



"Severe ME in 60 seconds"



Severe-Very Severe Myalgic Encephalomyelitis: What GPs need to Know 60-second Guide



Severe-Very Severe ME = profound multisystem disability.

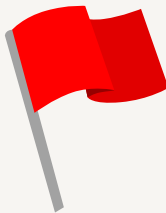


Patients May be:

- bedbound or room-bound
- unable to tolerate light, sound, touch
- unable to sit upright
- unable to speak more than a few words or non-verbal
- unable to eat normally due to GI dysfunction
- experiencing severe orthostatic intolerance or other dysautonomia
- experiencing extreme pain or sensory overload
- unable to attend clinic appointments

In Severe ME the patient may tolerate small transfers from bed to chair to toilet.

In Very Severe ME the patient is completely bedbound, requiring all care from others.



Red Flags for Severe ME

If a patient or their whānau/advocate reports:

- crashes lasting days to weeks
- inability to perform ADLs
- hypersensitivity to light/sound
- inability to stand or sit upright
- severe cognitive dysfunction
- severe dysautonomia
- inability to tolerate visitors or stimulation
- unable to communicate some days

→ Treat as Severe ME.
Do NOT recommend activity increases.
Do NOT use GET approaches.



Immediate Actions

- Protect from PEM triggers
- Provide home-based care options
- Refer to NASC (document ADL/IADL impairment)
- Coordinate MDT support (pain, GI, autonomic, mobility)
- Use low-stimulus communication (short visits, dim light, quiet voice)
- Utilise ANZMES Care Plans
- Work with whānau to adapt care plans to patients' needs
- Refer the patient and their family/advocate to their local support group
- Subscribe to M.E. Time for useful resources and evidence-informed education for you and your patients/whānau
- Register for Know M.E.

Why it Matters

**1 in 30 people in New Zealand have ME or Long COVID with ME-like features
That's 180-185,000 people.**

25% of ME cases are too sick to leave their rooms.

This invisible cohort lives with Severe ME.
Early recognition prevents deterioration.
Safe care prevents harm.

**Find out about
Know M.E.
Clinical Education
Programme
Earn CME/CPD**

