

National Disability Insurance Scheme Position Statement



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Statement

ME/CFS is a permanent condition for most people. Less than 10% recover to pre-illness functioning and 20% of patients may worsen with time.[1] Many patients are partially or completely excluded from social and economic participation, with 25% of patients housebound or bedbound due to their disabilities. Despite this, many people with ME/CFS experience significant difficulties accessing the National Disability Insurance Scheme (NDIS).

To achieve equitable access to the NDIS and improve long-term health and quality of life for people living with ME/CFS – including capacity to live independently – Emerge Australia recommends the National Disability Insurance Agency (NDIA):

- Collaborate with Emerge Australia, clinical experts and the ME/CFS community to develop assessment guidelines to support accurate, affordable and safe assessment of ME/CFS applicants
- Include ME/CFS on List B: Neurological conditions
- Fund a 'Link' worker position with Emerge Australia, to allow us to support individuals navigating and applying for the NDIS.

Background

The NDIS aims to give people with disabilities, and their carers, choice and control over the services and support they receive, to improve independence and wellbeing over time.[2] Despite this, many disabled people face challenges accessing the scheme and receiving adequate funding for the support they need.[3]

Individuals impaired by ME/CFS have been especially challenged because their condition is poorly understood by many NDIS assessors. Anecdotal evidence suggests many people with ME/CFS who are initially rejected from the NDIS gain access on appeal.

The Federal Government have indicated improving assessment accuracy is a priority for the NDIA. Improving assessment accuracy for people with ME/CFS will:

1. reduce the number of incorrect first round assessment decisions and subsequent assessment rounds;
2. reduce NDIA operating costs sustained through the appeals process;
3. ensure people disabled by ME/CFS can gain access to the support they need through the NDIS; and
4. avoid the negative impact the appeals process can have on the health of ME/CFS applicants.

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Supporting Australians Living with ME/CFS

Recommended actions to improve assessment accuracy

1. Develop appropriate NDIA assessment guidelines for ME/CFS

Tailored guidelines should be developed to provide assessors with accurate information about the fluctuating nature and permanency of ME/CFS for most patients. Guidance would also help build understanding of the disabling nature of symptoms and the delayed response nature of post-exertional malaise.

In their 2019 report on ME/CFS, the National Health and Medical Research Council (NHMRC) urged the NDIA to recognise ME/CFS as a serious and debilitating condition.[4] The NHMRC recommended collaboration with clinical experts and the ME/CFS community to develop assessment guidelines to support assessors in their role.

Medical practitioners face significant barriers accessing accurate information about ME/CFS and are currently directed to consult outdated clinical guidelines. ME/CFS is inaccurately considered to be a non-permanent condition by many in the medical community, despite low rates of recovery[5] and high rates of entrenched unemployment experienced by patients.[6]

This inaccurate understanding of the disease has implications for NDIA assessors, who similarly lack access to information to accurately assess NDIS clients with ME/CFS. Anecdotal evidence suggests many people with ME/CFS are rejected from the NDIS because their condition was considered temporary and treatable.

Emerge Australia would welcome the opportunity to collaborate on the development of appropriate assessment guidelines for people with ME/CFS with the NDIA, the ME/CFS community and clinical experts.

2. Recognise ME/CFS as a neurological condition under List B

Many disabling conditions are specifically named under List A or List B of the NDIS operational guidelines to provide guidance to assessors. At present, the NDIS operational guidelines do not include any specific reference to ME/CFS. Exclusion of ME/CFS from operational guidelines likely increases inaccurate initial assessment.

The NHMRC recommends ME/CFS is included on List B under neurological disorders, acknowledging that ME/CFS is classified as a neurological disorder by the World Health Organisation.[7] List B pertains to permanent conditions for which functional capacity are variable and further assessment of functional capacity is generally required. ME/CFS should be included in list B, as the experience of symptoms varies between patients.

Emerge Australia advocates for the creation of a functional assessment process that captures a clear picture of a patient's functional capacity, specific to the six domains of functional impairment[8], tailored to people with ME/CFS.

3. Utilise 'Link' workers to support patients to navigate the NDIS

The United Kingdom's National Health Service employs 'link' workers to support patients to navigate health and social care systems.[9],[10] Emerge Australia advocates for link workers to similarly be funded in Australia to support people who face barriers to access the care they need. Such support from link workers is particularly important for people whose condition/s is poorly understood in medical and social care spheres.[11]

Link workers can be funded and embedded within primary care services, to connect individuals to a range of relevant social and community resources and supports.[12] Link worker roles could also be funded within community organisations through PHN commissioning arrangements. Alternatively, a national link worker service for post-viral diseases could be established, enabling national consistency and quality with localised and community tailored delivery.

For people living with ME/CFS, the process of applying for the NDIS and appealing inaccurate decisions comes with a significant cost to health and wellbeing. Navigating the application and appeal processes can trigger post-exertional malaise, leading to a worsening of symptoms for days, weeks or even months.

Emerge Australia has a strong understanding of the health and social care landscape in Australia and is the leading source of trusted information for many ME/CFS patients. Emerge Australia is well-positioned to design and deliver a national linking function to triage patients accessing Telehealth Nurse Case Management and Patient Support Information services into the NDIS and other relevant services.

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