



SUPPORT WORKER SCREENING HANDOUT

Very Severe Myalgic Encephalomyelitis (ME)

As of 22 December 2025

Purpose of This Handout

This document is provided **before engagement** to ensure shared understanding of:

- what very severe ME is
- how support must be delivered safely
- whether this role is a suitable fit

This role requires **precision, consistency, and restraint**. It is not suitable for all workers.

What Is Very Severe ME?

Myalgic Encephalomyelitis (ME) is a **serious neuroimmune disease**.

In **very severe ME**, the person is:

- **bedridden and homebound**
- physiologically fragile
- unable to tolerate exertion, stress, unpredictability, or rushed care

The core feature is **Post-Exertional Neuroimmune Exhaustion (PENE)**: even minimal physical, cognitive, emotional, or sensory exertion can cause **disproportionate and prolonged worsening of symptoms**.

This is **not fatigue**, and it is **not psychological**.

What This Support Role Involves

Support focuses on **maintaining stability and preventing harm**, not improvement or progression.

Support workers may be required to:

- assist with personal care and basic daily tasks
 - follow established routines **exactly**
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- maintain a calm, low-stimulus environment
- work quietly and slowly
- respect written instructions without deviation

Workers are **not expected** to motivate, rehabilitate, encourage activity, or introduce changes.

How Support Must Be Delivered

Safe support for very severe ME requires:

- **predictability and consistency**
- unhurried, low-stimulus care
- minimal verbal interaction
- adherence to written guidance

Rushed, task-focused, or efficiency-driven care causes harm.

Communication Expectations

- Planning and instructions are provided **in writing**
- Verbal discussion is kept to a minimum
- Instructions are to be followed **as written**, without reinterpretation or challenge

Self-advocacy by the participant reflects **clinical necessity**, not preference.

Shift Timing

Due to a **reversed sleep-wake cycle**, support is required primarily:

- **afternoons and evenings**

Morning availability is generally **not suitable** for this role.

This Role Is *Not* a Good Fit If You:

- prefer fast-paced or varied work
- rely on improvisation or “trying different approaches”
- feel uncomfortable following strict routines
- are accustomed to directive or controlling care styles
- believe clients should be encouraged to push through symptoms

These approaches are unsafe in very severe ME.

This Role *May* Be a Good Fit If You:

- value calm, predictable work
- are detail-oriented and reliable
- are comfortable with quiet, routine-based care
- respect boundaries and written instructions
- understand that “doing less” can be the safest care

Key Expectation

Competence is essential.

In this role, competence means the ability to:

- follow instructions precisely
- respect self-advocacy
- prioritise safety and harm reduction
- maintain consistency over time

Workers who are competent in other settings may **not** be competent for this role due to the specific clinical requirements of very severe ME.

Final Note

This screening is intended to protect:

- the participant’s health and safety
- workers from being placed in unsuitable roles
- providers from preventable service breakdown

If this role does not align with your skills or preferences, that is respected.

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Framework of Case Definition and Primer in this document:

Myalgic Encephalomyelitis International Consensus Criteria (ME-ICC)

<https://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x>

ME International Consensus Primer for Medical Practitioners (ME-ICP)

<https://tinyurl.com/meicp2012>

Literatures may be referred:

ME/CFS – the Severely and Very Severely Affected

[https://mdpi-](https://mdpi-res.com/bookfiles/book/8496/MECFS_the_Severely_and_Very_Severely_Affected.pdf?v=1704392572)

[res.com/bookfiles/book/8496/MECFS_the_Severely_and_Very_Severely_Affected.pdf?v=1704392572](https://mdpi-res.com/bookfiles/book/8496/MECFS_the_Severely_and_Very_Severely_Affected.pdf?v=1704392572)

Position Statement:

Myalgic Encephalomyelitis Group Australia Ltd (MEGA) intentionally uses the name Myalgic Encephalomyelitis (ME) in alignment with the definitions and pathophysiology outlined in the ME-ICC and ME-ICP.

The term *ME/CFS* is frequently used as an umbrella label encompassing multiple, often incompatible, case definitions.

By adhering to the ME-ICC and ME-ICP, MEGA is able to advocate with clarity and confidence for safe, equitable, and continuous care for people with ME (pwME).

Acknowledgement of Country

Myalgic Encephalomyelitis Group Australia Ltd (MEGA) acknowledges the Aboriginal and Torres Strait Islander peoples of this nation. We acknowledge the Traditional Owners of the land across which we work. We recognise their continuing connection to land, water and community and pay respect to Elders past, present and future.

Acknowledgement of People with Myalgic Encephalomyelitis (ME)

Myalgic Encephalomyelitis Group Australia Ltd (MEGA) acknowledges the people living with Myalgic Encephalomyelitis (ME) in Australia and around the world.

We acknowledge the harms and trauma caused by decades of systemic neglect, misrecognition of disease, exclusion from social welfare and healthcare, and the lack of meaningful advancement from publicly funded research.

We pay respect to the resilience, courage, and ongoing advocacy of people with ME, who continue to strive for recognition, rights, and justice in the face of profound barriers.

Disclaimer

The contents of this document are for informational or educational purposes only and do not substitute professional medical advice or consultations with healthcare professionals.



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