Management of severe and very severe ME/CFS

Science for ME Fact Sheet by Prof. Jonathan Edwards and S4ME members

ME/CFS is a long-term illness, often life-long. It leads to major disability through generalised symptoms that we do not yet understand the cause of - feeling ill, exhausted, weak, and in pain, difficulty staying standing or sitting up, disturbed sleep pattern and problems thinking or concentrating (see Science for ME “Introduction to ME/CFS” Fact Sheet). In severe cases, the symptom burden means that the person is not only unable to work or go to school but is also confined to home or a single darkened room. In very severe cases, support is needed for basic personal activities like feeding, washing and toileting.

People with ME/CFS find that physical or mental exertion and environmental stimuli, including light, sound, touch and odours can be followed by a severe and prolonged exacerbation of symptoms and disability known as post-exertional malaise (see Science for ME “Post-Exertional Malaise” Fact Sheet).

There are no theory-based approaches to treatment shown to be of benefit. Regimens based on speculative theories, whether of brain blood flow, mast cell sensitivity, energy metabolism, HPA axis dysregulation, deconditioning or psychosomatic influences should be avoided. We do not know what ought to be the best way to manage ME/CFS. That being the case, care must focus on practical steps to minimise symptoms. Patients and carers should be encouraged to work out what routine works best for the individual, rather than being given protocols based on expectations that may not apply.

It is essential for health professionals to understand that ME/CFS presents a unique problem in terms of supportive care. Minimising environmental stimuli and demands on exertion is not simply a matter of kindness, as it would be for any other condition. It is a matter of protecting patients from the risk of subsequent deterioration, which in some cases is long term and irreversible. We have no understanding of why this should be, but it is a consistent experience for people with ME/CFS that must be respected at least until such time as we have an effective means of treatment.

Causes of severe/very severe ME/CFS

Susceptibility to ME/CFS appears to be greatest in teenage years and again in the mid-thirties in both sexes (McGrath et al 2026). It is more common in women and certain autosomal gene regions contribute a further level of risk (Boutin et al., 2025). Onset is often reported to follow an infection, in particular Epstein-Barr virus or Covid-19.

The symptoms of ME/CFS overlap to a large degree with those of resolving post-viral fatigue, which usually lasts for a period of months after such infections (including Covid-19), including some symptom exacerbation after exertion. However, the category of ME/CFS implies a longer course, often fluctuating or progressive, over a period of years. When ME/CFS becomes severe or very severe this is often years after initial onset. There are many reports of worsening occurring after courses of exercise-based treatment (Kindlon, 2019; McPhee et al., 2019) and also after infection with Covid-19.

The mechanism of this deterioration is not understood. The main clues are the link to infections and a genetic risk located in DNA regions associated with pain and both neural and innate immune signalling (Boutin et al., 2025). As yet, we know too little to inform any specific aspects of care, beyond avoidance of factors reported to be followed by prolonged worsening, including not only exertion and infection but also environmental stimuli.

The experience of severe/very severe ME/CFS

People with severe or very severe ME/CFS find it hard to describe their experience, being unlike anything they experienced in normal life. At best, they may struggle to carry out basic activities like washing and preparing food, but beyond brief periods of exertion they may find it physically impossible to carry on. At worst, they are overwhelmed by symptoms such as nausea and pain. They are unable to move, and the only tolerable position is lying flat.

Exertion or environmental stimuli can tip the person from a stable functional state to a very severe state for prolonged periods. Very severe cases may deteriorate progressively.

Worsening of symptoms is associated with a loss of capacity, such that the person requires increasingly comprehensive care, which may include artificial nutritional support. People with ME/CFS tend to move between levels of severity gradually or suddenly in either direction multiple times over the course of their illness. Some will improve from severe or very severe levels. Many do not. Care planning for an individual needs to cover all ranges of severity.

Severe and very severe grading

Definitions of severity vary and are arbitrary but are probably best linked to care needs.

In severe ME/CFS the person is housebound, the capacity for sitting and standing is very limited, so they need to lie down for much of the day and need some help with personal care, food preparation and mobility. Trips outside the home can cause major setbacks, so domiciliary care provision is needed.

In very severe ME/CFS the person is bedridden with very severe sensory and exertion sensitivity. They need total care, adapted to orthostatic intolerance and sensory sensitivities, including to touch, sound, light and movement. They may struggle with nutrition and need support with feeding including enteral or parenteral feeding.

Prevalence of severe/very severe ME/CFS

The number of people with ME/CFS at any one time is something between one in two hundred and fifty and one in a hundred (Nacul, 2011; Boutin et al., 2025). (As for any condition in which there are borderline cases there is probably no more precise figure.) It is estimated that about a quarter of people with ME/CFS fall into the severe or very severe categories. That suggests that about one person in a thousand may be housebound with ME/CFS. Very severe cases requiring comprehensive care are likely to be much less numerous. An estimate of about one in a hundred thousand has been suggested for the UK but it may be considerably higher.

Medical assessment

A diagnosis of ME/CFS is used to describe generalised debilitating symptoms as above, with post-exertional malaise, of no identifiable cause, sufficient to have a major impact on daily living. ME/CFS needs to be differentiated from a range of neurological, endocrine and other conditions which may mimic it in early stages, and it is particularly important in severe/very severe cases to review the diagnosis at least annually to ensure that other conditions have not become apparent. Significant long term rates of revised diagnosis have been reported (Devasahayam et al., 2012).

Treatment

There are currently no evidence-based treatments directed specifically at ME/CFS, other than practical measures to reduce symptom burden. Where symptoms such as pain or tachycardia are covered by drugs with general application these can be used. However, people with ME/CFS may have difficulty tolerating certain drugs. A number of drugs have been widely prescribed for people with ME/CFS based on weak theoretical evidence and anecdotal clinical experience. These include antihistamines, naltrexone, fludrocortisone and ivabradine. Partly due to the emergence of 'Long Covid' several of these drugs are now undergoing formal trials. However, evidence to date suggests that they probably produce little or no benefit and are more likely to produce adverse effects.

Rationing activity, in order to avoid symptom worsening following exertion, is referred to as pacing (for more detail see under 'Preventing deterioration'). Most people with ME/CFS find this important. However, there is no theoretical basis for focusing on physiological measures such as energy usage or heart rate.

In the past there has been a view that symptoms can be improved by deliberately increasing challenges in terms of exertion or environmental stimuli. There is no evidence for this being beneficial and there are many reports of worsening. Rehabilitation-based approaches have produced no significant benefits or impact on prevalence and have no place in management (Wearden et al., 2006; Wilshire et al, 201; Gaunt et al., 2024).

Care at home

Most people with severe/very severe ME/CFS cannot tolerate visits to surgeries or hospitals. Most care should be on a domiciliary basis or online. Very severe patients are likely to find internet interaction difficult or impossible, however.

Perhaps the most important contribution that can be made to care is provision of contact with a single health professional such as a specialist nurse with a deep understanding of the current state of knowledge about ME/CFS who can provide a fixed point around which the person with ME/CFS can build a sense of context and safety. Ideally this professional would liaise directly with a physician with specialist knowledge of the condition involved in initial assessment and diagnosis. Multidisciplinary teams of professionals assigned to different aspects of care are likely to be counterproductive.

General practitioners may be in a position to provide domiciliary support, but most will have little experience of managing severe and very severe ME/CFS cases and limited knowledge of the disease. District nurses may be able to provide services such as blood tests, vaccinations and blood pressure readings on a domiciliary basis. However, for very

severe cases a single professional such as a nurse specialist attached to a physician-led hospital unit is likely to be much better placed to combine care activities in an efficient and supportive framework.

Provision of aids and adaptations

Quality of life for people with severe/very severe ME/CFS and their carers can be very dependent on provision of aids such as wheelchairs, lifts, adjustable day-beds and aids for washing in bed, as for anyone with physical disability. A home-based Activities of Daily Living (ADL) assessment is an essential part of care. Aids for limiting environmental stimuli such as blackout curtains and ear defenders also need consideration.

Disability assessment

People with severe/very severe ME/CFS require assessments for work or education capacity and financial support. Provision must be made both for gathering information and for writing medical reports as required. Assessment needs to be based on an understanding of the fluctuating nature of ME/CFS and the limits on exertion.

Children with severe/very severe ME/CFS require detailed assessment by someone familiar with demands of education and options for provision of education within limited exertional resources. The FUNCAP questionnaire can provide a useful basis for assessment of function.

Preventing deterioration

Careful attention is required to reduce exertion and control environmental stimuli while supporting daily needs such as feeding and toileting, in order to avoid deterioration and unnecessary hospitalisations. The aim is to avoid activities where exertion leads to symptom worsening and to control environmental stimuli while also supporting quality of life by providing resources for activities and communication routes, such as the internet, the person can still make use of.

When first faced with ME/CFS people appreciate basic advice on how to pace their activities to minimise risk of symptom exacerbation. However, there is no evidence for value in any specific policies requiring wearable actimetry devices or activity diaries. Every person's requirements are likely to be different and unpredictable. Detailed focus on activity levels is likely only to distract from finding a means to live as well as possible

within exertion constraints (and all too easily leads to a ‘pacing-up’ agenda with activity increments).

Reducing environmental stimuli may help reduce symptoms but requirements will depend on the individual. Lighting can be reduced with curtains or dimmable lights. Limited access to sunlight may contribute to Vitamin D deficiency, which is likely to be an issue for all severe/very severe cases, and require supplementation. Sound can be reduced with ear defenders or earplugs and by reducing talking during visits. Scented toiletries and cleaning products may be best avoided. Movements when adjusting bedding or giving care may need to be slow and gentle and the person with ME/CFS should be warned about movement and touch beforehand. A position-adjustable hospital-style bed may be useful, to optimise positioning for orthostatic intolerance and feeding. Hoists and wheelchairs can both reduce unnecessary exertion and optimise scope for activities that can be tolerated.

If multiple carers are to be involved in home support it is likely to be useful to have an agreed set of guidelines for interacting with the person with ME/CFS, in terms of, for instance, speaking slowly and quietly, level of tolerable light.

Joint contractures can potentially occur with disuse, the most likely probably being plantar flexion at the ankle from the pressure of bedclothes. Passive movement and re-positioning and cradles for bedclothes may be needed.

Nutritional assessment and support

People with very severe ME/CFS have a high risk of malnutrition and unintended weight loss (Baxter et al, 2021). They may become unable to tolerate the exertion and sensory stimulus of eating and drinking but, as for other problems in ME/CFS, the precise mechanism is not understood. Other specific reasons for nutritional failure, such as motility problems, need to be kept in mind but are probably over-diagnosed. There is no evidence for any benefit from psychological measures; nutritional support for ME/CFS cases should not be delayed on the grounds that the problem is ‘functional’.

People with severe and very severe ME/CFS should be regularly screened for risk of malnutrition at clinic appointments, domiciliary visits and on admission to hospital. If there is major concern they should be referred to a specialist nutrition support team. Domiciliary carers should be trained in using a formal nutritional assessment such as the MUST system.

In order to ensure adequate nutritional intake, a stepwise approach should be taken.

Food-based approach

The first step in nutritional management involves trying to make normal oral intake easier. This may include providing food and drink little and often, making use of drinks and snacks with high nutrient content and providing food in forms easy to chew and swallow. It may include eating and drinking aids (modified spoons, cups etc.) for feeding while lying flat. Family or professional carers need to have clear responsibilities for food preparation and feeding support and an adequate understanding of the nutritional requirements.

If nutrition is not maintained with standard foods and drinks and weight loss continues liquid oral nutritional supplements may be used.

Enteral tube feeding

Enteral tube feeding should be considered if oral nutrition support strategies fail to meet nutritional needs, and nutritional status continues to decline, based on inadequate or unsafe swallow and a functional and accessible GI tract. A nasogastric tube may be useful for short periods but is often not well tolerated. If nutrition is likely to be a long-term problem a gastrostomy or jejunostomy is required.

Enteral tube feeding carries risks of local complications but should not be denied on grounds that the reasons for failure to maintain nutrition orally are often not well-defined in ME/CFS.

Parenteral nutrition

Parenteral nutrition (intravenous feeding) is rarely required. It carries greater risks, such as line infection, than enteral tube feeding, and is difficult to maintain for long periods. However, it may be necessary, at least in the short term, if there are reasons why nutrition cannot be maintained enterally.

People with severe/very severe ME/CFS often suffer with major orthostatic intolerance problems. It has been suggested that encouraging salt and fluid intake may help with this, although the value of fluid supplementation beyond the very short term has not been demonstrated. High fluid intake may simply increase the need to pass urine. People on parenteral nutrition will receive fluids as part of their total intake. However, there is no convincing evidence of benefit from intravenous fluid supplementation purely as a management of orthostatic intolerance.

Hospital admission

Hospital admission for a person with severe/very severe ME/CFS may be necessary for intercurrent medical problems. Hospital environments present many problems in terms of noise, movement, light, smells and extra exertion. Reasonable adjustments need to be made to make the hospital environment tolerable for a person with ME/CFS. These adjustments need to be factored in to planned admissions. A national or regional advisory service should be in place to assist with planning.

As emphasised in the introduction, the need for reduction in stimulation from exertion and environment for people with ME/CFS is a unique situation, being a medical necessity rather than a matter of kindness. In the absence of effective treatments, it is one of the few positive aspects of care we can offer, with major potential impact on long-term disability.

Hospital admission is not indicated for care of ME/CFS per se unless there are specific complications such as nutritional failure. Such cases should be admitted to units with specific expertise in managing nutritional support for very severe ME/CFS.

A recurring issue has been the question of a safe position for enteral tube feeding. People with very severe ME/CFS have difficulty maintaining anything other than a flat position. There appears to be no clear evidence for this position being less safe than with the trunk propped up for fully conscious people with competent reflexes (Page et al., 2019). Nevertheless, usual care with tube placement and careful control of feed volumes is essential.

Another recurring problem is withdrawal of drugs on admission to hospital. People with ME/CFS are often prescribed drugs for symptomatic control with a doubtful evidence base. These drugs may be considered unnecessary but there is no justification for withdrawing them at the time of a hospital admission, when such withdrawal is likely to add to other stresses produced by the inpatient environment.

In general terms the minimum reasonable adjustment for inpatient environment for a person with severe/very severe ME/CFS includes a single room, effective blinds for reducing light during the day and full darkness at night, freedom from intrusive noise and no use of scented cleaning products. Communication needs should be considered, including ready access to a staff alert signalling system and written rather than spoken messaging if needed.

If a person with severe/very severe ME/CFS is to be moved around the hospital for investigations they need to be accompanied by someone who understands their needs, for example, for lying flat and protection from sound, and who can ensure that exposure to environmental stimuli and change in position are minimised.

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