

Submission to National Disability Insurance Agency

## Impacts of Pricing Changes and Funding Periods on people living with ME/CFS and long COVID

**Emerge Australia Inc**

June 2025

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### Background

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**Emerge Australia Inc** 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.

**ME/CFS** is a complex, multisystem, debilitating neurological disease that affects many parts of the body such as the brain, muscles, digestive, immune and cardiac systems. It is characterised by post-exertional malaise (PEM), 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.

Twenty-five per cent of those who live with severe or very severe ME/CFS are house-bound or bed-bound, and less than 10% will recover. The degree of impairment exceeds that of other well-known diseases such as rheumatoid arthritis, multiple sclerosis, depression, heart disease, cancer and lung disease.<sup>1, 2, 3</sup>

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<sup>1</sup> C. Kingdon, et al. 'Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls' *Pharmacoeconomics- Open*, 2:4 (2018).

<sup>2</sup> L. 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>3</sup> M. Núñez, et al. 'Health-related quality of life in chronic fatigue syndrome versus rheumatoid arthritis as control group' *Journal of Chronic Fatigue Syndrome*, 14 (2008).

This group finds it difficult to access NDIS, even though their disability profoundly affects their ability to leave home, and is likely to be ongoing in the majority of cases. In-home services are therefore critical for this group.

The *NDIS Annual Pricing Review 2024 – 25* and *Pricing 2025 – 26* were released in June 2025. A change was also made to funding periods which are reduced to 3 months, rather than 12 months. These changes will compound the inequities people living with ME/CFS, who are NDIS participants, already face.

## Changes That Impact Our Community

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### Pricing Changes

The following changes will impact our community:

- Reduced pricing for essential therapy supports, including physiotherapy, dietetics and podiatry
- Provider travel claims are being halved, capped at 50% of the hourly rate
- No increases in pricing for level 2 and level 3 support coordination and plan management

These changes will adversely affect NDIS providers who deliver essential services to people living with severe and very severe ME/CFS and long COVID. Already, it is a post-code lotto in terms of access to NDIS providers. Those in our community who are house-bound or bed-bound are significantly reliant upon therapies provided in-home by allied health practitioners, particularly physiotherapy and dietetics.

Less than three weeks' notice about these significant changes also poses a risk to our community that some services will stop.

### Funding Periods

- Funding periods reduced to 3 months

A reduction in funding periods from twelve to three months will also adversely affect our community. This is likely to occur if a participant has used the three-month funding allocation early, and a critical need has arisen which they are unable to address until commencement of the next 3 month funding period.

The disability care needs of participants may vary significantly across a twelve-month period, according to fluctuating symptom severity. A twelve-month funding period allows participants with ME/CFS to better manage their needs, in accordance with fluctuating symptoms. Participants with ME/CFS are therefore at high-risk of spending funding before the end of the three-month period. This means they will be without supports while they either await a lengthy process for a change of circumstances or wait for the next three-month funding period to commence. This gap in services is likely to increase participant disability, contributing to poorer health and wellbeing. It can also have a significant impact on the person's mental health and quality of life. It also places pressure on carers to provide additional hours of unfunded care.

## Our Call To The NDIA

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Emerge Australia asks that the NDIA urgently consider the impacts of these changes.

Specifically, we call on the NDIA to:

- Reverse the decision to cap travel at 50% of the hourly rate
- Price all allied health practitioners equitably
- Prioritise equity and complexity in future pricing reform
- Enable participants with fluctuating ME/CFS symptoms to choose a funding period that best suits their disability care needs.

NDIS pricing decisions must reflect the true costs of delivering essential services.

Emerge Australia stands ready to support the NDIA in developing fairer, more inclusive pricing models.