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XX February 2025

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Email:

Dear

Election Commitments: myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and long COVID

I am pleased to send you the Federal Election Commitments sought by five of Australia's key ME/CFS organisations representing at least 500,000 people impacted by ME/CFS and long COVID.

Apart from Labor funding new ME/CFS clinical guidelines in 2024, there has been no other government investment in ME/CFS since 2018/19. Governments who don't address our community's needs must budget for total annual societal costs, estimated to be up to \$14.5 billion (pre-pandemic), with average annual total costs of \$63,400 per patient.^{1,2} Adding the economic cost of long COVID, this figure could be as much as double.

Our united request is for your commitment to invest in addressing the effects of these diseases. Over 3,300 patients per electorate are impacted. Electoral promises will significantly influence voting patterns, and this will make a difference in marginal seats.

We ask that you outline your policy and funding commitments to address the following key priorities:

1. **Invest in ME/CFS research** to identify research priorities which improve understanding of the cause of ME/CFS, develop diagnostic tests and identify effective treatments and approaches to management.
2. **Invest in clinical education** to ensure GPs and health providers are managing these conditions safely, underpinned by the latest evidence on diagnosis, management and treatment.
3. **Invest in ME/CFS and long COVID patient support and healthcare** including greater access to telehealth, allied health services and in-home care
4. **Deliver equitable access to, and within, the NDIS and Disability Support Pension** for people with ME/CFS and long COVID.

We will compile a scorecard of your commitments, which will be widely distributed to the community prior to the 2025 federal election.

¹ Zhao et al. (2023). 'The economic burden of myalgic encephalomyelitis/chronic fatigue syndrome in Australia'. AustralianHealth Review

² Close et al (2020). 'The Economic Impacts of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in an Australian Cohort' Front Public Health 8:420.



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We ask you to stand with us to ensure that the needs and voices of people in Australia living with energy limiting disease are addressed.

Together we are stronger.

Thank you for your time and consideration. We would welcome the opportunity to discuss how you will support our community if elected.

Yours sincerely

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The Facts

Conservative prevalence estimates of ME/CFS in Australia based on 2022 statistics are 500,000 with rapid growth expected, commensurate with acute COVID infections .

Jason LA & Islam MF, "A Classification System for Post-Acute Sequelae OF SARS CoV-2 Infection", Central Asian Journal of Medical Hypotheses and Ethics 2022; Vol 3(1)

Putrino D, "Long COVID: current care ideology, pathobiology and future research directions", Long Covid Physio International Forum, 1 Nov 2022

Kedor C et al, "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, 5104 (2022).

Choutka J et al, "Unexplained post-acute infection syndromes". Nature Medicine 28, 911-923, 2022.

SARS-CoV-2 can trigger ME/CFS. 51% of people with long Covid meet the diagnostic criteria for ME/CFS(1) thereby contributing to the substantial increase in ME/CFS prevalence, disease burden, and economic impact.

Dehlia A and Guthridge MA. The persistence of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) after SARS-CoV-2 infection: A systematic review and meta-analysis. [Journal of Infection Volume 89, Issue 6](#), December 2024, 106297.

Estimates of ME/CFS prevalence vary significantly because of differences in case criteria and study conduct differences.

Mirin AA et al. Updated ME/CFS prevalence estimates reflecting post-COVID increases and associated economic costs and funding implications. *Fatigue: Biomedicine, Health and Behavior*. 10(2), 2022 83-93.

The estimated cost of long COVID in 2022 was between \$1.7 billion to \$6.3 billion.

[Angeles](#) MR et al. The economic burden of long COVID in Australia: more noise than signal?. 3 November 2024. Medical Journal of Australia.

Total annual societal costs of ME/CFS, are estimated to be up to \$14.5 billion (pre-pandemic), with average annual total costs of \$63,400 per patient.

Zhao et al. The economic burden of myalgic encephalomyelitis/chronic fatigue syndrome in Australia'. Australian Health Review. 2023

Close et al. The Economic Impacts of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in an Australian Cohort. Front Public Health 8:42. 2020.

