Supporting People with Severe and Very Severe ME/CFS: A Resource Guide for Clinicians

"*Severe and very severe ME/CFS represents one of the most profound states of disability found in medicine.*" - Bateman Horne Center USA

What is ME/CFS?
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a serious multisystem disease causing neurological, immunological, autonomic, and metabolic dysfunction. The hallmark symptom is *post-exertional malaise* (PEM)—a worsening of symptoms after minimal effort (physical, cognitive, or sensory). ME/CFS is classified by the WHO as a neurological disease and affects an estimated 50 million people worldwide.

Severe and Very Severe ME/CFS
Around 25% of people with ME/CFS are housebound or bedbound. Severe patients:

- Experience extreme pain and energy loss, gastrointestinal and sleep disturbance, and orthostatic intolerance
- May struggle to or be unable to speak, process information, tolerate light, noise, fumes or touch
- May require help with feeding, washing or going to the toilet
- May be unable to tolerate standard medical environments or interventions
- May need intravenous fluids, or tube feeding if very severely affected

Despite their severe loss of function, these patients often remain unseen and underserved by health systems. This is especially true for those with marginalised racial or gender identities.

Urgent Care Principles

- **Do no harm**: Pushing a patient to exceed their energy limits can worsen disability irreversibly. Avoid unnecessary transfers and exertion.
- **Respect sensory limits**: Provide care in a quiet, dark room. Limit touch, conversation and scents. Allow the patient to communicate in their preferred way, including with help from family or friends.
- **Respect pacing plans:** Support patients to pace their energy across necessary tasks. Be aware that doing a task once does not mean it can be safely repeated.
- **Support basic needs**: Offer gentle help with hygiene, toileting, and feeding. Use low-exertion nutrition (soft foods, shakes) or tube feeding if needed.
- **Provide supine transfer**: Many patients cannot sit or stand due to orthostatic intolerance.
- **Home care or telehealth** is often preferred and safer than hospitalisation.

Important Note on Harmful Approaches
ME/CFS is a neurological disease, not a psychiatric condition.

While patients may experience secondary psychological distress due to prolonged illness and isolation, ME/CFS itself is not caused by deconditioning, anxiety, depression or other psychological processes. Graded exercise therapy is never appropriate. Psychotherapy aimed at reversing ME/CFS is not appropriate. These interventions can worsen symptoms and lead to deterioration.

People with Severe and Very Severe ME are vulnerable to abuse because of their need for significant care. For stabilisation or improvement to occur, a calm and supportive environment is crucial.

Recommended Resources
Please refer to the following reliable, evidence-based sources for more detailed care recommendations:

- **Bateman Horne Center: Clinical Care Guide 2025** pg 49
  batemanhornecenter.org/clinical-care-guide/
- **UK NICE Guideline: ME/CFS – Diagnosis and Management 2021** section 1.17
  nice.org.uk/guidance/ng206
- **US CDC: Clinical Care for Severely Affected Patients 2024**
  cdc.gov/me-cfs/hcp/clinical-care/me-cfs-clinical-care-for-severely-affected-patients.html
- **Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis /Chronic Fatigue Syndrome - Jose Montoya et al 2021**
  https://www.mdpi.com/2227-9032/9/10/1331
- **Life-Threatening Malnutrition in Very Severe ME/CFS - Helen Baxter et al 2021**
  https://www.mdpi.com/2227-9032/9/4/459
- **Mayo Clinic: Diagnosis and Management of ME/CFS - Stephanie L. Grach et al 2023**
  https://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/fulltext
  French translation https://cloud.millionsmissing.fr/s/4438LjtonpJk2Zj
- **Video: Dialogues of a Neglected Illness: Severe and Very Severe ME/CFS**
  https://www.dialogues-mecfs.co.uk/films/severeme/
- **World ME Alliance: Safer Hospital Care for Severe ME**
  www.worldmealliance.org/severe-me

Thank you for providing compassionate, evidence-based care.

*Compiled in partnership with the **Severe ME Advocacy Group**.*