

## Independent Review of the National Disability Insurance Scheme

**“It’s horrendously stressful to apply, and if you’re accepted that stress then never ends. There’s always the threat of losing support.”**

- Anonymous NDIS participant with ME/CFS

### Myalgic encephalomyelitis/chronic fatigue syndrome and the NDIS

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a multisystemic, highly disabling disease characterised by post-exertional malaise (PEM). PEM is a worsening of symptoms such as fatigue, pain and cognitive impairment following physical or mental effort. Other common symptoms of ME/CFS include problems with sleep, thinking and concentrating, orthostatic intolerance, dizziness and hypersensitivity to light and sound. ME is classified as a neurological disorder by the World Health Organization.

Despite the significant number of people who live with ME/CFS, and the severity of disability it can cause, the disease remains widely misbelieved, or disbelieved. People living with ME/CFS are constantly required to prove legitimacy, despite the condition being more disabling than many other chronic health conditions, such as MS, depression and cancer.<sup>1</sup>

Misbelief and disbelief have resulted in systemic discrimination from the medical profession and exclusion from adequate research funding. Lack of knowledge about ME/CFS means many highly disabled people are missing out on NDIS support.

While research is yet to confirm the cause of ME/CFS, most people can attribute onset of symptoms to a viral infection.<sup>2</sup> A new cohort of post-viral patients are those with Long COVID. Long COVID will increase the number of people living with ME/CFS over the coming months and years, as current research estimates 45% of people with Long COVID meet the diagnostic criteria for ME/CFS.<sup>3</sup> Evidence from our own, growing Long COVID community suggests Long COVID patients are already facing similar obstacles and challenges as people living with ME/CFS, especially encountering stigma and disbelief.

This submission focuses on issues accessing the NDIS which people with ME/CFS experience. These issues are causing enormous stress in the ME/CFS community, for both people living with the condition and their carers.

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<sup>1</sup> Nacul, *et al.* ‘The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers’ *BMC Public Health*, 11 (2011).

<sup>2</sup> Naess, *et al.* ‘Postinfectious and chronic fatigue syndromes: clinical experience from a tertiary-referral centre in Norway’ *Vivo*, 24:2 (2010).

<sup>3</sup> Davis, *et al.* ‘Characterizing long COVID in an international cohort: 7 months of symptoms and their impact.’ *EClinicalMedicine* 38, 101019 (2021).

Emerge Australia would like to acknowledge that there are also many issues which people with ME/CFS encounter once they are accepted onto the NDIS. For example, NDIS participants face the constant threat of their supports or plan being cut, which causes unnecessary stress. The misconception that ME/CFS is non-permanent results in NDIS participants with ME/CFS feeling under constant scrutiny and likely to have their eligibility reviewed. But if a participant has proven their condition is permanent, this is unlikely to change.

In addition, the NDIS is built on the assumption that participants will improve with time. The focus on goal setting also assumes this. ME/CFS generally doesn't allow for improvement. People with ME/CFS are trying to get their basic needs met: cooking, cleaning, showering, transportation. There is a perception that unless a participant is setting stretch goals, and striving to meet them, they are not meeting expectations. The NDIS should reflect participants' needs, not the NDIA's objectives.

To address these issues, significant culture change within the NDIA is needed. We welcome Minister Shorten's plan for reform to ensure the NDIA focusses on what is in the best interests of participants.

#### A. What are the three main problems or concerns with the NDIS and how do they affect you/others?

##### 1. Lack of knowledge and/or understanding of ME/CFS

Lack of specialists with sufficient knowledge of the disease makes it difficult to obtain the necessary evidence required for the application. Although GP evidence is often not regarded as sufficient to approve NDIS claims, even finding a GP with sufficient knowledge and experience in managing people with ME/CFS can be extremely difficult, particularly for those who do not live in an eastern-seaboard, capital city.

If the applicant can gather the required documentation, the next obstacle they face is that **ME/CFS is often misunderstood by NDIA assessors**. With ME/CFS-specific NDIS assessment guidelines lacking, assessors are not assisted to understand the disabling and often delayed nature of post-exertional malaise (PEM), or other disabling symptoms of ME/CFS. With Long COVID cases starting to apply for NDIS, it is even more important for NDIA assessors to understand how to assess these fluctuating conditions. Such guidelines would also assist to dispel the belief that ME/CFS is not permanent: recovery to pre-illness functioning is extremely low, at 5-10%.

The result of these obstacles is typically one of two outcomes:

- a) The application is incorrectly rejected, or
- b) Inconsistent assessment decisions are made: one person might get accepted, another with same or even worse level of disability may not.

##### 2. There are no effective treatments for ME/CFS. NDIA is coercing people to undergo ineffective treatments without consent, denying them the right to refuse treatments.

Despite medical reports indicating the extensive treatments applicants have tried, people with ME/CFS are being forced to undertake graded exercise therapy and other, additional treatments to access the NDIS. This occurs even when medical reports indicate these are either inappropriate

treatments, or unlikely to result in improvement in their condition. For example, graded exercise therapy has been shown to cause harm and is no longer recommended in the US or UK.<sup>4, 5, 6</sup>

Coercing patients to undergo treatments which have been deemed medically inappropriate or unlikely to result in significant improvement, or to which the patient has not freely consented, in order to access the NDIS, is a breach of the human rights to informed consent and the right to refuse treatment.

For people with ME/CFS, trying any new treatment carries a risk of harm, due to medication and treatment sensitivities. Coercing people to undergo further treatments beyond what has been tried, when there is low likelihood of benefit (due to lack of effective treatment options), risks harm.

### **3. The application process is incredibly stressful and costly, to their health and financial situation.**

Due to the energy limiting nature of this disease, people with ME/CFS report their condition is made permanently worse by the effort and stress involved in the application process. The risk of being left with worsened health and no supports is putting some people off applying for the scheme. For those who do apply, the result is either:

- a) They are accepted onto NDIS, but need more supports than before they applied, adding to the cost of the scheme.
- b) Their application is rejected, their condition has been worsened by the application process and are in even more need of support, but they have none.

People with ME/CFS pay thousands of dollars to obtain medical reports for NDIS. Not only is this money that should be spent elsewhere, like on supporting their own healthcare, it makes the scheme inaccessible to those on low incomes, like DSP or JobSeeker.

## **B. What are possible solutions to those problems?**

There are several solutions to the problems discussed in section A. Many of these problems could be significantly alleviated through education about ME/CFS including severity, core symptom of post-exertional malaise, and fluctuating nature of symptoms. Emerge Australia strongly advocates for:

- i. New, co-designed ME/CFS and Long COVID specific assessment guidelines. This will enable NDIS assessors to have a greater understanding of the condition. Emerge Australia is well placed to assist the NDIA with the development of such assessment guidelines.
- ii. Similarly, to make the application process less stressful, money and energy consuming, the application process should be made less onerous. There are two simple steps which will assist this to occur:
  - a. GP reports, where functional capacity is addressed, should be considered sufficient evidence. As discussed above, there is no medical specialty in ME/CFS. Due to the widespread lack of knowledge about ME/CFS, it is often difficult for applicants to obtain reports from medical professionals other than GPs.

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<sup>4</sup> Bateman, *et al.* 'Myalgic encephalomyelitis/chronic fatigue syndrome: Essentials of diagnosis and management'. *Mayo Clinic Proceedings*, 96:11, 2861–2878 (2021).

<sup>5</sup> Centers for Disease Control and Prevention. 'Clinical care for patients with ME/CFS' (2021). Available at: <https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/index.html>.

<sup>6</sup> National Institute for Health and Care Excellence. 'Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management' (2021). Available at: <https://www.nice.org.uk/guidance/ng206>.

- b. When an applicant has gained medical evidence of permanence and disability, this evidence should be accepted by the NDIA. Currently, such evidence is often ignored or overridden by NDIA assessors. This is primarily due to inadequate training and education of NDIA assessors.
- iii. As discussed in section A.2., people are being forced to undergo treatments known to cause harm. The NDIA should support the right of applicants to refuse treatments and the right to consent to medical treatments.
- iv. In addition, graded exercise therapy, no longer recommended as a treatment in the US and the UK, should not be required to access the NDIS.

Further to these recommendations, Emerge Australia would like to raise the issue of where those who are rejected from the NDIS, or not disabled enough to apply but still require support, can turn. There is a dearth of other support options.

Adequate support for those who are less severely disabled will help prevent these people from becoming more severely disabled, and ultimately eligible for the NDIS. This results in both health and cost savings. Despite the many issues outlined above, all of which are well known to the ME/CFS community, some still apply for NDIS, on the off chance they might get accepted. They waste money and energy, and risk their health because they need support and don't know where else to turn.

Emerge Australia is also concerned about people with Long COVID who are also starting to apply for the NDIS, and are facing some of the same issues. For example, there is a growing narrative that most people with Long COVID will recover. Many people with post-infection conditions, caused by COVID or another infection<sup>7</sup>, will recover within the first 12 months. However, there is also a cohort of people for whom this is not the case, and for whom the post-infection condition may be lifelong.

People living with Long COVID and/or ME/CFS should be able to access government support appropriate to their level of disability. Possible solutions to these problems include:

- i. Provide disability supports outside the NDIS, including for those who are less severely impaired.
- ii. If the permanent disability criterion cannot be applied to people with ME/CFS at this stage, a different, medium-term option must be found to support these people.

### C. What parts of the NDIS are working well?

Those people who do obtain appropriate NDIS support report a sense of relief and improvement in their ability to manage their lives, because they are better able to manage their energy expenditure. However, as the quote at the start of this submission describes, there is a constant fear that such supports, which have made such a difference in their lives, will be cut at the next assessment round. For those severely disabled and isolated people living with ME/CFS, such a threat is overwhelmingly stressful.

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<sup>7</sup> The Lancet. 'Long COVID: An opportunity to focus on post-acute infection syndromes'. *The Lancet Regional Health - Europe*, vol 22 (2022).