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Myalgic Encephalomyelitis Group Australia
ME/CFS AUSTRALIA
Bridges & Pathways
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Equity and Access

Addressing the needs and rights of Australians living with ME/CFS and long COVID

It is the right of every Australian living with ME/CFS and long COVID to equitably access:
- evidence-based, best-practice healthcare
- disability and income supports.

These should be:
- **informed** by latest research
- **underpinned** by subsidised clinical services
- **provided** by educated, knowledgeable clinicians.

FEDERAL ELECTION COMMITMENTS
2025

The ME/CFS and long COVID community urgently calls for your help!

It is the right of every Australian living with myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS) and long COVID to equitably access best-practice, evidence-informed healthcare and other essential supports.

The next Federal Election presents an opportunity for all parties and candidates to pledge their commitment to make a difference to the hundreds of thousands of people impacted by ME/CFS and long COVID in Australia.

No longer can our needs be overlooked.

Urgent change can only be achieved if people living with these conditions receive equitable access to subsidised, effective, evidence-based services, without stigma or discrimination.

We need better understanding of these complex conditions, how they affect different groups, and translate research outcomes into:

- practical policy guidance to governments; and
- effective health and support system responses.

Our organisations ask for your commitment to:

- Invest in ME/CFS research to identify research priorities, improve understanding of the cause, development of a diagnostic test and identify effective treatments.
- Invest in clinical education to ensure GPs and health providers are managing these conditions safely, underpinned by the latest evidence.
- Invest in ME/CFS and long COVID healthcare and patient support, including access to telehealth, allied health services and in-home care.
- Equitable access to and within the NDIS and Disability Support Pension for people with ME/CFS and long COVID.

The Government is aware that more must urgently be done to help people with ME/CFS.

The need for research and patient support was acknowledged by the Inquiry into long COVID and repeated COVID infections[1] which recommended that, in consultation with ME/CFS organisations, funding be made available for:

- ME/CFS research
- Patient supports.

The Inquiry found that GPs have little knowledge of ME/CFS, with a consequent need for greater ME/CFS clinical education.

Early in 2024, the Albanese Government committed $1.13M to the NHMRC to update the ME/CFS clinical guidelines. This work is underway and will underpin clinical education and best-practice health support. We cannot wait for three years for our clinicians to be educated – this work needs to be funded to ensure that those with ME/CFS are diagnosed and not left out.

[1] House of Representatives Standing Committee on Health, Aged Care and Sport (2023). ‘Sick and tired: Casting a long shadow, Inquiry into Long COVID and Repeated COVID Infections.’

Background

ME/CFS and long COVID have a devastating impact on the lives of people with these conditions and their families, friends and loved ones.

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a neurological multisystemic, highly disabling disease characterised by post-exertional malaise[2], and orthostatic intolerance.[3]

The further the disease progresses without diagnosis or clinical intervention, the worse outcomes become for patients. Twenty-five per cent of people living with ME/CFS are house-bound or bed-bound.

Despite its severity, only a small number of people have accessed the NDIS with ME/CFS as their primary diagnosis.

ME/CFS shares many symptoms and biological abnormalities with long COVID.[4] Research suggests almost half of people with long COVID meet the diagnostic criteria for ME/CFS.[5]

Data on the impact of ME/CFS on the Australian economy is scarce. However, given that **most patients experience ME/CFS as a permanent disease, the lifelong cost to the individual and Australia's economy is significant. The total annual societal costs of ME/CFS in Australia is estimated to be up to $14.5 billion,** with average annual total costs of $63,400 per patient. [6],[7]. When factoring in the economic cost of long COVID, these figures could be as much as double. ME/CFS and long COVID pose a significant economic burden in Australia, owing mainly to high indirect and informal care costs.

ME/CFS affects the individual's economic position because capacity to work is typically significantly reduced; **people with ME/CFS are able to work less hours per week than people with multiple sclerosis.**

ME/CFS remains under-diagnosed and under-funded. Recovery is not common; it is estimated only 5-10% return to pre-illness functioning.[8],[9]

We need a program of research to inform clinical education, treatment and management.

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[2] "PEM", the hallmark symptom of ME/CFS and common in long COVID and fibromyalgia, is a worsening of symptoms after minimal exertion.
[3] Symptoms that occur when standing upright.
[4] Komaroff and Lipkin (2023). "ME/CFS and Long COVID share similar symptoms and biological abnormalities: road map to the literature'. Front Med.
[5] C. Kedor, et al (2022). 'A prospective observational study of post-COVID-19 chronic fatigue syndrome following the first pandemic wave in Germany and biomarkers associated with symptom severity'. Nature communications, 13:1.
[6] Zhao et al. (2023). 'The economic burden of myalgic encephalomyelitis/chronic fatigue syndrome in Australia'. Australian Health Review.
[7] Close et al (2020). 'The Economic Impacts of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in an Australian Cohort' Front Public Health 8:420.
[8] R. Nisenbaum, et al (2003). 'A population-based study of the clinical course of chronic fatigue syndrome' Health and Quality of Life Outcomes, 1:1.
[9] J. Baraniuk, (2017). 'Chronic Fatigue Syndrome: BMJ Best Practice guideline' BMJ (updated August 2018). Available at https://bestpractice.bmj.com/topics/en-gb/277.

Together we are stronger.

Will you help make a difference for Australians living with ME/CFS and long COVID?

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