe or very severe ME/CFS should also be referred for a dietetic assessment by a dietitian with a special interest in ME/CFS, especially if they are losing weight, or are at risk of malnutrition.

Nutritional assessment should include a malnutrition universal screening tool (MUST) which evaluates BMI, unintentional weight loss, and acute illness.

NICE guideline G32 (13) covers identifying and caring for adults who are malnourished or at risk of malnutrition in hospital or in their own home or a care home. The guideline offers advice on how oral, enteral tube feeding and parenteral nutrition support should be started, administered and stopped. It aims to support healthcare professionals identify malnourished people and help them to choose the most appropriate form of support.

The **clinical examination** should note the presence of any complications listed above and any signs of protein energy malnutrition:

- decreased subcutaneous tissue – areas most affected are the legs, arms, buttocks, and face

- oedema - areas most affected are the distal extremities
- oral changes - cheilosis, angular stomatitis, and papillar atrophy
- abdominal findings - abdominal distension secondary to poor abdominal musculature; hepatomegaly secondary to fatty infiltration
- skin changes - dry peeling skin with raw exposed areas; hyperpigmented plaques over areas of trauma
- nail changes - nails may become fissured or ridged
- hair changes - hair is thin, sparse, brittle, and easily pulled out and may turn a dull brown or reddish colour

The NICE guideline list of basic **investigations** that are used in the process of diagnosing ME/CFS should be checked if not recently done. People with very severe ME/CFS are at risk of vitamin D deficiency – so the vitamin D level should be checked.

Note that prolonged immobility can cause metabolic disturbances resulting in a raised level of calcium, lowered level of sodium and potassium imbalance,

## 7 Disability Rating Scales

The MEA has a Disability Rating Scale that provides basic descriptions of disease severity that can be used for monitoring and other purposes (14).

Jahanbani et al have produced a disability rating scale that provides five different grades of extremely severe ME/CFS (15).

## 8 Authorship and acknowledgements

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## 9 Addendums

A SNOMED code for very severe ME/CFS has now been issued: https://meassociation.org.uk/2026/05/a-step-forward-in-recognition-new-very-severe-me-cfs-snomed-ct-code/

## 10 References


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4 DHSC Delivery Plan

https://www.gov.uk/government/publications/mecfs-the-final-delivery-plan/myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs-the-final-delivery-plan

5 NHS England e-learning modules on severe ME/CFS:

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6 Prevention of Future Deaths Report for Maeve Boothby O'Neill and responses from MRC, NICE, NHS England etc:

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13 NICE guideline 32: Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition

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14 ME Association Disability Rating Scale: https://meassociation.org.uk/2024/04/the-me-association-disability-rating-scale/

15 Extremely severe ME/CFS rating scale

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