

Severe ME Day - 8th August 2025

Urgent Action Needed For Severe ME

I am writing to you as I am deeply concerned about the lack of support for New Zealanders living with Severe and Very Severe Myalgic Encephalomyelitis (ME). This Severe ME Day, August 8th, I urge you to address the critical needs of this profoundly ill and vulnerable group.

An estimated 25% of people with ME are housebound or completely bedridden, hidden from public view and trapped by a condition that can make even light, sound, or human touch unbearable. They are the unseen, and they are being failed by a system that does not understand their needs. Many require 24/7 care, often provided by desperate family members, because there are no appropriate care facilities.

This is a crisis of systemic neglect. I am asking you to push for urgent, life-saving changes for the most severely impacted in our community. On behalf of those too ill to advocate for themselves, I urge you to prioritise the following actions recommended by ANZMES, the National Advisory on ME:

1. **Fund Dedicated ME-Aware Care:** Champion funding for specialised long-term residential care facilities with staff trained by ANZMES to provide safe, compassionate care for those with Severe ME.
2. **Mandate Specific Education for Health Professionals:** Ensure all healthcare professionals receive mandated education on the management of Severe ME, including the cardinal symptom of Post-Exertional Malaise (PEM), the dangers of Graded Exercise Therapy (GET), and the need for low-stimulus environments.
3. **Ensure Disability Policies Provide for Severe Needs:** Fight to ensure that national disability support policies are updated to explicitly recognise the 24/7 and complex care needs of New Zealanders with Severe and Very Severe ME, aligning with UN recommendations.*

What specific actions will you take to ensure those with Severe ME are no longer ignored? The voices of thousands of individuals and their families are counting on your leadership.

**United Nations Committee on the Rights of Persons with Disabilities (CRPD). In its 2022 review, the Committee made a recommendation that the New Zealand government should: "Expressly include ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) in disability policy and practice, to ensure access for persons with ME/CFS to health care and disability services".*