

SEVERE ME/CFS AND LONG COVID IN SECONDARY CARE

Guide to management during patient hospital stays

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

WHAT IS ME/CFS?

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a long-term, multi-systemic illness involving the nervous, endocrine, autonomic, and immune systems. Primary symptoms include severe fatigue, post-exertional malaise (PEM), unrefreshing sleep, cognitive impairment, and orthostatic intolerance. There are 100-200+ symptoms that can present in patients and their impact can vary greatly among individuals, making diagnosis and management complex and individualised.

LONG COVID AND THE OVERLAP WITH ME/CFS

Long COVID is characterised by persistent, unexplained symptoms following infection with COVID-19 (SARS-CoV-2 infection), lasting more than 12 weeks and not explained by an alternative diagnosis.

Both conditions share similarities including: extreme fatigue, cognitive dysfunction, and PEM or post-exertional symptom exacerbation (PESE). Up to 50% of all long COVID cases will fit the IoM (2015) and International Consensus Criteria (ICC) diagnostic criteria for ME/CFS.

SEVERE ME/CFS SYMPTOMS:

Severe symptoms include intense muscle and joint pain, headaches, and sore throat that do not respond to standard pain medications. Patients may experience extreme sensitivity to light, sound, touch, and chemicals, which can worsen other symptoms. Impaired mobility often necessitates the use of a wheelchair or results in being bed-bound for extended periods. Severe gastrointestinal issues, such as abdominal pain, irritable bowel syndrome (IBS), nausea, and other digestive disturbances, are common. Under-nutrition or malnutrition can result, and tube feeding may be required.

Additionally, patients have increased susceptibility to infections and prolonged recovery times due to immune dysfunction. All hospital staff that interact with the patient during their admission should ensure they wear masks and protective clothing that they put on and remove before and after visits with the patient - to protect the patient from contracting infections.

The Severe-Very Severe category accounts for an estimated 25% of all ME/CFS cases and require significant medical and care assistance.*

The Severe category are considered housebound and the very severe are bedbound. At times during the course of their chronic illness, hospital admission may be required for the treatment of undernutrition, infections, orthostatic or dysautonomic issues, etc. Ensure the admission process is as quick as possible. Patients may need to lie flat even during this time. You may also need to stagger investigations and use the least invasive techniques (where possible) to conserve their energy.

*www.ncbi.nlm.nih.gov/pmc/articles/PMC8535418/

*[www.mayoclinicproceedings.org/article/S0025-6196\(23\)00402-0/fulltext](http://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/fulltext)



SYMPTOM MANAGEMENT IN HOSPITAL

Environmental Adjustments:

Lighting: Dim lighting to reduce sensory stress. Be aware patients may wear eye masks to combat this.

Noise: Minimise noise; provide a quiet or soundproofed environment. Patients may wear noise cancelling headphones.

Room: Offer a private room to limit sensory exposure and interruptions.

Disruptions: Minimise nighttime interruptions.

Smell: Be aware that odours, perfumes, cleaning chemicals, etc, can cause symptom flare ups in some patients who are especially sensitive, or may be distressing if they are very sensitive to odours/smells.*

Medication and Nutrition

Medication: Avoid histamine-releasing anaesthetics and muscle relaxants. Use medications like propofol, midazolam, and fentanyl (generally well-tolerated but use always with caution).*

- Start with low doses and monitor for adverse reactions.
- Check for allergies, sensitivities and intolerance before giving medications or swabbing skin.
- Be cautious with sedatives and other medications that could exacerbate symptoms.

Hydration: Monitor and maintain hydration, considering IV saline if necessary.

- IV saline can be used to manage orthostatic intolerance, and low blood pressure and volume.

Nutrition: Allow special diet foods, flexible meal times, and adjusted feeding positions. Use oral nutrition support or tube feeding if necessary.

NOTE: Some patients may need to bring their own food, water, or other necessities due to chemical and food intolerances, and sensitivities

Activity and Rest:

Any form of interaction, such as being spoken to or exposure to light, can trigger a reaction causing PEM. Encourage extreme caution with any activity and prioritise rest to avoid exacerbating symptoms. Activity pacing should be individualised, recognising that even minimal exertion can lead to significant setbacks for the patient.

Communication and Cognitive Support:

Compassionate Communication: Give extra time for patients to process information. Involve them in decision-making and speak clearly and gently.

Cognitive Impairment: Simplify communication, provide written instructions of any care discussions and management plans, and involve family or caregivers in discussions. Recognise and involve family and caregivers as representatives for the patient, with the patient's permission, especially when the patient cannot communicate easily. Many very severe ME/CFS patients require 24/7 care and rely on family to advocate for them. Acknowledge their role even without formal EPOA/medical proxy forms.

Care and Support:

Emotional Support and Validation: Recognise the psychological impact and acknowledge severity of condition. Make an active effort to reduce their anxiety as it can worsen the condition. Treat patients with respect and take their symptoms seriously. Provide access to counselling and mental health support if needed.

Role of Advocates: Allow a family member or carer to stay with the patient at all times if requested. Include an advocacy worker to speak on their behalf if needed.

Personalised Care: Always listen to the patient and their caregivers. Use their insights to create personalised care plans.

Support Groups: Connect patients with local support groups and resources for additional support and advocacy.

Remote and Home Care: Recommend remote consultations and home visits to avoid unnecessary hospital admissions. Provide ME/CFS-sensitive transport options and appropriate waiting areas in hospitals.

*www.mayoclinic.org/diseases-conditions/chronic-fatigue-syndrome/symptoms-causes/syc-20360490

*<https://drlapp.com/resources/advice-for-pwcs-anticipating-anesthesia-or-surgery/>



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