# Submission to National Disability Insurance Agency

## Impacts of changes to NDIS Support Rules on people living with ME/CFS and long COVID

Emerge Australia

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Emerge Australia is the national patient organisation representing 250,000 Australians with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). We also support people with other energy-limiting post-infection diseases, including the growing number of people (estimated to be up-to 400,000 Australians) who experience long COVID.

**What would help make the NDIS Supports rules, or the lists of supports, easier to use and understand?**

The new NDIS Supports rules lack clarity and detail, making them difficult for participants to navigate. There is no central, accessible source outlining what is and is not funded. Information on the NDIS website is fragmented and often contradictory. The lack of detail defining each NDIS Support leaves it open to interpretation, and therefore at the individual decision of the plan manager.

For example, "home maintenance" appears on both the supported and unsupported lists, leaving participants uncertain about what tasks, such as hiring a handyman, assembling flatpack furniture, or changing a smoke detector battery, are eligible.

ME/CFS and long COVID are complex, invisible and disabling conditions that severely limit participants' available energy to do even small, day to day tasks. NDIS planners often have poor understanding of the disability such energy-limiting conditions cause, and the supports that are reasonable and necessary for this cohort.

Participants with ME/CFS often require support with tasks like moving furniture, installing shelves, or cleaning gutters. These tasks are reasonable and necessary, and essential for daily living, yet there is no clear guidance about whether the NDIS will fund such supports.

**Please tell us more about challenges where the rules have not been understood or interpreted in the same way.**

The new rules are being applied inconsistently, and their emphasis on disability-specific supports disadvantages people with non-traditional or less visible disabilities such as ME/CFS and long COVID. Participants with ME/CFS report increased difficulty accessing assistive technology, mobility aids, home modifications, and low-cost items due to excessive evidentiary requirements.

Plan managers play a critical gatekeeping role, which appears to be focused more on compliance rather than empowering participants to live their best lives. Many will not approve even low-cost items without formal reports or letters. This presents three issues for participants with energy limiting conditions:

First, they are forced to use their limited energy to obtain documentation for routine needs.

Second, obtaining such documentation uses limited plan funds to pay for costly reports justifying often inexpensive items. Many feel their evidence is not adequately considered before being denied, which makes the process feel wasteful of their energy and resources.

Third, particularly for those who are most severely affected, the energy required to gather this documentation is prohibitive. As a result, these participants forgo seeking many essential supports altogether.

The system is increasingly inflexible and unable to accommodate individualised needs. For example, one participant requested funding for dog training, not to teach general obedience, but to enable her to safely walk her dog while using a reclining wheelchair. This support would improve her safety and independence but was rejected as non-disability-specific and not covered by the new rules.

Participants also report that some disability-specific items are deemed not value for money due to high costs, yet no alternatives are offered. This leaves them without access to critical supports.

Greater clarification is also needed between health and disability supports. Services such as physiotherapy, exercise physiology, osteopathy, and nutrition support are often essential for people with ME/CFS to maintain or manage functional capacity. However, these are frequently denied as "health" services, despite their direct relevance to the disability-related needs of this cohort.

These barriers have real consequences: participants are going without reasonable and necessary supports. Due to new, onerous processes, and the lack of knowledge about energy limiting conditions, some have unspent funds, not because their needs have diminished, but because they have given up trying to navigate the system.

Non-reviewable decisions:

Emerge Australia raised concerns about non-reviewable decisions during previous consultations. The needs of people with ME/CFS are often not well understood and the inability to challenge or provide additional evidence for decisions further disadvantages this group.

When a request for a support has been denied, participants are unable to request reconsideration of rejections, even when the supports are reasonable and necessary. For participants whose disability is often not well understood, this means supports are often rejected unreasonably and they have no recourse to explain their needs. This undermines the principle of individualised funding and contributes to significant unmet needs.

The implementation of the new rules created inconsistencies:
Some participants who submitted reimbursement claims for pre-approved supports before 3 October were reimbursed, while others who submitted on or just after that date were not. This has left some participants out of pocket for expenses they had understood to be covered in their plans.

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**Are there any products or services that should be available to NDIS participants that are not on the list of available NDIS supports? If yes, please list or describe these products or services.**

Many supports critical to people with ME/CFS and long COVID are excluded from the list because they are considered everyday items. These supports are adapted or used in specific ways by people with ME/CFS and long COVID to meet their disability-related needs.

Forcing participants to use disability-specific equipment or support workers instead of practical, lower-cost alternatives can increase overall expenditure and reduce plan sustainability. This also reduces participants' independence and choice.

Examples of essential but currently excluded or inconsistently approved items include:

- Air and water filters (to manage chemical sensitivity)
- Bedsore prevention cushions
- Compression garments
- Cooling devices (ice packs, neck collars, vests)
- Dishwasher (as assistive technology)
- Electric blankets
- Electrolytes (to manage orthostatic intolerance)
- Grocery and other delivery services
- Laptop and tablet stands
- Low-decibel vacuum cleaners
- Noise-cancelling headphones
- Period underwear

- Replacement batteries and charging cables for assistive technology
- Robot vacuum cleaners
- Smart household devices (e.g. light bulbs, doorbells, locks)
- Smartwatches (for heart rate monitoring and falls detection)
- Sound proofing materials.

Participants also report being denied access to therapies such as psychology, which are wrongly categorised as medical care. For people with ME/CFS, these therapies are disability supports that help manage isolation and psychosocial impacts.

Many allied health professionals have also stopped offering home visits due to changes in pricing. This creates access barriers for homebound participants who cannot attend clinics for assessments or therapy.

For participants who are housebound or bedbound, the NDIS should fund delivery or service fees associated with everyday items or services, even if the item or service itself is not funded. For example, while it is reasonable that the NDIS does not cover the cost of a haircut or dental treatment, it should cover the additional fee charged for a home visit, as these participants cannot travel to access such services.

There are dual benefits to funding delivery fees:

1. Provides a more cost-effective solution than using support workers to perform a task such as grocery shopping.
2. Reduced reliance on support workers increases participants' independence.

The exception here is when a participant is unable to travel to the service, the cost of the home visit and the service should be funded. Clarification needs to be provided that the service is a disability support for those who are bedbound, where they are unable to wash their own hair at home.

Short Term Accommodation (STA) has also become inaccessible. For many, STA provides essential respite, not a holiday. Group situations are unsuitable due to noise and chemical sensitivity, and disallowing holiday accommodation such as hotels to be used, make options very limited.

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**Are there any household items you used to buy with NDIS funds that you can no longer easily get because of the NDIS Support lists? If yes, please list or describe these household items.**

Participants with ME/CFS frequently cite smart devices and household appliances, such as dishwashers, as key supports they previously accessed but can no longer obtain. These items promote independence and reduce the need for support workers.

For people with ME/CFS and long COVID, having others enter their home uses their limited energy. Devices that allow them to maintain a clean, functional environment independently are not luxuries, they are essential. They are also more cost-effective than support workers, but requests to use plan funds on such devices are often rejected.

**Do you think there are other types of supports which should be available as replacement supports?**

Replacement supports are the only mechanism for individualised supports that aren't on the NDIS Supports list, but the replacement supports criteria are very restrictive. Despite participants providing "clear evidence that the need for the item relates specifically to the participant's impairment" and that the item increases their independence and reduces the need for a support worker, participants have had requests for replacement supports rejected, largely due to lack of understanding of ME/CFS and long COVID impairments and appropriate support needs.

The criteria require that replacement supports "must increase whole task independence and reduce or eliminate the need for a support worker." However, some supports may increase independence without enabling completion of the entire task. For example, a dishwasher allows a participant to load dishes rather than leave them in the sink when a support worker isn't present, promoting a cleaner environment. While this reduces reliance on support, the participant may still need help unloading the dishwasher due to higher energy demands. Thus, the support increases independence and reduces support needs, even if full task independence isn't achieved.

While replacement supports will reduce the need for a support worker, it may not be easy for participants to estimate how much less they would need a support worker. Participants are anxious about getting this estimate wrong and this affecting funding elsewhere in their plan.

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**Is there anything else you would like to tell us about the NDIS Supports rules or NDIS Supports lists? Please tell us in the box below.**

Emerge Australia has been observing the impact of the NDIS on people with ME/CFS and long COVID since the inception of the scheme. The implementation of the NDIS Supports has had the most negative impact on participants with ME/CFS and long COVID of any change in the scheme. Participants have reported a significant negative impact on their mental health. Increased uncertainty, administrative burden, and significant loss of choice and control have led to feelings of anxiety, helplessness, loss of dignity and dehumanisation.

Many feel the NDIS has moved away from its core principle of choice and control, reverting instead to a more paternalistic model that maintains strict control and fails to meet their needs.

The rigid application of the new rules disproportionately impacts people with energy-limiting conditions like ME/CFS and long COVID, which are poorly understood. The NDIS support lists were not designed with their needs in mind, excluding many common, reasonable and necessary supports. Previously, flexibility allowed for individualised support; the move toward standardisation has reduced this flexibility and limited access to much needed supports for many with these conditions.

People with ME/CFS and long COVID often need support for daily tasks not because they lack the skills, but because they lack the energy. Supports like meal preparation or cleaning are essential. Capacity-building supports (e.g. learning to cook) are not useful for people whose limitations are physical, not skill-based.

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**Emerge Australia's recommendations regarding NDIS Support Rules:**

1. **Reinstate flexibility and individualisation**
   Rigid application of standardised rules is undermining participant choice and control. The scheme must return to individualised, needs-based decision-making.

2. **Recognise and accommodate energy-limiting conditions**
   NDIA processes must account for the functional impacts of conditions like ME/CFS and long COVID, which are often invisible and misunderstood.

3. **Improve clarity and consistency**
   The NDIS Support rules and lists need to be simplified, centralised and clearly explained to ensure participants and plan managers interpret them consistently.

4. **Reduce administrative barriers**
   Excessive evidentiary and compliance requirements are preventing access to essential supports and should be streamlined, especially for low-cost items.

5. **Expand and clarify eligible supports**
   The support lists should include practical, disability-related items and services that promote independence and reduce reliance on support workers.

6. **Ensure fair review and appeal rights**
   All support decisions should be transparent and reviewable to uphold equity and address gaps in understanding of less visible disabilities.