ME/CFS AUSTRALIA

Advocacy | Education | Collaboration

The peak body for patient-led ME/CFS charities across Australia

Submission to the NDIS Support rules consultation

30 July 2025

ME/CFS is highly disabling across all domains

ME/CFS, myalgic encephalomyelitis/chronic fatigue syndrome, is a complex neuroimmune condition with Disability-Adjusted Life Year scores reflecting the severe, multi-domain impairments that affect the daily lives of people with ME/CFS:

- Mild handicap 0.137
- Moderate handicap 0.449
- Severe or profound handicap 0.760

25% of people with ME/CFS have severe or profound ME/CFS, defined as mostly housebound through to fully bedbound. Most often, NDIS participants are drawn from this group.

Few people with ME/CFS have the functional capacity for paid employment. This is particularly so for those with severe or profoundly severe ME/CFS. Additionally, family carers for this cohort may leave paid employment or reduce paid hours to support the person with severe or profoundly severe ME/CFS. Disability-related poverty is common.

Post-exertional malaise (PEM) is the unique, identifying feature of ME/CFS. It involves a pathological loss of energy and worsening of all symptoms following minimal physical, mental or emotional effort, or other triggers**.** The severity of symptom exacerbation is out of proportion to the intensity and duration of the triggering effort. When people with ME/CFS push themselves to use more than their available energy reserves, a loss in functional capacity is inevitable and cannot be reversed simply by a long rest or a good night's sleep.

Due to the unique characteristics of post-exertional malaise, **maintenance of functional capacity requires supports to reduce the energy demands of daily living and other activities.**

The complexity of ME/CFS means that many of our impairments and special support needs intersect with a range of other conditions. For example,

- Energy limitation: like other Energy Limiting Chronic Illnesses, our capacity to engage may dwindle rapidly
- Sensitivity to airborne chemicals: like asthma, we need clean air, including avoidance of fragrances
- Sensitivity to noise, light, movement: like ASD, we need quiet, calm spaces
- Inability to stay upright: like 70% of people with Long COVID and others who have POTS, we cannot remain upright for long, may not be able to sit for long, and in profoundly severe ME/CFS, may not even be able to have the head of the bed elevated
- Mobility challenges: the combination of limited energy and limited ability to remain safely upright mean that wheelchairs, transport support and other mobility assistance are essential for preventing injury and avoiding deterioration in functional capacity
- Communication challenges: we may experience slower processing and other barriers when seeking to communicate with others
- Neurocognitive challenges: we may need supports for memory, decision-making, administrative tasks and other cognitive functions

ME/CFS and the NDIS Support rules

The complexity and severity of the impairments associated with ME/CFS place our community in a strong position to reflect on the support rules.

While the concept-based approach to choice and control, for example 'reasonable and necessary', resulted in confusion and high demand for review and appeal, the lists-based approach has proven to be less simple, fair and accepted than anticipated. It is the contention of ME/CFS Australia that **no simple list can equitably reflect the complexity of the impairments, circumstances and goals of each individual with severe disability.**

Qualifying the lists

We propose that both the 'in' and 'out' lists need to be supported by qualifying remarks related to impairment, circumstances and goals.

An important form of qualifying statement must relate to the input of relevant registered professionals who are familiar with the individual, such as Occupational Therapists, Continence Nurses, Exercise Physiologists, Psychologists, and more. When a relevant registered professional indicates that a support is essential or important for an individual, that opinion needs to be respected by the decision-maker when considering the funding of that support. Where appropriate, the lists can name the professions that are relevant to the particular support. Identification of relevant professions should be done in consultation with both participants and experienced report writers. Without this form of qualifying remark, the lists become arbitrary and open to potential exploitation as shopping lists for the 'in' list or unconsidered refusals to fund for the 'out' list.

Some items on the lists could be qualified by the domain of impairment, such that the support is 'in' or 'out' for participants whose impairments are relevant to the support. Again, it is important that participants and relevant professionals assist in designing such qualifying remarks.

Cost-effectiveness should be identified as a qualifier where it is relevant to the listed item. Funding for that support could be contingent on cost-effective comparison to alternative supports to serve the same purpose. This is particularly relevant where an item in use by the wider population (an 'everyday' item) is more cost-effective than a support specifically designed for use by people with disabilities. It is also relevant to decisions about whether to fund an assistive technology or to fund support worker hours to perform the same task.

Other identified examples of qualifying remarks include: the level of mobility challenge; safety for the particular individual compared to potential benefit; prior approval of a plan with goals that relate to the support; poor availability of alternatives to the support in the participant's region, especially supply of support workers with relevant skills. Consultation may identify further important qualifiers to assist in fair decisions about funding particular supports for specific individuals.

Search function

For ease of use, the lists must be easily searched. This would need to include frequent review based on the experience of users, regarding synonyms, emerging vocabulary, common misspellings, and other challenges to easy search.

Exemptions

Participants must be able to seek an exemption through a clear process that is not a review or appeal, but a simple request for exemption from the qualifying factors based on need consistent with their Plan, including impairments and goals.

Other support considerations

Poverty

The designation of 'everyday expense' to assistive technologies that cannot be afforded by people living long-term on incomes well below the poverty line is costing the NDIS by forcing people to find more expensive solutions, such as disability-specific assistive technologies or frequent use of support workers to assist where a long-term assistive technology would suffice. ME/CFS Australia seeks assurance that poverty will not continue to disadvantage participants who cannot afford a much-needed support that currently sits on the 'out' list due to being considered an everyday expense.

Independence

People with ME/CFS can experience significant loss of independence, personal efficacy and life roles due to their impairments. We contend that for both personal safety and wellbeing, when a participant identifies that a support will increase their independence, this must be given weight in funding decisions.

Maintenance of functional capacity for people with ME/CFS

Due to the loss of functional capacity associated with post-exertional malaise, being supported to expend less energy to complete Activities for Daily Life and to meet goals is essential for people with ME/CFS. This means including funding for supports that do tasks for the individual, in contrast to the common expectation that supports will assist the participant to act with assistance. To illustrate, one example is funding meal preparation, rather than funding a support worker to assist the participant to prepare their own meals.

Evidence base for supports and therapies

People with severe disabilities are rarely represented in research cohorts, so the evidence base for supports and therapies is limited. Participants require access to supports and therapies where professional opinion can compensate for the lack of research attention.

Moving forward

ME/CFS Australia and its patient-led member charities would welcome engagement with the NDIS on refining and redefining the support rules:
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