



ME/CFS Australia Ltd

ABN: 23 088 896 299

ACN: 088 896 299

Ph: 0414 014 365 (Chair)

Postal: PO Box 6176, Upper Mount Gravatt QLD 4122

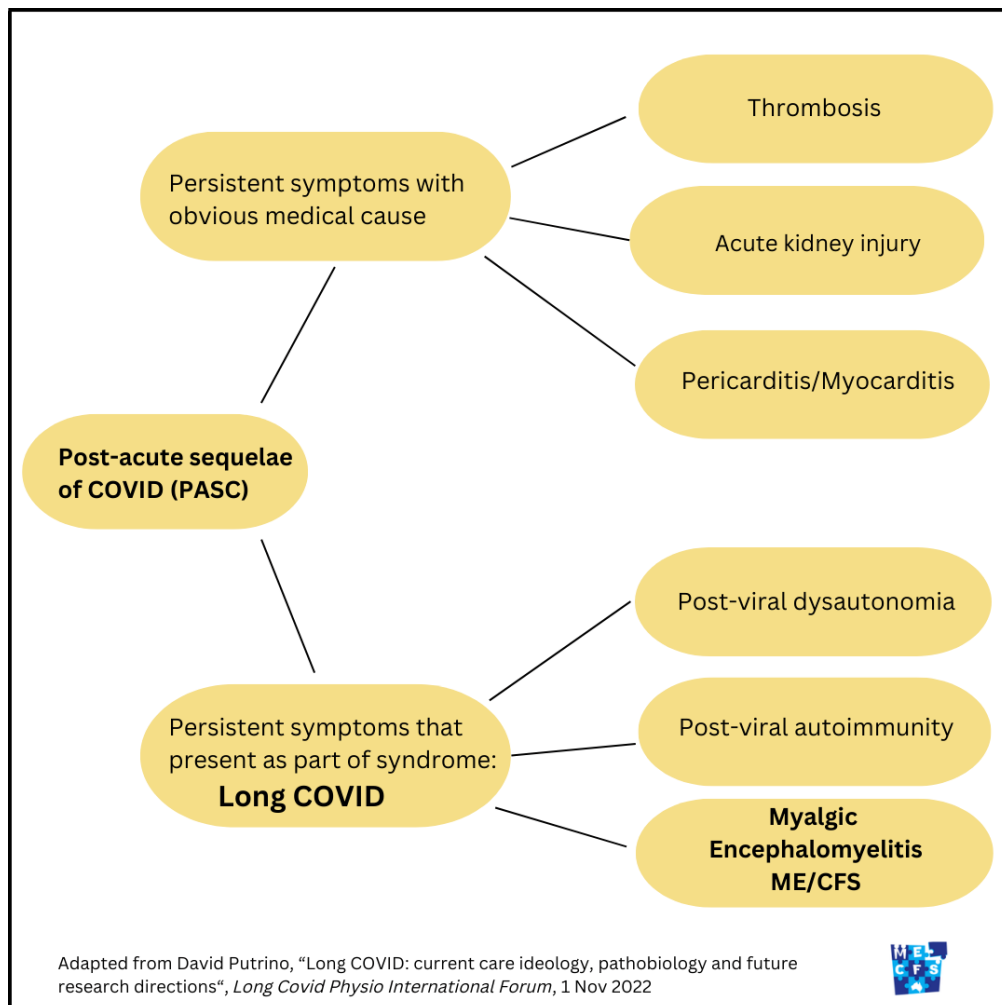
Registered Office: 13 Forestoak Way Goonellabah NSW 2480

Email: info@mecfs.org.au

Website: www.mecfs.org.au

Inquiry into Long Covid and Repeated Covid Infections Nov 2022
Terms of Reference 1,3,4,6

Why is ME/CFS relevant to Long Covid?



"We now have literature to support the fact that 50% of people with Long Covid meet diagnostic criteria for Myalgic Encephalomyelitis."¹

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

OUR ORGANISATION

ME/CFS Australia Ltd is the peak body for patient-led ME/CFS organisations in Australia, all of which are volunteer-run charities. Most of these volunteers have lived experience of the complex, disabling illness Myalgic Encephalomyelitis (ME/CFS) or are carers for someone with ME/CFS. People with Long Covid are seeking support from ME/CFS Australia and its member organisations.

PREVALENCE OF ME/CFS

Based on the most recent Australian infection statistics and on global rates of ME/CFS incidence post-Covid, it is estimated that the Australian prevalence of ME/CFS has grown from an estimated 260,000 pre-pandemic to at least 500,000 currently, with rapid growth expected to continue as long as acute Covid infections remain common.²³⁴⁵

ASSOCIATED ECONOMIC BURDEN

The economic burden of ME/CFS in Australia is likely to have risen from \$14 billion annually to nearing \$30 billion annually, and rising.⁶

URGENTLY NEEDED RESOURCES

There is an urgent need for expansion of existing ME/CFS infrastructure, including:

- current Australian clinical guidelines for ME/CFS
- specialist multi-disciplinary clinics for ME/CFS
- inclusion of ME/CFS in undergraduate education for health practitioners
- expansion of continuing education in ME/CFS for health practitioners
- development of resources to support delivery of ME/CFS care in General Practice
- embedded supports for the health, education, disability, welfare and community service sectors, for people with ME/CFS and those who care for them

IMMEDIATE NEED

Without multi-disciplinary clinics or current Australian clinical guidelines, and with a scarcity of health practitioner expertise, people with Long Covid and ME/CFS turn to the lived experience and knowledge of peers. The patient-led, volunteer-run member organisations of ME/CFS Australia provide services and supports to thousands of Australians. These organisations require funds to support them to meet the current and growing demand for local and national services.

² Putrino D, "Long COVID: current care ideology, pathobiology and future research directions", *Long Covid Physio International Forum*, 1 Nov 2022

³ 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)

⁴ Kedor C, Freitag H, Meyer-Arndt L, Wittke K, Hanitsch LF, Zoller T, Steinbeis F, Haffke M, Rudolf G, Heidecker B, Bobbert T, Spranger J, Volk H, Skurk C, Konietschke F, Paul F, Behrends U, Bellmann-Strobl J & Scheibenbogen C, "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)

⁵ Choutka J, Jansari V, Hornig M & Iwasaki A, "Unexplained post-acute infection syndromes", *Nature Medicine* 28, 911–923, 2022

⁶ Close S, Marshall-Gradisnik S, Byrnes J, Smith P, Nghiem S & Staines D, "The Economic Impacts of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in an Australian Cohort", *Frontiers in Public Health*, 21 August 2020

CONTENTS

❖ Current Australian clinical guidelines for ME/CFS	4
❖ Specialist multi-disciplinary clinics for ME/CFS	6
❖ Inclusion of ME/CFS in undergraduate education for health practitioners	7
❖ Expansion of continuing education in ME/CFS for health practitioners	7
❖ Development of resources to support delivery of ME/CFS care in General Practice	8
❖ Embedded supports within the health, education, disability, welfare and community service sectors, for people with ME/CFS and those who care for them	9
❖ Immediate need to support ME/CFS Australia and its member organisations to provide local and national services	10

CURRENT AUSTRALIAN CLINICAL GUIDELINES

Urgent need for current clinical guidelines for ME/CFS

Unlike other chronic illnesses triggered by acute Covid infection, such as Diabetes and Parkinson's Disease, there are no current Australian clinical guidelines for ME/CFS. Development of such guidelines were recommended by the ME/CFS Advisory Committee to the CEO of the NHMRC in 2019 and the recommendation was accepted by the CEO.⁷⁸

Allocation of \$1.5 million to the NHMRC will enable convening of an expert panel, including consumers, for the development of clinical guidelines for the estimated half a million Australians now living with ME/CFS, including those whose Long Covid manifests as ME/CFS.

This will cost \$3 per person, compared to the Medicare subsidy of \$39.75 per person for just one short GP consultation.

Use of outdated clinical guidelines

The most recent Australian clinical guidelines for ME/CFS are 20 years old. They are being followed by some medical practitioners, by the NDIS and by Social Security. NHMRC has recommended international guidelines for interim Australian use, but the NDIS and DSP refuse to recognise these guidelines on the grounds that the NDIS and DSP are required to use only Australian clinical guidelines.

The 2002 guidelines recommend treatments that are no longer recommended in the UK and US, and have been shown to be harmful to people with ME/CFS.

Such ill-informed clinical guidance risks harming people with ME/CFS and now many of those with Long COVID, potentially increasing levels of disability and the associated economic burden.

Evidence base and need for research

Clinical guidance must be based on evidence. Internationally, decades of research funding neglect for ME/CFS has limited the availability of evidence-supported treatments and management strategies for ME/CFS and now Long Covid. The impact of this lack of funding is being exacerbated by the conduct of Long Covid research without consulting experts in post-infectious conditions, including ME/CFS.

⁷ ME/CFS Advisory Committee Report to NHMRC Chief Executive Officer 30 April 2019
<file:///C:/Users/pelj5/Downloads/MECFS-CEO-Report-accessible-1.pdf>

⁸ CEO response – open letter to stakeholders 18 October 2019 <file:///C:/Users/pelj5/Downloads/open-letter-ceo-response-Oct-19-1.pdf>

NHMRC Research Funding 2021

<u>Disease</u>	<u>Prevalence 2021</u>	<u>NHMRC Funding 2021</u>	<u>Per Person</u>
Dementia	487,500	\$55,336,506	\$113
MND	2,000	\$9,675,693	\$4837
Parkinson's	75,629	\$9,847,556	\$130
MS	25,600	\$6,062,789	\$236
COVID-19	395,504	\$1,392,720	\$4
ME/CFS	Conservative 108,042	\$972,118	\$9

Sources are available on request

With no validated ME/CFS or Long Covid treatments, the scope, scale and speed of research must be expanded. ME/CFS Australia seeks an MRFF budget allocation dedicated to Long Covid and other infection-associated chronic illnesses, including ME/CFS, with funding on par with other diseases that have similar prevalence and economic burden.

Improved research, knowledge and understanding can assist in improving management, quality of life and function, with further positive impacts for families and carers, health and welfare sectors, disability supports, and the economy as a whole.

SPECIALIST MULTIDISCIPLINARY CLINICS FOR ME/CFS

Current ME/CFS clinic

Australia has one multidisciplinary clinical research centre for ME/CFS, to serve both those newly diagnosed with ME/CFS following acute Covid infection and those who have experienced long-term ME/CFS.⁹ This Bridges & Pathways clinic in South Australia requires further funding to develop their outreach and clinician education strategies, as well as funding for evaluation of existing and upcoming programs.

Current Long Covid clinics

Governments have supported the creation of dedicated Long Covid clinics across Australia. However, there is little if any ME/CFS expertise in these clinics. There is no anecdotal or other evidence to suggest that those clinic patients whose Long Covid manifests as ME/CFS are being diagnosed or assisted to manage ME/CFS symptoms.

Anecdotal evidence suggests that there are few services to which these Long Covid clinics can refer patients for treatment and ongoing management, one notable exception being the dysautonomia specialists at the Royal Adelaide Hospital.

Early intervention clinics post-infection

Multidisciplinary clinics with high levels of expertise hold the potential to support people in the early stages of Long Covid and other post-infection conditions, with the goal of lowering the conversion rates from acute infection into early post-infection syndromes and then into lifelong serious illnesses such as ME/CFS.

Best practice

Best practice clinics offering multidisciplinary ME/CFS care, combined with data collection and ongoing evaluation, are urgently needed across Australia. These clinics can offer both early intervention and care for those with long-standing illness. Collaboration with each patient's local general practice can ensure the development of effective Team Care Arrangements and GP Management plans.

⁹ Bridges and Pathways *Clinical Research Centre*, Bridges and Pathways, 2022
<https://bridgesandpathways.org.au/service/me-cfs-multidisciplinary-clinical-and-research-centre/>

INCLUSION OF ME/CFS IN UNDERGRADUATE EDUCATION FOR HEALTH PRACTITIONERS

Consistent with international trends, few Australian health and medical undergraduate courses include post-infection conditions in general or ME/CFS in particular, despite the high prevalence, high severity of disability, and high economic burden.

This results in a lack of awareness that leads to low confidence in the ability to diagnose or care for people with post-infection conditions, including ME/CFS.

EXPANSION OF CONTINUING EDUCATION IN ME/CFS FOR HEALTH PRACTITIONERS

Evidence continues to indicate that people with ME/CFS are disparaged by many health practitioners, experiencing stigma that impacts the health and well-being of those affected and undermining the prevention, early diagnosis, management and health outcomes of the condition. Most recently:

The results show physicians discuss ME/CFS, depression, and Lyme disease with more negative language than the other [eighteen] diseases in the set. The results for ME/CFS included over four times more negative words than the results for depression.¹⁰

Anecdotally, many people with Long Covid report similar disparagement.

In conjunction with current clinical guidelines for ME/CFS, continuing education for all branches of medicine, nursing and allied health practitioners is required to ensure that patients are identified and receive effective, evidence-based care.

Continuing education must be developed in collaboration with those who have lived experience, supported by funding to allow for codesign involving patients, carers, researchers and clinicians.

This initiative is consistent with the published objective of the NHMRC ME/CFS Advisory Committee's Strategic Focus 3 for the development of health advice and recommendations:

Collaborate nationally in the dissemination and implementation of clinical resources, including the education of clinicians.¹¹

¹⁰ Scoles B & Nicodemo C, "Doctors' attitudes toward specific medical conditions", *Journal of Economic Behavior & Organization*, Volume 204, December 2022, Pages 182-199

¹¹ ME/CFS Advisory Committee Report to NHMRC Chief Executive Officer 30 April 2019
<file:///C:/Users/pelj5/Downloads/MECFS-CEO-Report-accessible-1.pdf>

DEVELOPMENT OF RESOURCES TO SUPPORT DELIVERY OF ME/CFS CARE IN GENERAL PRACTICE

There is no designated specialty for ME/CFS, so diagnosis and management usually take place in primary care. Doctors, nurses and allied health practitioners in General Practice need to be supported by information, education and tools to deliver both early diagnosis and effective ME/CFS care.

Translational research

Translational research funding is needed to evaluate identified best practice and disseminate evidence-based approaches to diagnosis, treatment and management. For example,

Translational research for supporting GP Practice Nurses for ME/CFS:

Support for practice nurses holds significant potential for improved care of those with ME/CFS.

Bridges & Pathways Institute Inc is seeking \$190,000pa for two years to implement a trial under research conditions:

- \$100,000 per year for research statistician and journal articles
- \$60,000 per year for nurse researchers
- \$30,000 per year for implementation expenses

Addressing access to primary health care for people who are homebound

In 2018, the Australian Bureau of Statistics estimated that around 600,000 Australians with disabilities rarely leave their home. More than half of these people are under the age of 65. This number includes the 25% of people with ME/CFS whose illness severity leaves them homebound.¹²

On 21 July 2020, universal access to telehealth was abolished. The face-to-face eligibility requirement prevents people who are homebound, including those with severe ME/CFS and Long Covid, from accessing Medicare-subsidised telehealth. They currently have no option but to meet their primary health care needs through the hospital system, where they contribute a significant pressure on hospital services.

Medicare funding is required to allow GPs to make annual home visits to homebound patients, for assessment and to establish eligibility for telehealth. Funding is also required for practice nurses and allied health practitioners to visit the home when telehealth is inappropriate.

¹² Pendergrast T, Brown A, Sunnquist M, Jantke R, Newton JL, Strand EB & Jason LA, "Housebound versus nonhousebound patients with myalgic encephalomyelitis and chronic fatigue syndrome", *Chronic illness*, 12(4), 292–307 2016

EMBEDDED SUPPORTS WITHIN THE HEALTH, EDUCATION, DISABILITY, WELFARE AND COMMUNITY SERVICE SECTORS, FOR PEOPLE WITH ME/CFS AND THOSE WHO CARE FOR THEM

Safe and equitable support for people with ME/CFS must be embedded across government and non-government services, with integration across sectors. Currently, people with ME/CFS do not have equitable access to:

- accessible primary health care
- safe hospital care
- individualised schooling plans, including access to distance education
- disability access plans in tertiary education
- the National Disability Insurance Scheme
- income support, including the Disability Support Pension
- social housing
- residential care
- carer support
- protection from violence, abuse, neglect and exploitation

For example:

People who are severely disabled by ME/CFS are reporting significant difficulties accessing the NDIS. The NDIS has provided information to ME/CFS Australia demonstrating that the NDIS assessment criteria and treatment expectations for ME/CFS are significantly out of date.

In 2018, the NDIS worked with the Autism community to create the Autism Advisory Group, which was made up of Autism experts, service providers, and people with lived experience of Autism, in order to advise the NDIS. ME/CFS Australia approached the then CEO, Mr De Luca, who referred the issue to Operations Manager, Ms Christine Faulkner. Ms Faulkner invited ME/CFS Australia to put forward a proposal for the formation of an Advisory Group. Following a change in management, the replacement for Ms Faulkner shut down the proposal.

Given that the NDIS advice with respect to ME/CFS comes from a single source and this source is not reflective of current knowledge, it is imperative that the NDIS work with ME/CFS Australia and other stakeholders to collaboratively develop an approach to assessment for access and participation of people with ME/CFS, that is based on current evidence.

IMMEDIATE NEED TO SUPPORT ME/CFS AUSTRALIA AND ITS MEMBER ORGANISATIONS TO PROVIDE LOCAL AND NATIONAL SERVICES

Funding of patient-led organisations

Volunteer-run, patient-led organisations, including the peak body ME/CFS Australia and its member organisations, would benefit from paid administrative support, so that important services which are directly informed by lived experience can be maintained and extended. Pressure on these services has increased significantly as people with Long Covid seek help.

Services currently supplied by volunteers, most of them with ME/CFS, include telephone and email support and information services; magazines and newsletters; websites; education for patients and carers, clinicians, community service providers and the media; federal and local advocacy; in-person social support, peer support, and online support groups.

Extending services to vulnerable people, including CALD and ATSI communities

Epidemiological research in the US has identified that “the highest levels of CFS were consistently found among women, minority groups, and persons with lower levels of education and occupational status.”¹³

ME/CFS Australia and its member organisations seek funding to provide appropriate services and outreach to people who may have poor health literacy, lack access to the internet, experience barriers to cultural safety, and/or experience difficulty using English language resources.

Training people with lived experience to work with and for the ME/CFS community

ME/CFS Australia and its member organisations struggle to recruit volunteers with lived experience who have the confidence, capacity and skills to deliver the much-needed services. Funding is sought to train and support people with lived experience to participate in designing and delivering services.

Information, Linkages and Capacity-building grants through the NDIS

As patient-led, volunteer-run organisations, ME/CFS Australia and its member organisations have failed to access ILC grants. Funding records suggest that the ILC grant process entrenches disadvantage, favouring large, well-funded organisations. ME/CFS Australia is seeking a review of the process, so that patient-led projects are funded for people with post-infection conditions, including Long Covid and ME/CFS.

¹³ Jason LA, Richman JA, Rademaker AW, Jordan KM, Plioplys AV, Taylor RR, McCready W, Huang C-F, Plioplys S, “A Community-Based Study of Chronic Fatigue Syndrome”, *International Archives of Internal Medicine*, 1999;159(18):2129-2137