Bridges & Pathways

emerge australia

meana
ME Advocacy Network Australia

ME/CFS AUSTRALIA

Myalgic Encephalomyelitis Group Australia

Scan for speaker bios and full program information

Parliamentary Friends of ME/CFS
Fluctuating Energy, Fixed Systems

ME/CFS is a chronic, complex and disabling neurological condition and is marked by post-exertional malaise.

Impacting **approximately 250,000 Australians**, common symptoms include sleep disturbance, cognitive issues and orthostatic intolerance. It often develops after an infection such as glandular fever or influenza.

Up to 400,000 Australians are living with long COVID[1] and up to 50% meet the diagnostic criteria for ME/CFS.[2]

Long COVID’s prevalence is rising as COVID-19 is now endemic.

What we’re asking for

- **Investment** in clinical education for accurate diagnosis and management of ME/CFS
- **Support services** for people living with ME/CFS, their families and carers
- **Investment in ME/CFS** research
- **Equitable access** to disability and social supports

Agenda

Anne Wilson, Chair, ME/CFS Alliance Australia, CEO, Emerge Australia
Welcome, meeting aims and housekeeping

Dr Mike Freelander MP, Member for Macarthur, Parliamentary Friends of ME/CFS Co-Chair
Welcome to Australian Parliament House

Henry Barker
Young person living with ME/CFS and long COVID

Prof Peter Schofield AO, The Mason Foundation
The importance of coordination in research

Dr Monique Ryan MP, Member for Kooyong
MRFF research funding

James Dunn
Person living with ME/CFS

Dr Emma Tippett, Clinic Nineteen
GP and specialist education needs

Prof Michael Kidd AO, Chief Medical Officer
National Chronic Conditions Framework

Hon. Rebecca White MP, Assistant Minister for Women, Indigenous Australians, Health and Aged Care

Presentation of Emerge Australia’s Award for Journalism Excellence

Sandra Goodyer
Carer of adult child living with ME/CFS

Contact Anne Wilson ceo@emerge.org.au

www.emerge.org.au

How **YOU** can support Australians living with ME/CFS

Support on social media

Post a photo from today's event

Share a short message of support

Use #**MECFSAllianceAustralia** and #**FairGoForME**

Support practical action

- **Advocate** for dedicated ME/CFS financial investment and research funding
- **Raise ME/CFS** issues with Ministers
- **Support policies** and investment that provide equitable access to services for patient care and disability support.

Stay engaged

- **Stay active** in the Parliamentary Friends of ME/CFS
- **Meet with constituents** living with ME/CFS
- **Share our stories** to inform questions and letters to ministers
- **Speak up on social media** to show support and raise awareness
- **Champion ME/CFS** in newsletters and public communications
- **Ask a question or make a statement** about ME/CFS in Parliament/Senate estimates

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Key Facts

75% are women[3]

25% are housebound or bedbound[4]

Costs Australia $14.5 billion per annum[5]

Level of impairment can be greater than in conditions like MS, depression and cancer[6]

Key issues

Long delays to diagnosis

Poorly educated GPs and healthcare providers

Medical gaslighting[8]

Harmful advice to "push through" symptoms

Barriers to disability and income supports

Loss of income, independence and quality of life: a "living death"

Significant economic cost to families and the economy

1. Lorusso, L., et al. (2009). 'Immunological aspects of chronic fatigue syndrome' *Autoimmun Rev*, 8 (2009); Costantino, V., et al. (2024). 'The public health and economic burden of long COVID in Australia, 2022–24: a modelling study' *MJA 221* 4: 217-233.
2. Jason & Islam. A classification system for Post-Acute Sequelae of SARS CoV-2 Infection. *Cent. Asian J. Med. Hypotheses Ethics*. 2022;3:38–51.
3. Committee on the Diagnostic Criteria for ME/CFS, Board on the Health of Select Populations, & Institute of Medicine (2015). 'Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness' *National Academies Press* (US).
4. Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis.'
5. Close, S., et al. (2020). 'The Economic Impacts of ME/CFS in an Australian Cohort' *Front Public Health* 8:420.
6. Kingdon, C., et al. (2018). 'Functional Status and Well-Being in People with ME/CFS Compared with People with Multiple Sclerosis and Healthy Controls' *PharmacoEconomics-Open*, 2:4; Nacul, L., et al. (2011). 'The functional status and well being of people with ME/CFS and their carers' *BMC Public Health*, 11.