



Safer Hospital Care for Severe ME

Information for health providers

August 2024

ME (also known as ME/CFS) is a neurological disease with widespread dysfunction of the immune system and impaired cellular energy capacity. Severe ME has been described as a 'living death' because of the level of disability and suffering it causes. Severe ME patients are as ill as AIDS patients in the final weeks of life, but they can survive in this state for years or decades.

Current Challenges in Hospital Settings

People with Severe ME live with the hallmark characteristic of Post Exertional Malaise (PEM) coupled with constant crushing fatigue and unrelenting pain plus extreme sensitivity to stimuli such as touch, noise, light and smells/odour leaving them both confined to their bed and home

PEM is an acute worsening of symptoms after even minimal physical, mental, or emotional exertion. For Severe ME patients, even minimal sensory overload (light, sound, smell, touch) can induce painful and disabling PEM that may last days, weeks, or permanently. Severe and very severe patients may experience periods of paralysis and are completely reliant on caregivers for their survival.

Leaving the house is such a dangerous prospect for people with Severe ME, that they will only consider going to hospital, whether due to ME or other medical issue, in a dire emergency. Just travelling in a car or ambulance and interacting at reception is likely to be impossible for most and could have neurological impacts that trigger a huge reduction in their quality of life for months to follow. A **hospital admission is a huge risk** and needs to be acknowledged as such by health authorities.

Unfortunately, most individuals with Severe ME report poor experiences in hospital settings. Stigma, misunderstanding, environmental sensitivities and inadequate care can often result in dramatically increased suffering and early and ill-advised discharge into the community.

Alternatives to Hospital Admission

To assist Severe ME patients to avoid risking extreme PEM and baseline deterioration with unnecessary hospital admissions, medical authorities should seek to offer **remote consultations, home visits and palliative care**. If hospital admission is imperative, people with energy-limiting conditions will need **ME-sensitive transport, dim lights and flat surfaces to lie on** in waiting areas or a stretcher in a separate darkened room.

The onus should be on medical authorities to coordinate multi-disciplinary, connected and continuous care rather than forcing the severely ill to waste scarce energy on driving the process, risking further deterioration. There should also be an acknowledgement of intersectional challenges and poverty, compounding difficulties of obtaining treatment.

Improving Hospital Care for People with Severe ME

Best practices to prevent exacerbating PEM and causing unnecessary harm:

- 1. LISTEN to ME:** Listen to people with ME and their carers who have lived experience of the condition. Develop personalised care plans with family members and/or carers that respect their knowledge of the patient's unique needs. Do not ignore their requests to protect the patient from actions they know to trigger PEM. Take advice from ME specialists on all aspects of care including the dangers of PEM.
- 2. Educate healthcare staff:** Provide comprehensive training to healthcare professionals on ME, particularly the severe form of the condition, and common comorbidities. Discredited treatments CBT and GET are inappropriate for Severe patients and may cause deterioration. Consider appointing a specialist nurse or OT in each hospital to act in an advisory capacity.
- 3. Allow advocates:** Allow a family member or carer to stay at all times if requested by the patient. Obtain consent from the outset to have a family member or advocacy worker to speak on their behalf.
- 4. Safeguard rest:** Undisturbed sleep is vital to prevent decline. Respect the patient's need for strict pacing of activities to survive hospital admission and prevent adrenaline surges. Eliminate all non-essential interaction, move slowly and quietly around the patient.
- 5. Ensure a low-stimulus environment:** Prioritise allocation of private single side rooms that are soundproofed and dimly lit. Minimise chemical or fragrance smells, sensory overload and physical contact. Work with carers to establish sustainable temperature levels and access times.
- 6. Support nutritional care:** Recognise that people with Severe ME have acute food intolerances and may not have enough energy to swallow or digest. Allow special diet foods, flexible meal times and adjusted feeding positions. Initiate IV hydration, oral nutrition support, enteral tube feeding or parenteral nutrition where appropriate.
- 7. Enable medication management:** Most people with ME have extreme sensitivities and potential adverse reactions to drugs. Start medications one at a time and taper up slowly from a fraction of normal dose to avoid harm.
- 8. Respect reasonable adjustments:** People with Severe ME need dark glasses, headphones or earplugs/ear defenders and eye-masks. They usually have orthostatic intolerance and need to lie flat at all times. Many are hypermobile and hypersensitive to touch and simple movement may cause pain for weeks afterwards. Be guided by caregivers.
- 9. Prioritise communication:** It is vital to provide clear and compassionate communication with cognitively compromised patients and their families, and involve them in decision-making processes. If patients can tolerate conversation, speak slowly and quietly; provide additional time for them to process information.
- 10. BELIEVE ME:** Severe ME has a [much lower quality of life](#) than cancer, stroke, MS and chronic renal failure. Patients should be treated with respect, their physiological disease recognised, and their symptoms addressed. Please don't magnify distress with disdain or medical gaslighting.

By fostering an informed and compassionate healthcare environment, the hospital experiences and overall well-being of people with Severe ME can be substantially improved.

Acknowledgements

The content of this leaflet is drawn from:

NICE guideline [NG206] for ME/CFS: diagnosis and management 2021

<https://www.nice.org.uk/guidance/ng206>

World ME Alliance: Safer hospital care for severe ME

<https://worldmealliance.org/2024/08/safer-hospital-care-for-severe-me-severemeday-2024/>

More resources

Dialogues videos: Doctors and patients explain the symptoms and management of severe and very severe ME (links to further resources are included) -

<https://www.dialogues-mecfs.co.uk/films/severeme/>

ME/CFS CPD Module by Dr Nina Muirhead - FREE online CPD module composed of 10 clinical cases assessing your knowledge of ME/CFS. Receive a 1 Hour CPD Certificate on successful completion of this module - <https://www.studyprn.com/p/chronic-fatigue-syndrome>

Severe ME/CFS CPD short module by Dr Nina Muirhead - This is an updated free short version of the above training but for the severely affected person with ME/CFS. This also offers CPD Certification -

<https://mecfs-med-ed.org/2023/08/09/new-free-short-module-on-severe-me-cfs/>

A Severe ME-aware nursing model, by Greg Crowhurst RNLD, PgDip

[https://asquifyde.es/uploads/documentos/METCO-A-Severe-ME-Nursing-Model-%20\(Inglés\).pdf](https://asquifyde.es/uploads/documentos/METCO-A-Severe-ME-Nursing-Model-%20(Inglés).pdf)

Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, by JG Montoya, TG Dowell, AE Mooney, ME Dimmock, L Chu. Healthcare 2021, 9, 1331 -

<https://doi.org/10.3390/healthcare9101331>

Identifying and Managing Suicidality in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, by L Chu, M Elliott, E Stein, LA Jason. Healthcare 2021, 9, 629. -

<https://doi.org/10.3390/healthcare9060629>

Life-Threatening Malnutrition in Very Severe ME/CFS, by H Baxter, N Speight, W Weir. Healthcare 2021, 9, 459. - <https://doi.org/10.3390/healthcare9040459>

Extremely Severe ME/CFS—A Personal Account, by W Dafoe. Healthcare 2021, 9, 504 -

<https://doi.org/10.3390/healthcare9050504>

Severe ME in Children, by N Speight. Healthcare 2020, 8, 211 -

<https://doi.org/10.3390/healthcare8030211>



Severe ME Day, held on the 8th of August each year is dedicated to shedding light on the experience of people with the most severe forms of ME enduring a life of relentless suffering in darkened rooms, as well as honouring those who have tragically lost their lives to this debilitating condition.