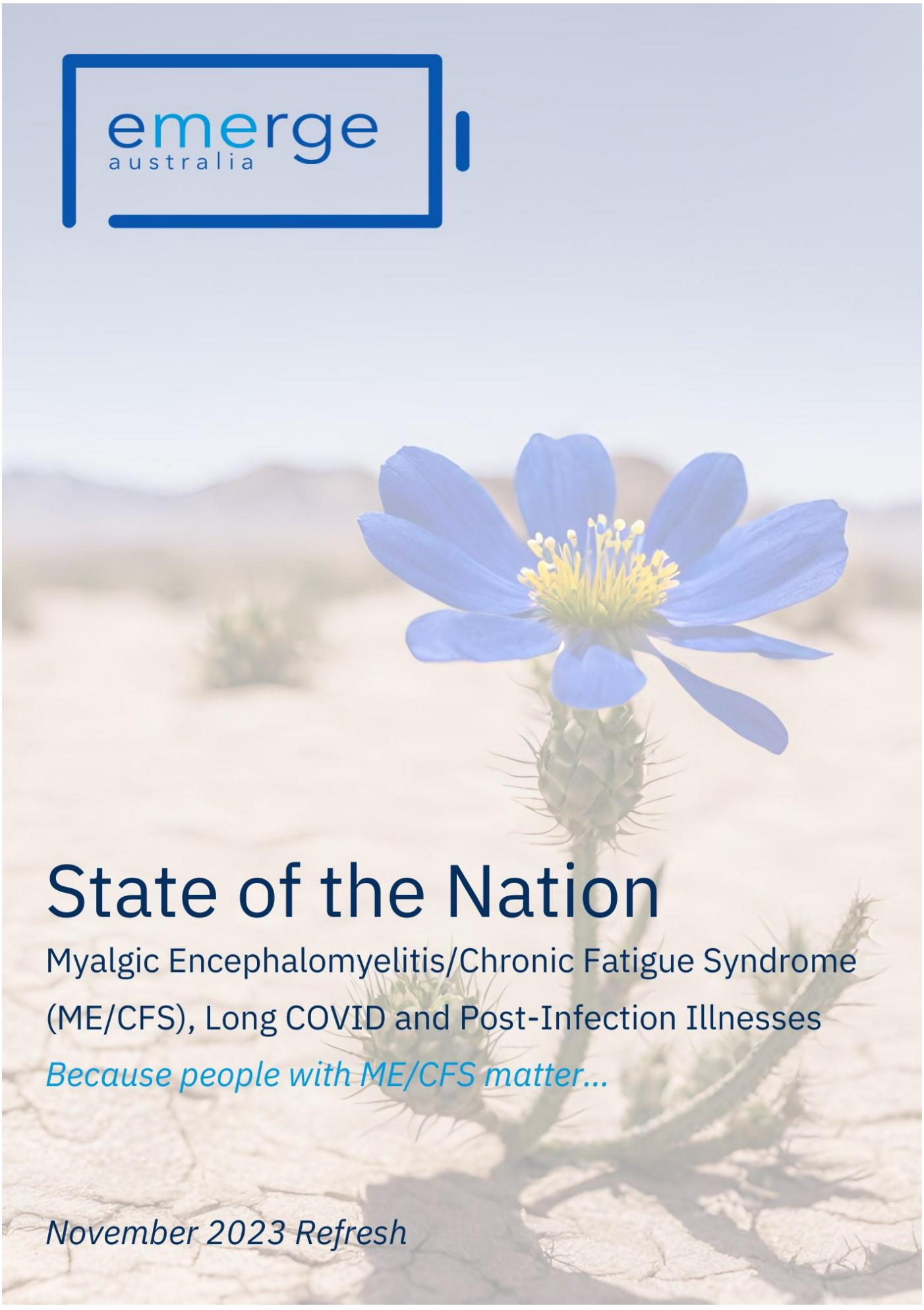

State of the Nation

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Long COVID and Post-Infection Illnesses

Because people with ME/CFS matter...

November 2023 Refresh

Executive Summary

In April 2022, Emerge Australia published the first version of this report. Following release of new research and associated reports, it was updated in November 2022 and, again, in this version in November 2023. This edition discusses new research findings regarding the similarities between Long Covid and ME/CFS, and the final report from the Disability Royal Commission.

Despite having been described in the medical literature for several centuries, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) has been overlooked by research, policy and systems responses. Other post infection diseases (PIDs) have similarly been ignored and their economic burden in Australia is unknown. The advent of the COVID-19 pandemic and emergence of Long COVID (LC) shone a light on PIDs. It also raised the profile of ME/CFS, which often develops after contracting a viral or bacterial infection. LC and ME/CFS are similar diseases, sharing many symptoms and biological abnormalities.[1] As the national patient organisation for people living with ME/CFS and LC, Emerge Australia has a strong interest and involvement in PID research, with Emerge Australia's *ME/CFS Biobank* and *Registry* active in finding biological links between these and other PIDs.

Up to 250,000 Australians live with ME/CFS and an estimated 325,000 people live with Long COVID. Both groups have just as poor or poorer employment, social and physical health outcomes than many other well-known diseases, such as multiple sclerosis, HIV/AIDS, cancer and depression.[2,3,4] Once fit, healthy and active, people with ME/CFS experience post-exertional malaise, cognitive impairment, reduced energy and an inability to function at pre-illness levels. People with Long COVID experience similar symptoms[5] with up to 45% meeting the diagnostic criteria for ME/CFS.[6] Due to these similarities, Emerge Australia understands the challenges people with Long COVID face in navigating and accessing the health care system, social support and care.[7]

Disability is something that some people with energy limiting conditions such as ME/CFS, Long COVID and other post-infection illnesses live with every day. In 2023, the final report from the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was released. It detailed the discrimination, violence and neglect people with disability, including people with ME/CFS, experience.[8] The final report makes a number of recommendations, including for a Disability Rights Act to enshrine in law the human right of people living with disability to equitably access and receive appropriately adapted quality health services, social and income support, without discrimination.

Emerge Australia strongly supports a Disability Rights Act and wrote a submission about the proposed amendments to the Disability Services Act which, in part, sought to address the rights of people with disability in the context of services and supports. We sought to raise awareness about how the Disability Services Act could assist those living with PID. In this submission, Emerge Australia presented the systems and policy changes required to ensure the rights of people with ME/CFS and Long COVID are met. Such awareness is underpinned by more widespread and in-depth understanding of PIDs, informed by peer reviewed research and education. Tailored health care and support will enable individuals to achieve a better quality of life and, for some, potentially return to work, study and social activities.

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[1] Komaroff and Lipkin "ME/CFS and Long COVID share similar symptoms and biological abnormalities: road map to the literature (2023).

[2] 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' *Pharmaco Economics – Open,* 2 (2018).

[3] 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).

[4] 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).

[5] S. Marshall-Gradisnik & N. Eaton-Fitch. 'Understanding myalgic encephalomyelitis' *Science*, 377:6611, (2022).

[6] C. Kedor, 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*, 13:1 (2022).

[7] N. Goldberg, et al. 'A new clinical challenge: supporting patients coping with the long-term effects of COVID-19,' *Fatigue: Biomedicine, Health & Behavior*, (2022) DOI: 10.1080/21641846.2022.2128576.

[8] Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023)

Emerge Australia looks forward to a future where people with impairments caused by ME/CFS and Long COVID no longer experience barriers to financial security and health and wellbeing support. The updates contained in this report edition highlight new possibilities for people with post-infection disease. Governments, researchers and health practitioners must be open to making changes to the ways they have viewed and supported (or not supported) this disease group.

The following priority actions were identified in the first edition of this report in April 2022 and, along with some new recommendations for policy change, remain the focus of Emerge Australia's work.

To increase support for people living with ME/CFS, Long COVID and post-infection disease, without stigma or discrimination, Emerge Australia advocates for:

1. GP education

Increased education of doctors to diagnose ME/CFS and Long COVID and provide evidence-based support to people with these diseases.

2. Coordination of care through multidisciplinary health and support services

Creation of an Optimal Care Pathway[9], placing people with ME/CFS and Long COVID at the centre of care decisions by expanding Emerge Australia's telehealth services with additional allied health support services addressing mental health issues through psychology, physical activity through physiotherapy and functional assessment for NDIA support through occupational therapy.

3. Funding for collaborative translational research

Ensure knowledge from ME/CFS research and the emerging field of Long COVID is shared and integrated.

4. Australian Clinical Guidelines

Update Australia's clinical guidelines bringing them in line with the latest research in Australia and internationally and assist in increasing safety and quality of diagnosis as well as establish shared care.

5. Recommendations for policy change

Changes to policy are required to:

a) create two new strategies to create sector wide focus and collaboration on Long COVID, ME/CFS and other related post-infection diseases, in line with international trends through the creation of:
   i. National Post-infection Disease Syndrome Strategy
   ii. Post-infection Disease Syndrome becoming the next NHPA

b) expand access to telehealth and provide equitable access to government support for people with ME/CFS, Long COVID and post-infection diseases. This includes MBS rebated chronic disease management plans that incorporate clinically indicated home visits and telehealth for all types of healthcare consultations for people whose disabling medical conditions restricts them from accessing face-to-face healthcare.

c) Enable equitable access to government support for people with ME/CFS, Long COVID and post-infection diseases.
   I. Develop tailored NDIS and Disability Support Pension assessment guidelines.
   II. Create 'Link' workers for health and social support service navigation.

[9] A framework for improving patient outcomes via consistent, safe, high-quality, and evidence-based care

Contents

Introduction

People with ME/CFS have long been overlooked by research, government and healthcare organisations. This report describes the experience of people living with ME/CFS and the priority actions that must be taken to reduce disease burden, especially for those who live with its debilitating effects. People with Long COVID experience similar symptoms[10] with up to 45% meeting the diagnostic criteria for ME/CFS.[11] As this patient group grows, so does the burden of ME/CFS in Australia.

Patients with ME/CFS have been fighting for decades to have their symptoms and experiences acknowledged and to gain access to necessary health and social care. Developments in the past three years, such as recommendations from the Disability Royal Commission[12] and research into similarities with Long COVID, present opportunities for ME/CFS and patients living with the disease, to experience the changes required so they can finally receive equitable funding and access to healthcare and support.

Government and the healthcare system must learn from this history of neglect. If this occurs, thousands of Long COVID patients and new ME/CFS patients will not experience the same indifference. For those Australians with ME/CFS who have already lost years of their lives to this disease, the Disability Royal Commission's final report and recommendations hold promise for ensuring they are seen, understood and supported.

This document is divided into three sections. Section *1. ME/CFS, Long COVID and post-infection diseases* introduces the critical challenge of ME/CFS: lack of recognition and inadequate biomedical understanding. While ME/CFS has been described in research for over 200 years, it has been largely overlooked globally by the medical community and governments. As a result, ME/CFS research has been severely underfunded, which has led to a limited understanding of the underlying pathophysiology of the disease. This section presents what is known about ME/CFS, including current biomedical knowledge and gaps, estimates regarding prevalence, prognosis and mortality, and the relationship with Long COVID.

Section *2. State of the Nation: Burden of ME/CFS* describes the lived experience of Australian ME/CFS patients in 2023 including disability and wellbeing, economic outcomes, and access to appropriate care. For a person with ME/CFS, every aspect of life is impacted by their symptoms. Even those who are moderately unwell are often socially isolated, unable to work and often require assistance with activities of daily living. This has significant implications for the Australian economy and for the individual, with many living below the poverty line. Despite the severity and prevalence of ME/CFS, the lack of biomedical understanding of the disease, as described at section 1., has contributed to an entrenched misunderstanding and disbelief of the disease and patients by medical practitioners. Implications for the availability of safe, appropriate care are also described.

Finally, section *3. Priority actions to improve outcomes for people living with ME/CFS and Long COVID* draws on the previous two sections to outline actions that will assist people with ME/CFS and other post-infection diseases, including Long COVID. Changes are required across our health and social care systems:

- A Disability Rights Act, as recommended in the Disability Royal Commission's Final Report, would enshrine in law the rights of people with ME/CFS and other post-infection diseases to equitably access tailored health and social supports.
- General practitioners urgently need updated clinical guidelines to speed up diagnosis and implementation of safe management techniques and they need to be educated about how to use these guidelines in clinic.
- Updated clinical guidelines will inform the development of co-designed assessment tools for access to the NDIS and Disability Support Pension (DSP) which are needed to remove barriers to accessing income and NDIS support.

[10] S. Marshall-Gradisnik & N. Eaton-Fitch. 'Understanding myalgic encephalomyelitis' *Science*, 377:6611, (2022).
[11] C. Kedor, 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*, 13:1 (2022).
[12] Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023

- Greater funding for non-clinical services and multidisciplinary health professionals through an Optimal Care Pathway will help people with ME/CFS access a range of health care practitioners who can help them adapt to life with chronic illness and reduce the burden on the health care system.
- In addition to more research into ME/CFS, research needs to focus and understand the lessons learned and knowledge gained from ME/CFS to inform Long COVID research as has occurred in the US.
- Recommendations are made for policy changes so individuals have equitable access to the NDIS, DSP and telehealth consults. Current barriers to access need to be addressed as a matter of urgency, to ease the burden of daily living chronic and disabling post-infection disease.

1. ME/CFS, Long COVID and post-infection diseases

This section describes existing knowledge about ME/CFS. Subsection 1.1 explains the symptoms of ME/CFS and recommended diagnostic criteria. Subsection 1.2 discusses what is known about the prevalence and mortality of the disease. The existing, limited biomedical understanding of ME/CFS is included in subsection 1.3, and reasons for such limited understanding are explained in subsection 1.4. Finally, known links between Long COVID, ME/CFS and post-infection diseases are explained in subsection 1.5 which includes the addition (Table 2) of a comparison of ME/CFS and Long COVID symptoms and the findings from Australia's Long COVID Inquiry.

1.1. What is ME/CFS?

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a multisystemic, highly disabling disease characterised by post-exertional malaise (PEM). PEM is 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.

ME/CFS is classified as a neurological disorder by the World Health Organization. It is a complex, multisystem disease that affects many parts of the body such as the brain, muscles, digestive, immune and cardiac systems.
While research is yet to confirm the cause of ME/CFS, a majority of people with ME/CFS attribute onset of symptoms after viral infection.[13] Other triggers of ME/CFS may include bacterial infection, physical trauma, environmental toxins and physical, mental or emotional stress, while genetic factors may contribute to an individual's susceptibility to these triggers.

The US National Academy of Medicine (NAM) estimates 90% of people living with ME/CFS are undiagnosed.[14] The NAM developed diagnostic criteria in 2015 to make it easier for doctors to diagnose ME/CFS. Emerge Australia recommends the US National Academy of Medicine (NAM) criteria for clinical diagnosis of ME/CFS. The symptoms included in the NAM criteria are not the only symptoms that people with ME/CFS experience, nor are they the only common symptoms. They are the minimum symptoms required to meet the diagnosis of ME/CFS using the NAM criteria.

[13] H. Naess, et al. 'Postinfectious and chronic fatigue syndromes: clinical experience from a tertiary-referral centre in Norway' *Vivo*, 24:2 (2010).
[14] Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Board on the Health of Select Populations, & Institute of Medicine. 'Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness' *National Academies Press (US)* (2015).

Symptoms required for a diagnosis of ME/CFS using the NAM criteria[15]

- **substantial reduction** in the ability to engage in pre-illness activity. This must have persisted for six months or more, and be accompanied by profound fatigue that isn't substantially improved with rest
- **post-exertional malaise (PEM**), which is the worsening of symptoms following physical or mental exertion
- **unrefreshing sleep**

Plus, either:

- **cognitive impairment** (problems with memory, thinking or concentration)
- **orthostatic intolerance** (problems with sitting or standing, that may include dizziness, sweating, nausea and reduce or resolve when lying down)

1.2. Prevalence, prognosis and mortality

The lack of funding over many decades for ME/CFS research means there are large gaps in our understanding of prevalence, prognosis and mortality. Prevalence provides an overall picture of how many people have a particular disease, which informs disease burden. Long COVID means the prevalence of ME/CFS is expected to rise. It also means we have little understanding of how the disease affects diverse groups, such as Aboriginal and/or Torres Strait Islander peoples, LGBTIQA+ people and people from multi-cultural backgrounds.

Prevalence

Accepted prevalence estimates vary from 0.4 to 1% of people living with ME/CFS.[16,17] Based on these numbers it is estimated up to 250,000 people live with ME/CFS in Australia. However, this is most likely an underestimate due to underdiagnosis and inaccurate records. Up to 90% of people may be undiagnosed or misdiagnosed.[18,19,20] Additionally, when patients visit their health care provider, it is likely ME/CFS is not reliably coded, which contributes to inaccuracies in the reported prevalence.[21]

While ME/CFS can affect anyone of any age, gender or socio-economic or cultural background, there are some noteworthy patterns:

- Women are three times more likely to be affected than men[22]
- The two most common ages of onset occur between the ages of 10 to 19 years and 30 to 39 years. The average age of onset is 33 years[23,24]
- Approximately 25% of people experience severe symptoms, leaving them housebound or bedbound[25] (see 2.1 Disability and wellbeing).

[15] Centers for Disease Control and Prevention. 'CDC: IOM 2015 Diagnostic Criteria' (2015). Available at: https://www.cdc.gov/me-cfs/healthcare-providers/diagnosis/iom-2015-diagnostic-criteria.html.
[16] L. Jason, et al. 'A community-based study of Chronic Fatigue Syndrome' *Arch Int Med,* 159 (1999).
[17] L. Lorusso, et al. 'Immunological aspects of chronic fatigue syndrome' *Autoimmun Rev,* 8 (2009).
[18] Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis'.
[19] M. Reyes, et al. 'Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas' *Arch Intern Med,* (2003).
[20] Jason. 'A community-based study of chronic fatigue syndrome'.
[21] Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Advisory Committee. 'Report to the NHMRC Chief Executive Officer' *Australian Government*, (2019), p. 10.
[22] Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis'.
[23] P. Rowe, et al. 'Myalgic encephalomyelitis/chronic fatigue syndrome diagnosis and management in young people: a primer' *Front Pediatr*, 5 (2017), p. 121.
[24] I. Bakken, et al. 'Two age peaks in the incidence of chronic fatigue syndrome/myalgic encephalomyelitis: a population-based registry study from Norway 2008-2012' *BMC Med*, 12:1 (2014), p. 167.
[25] Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis'.

Despite the "Yuppie Flu" myth that ME/CFS is a disease of middle-class white people, research shows that people from minority groups and lower socio-economic status have as high, or higher, prevalence rates, than middle class white people.[26] Despite this, research studies continue to largely include only white people.

Prognosis

Long term prognosis of ME/CFS is difficult to predict. While some patients improve over time, full recovery, defined as a return to pre-illness functioning, is not common.[27, 28, 29] Recovery rates are estimated to be just 5-10%.[30, 31] Prognosis is better for young people (children and adolescents) and those with mild forms of the disease than it is for those middle-aged and older, and for those who are more severely unwell.[32]

ME/CFS can take a relapsing/remitting course, like multiple sclerosis.[33, 34, 35] This makes it difficult to determine whether cases of recovery are more accurately in remission, and at risk of relapse in the future. In up to 20% of cases the disease worsens over time.[36]

Mortality

It is similarly unclear whether ME/CFS increases risk for earlier mortality. Some studies suggest an elevated risk of suicide and earlier mortality compared to national norms.[37] However, this is another area where more research is required.

1.3. Biomedical understanding of ME/CFS

Persistent underfunding of research into ME/CFS has led to poor understanding of its pathophysiology. Another limitation is the lack of a consensual study protocol, making comparison with other findings difficult. However, some gains have been made identifying body systems affected by the disease. A sample of these systems and their features is provided in Table 1, demonstrating the biological and wide-ranging impact of the disease.

System	**Tissue/Cell**	**Feature**
Metabolomics and mitochondria	Amino acid metabolism	Abnormalities in cellular energy production by mitochondria, including an increased use of amino acids over sugars.[38, 39, 40, 41]

[26] S. Kamaldeep, et al. 'Chronic fatigue syndrome in an ethnically diverse population: the influence of psychosocial adversity and physical inactivity' *BMC Medicine*, 9:26 (2011).
[27] International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. 'Chronic Fatigue Syndrome Myalgic Encephalomyelitis Primer for Clinical Practitioners' (2014) available at https://www.massmecfs.org/images/pdf/Primer_2014.pdf.
[28] J. Baraniuk. 'Chronic Fatigue Syndrome: BMJ Best Practice guideline' *BMJ* (2017).
[29] L. Jason, et al. 'A natural history study of chronic fatigue syndrome' *Rehabilitation Psychology,* 56:1 (2011).
[30] Baraniuk. 'Chronic Fatigue Syndrome: BMJ Best Practice guideline'.
[31] R. Nisenbaum, et al. 'A population-based study of the clinical course of chronic fatigue syndrome' *Health and Quality of Life Outcomes*, 1:1 (2003).
[32] International Association for CFS/ME. 'Chronic fatigue syndrome/myalgic encephalomyelitis: Primer for clinical practitioners'.
[33] International Association for CFS/ME. 'Chronic fatigue syndrome/myalgic encephalomyelitis: Primer for clinical practitioners'.
[34] G. Morris, and M. Maes. 'Myalgic encephalomyelitis/chronic fatigue syndrome and encephalomyelitis disseminata/multiple sclerosis show remarkable levels of similarity in phenomenology and neuroimmune characteristics' *BMC Medicine*, 11:1 (2005).
[35] L. Jason, S. Torres-Harding, and M. Njoku. 'The face of CFS in the US' *CFIDS Chronicle*, (2006).
[36] International Association for CFS/ME. 'Chronic fatigue syndrome/myalgic encephalomyelitis: Primer for clinical practitioners'.
[37] S. McManimen, et al. 'Mortality in Patients with Myalgic Encephalomyelitis and Chronic Fatigue Syndrome. Fatigue: biomedicine, health & behavior' 4:4, (2016).
[38] D. Missailidis, et al. 'An isolated Complex V inefficiency and dysregulated mitochondrial function in immortalized lymphocytes from ME/CFS patients' *Int. J. Mol. Sci.* 21:3 (2020).
[39] D. Missailidis, et al. 'Dysregulated Provision of Oxidisable Substrates to the Mitochondria in ME/CFS Lymphoblasts' *Int. J. Mol. Sci*, 22 (2021).
[40] Ø. Fluge, et al. 'Metabolic profiling indicates impaired pyruvate dehydrogenase function in myalgic encephalopathy/chronic fatigue syndrome' *JCI Insight,* 22:1:21 (2016).
[41] C. Armstrong, et al. 'Metabolic profiling reveals anomalous energy metabolism and oxidative stress pathways in chronic fatigue syndrome patients' *Metabolomics* 11, (2015).

System	Tissue/Cell	Feature
	Slowed cellular metabolism	Significant decreases in metabolites indicating slowed metabolism overall. Changes in important cell membrane compounds, like sphingolipids and cholesterol.[42, 43, 44]
	Fatty acid processing	Dysregulation of fatty acid metabolism. [14] metabolites significantly altered in people with ME, including high heme levels; low cAMP (an important second messenger necessary to activate many proteins in cells); and several molecules associated with ketosis, the breakdown of fats in place of sugars.[45, 46]
Autonomic Nervous System		Measurable alterations in the functions of the cardiovascular system and autonomic nervous system have been observed in people with ME. Reduced blood volume and blood flow, issues with regulating heart rate and blood pressure, a lower VO2 max during exercise testing, and an inability to replicate levels of exertion on successive days have been found in multiple studies.[47]
Central Nervous System	Neuron	The symptomatology is related to a variety of sources of chronic neurological disturbance and associated distortions and chronicity in noxious sensory signalling and neuroimmune activation.[48]
	Glial cells	There is a significant blood–brain barrier permeability, microglia activation through toll-like receptors (TLR) signalling, secretion of IL-1B, upregulation of 5-HTT in astrocytes, reduced extracellular 5-HT levels, and hence a reduced activation of 5-HT receptors.[49]
Central nervous system (cont.)	Neuroimaging	There is currently no neuroimaging finding or specific laboratory test to diagnose ME/CFS. There have been changes reported in brain volume[50, 51, 52], cerebral blood flow[53, 54, 55], anatomy[56, 57] and functional connectivity[58, 59, 60] but their meaning is yet to be determined.
Immune System	Lymphocytes Th1/Th2	Significant bias toward Th2 immune responses in ME/CFS patients leading to an effector memory cell bias toward type 2 responsiveness.[61]

[42] Naviaux et al. 'Metabolic features of chronic fatigue syndrome' *PNAS*, (2016).
[43] C. Armstrong, et al. 'The association of fecal microbiota and fecal, blood serum and urine metabolites in myalgic encephalomyelitis/chronic fatigue syndrome' *Metabolomics* 13:8 (2017).
[44] D. Nagy-Szakal, et al. 'Insights into myalgic encephalomyelitis/chronic fatigue syndrome phenotypes through comprehensive metabolomics' *Sci Rep* 8:10056 (2018).
[45] A. Germain, et al. 'Metabolic profiling of a myalgic encephalomyelitis/chronic fatigue syndrome discovery cohort reveals disturbances in fatty acid and lipid metabolism' *Mol Biosyst*., 31:13:2 (2017).
[46] D. Nagy-Szakal, et al. 'Fecal metagenomic profiles in subgroups of patients with myalgic encephalomyelitis/chronic fatigue syndrome' *Microbiome*. 26:5(1):44 (2017).
[47] For a list of studies, see #ME Action, 'ME Research Summary' (2019), available at: http://www.meaction.net/wp-content/uploads/2019/06/19_MEA_Revised_2019_Research_Summary_190610.pdf, pp 2-4.
[48] L. Komaroff. 'Advances in Understanding the Pathophysiology of Chronic Fatigue Syndrome' *JAMA* (2019).
[49] M. Noda, et al. 'T. Glial Activation and Expression of the Serotonin Transporter in Chronic Fatigue Syndrome' *Front. Psychiatry.* 9:589 (2018).
[50] A. Finkelmeyer, et al. 'Grey and white matter differences in Chronic Fatigue Syndrome – A voxel-based morphometry study' *NeuroImage: Clinical,* 17 (2018).
[51] L. Barnden, et al. 'Hyperintense sensorimotor T1 spin echo MRI is associated with brainstem abnormality in chronic fatigue syndrome' *NeuroImage: Clinical,* 20 (2018).
[52] Z. Shan, et al. 'Progressive brain changes in patients with chronic fatigue syndrome: A longitudinal MRI study' *Journal of Magnetic Resonance Imaging,* 44 (2016).
[53] B. Natelson, et al. 'Multimodal and simultaneous assessments of brain and spinal fluid abnormalities in chronic fatigue syndrome and the effects of psychiatric comorbidity' *Journal of the Neurological Sciences,* 375 (2017).
[54] J. He, et al. 'Cerebral vascular control is associated with skeletal muscle pH in chronic fatigue syndrome patients both at rest and during dynamic stimulation' *NeuroImage: Clinical,* 2 (2013).
[55] B. Biswal, P. Kunwar and B. Natelson. 'Cerebral blood flow is reduced in chronic fatigue syndrome as assessed by arterial spin labeling' *Journal of the Neurological Sciences,* 301 (2011).
[56] M. Zeineh, et al. 'Right arcuate fasciculus abnormality in chronic fatigue syndrome' *Radiology,* 274 (2015).
[57] L. Barnden, et al. 'Evidence in chronic fatigue syndrome for severity-dependent upregulation of prefrontal myelination that is independent of anxiety and depression' *NMR Biomedicine* 28:3 (2015).
[58] X. Caseras, et al. 'Probing the working memory system in chronic fatigue syndrome: A functional magnetic resonance imaging study using the n-back task' *Psychosomatic Medicine,* 68 (2006).
[59] C. Gay, et al. 'Abnormal Resting-State Functional Connectivity in Patients with Chronic Fatigue Syndrome: Results of Seed and Data-Driven Analyses' *Brain Connectivity,* 6 (2016).
[60] Z. Shan, et al. 'Brain function characteristics of chronic fatigue syndrome: A task fMRI study' *NeuroImage: Clinical,* 19 (2018).
[61] A. Skowera, A. Cleare and D. Blair. 'High levels of type 2 cytokine-producing cells in chronic fatigue syndrome' *Clin. Exp. Immunol,* 135 (2004).

System	Tissue/Cell	Feature
	NK cells	Reduction of cytotoxic activity in ME/CFS, leading to a higher susceptibility of infection.[62]
	B cells	Studies have highlighted B cell response appears dysregulated in ME/CFS, suggesting the ME/CFS immune system is dysfunctional.[63, 64]
Neuroendocrine System	Hypothalamus–pituitary–adrenal (HPA) axis	Dysfunction of the hypothalamus-pituitary adrenal-axis (HPA) has been proposed as a contributing factor of ME/CFS. In a proportion of ME/CFS patients, mild hypocortisolism[65, 66], reduced ACTH responses[67] and enhanced negative feedback responses to glucocorticoids (GCs) have been reported[68, 69].

Table 1: A sample of body systems affected by myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Adapted from [70, 71]

[62] J. Rivas, et al. 'Association of T and NK Cell Phenotype with the Diagnosis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)' *Front. Immunol*., 9:1028 (2018).
[63] A. Bradley, B. Ford and A. Bansal. 'Altered functional B cell subset populations in patients with chronic fatigue syndrome compared to healthy controls' *Clin. Exp. Immunol.,* 172 (2013).
[64] H. Ono, et al. 'Dysregulation of T and B cells in myalgic encephalomyelitis/chronic fatigue syndrome' *J Neuro Sci*, 381 (2017).
[65] F. van den Eede, et al. 'Hypothalamic-pituitary-adrenal axis function in chronic fatigue syndrome' *Neuropsychobiology* 55 (2007).
[66] L. Tak, et al. 'Meta-analysis and meta-regression of hypothalamic-pituitary-adrenal axis activity in functional somatic disorders' *Biological Psychology* 87 (2011).
[67] M. Demitrack, et al. 'Evidence for impaired activation of the hypothalamic-pituitary-adrenal axis in patients with chronic fatigue syndrome' *Journal of Clinical Endocrinology and Metabolism* 73 (1991).
[68] Van den Eade, 'Hypothalamic-pitutary-adrenal axis function'.
[69] J. Visser, et al. 'Increased sensitivity to glucocorticoids in peripheral blood mononuclear cells of chronic fatigue syndrome patients, without evidence for altered density or affinity of glucocorticoid receptors' *Journal of Investigative Medicine* 49 (2001).
[70] M. Cortes Rivera, et al. 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Comprehensive Review' *Diagnostics,* 9:3, 91 (2019).
[71] #ME Action, 'ME Research Summary'.

1.4. Gaps in biomedical understanding of ME/CFS

Despite ME/CFS impacting up to 1% of the population, biomedical research into ME/CFS and post-infection diseases has been critically underfunded for decades in Australia and overseas.

In Australia, most research funding has come from philanthropy.[72] In 2019, NHMRC allocated $4.2m in funding for biomedical research into ME/CFS. This was after more than a decade of no funding. This $4.2 million has been distributed through four research teams to investigate metabolic and biological indicators. These projects are in progress and outcomes reports will not be available for some time.

In addition to being underfunded, the complex nature of ME/CFS creates a challenge for researchers. The diagnosis and treatment of ME/CFS for individuals is confounded by the extensive range, disparity and dissimilarity of presenting symptoms. This contributes to inconsistent use of diagnostic criteria in research and other methodological issues such as small sample sizes, largely due to lack of funding that have hampered progress. As a result, research to date has failed to identify a cause, clinically applicable diagnostic biomarker, effective treatments or a cure.

There has been widespread acknowledgement that more research is urgently needed to fill gaps in our biomedical understanding of the disease, its aetiology, pathophysiology, diagnosis and treatment.[73, 74, 75] *Section 3.3 Funding for collaborative translational research*, expands on priority areas for research funding.

1.5. Relationship with Long COVID

While COVID-19 is a relatively new illness, post-acute sequelae of SARS-CoV-2 infection, referred to as Long COVID[76] in this document, is most likely the latest post-infection disease in a long history. Post-infectious illness consistent with the symptoms of ME/CFS has been described in the scientific literature for over 200 years.[77] Post-infectious illness can be triggered by many different pathogens, such as Epstein Barr virus,[78, 79] Ross River virus,[80] Human Herpes Virus 6 (HHV6)[81] and even Ebola virus.[82] The acute symptoms of these illnesses, and the organ damage they cause, can be very different. However, the lingering illness following each infection appears to be quite similar, both in symptomatology and underlying biology.[83,84,85]

Table 2 compares symptoms of ME/CFS and Long COVID.

Symptom	ME/CFS	Long COVID	Symptom	ME/CFS	Long COVID
Fatigue	✓	✓	Poor appetite	✓	✓
Post-exertional malaise	✓	✓	Orthostatic intolerance	✓	✓
Headaches	✓	✓	Palpitations	✓	✓
Sleep disorder	✓	✓	Breathlessness	✓	✓
Impaired reasoning	✓	✓	Nausea and diarrhea	✓	✓
Impaired memory	✓	✓	Chills	✓	✓

[72] ME/CFS Advisory Committee, 'Report to the NHMRC', p. 3.
[73] Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis', p 225.
[74] Ø. Fluge, K. Tronstad and O. Mella. 'Pathomechanisms and possible interventions in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)', *The Journal of Clinical Investigation*, 131:14 (2021).
[75] ME/CFS Advisory Committee, 'Report to the NHMRC', pp. 16-17.
[76] N. Nabavi. 'Long covid: How to define it and how to manage it' *BMJ (Clinical research ed.),* 370 (2020).
[77] L. Komaroff & W. Lipkin. 'Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of postacute COVID-19 syndrome' *Trends in molecular medicine*, 27:9 (2021).
[78] J. Jones, et al. 'Evidence for active Epstein-Barr virus infection in patients with persistent, unexplained illnesses: elevated anti-early antigen antibodies' *Ann Intern Med,* 102 (1985).
[79] P. White, et al. 'Incidence, risk and prognosis of acute and chronic fatigue syndromes and psychiatric disorders after glandular fever' *Br J Psychiatry,* 173 (1998).
[80] I. Hickie, et al. 'Post-infective and chronic fatigue syndromes precipitated by viral and non-viral pathogens: prospective cohort study' *BMJ,* 333 (2006).
[81] A. Komaroff. 'Is human herpesvirus-6 a trigger for chronic fatigue syndrome?' *J Clin Virol.,* 37 (2006).
[82] L. Epstein, et al. 'Post-Ebola signs and symptoms in U.S. survivors' *N Engl J Med,* 373 (2015).
[83] S. Marshall-Gradisnik & N. Eaton-Fitch. 'Understanding myalgic encephalomyelitis' *Science*, 377:6611, (2022).
[84] A. Komaroff and L. Bateman. 'Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?' *Frontiers in Medicine*, 7 (2021).
[85] Komaroff and Lipkin. 'Insights from ME/CFS' (2021).

Impaired attention	✓	✓	Cough	✓	✓
Secondary depression	✓	✓	Decreased smell & taste		✓
Secondary anxiety	✓	✓	Rash and hair loss		✓
Reduced activity	✓	✓	Painful lymph nodes	✓	
Myalgia/arthralgia	✓	✓	Chemical sensitivity	✓	
Muscle weakness	✓	✓	Tinnitus	✓	
Hot and cold spells	✓	✓			

Table 2 Comparison of symptoms of ME/CFS and Long COVID[86]

The development of illness post-infection suggests an abnormal immune response is involved in Long COVID and ME/CFS.[87] Redox imbalance, inflammation and problems with energy production at a cellular level may explain the shared symptoms between the two diseases.[88,89]

Both illnesses share abnormalities involving the central and autonomic nervous systems, the immune system, reactivation of latent infectious agents (primarily herpesviruses), the gut microbiome, energy metabolism, a hypometabolic state, redox imbalance, and various cardiac, pulmonary and vascular abnormalities. The similar underlying biology of ME/CFS and Long COVID suggest that insights into each disorder will have implications for the other. Research into their pathophysiology has the potential to lead to new strategies for reducing the morbidity of ME/CFS and Long COVID and of similar illnesses that can follow a variety of infections[90]. In August 2023, Yale School of Medicine (USA) launched a Center for Infection & Immunity which will investigate Long COVID, ME/CFS and post-treatment Lyme disease and provide greater understanding of the basic science behind infectious diseases. However, whilst acknowledging the possible overlap between ME/CFS and Long COVID, in Australia, the Federal Inquiry into Long COVID found that "whilst there may be some crossover with Long COVID, we believe that long COVID is a separate issue"[91] . This perspective means that Australia is out of step with international thinking, leading to missed opportunities for the conditions to be considered together, and known overlaps to be researched resulting in financial efficiencies and ROI benefits.

It is unsurprising that up to 45% of Long COVID patients meet the diagnostic criteria for ME/CFS.[92] Despite this, rates of diagnosis of ME/CFS in Long COVID patients are currently low. One of the largest studies to date, which surveyed 3762 people from 56 countries 7 months post COVID infection, found that while many patients reported significant overlap in symptoms, including 89.1% who experienced post-exertional malaise, the hallmark symptom of ME/CFS, only 14.7% of patients had been diagnosed with ME/CFS.[93] It is concerning that few clinicians are thinking of ME/CFS as a diagnosis, despite the significant overlap in the diseases.

If like ME/CFS, 90% of Long COVID patients are misdiagnosed or undiagnosed, the actual numbers of people with Long COVID are already much higher than this research suggests.[94, 95, 96] Long COVID studies such as these imply that there will be a considerable increase in the number of people with ME/CFS in the foreseeable future.[97]

[86] Komaroff and Lipkin. ME/CFS and Long COVID share similar symptoms and biological abnormalities: road map to the literature (2023)
[87] Komaroff and Lipkin, 'Insights from ME/CF'S (2021).
[88] B. Paul, et al. 'Redox imbalance links COVID-19 and myalgic encephalomyelitis/ chronic fatigue syndrome' *PNAS*, 118:34 (2021).
[89] M. Haffke, et al. 'Endothelial dysfunction and altered endothelial biomarkers in patients with post-COVID-19 syndrome and chronic fatigue syndrome (ME/CFS)'. *J Transl Med* **20**, 138 (2022).
[90] Komaroff and Lipkin (2023)
[91] Sick and tired: Casting a long shadow Inquiry into Long COVID and Repeated COVID Infections. Parliament of Australia House of Representatives Standing Committee on Health, Aged Care and Sport (2023)
[92] C. Kedor, 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*, 13:1 (2022).
[93] H. Davis, et al. 'Characterizing long COVID in an international cohort: 7 months of symptoms and their impact' *EClinicalMedicine,* 38:101019 (2021).
[94] Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis'.
[95] Reyes, et al. 'Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas'.
[96] Jason. 'A community-based study of chronic fatigue syndrome'.
[97] Nabavi. 'Long covid: How to define it'.

2. State of the Nation: Burden of ME/CFS and Long COVID

This section describes the burden of disease for ME/CFS and Long COVID. Subsection 2.1 discusses the individual burden on people living with the diseases. The addition of 2.2 shows Long COVID prevalence data published in 2023, while 2.3 considers the broader impacts on the economy including the addition of updated figures published in 2023. The increasing wave of people with Long COVID significantly adds to the individual and system wide implications described here.

It continues to be common for patients to have their symptoms disbelieved and dismissed. In subsection 2.4, the contribution that disbelief makes to inadequate clinical care for individuals is explained with the addition of information from the Disability Royal Commission.

2.1. Disability and wellbeing

ME/CFS is a debilitating disease, experienced as a permanent disease by most patients.[98, 99] Despite its prevalence, severity and permanent nature for most patients, there is inadequate data explaining disease burden in Australia.[100]

National longitudinal and one-off health and wellbeing research studies rarely consider the impacts of ME/CFS on the Australian population. Australia's national disease survey, the Australian Burden of Disease Study (ABDS), conducted by the Australian Institute of Health and Welfare (AIHW), has not listed ME/CFS as a separate disease since 2003. In the 2011 ABDS study, ME/CFS was excluded as a separate disease due to outdated prevalence estimates used in 2003.[101]

Up-to-date statistics are essential to enable Australia's health and social care systems to support ME/CFS patients, including those who have Long COVID. **Emerge Australia advocates for ME/CFS to be included as a separate disease in the next ABDS, and in all subsequent national health surveys.** This inclusion was similarly recommended to the NHMRC in 2019.[102]

People with ME/CFS experience a number of symptoms that may contribute to impairment or disability. These symptoms include, but are not limited to, post-exertional malaise, fatigue, cognitive dysfunction, pain, sleep disturbance, and secondary depression or anxiety.[103] Such symptoms impact all facets of life, occupational, educational, social and personal activities. The degree of impairment exceeds that of other well-known diseases such as rheumatoid arthritis, multiple sclerosis, depression, heart disease, cancer and lung disease.[104, 105, 106]

Figure 2 shows ME/CFS patients scored lower than Multiple Sclerosis (MS) patients across all functions measured, with the data particularly stark for social function.

[98] Baraniuk. 'Chronic Fatigue Syndrome: BMJ Best Practice guideline'.
[99] R. Nisenbaum, et al. 'A population-based study of the clinical course of chronic fatigue syndrome' *Health and Quality of Life Outcomes*, 1:1 (2003).
[100] ME/CFS Advisory Committee. 'Report to the NHMRC'.
[101] ME/CFS Advisory Committee. 'Report to the NHMRC', p 9.
[102] ME/CFS Advisory Committee. 'Report to the NHMRC'.
[103] Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis', pp. 31–33.
[104] 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).
[105] 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).
[106] 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).

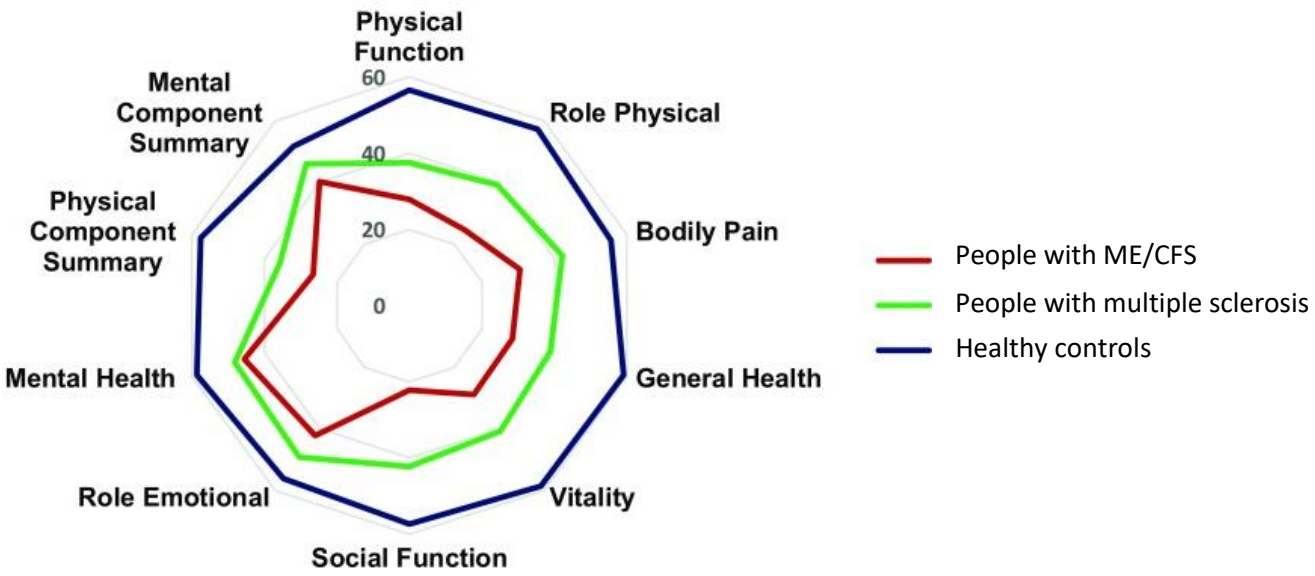

Figure 1: People with ME/CFS have worse functional measures than people with Multiple Sclerosis[107]

Emerge Australia's robust health and wellbeing survey, conducted every three years, supports this data. Of the 1055 people surveyed in 2019 who live with ME/CFS, 85% said that ME/CFS had significantly affected their ability to engage in social activities. This rose to 98% for people with severe or very severe symptoms. This indicates significant wellbeing implications for people living with ME/CFS and highlights need for social support.

Figure 1 also shows people with ME/CFS score significantly lower than those with MS in the areas of physical capacity, pain and general health. Despite the overall greater impact of ME/CFS on wellbeing, ME/CFS patients' mental health is generally no worse than people with MS, although it is unsurprisingly poorer than for healthy controls.

2.2. Long COVID

The Australian Institute of Health and Wellbeing's 2022 burden of disease report recognised COVID-19 as the tenth leading contributor to Australia's disease burden and the only infectious disease in Australia's top 25 contributors to the national burden of disease. In 2022, Long COVID accounted for 10% of the total Australian COVID-19 burden and almost half of COVID-19's non-fatal disease burden for the year. Due to the incurable nature of Long COVID, case numbers of people with complex support needs are rising, exacerbating Australia's existing and future chronic disease burden. Given that people with existing chronic conditions are disproportionately affected by Long COVID, the emergence of the condition also threatens to inflate Australia's multimorbidity burden[108].

2.3. Economic impacts

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 most recent estimated total annual societal costs of ME/CFS in Australia ranged between $1.38 and $14.5 billion, with average annual total costs of $63,400 per patient. Three-quarters of these costs were due to indirect costs ($46,731).

[107] Kingdon, et al. 'Functional Status and Well-Being in People with Myalgic Encephalomyelitis'.

[108] Weigel and Haddock, Issues Brief no: 53 26 September 2023 How patient experiences can guide the development of Long COVID health policy.

Disability severity was the key factor associated with higher costs, particularly for indirect costs (being 2.27-fold higher for severe disability than no/mild disability). ME/CFS therefore poses a significant economic burden in Australia, owing mainly to high indirect and informal care costs.[109] [110]

More data exists about the financial burden of ME/CFS on the individual. ME/CFS affects the individual's economic position in a number of ways. Capacity to work is typically severely affected with high unemployment rates.[111] As shown in Figure 2, people with ME/CFS are able to work less hours per week than people with MS.[112]

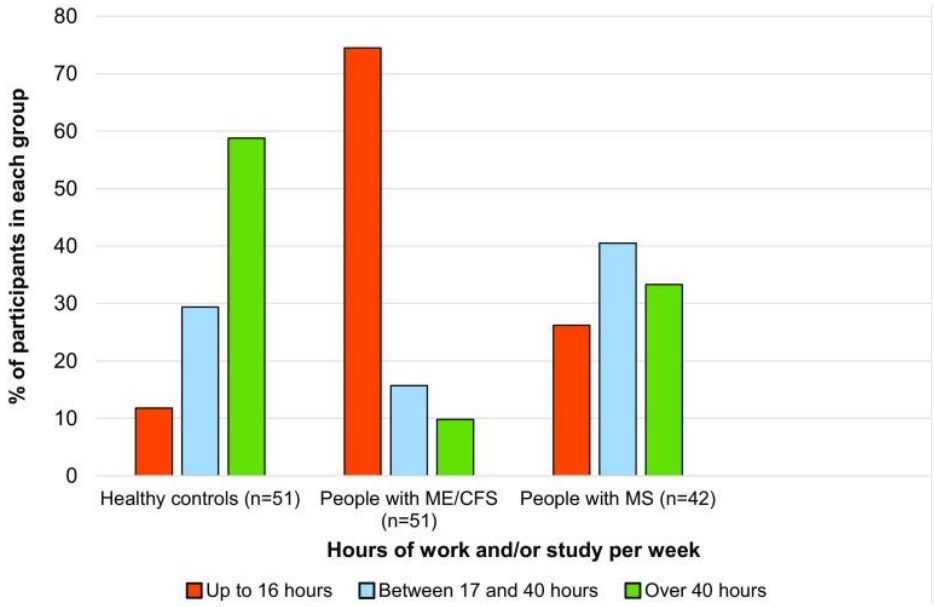

Figure 2: Work/study capacity by hours per week, comparing healthy people with ME/CFS and multiple sclerosis[113]

Emerge Australia's health and wellbeing survey found 89% of respondents ceased or significantly reduced paid work after illness onset, and more than two-thirds of patients live below the poverty line.[114] Another study found unemployment rates ranged from 35% to 69%.[115]

The total average, annual cost per person with ME/CFS in Australia is $75,697. Most of this cost was borne by the patient at $71,215, compared to healthcare costs borne by the government at $4,482.[116]

People with ME/CFS spend considerably more on health care than the general population and visit healthcare providers more often.[117, 118] This is despite most experiencing difficulties accessing healthcare due to their illness and financial considerations, further described at sections 2.3 and 3[119, 120, 121]

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

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

[111] Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis'.

[112] Kingdon, et al. 'Functional Status and Well-Being in People with Myalgic Encephalomyelitis'.

[113] Kingdon, et al. 'Functional Status and Well-Being in People with Myalgic Encephalomyelitis'.

[114] Emerge Australia. 'Health and Wellbeing Survey 2019', available at https://www.emerge.org.au/health-and-wellbeing-survey-2019.

[115] R. Taylor and G. Kielhofner. 'Work-related impairment and employment-focused rehabilitation options for individuals with chronic fatigue syndrome: A review' *Journal of Mental Health,* 14:3 (2005).

[116] Close, et al. 'The Economic Impacts of Myalgic Encephalomyelitis'.

[117] S. Twemlow, et al. 'Patterns of utilization of medical care and perceptions of the relationship between doctor and patient with chronic illness including chronic fatigue syndrome' *Psychological Reports,* 80:2 (1997).

[118] S. Thanawala and R. Taylor. 'Service utilization, barriers to service access, and coping in adults with chronic fatigue syndrome' *Journal of Chronic Fatigue Syndrome,* 14:1 (2007).

[119] J. Lin, et al. 'The economic impact of chronic fatigue syndrome in Georgia: Direct and indirect costs' *Cost Effectiveness and Resource Allocation*, 9:1 (2011).

[120] Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis', pp. 31-33.

[121] Thanawala and Taylor. 'Service utilization'.

ME/CFS also has a profound impact on carers, particularly those who provide support to the 25% of patients who are house or bed bound. Emerge Australia's 2019 health and wellbeing survey reported 90% of carers were financially unsupported in their role as carer.[122] This causes inter-generational financial burden in the case of parents, and compounds financial stress for domestic partners.[123]

2.4. Impacts of disbelief and inadequate clinical care

People living with ME/CFS consistently experience humiliation, intimidation and offence when medical professionals have not acknowledged their experiences, not followed clinical guidelines and refused to offer a diagnosis[124]. Despite being proven not to be a psychiatric illness, many medical practitioners continue to deny the biological and pathological roots of ME/CFS,[125] making it difficult for patients to access appropriate care. Only 31% of respondents to Emerge Australia's 2019 survey regarded health professionals as a key source of information about their disease.[126] Dismissive attitudes by many doctors have contributed to persistent misconceptions about ME/CFS. Ongoing, inadequate teaching of ME/CFS to undergraduate and post-graduate students perpetuates this cycle,[127] because they don't believe the diagnosis is real or they refuse to acknowledge it as a physical rather than psychological condition.

Numerous research studies have identified patients feeling dismissed, negatively stereotyped and stigmatised after attending health care services.[128, 129, 130] ME/CFS patients report continuous experiences of poor treatment when appealing on rejected DSP and NDIS applications[131]. ME/CFS patients whose disease is questioned and stigmatised by clinicians, family and friends are more likely to experience suicidal ideation than those who do not experience such stigma.[132] and are at risk of violence and neglect from family and carers[133]. Unnecessarily, the same mistakes are being made with Long COVID.[134]

Delays in diagnosis

GPs' lack of knowledge and understanding of ME/CFS often leads to long delays in diagnosis.[135] From onset of symptoms, it takes on average takes two to five years to receive a diagnosis of ME/CFS. During this delay in diagnosis, patients can experience exacerbation of symptoms and disability,[136] which can be permanent.

Decades of poor experiences with medical services have left many patients disempowered, and it is crucial that efforts are made to build trusting relationships between practitioners and those in their care. See subsection 3.4 for further detail about the ongoing legacy of harmful treatments.

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[122] Emerge Australia. 'Health and Wellbeing Survey 2019'.
[123] Emerge Australia. 'Health and Wellbeing Survey 2019'.
[124] Disability Royal Commission into Violence, Neglect and Exploitation of People with Disability final report (2023)
[125] ME/CFS Advisory Committee. 'Report to the NHMRC'.
[126] Emerge Australia. 'Health and Wellbeing Survey 2019'.
[127] D. Pheby, et al. 'A literature review of GP knowledge and understanding of ME/CFS: A report from the socioeconomic working group of the European network on ME/CFS' *Medicina* (Lithuania), 57 (2021).
[128] V. Anderson, et al. 'A review and meta-synthesis of qualitative studies on myalgic encephalomyelitis/chronic fatigue syndrome' *Patient education and counselling,* 86:2 (2012).
[129] C. Blease, H. Carel and K. Geraghty K. 'Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome' *Journal of Medical Ethics,* 43 (2017).
[130] M. Drachler, et al. 'The expressed needs of people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A systematic review', *BMC Public Health* 9:458 (2009).
[131] Disability Royal Commission into Violence, Neglect and Exploitation of People with Disability final report (2023)
[132] S. McManimen, D. McClellan, J. Stoothoff and L. Jason. 'Effects of unsupportive social interactions, stigma, and symptoms on patients with myalgic encephalomyelitis and chronic fatigue syndrome' *J Community Psychol,* 46:8 (2018).
[133] Disability Royal Commission into Violence, Neglect and Exploitation of People with Disability final report (2023)
[134] Goldberg. 'A new clinical challenge: supporting patients coping with the long-term effects of COVID-19.'
[135] Pheby, et al. 'A Literature Review of GP Knowledge'.
[136] F. Friedberg, M. Sunnquist and L. Nacul. 'Rethinking the Standard of Care for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome' *Journal of General Internal Medicine,* 35 (2020).

Accessing experienced GPs is difficult

Accessing the small number of GPs who do have expertise in ME/CFS is difficult due to overwhelming demand and prohibitive costs. The multi-system, heterogenous nature of ME/CFS means GPs often require lengthy consultation time with patients, which is not well supported by the Australian healthcare system.

Despite the introduction in November 2023 of Level E MBS items, Medicare rebates generally reduce for longer consultations for complex conditions, leaving patients with large out of pocket expenses. This limits access to those who can afford it.

For patients in regional areas, access to specialised care is usually even further out of reach and limited to those who have the means and the ability to travel considerable distances. Telehealth offers rural and remote patients, as well as those who find attending appointments exacerbates their symptoms, a solution to greater access to care. However, the current Medicare rebates for telehealth are undermining this resource for these patients. Section 3.5 expands on this topic and advocates for special telehealth provisions for people with debilitating chronic conditions such as ME/CFS and Long COVID who are unable to travel to initial appointments required under current telehealth rules.

3. Priority actions to improve outcomes for people living with ME/CFS, Long COVID and post-infection diseases

This section describes priority actions to improve quality of life for people living with ME/CFS, Long COVID and post-infection diseases. These actions carry a common theme: don't reinvent the wheel or make the same mistakes again. Although research into ME/CFS has been underfunded, the ME/CFS community, Emerge Australia and a small but growing number of health and social care experts are informed by soundly researched knowledge about the disease, its effect on people who live with it, and the issues they face. This knowledge should be used to guide the implementation of actions described here, including the development of research and clinical guidelines, Disability Support Pension and National Disability Insurance Scheme specific assessment guidelines, healthcare practitioner education, prioritisation of post-infection disease through systemic health system responses, and improved equitable access to healthcare and financial support.

3.1. GP education

Educate doctors to diagnose ME/CFS and Long COVID and provide evidence-based support to people with these diseases.

Underdiagnosis, misdiagnosis, disbelief and inappropriate management from GPs prevent patients from receiving correct care for their condition. There is a significant need for greater GP education for those already practicing and for medical trainees in undergraduate programs. This will ensure the next generation of people with diseases like ME/CFS and Long COVID don't suffer the same stigma or poorly informed healthcare.

Research estimates 90% of people with ME/CFS have not been diagnosed and GPs often lack knowledge and confidence in diagnosing the disease.[137] This data is consistent with Emerge Australia's survey of people living with ME/CFS, which found:

- 48% said their GP was either poorly or very poorly informed about ME/CFS
- 60% were diagnosed within 2 years, while the remainder waited anywhere from 3 to 10 years
- 73% said lack of knowledge from their healthcare provider was an obstacle to accessing healthcare.[138]

In addition to underdiagnosis, misdiagnosis is also common, and has significant implications for patient care. One study found that more than a third of patients diagnosed by their GP with ME/CFS either didn't meet the criteria for ME/CFS or had other exclusionary conditions, which meant they couldn't be diagnosed with ME/CFS.[139]

GPs also need to be educated about safe symptom management approaches that can provide relief from symptoms and improve a patient's quality of life. There are two recommended approaches: pacing and stepwise symptom management, described below. Some patients with Long COVID may also benefit from approaches such as pacing.[140]

[137] Pheby, et al. 'A Literature Review of GP Knowledge'.
[138] Emerge Australia. 'Health and Wellbeing Survey 2019'.
[139] Johnston, Staines & Marshall-Gradisnik, 'Epidemiological characteristics of chronic fatigue syndrome/myalgic encephalomyelitis in Australian patients' *Clin Epidemiol*, 8 (2016).
[140] Decary, et al. 'Humility and Acceptance'.

The patient: pacing and rest

Pacing is proven to be safe, effective and practical for the majority of people living with ME/CFS.[141]To implement pacing, patients must: STOP pushing their limits; REST before they feel symptoms and PACE their daily mental and physical activities[142]

Pacing involves undertaking less activity than what the patient has energy for on a given day, and breaking activities down into short bursts, with added rest breaks. The aim is to help manage limited energy and reduce how often the person experiences post-exertional malaise.

Pacing activity in ME/CFS is "symptom contingent", which means the person with ME/CFS will have to adjust how much or little they do based on how they respond to activity. The amount a person can do may change from day to day. This is in contrast to some forms of pacing that are 'quota contingent', meaning that the patient does a set amount of activity each day regardless of their symptoms.

The healthcare practitioner: stepwise symptom management

While pacing and rest are self-management approaches, doctors and healthcare practitioners can help with stepwise symptom management. This involves ranking symptoms from most to least problematic and exploring options to help reduce symptoms, starting with the most problematic. This approach to management isn't treating the underlying cause of ME/CFS or Long COVID, but it can help to improve overall quality of life.

As evident from these brief explanations, pacing and rest and stepwise symptom management are basic but practical steps that can be taken to attempt to gain some control over symptoms. They do, however, have limited application and limited results for many, particularly those who are very unwell.

3.2. Coordination of care through multidisciplinary health and support services

Create an Optimal Care Pathway[143] placing people with ME/CFS and Long COVID at the centre of care decisions and expand Emerge Australia's patient support services

People with ME/CFS and post-infection diseases do not routinely receive appropriate, coordinated shared care. Further, they face barriers accessing evidence-based information and integrated non-clinical support, all of which can inhibit symptom management and recovery. It is critical that ME/CFS and Long COVID patients are empowered to understand their unique needs and become partners in their own care.

Clinical guidelines provide support to GPs. However, GPs cannot meet all care support needs for Australian patients with these diseases. Optimal Care Pathways (OCPs) support integrated shared care across the entire health system. Care provided in accordance with an OCP reduces unwarranted variations in treatment and improves efficiency, equity and patients' experience of care. Such innovative approaches to the coordination of non-clinical service delivery have achieved improved outcomes for patients in other settings.

For example, shared care, in which care is shared between specialist and primary care or other health professionals, has been implemented successfully for people with diabetes, cancer, paediatric oncology and those requiring obstetric care.[144] Shared care enables multi-disciplinary collaboration between specialist/ hospital care and primary care clinicians.

[141] Decary, et al. 'Humility and Acceptance'.

[142] Decary, et al. 'Humility and Acceptance'.

[143] A framework for improving patient outcomes via consistent, safe, high-quality, and evidence-based care

[144] W. Brodribb. 'Maternity care in general practice' *The Medical Journal of Australia* 201:11 (2014).

An OCP for ME/CFS and Long COVID would ensure each patient receives equitable and safe care from a breadth of healthcare professionals where the health system is responsible for delivering an appropriate and coordinated care experience. Health professionals like nurses, physiotherapists, exercise physiologists, occupational therapists and psychologists can provide critical support with symptom management. Similarly, specialists including cardiologists, gastroenterologists and rheumatologists can help with symptoms of ME/CFS and Long COVID and common comorbid conditions, like postural orthostatic tachycardia syndrome, irritable bowel syndrome and fibromyalgia.

The OCP should be developed though a multi-disciplinary clinician consensus process that includes people with ME/CFS, carers and allied health professionals to establish the elements of quality care that should be offered. A thorough monitoring and evaluation process would similarly ensure the OCP is delivering efficient, appropriate and equitable care.

3.3. Funding for collaborative translational research

Ensure knowledge from ME/CFS research and the emerging field of Long COVID is shared and integrated.

As demonstrated in *1.5 Relationship with Long COVID,* researchers have already established strong links between ME/CFS, Long COVID and other post-infection diseases. This high degree of similarity offers opportunities for researchers to work across both diseases at the same time.

There are many highly qualified researchers and research centres that need support to conduct these studies. For example, Emerge Australia, in partnership with La Trobe University, manages Australia's only ME/CFS Biobank which includes Long COVID samples, allowing researchers to compare patient cohorts. This is a unique resource in Australia.

New research would be more efficient and effective if researchers:

a) Don't reinvent the wheel: consider findings from ME/CFS research to inform research topics, design, recruitment and analysis.

There is no need to start from scratch with Long COVID research. Existing findings from ME/CFS research can provide clear guidance for research into cause and treatment options. If treatments are found that help people with Long COVID, these are potentially applicable for people with ME/CFS.[145] People with ME/CFS should be used as comparison cohorts to people with Long COVID, in addition to healthy control groups. In the US research findings from ME/CFS have been used to guide collaborations for Long COVID research – the polar opposite to what is occurring in Australia.

b) Researchers should partner with ME/CFS and Long COVID patients to codesign, conduct and analyse research

Underfunded biomedical research lacking patient codesign has contributed to the poor health and wellbeing outcomes post-infection patients experience today. It has also contributed to a mistrustful relationship between patients, researchers and clinicians. ME/CFS and Long COVD research must involve patients in codesign and recruitment to ensure research efforts are not wasted and to deliver relevant and better outcomes.

[145] Wong and Weitzer. 'Long COVID and Myalgic Encephalomyelitis'.

3.4. Update Australia's clinical guidelines and develop tailored NDIS and DSP assessment guidelines

Update Australia's clinical guidelines to increase safety and quality of care and establish shared care and develop assessment guidelines for Centrelink and National Disability Insurance Scheme (NDIS) ***based on these.***

It is a matter of urgency for Australia to update its clinical guidelines for ME/CFS, to ensure Australian ME/CFS patients have access to the best possible care, based on current understanding of the disease and latest evidence. As ME/CFS research continues to evolve, clinical guidelines quickly become outdated.

Current Australian clinical management of ME/CFS is out of step with international best practice and ME/CFS patients remain at risk of harm. In reviewing these issues, the 2019 report of NHMRC's ME/CFS Advisory Committee recommended that Australia's clinical guidelines for ME/CFS be updated.[146]

Emerge Australia believes that new ME/CFS guidelines should be living documents which are regularly updated by a standing committee of clinicians, researchers, patients and carers, as new evidence comes to light. Australia's current clinical guidelines were published in 2002, by a working group under the auspices of the Royal Australia College of Physicians and reflect standard clinical management of ME/CFS at the time.[147] Australia's 2002 clinical guidelines use the Fukuda (1994) criteria,[148] developed by the US Centers' for Disease Control and Prevention. These criteria are no longer recommended, as they do not include post-exertional malaise as a mandatory criterion for diagnosis, despite it being a core feature of the disease.[149] The CDC itself no longer recommends these diagnostic criteria.[150]

Furthermore, Australia's current clinical guidelines focus on physical rehabilitation and encourage ME/CFS patients to undertake exercise, while discouraging excessive rest and activity avoidance. They suggest patient concerns that physical activity may be harmful are "unwarranted", despite current consensus that physical activity beyond a person's tolerance for movement can trigger or exacerbate post-exertional malaise in ME/CFS patients.[151] The guidelines also falsely that claim graded exercise programs have been shown to be effective treatments for ME/CFS.[152] Proponents of graded exercise therapy for ME/CFS claim that avoiding activity so symptom exacerbation does not occur can become a vicious cycle of increased disability and more avoidance, and that patients' beliefs about their disease contribute to their prognosis. This approach to managing ME/CFS is no longer recommended and totally invalidates the experiences of patients.[153, 154, 155]

The harmful nature of Graded Exercise Therapy and Cognitive Behaviour Therapy

In the past, graded exercise therapy (GET) and cognitive behaviour therapy (CBT) have been commonly recommended treatments for ME/CFS. GET assumes the symptoms of ME/CFS are largely the result of physical deconditioning, due to lack of activity. GET has often been combined with cognitive behaviour therapy (CBT) on the assumption that activity avoidance in people with ME/CFS was fear-based, and the treatment focussed on challenging these presumed fears and encouraging increased activity.

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[146] ME/CFS Advisory Committee. 'Report to the NHMRC'.
[147] Working group of The Royal Australasian College of Physicians (RACP). 'Clinical practice guideline: Chronic Fatigue Syndrome' *The Medical Journal of Australia*, 176:9 (2002).
[148] K. Fukuda, S. Straus, I. Hickie, M. Sharpe, J. Dobbins, A. Komaroff & International Chronic Fatigue Syndrome Study Group. 'The chronic fatigue syndrome: a comprehensive approach to its definition and study.' *Annals of internal medicine*, 121:12 (1994).
[149] ME/CFS Advisory Committee. 'Report to the NHMRC'.
[150] Centers for Disease Control and Prevention. 'CDC: IOM 2015 Diagnostic Criteria'.
[151] L. Bateman, et al. 'Myalgic encephalomyelitis/chronic fatigue syndrome: Essentials of diagnosis and management'. *Mayo Clinic Proceedings*, 96:11 (2021).
[152] Graded exercise therapy (GET) is based on the false assumption that ME/CFS symptoms are due to physical deconditioning. The treatment aims to reduce symptoms by improving physical fitness through gradually increasing exercise, regardless of symptom exacerbation.
[153] Bateman. 'Myalgic encephalomyelitis/chronic fatigue syndrome: Essentials'.
[154] Centers for Disease Control and Prevention. 'Clinical care for patients with ME/CFS' (2021). Available at: https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/index.html.
[155] National Institute for Health and Care Excellence. 'Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management' (2021). Available at: https://www.nice.org.uk/guidance/ng206.

It was assumed GET and CBT treatment would reverse both activity avoidance and deconditioning. This would lead to a reduction in symptoms and even full recovery. However, biomedical research into ME/CFS does not support the deconditioning hypothesis of ME/CFS, while GET and CBT studies do not show the high rates of recovery and improvement which would be predicted by the deconditioning hypothesis.

Mistakes of the past managing people with ME/CFS are reoccurring in the management of people with Long COVID. For example, the RACGP guide[156] fails to acknowledge the second most commonly reported symptom in people with Long COVID, post-exertional malaise (PEM).[157] In addition, the RACGP guide highly promotes the use of exercise as treatment, with almost no caution. The guide suggests reducing exercise if symptoms increase but offers no explanation why these patients would experience increased symptoms after exercise. However, just as evidence suggests that graded exercise therapy may accentuate post-exertional malaise in ME/CFS[158, 159, 160], the same effect has been observed in Long COVID patient narratives.[161, 162, 163] For this reason, graded exercise therapy should only be prescribed with great caution for management of Long COVID.[164]

3.5. Recommendations for policy changes

a) Advocacy for a Health System Response

The burden of disease for ME/CFS, as described above, should be read as a warning about the potential impact of Long COVID. We may anticipate that as COVID-19 becomes endemic in the future, so too will be an ongoing stream of patients whose infections develop into Long COVID, even if they have been vaccinated. This new cohort of post-infection patients is in addition to the 250,000 people in Australia who already experience the frustrations of Australia's current, siloed approach to health care. Our health systems must move quickly to support this growing cohort of post-infection patients, and to manage the increasing public health crisis and consequent economic impacts posed by Long COVID.

Since 1999, the Federal Department of Health has sought to focus public attention and health policy on areas considered to contribute significantly to the burden of disease in Australia, and for which there is potential for health gain. Accordingly, as a collaborative effort involving Commonwealth, State and Territory governments, nine National Health Priority Areas (NHPA's) have been created.

Current predictions suggest up to 325,000 people may be affected by Long COVID, in addition to the 250,000 living with ME/CFS. With more than half a million people affected by post-infection disease in the coming years, **Emerge Australia advocates that Post-infection Disease become the 11th NHPA.**

In addition, Emerge Australia advocates for the collaborative development of a **National Post-infection Disease Strategy** to address the impact of Long COVID, ME/CFS and other post-infection diseases. A National Post-infection Disease Strategy would allow for the allocation of funds that address the interface between post-infection disease, addressing them systemically and programmatically. Such a strategy would contribute to alleviate the current siloed approach, providing a platform to address the needs of Australia's 250,000 people with ME/CFS, plus the hundreds of thousands of other people with other post-infection illnesses.

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[156] RACGP. 'Patient resource: Managing post-COVID-19 symptoms', available at: https://www.racgp.org.au/clinical-resources/covid-19-resources/patient-resources/patient-resource-managing-post-covid-19-symptoms/introduction (2022).
[157] Davis et al. 'Characterizing long COVID'.
[158] T. Kindlon. 'Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome' *Bull IACFS ME,* 19 (2011).
[159] D. Kim, et al. 'Systematic review of randomized controlled trials for chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME)' *Journal of Translational Medicine,* 18 (2020).
[160] L. Larun, et al. 'Exercise therapy for chronic fatigue syndrome' *Cochrane Database of Systematic Reviews,* (2019).
[161] H. Salisbury. 'Helen Salisbury: When will we be well again?' *The BMJ,* 369 (2020).
[162] M. Peel. 'What can we tell patients with prolonged covid-19' *The BMJ,* 370 (2020).
[163] R. Perrin, et al. 'Into the looking glass: Post-viral syndrome post COVID-19' *Medical Hypotheses,* 144 (2020).
[164] Decary, et al, 'Humility and Acceptance: Working Within Our Limits with Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome' *Journal of Orthopaedic & Sports Physical Therapy,* 51:5 (2021).

b) *Expand access to MBS rebated telehealth to increase access to care*

A range of Medicare-subsidised telehealth services via phone or video call were introduced in response to the COVID-19 pandemic. This enabled some people with ME/CFS to access essential health services for the first time in years. Previously, these patients could not attend clinics in-person because of the severe effects on their health or they lived in rural/regional areas. Attending appointments in-person can cause people living with ME/CFS to experience orthostatic intolerance and/or post-exertional malaise for hours, days or weeks afterwards so attending appointments makes them sicker or they simply do not seek medical care. People who are immunocompromised are at risk when accessing in-person healthcare because of lack of airborne infection prevention. ME/CFS often takes years to diagnose, requiring multiple medical consultations. Patients with Long COVID have reduced access to treatment options with many Long COVID clinics reducing their capacity or closing in 2023.

Telehealth works for people with ME/CFS and Long COVID

In June 2020, Emerge Australia conducted an online survey of 419 people to understand how ME/CFS patients and their carers experienced telehealth services. Results found the introduction of Medicare rebates had improved access to health services for 82% of respondents.[165]

Results also found telehealth worked to:

- reduce the risk of experiencing the disabling effects of PEM
- reduce the number of appointments cancelled at the last minute
- alleviate burden on carers who accompany patients to-and-from appointments
- increase patient independence.

Whilst some telehealth services are now permanently accessible through Medicare, rebates for complex specialist consultations and longer telehealth consult ceased in June 2022. The requirement for an annual, face-to-face GP appointment further excludes patients who are house or bed-bound from accessing healthcare. In late 2023, the MBS Review Advisory Committee recommended the removal of MBS initial non-GP telehealth consultations. If the Disability Royal Commission's recommendation for a Disability Rights Act is accepted, the right for people with disability to access services in an appropriate format (such as telehealth) will be enshrined in law.

Emerge Australia therefore urges the Federal Government to make Medicare telehealth rebates permanently available for long and short consultations, including all GP consultations, and continue to offer initial non-GP telehealth consults for people with chronic illnesses, who are otherwise unable to attend clinics.

c) *Enable equitable access to government support for people with ME/CFS, Long COVID and post-infection diseases*

Develop tailored NDIS and Disability Support Pension assessment guidelines

Just as many medical practitioners face challenges providing appropriate care to their patients due to out-of-date clinical guidelines (see subsection 3.4), Centrelink and National Disability Insurance Scheme (NDIS) assessment staff similarly lack access to information to accurately assess clients with ME/CFS.

[165] Emerge Australia. 'Telehealth campaign'. Available at: https://www.emerge.org.au/telehealth-campaign (accessed 20 January 2022).

The Disability Royal Commission found that people with ME/CFS are often rejected from the NDIS or DSP because their disease was considered temporary and treatable. However, many gain access on appeal. This apparent pattern of rejection followed by a successful appeal suggests that ME/CFS is poorly understood by assessors [166]

Improving assessment accuracy is critical to reduce the number of incorrect first round assessment decisions and subsequent assessment rounds. This would improve timely access to the support people disabled by ME/CFS need, while reducing operating costs sustained through the appeals process.

Tailored guidelines are needed to provide assessors with accurate information about the fluctuating nature and permanency of ME/CFS for most patients. Such guidance would also help build understanding of the disabling nature of symptoms and the delayed response of post-exertional malaise. Emerge Australia would welcome the opportunity to collaborate on the development of such guidelines with the National Disability Insurance Agency (NDIA), Centrelink, the ME/CFS community and clinical experts.

'Link' workers for health and social support service navigation

Emerge Australia has long advocated for "link workers" who support patients that face barriers to navigate the health and social care system to be funded. Whilst Emerge Australia's helpline navigators provide this function, it is unable to keep up with the burgeoning demand from people affected by Long COVID. Emerge Australia welcomes the Disability Royal Commission's recommendation (Recommendation 6.34) to introduce disability health navigators to support navigation of health care for people with disability. An expanded multi-disciplinary telehealth team with nuanced understanding of the diseases and healthcare landscape is much needed.

For people living with ME/CFS, the process of applying for the NDIS or DSP and appealing inaccurate decisions comes with a significant cost to health and wellbeing. Navigating the application and appeal processes can trigger post-exertional malaise, leading to a worsening of symptoms for days, weeks or even months.

Emerge Australia has a strong understanding of the health and social care landscape in Australia and is the leading source of trusted information for many ME/CFS patients. Emerge Australia is well-positioned to design and deliver a national linking function to triage patients accessing Telehealth Nurse Case Management and Patient Support Information services into the NDIS and other relevant services.

[166] A Reilly, ME/CFS & the NDIS Facebook Group, R. Buchanan, Not Done Living. ME/CFS National Disability Agreement Review Submission (2018)

Conclusion

ME/CFS has been overlooked for too long. This highly disabling disease affects up to 250,000 Australians, up to 10 times more than multiple sclerosis. The degree of impairment exceeds that of other well-known diseases like multiple sclerosis, depression and cancer.

Despite these numbers and severity, ME/CFS has had only recent and limited research funding. Consequently, causes of the disease remain unknown and there is no biomarker to aid diagnosis. Further, people with ME/CFS have no evidence-based treatment options. At best, patients have the management techniques of pacing and rest, at worst, they are prescribed harmful graded exercise therapy. Many people with Long COVID have now joined this patient cohort and face similar experiences. As with ME/CFS, there is considerable risk that harmful management techniques are being prescribed.

The burden of ME/CFS on the individual and the economy is large. It is estimated that ME/CFS costs the national economy between $1.38 and $14.5 billion[167] [168] with average annual total costs of $63,400/patient. Post-infection syndromes, whether ME/CFS, Long COVID or some other post-infection disease, will affect many people in our community for a long time.

This outlook is unlikely to change unless a number of steps are taken. This report has outlined the multitude of issues that people with ME/CFS and now Long COVID face within the healthcare system. It has also presented solutions and outlined five priority actions for governments, healthcare and research sectors in section 3. These steps have a central theme: there is no need to reinvent the wheel, and don't repeat the mistakes made in ME/CFS.

The highly disabling, life-altering nature of ME/CFS and the lack of support people living with it has been provided must be acknowledged. The promise of a Disability Rights Act is encouraging. All individuals living with ME/CFS and post-infection diseases, like Long COVID, and their carers should receive care and support in a format that is cognisant of the disabling impacts and navigation support to help them improve their health and quality of life across the journey of their disease. This will enable them to better manage their personal lives and participate socially and economically to the extent they are able.

[167] Close et al. 'The Economic Impacts of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in an Australian Cohort' *Front Public Health* 8:420 (2020).
[168] Zhao et al., 'The economic burden of myalgic encephalomyelitis/chronic fatigue syndrome in Australia'. Australian Health Review. November 2023

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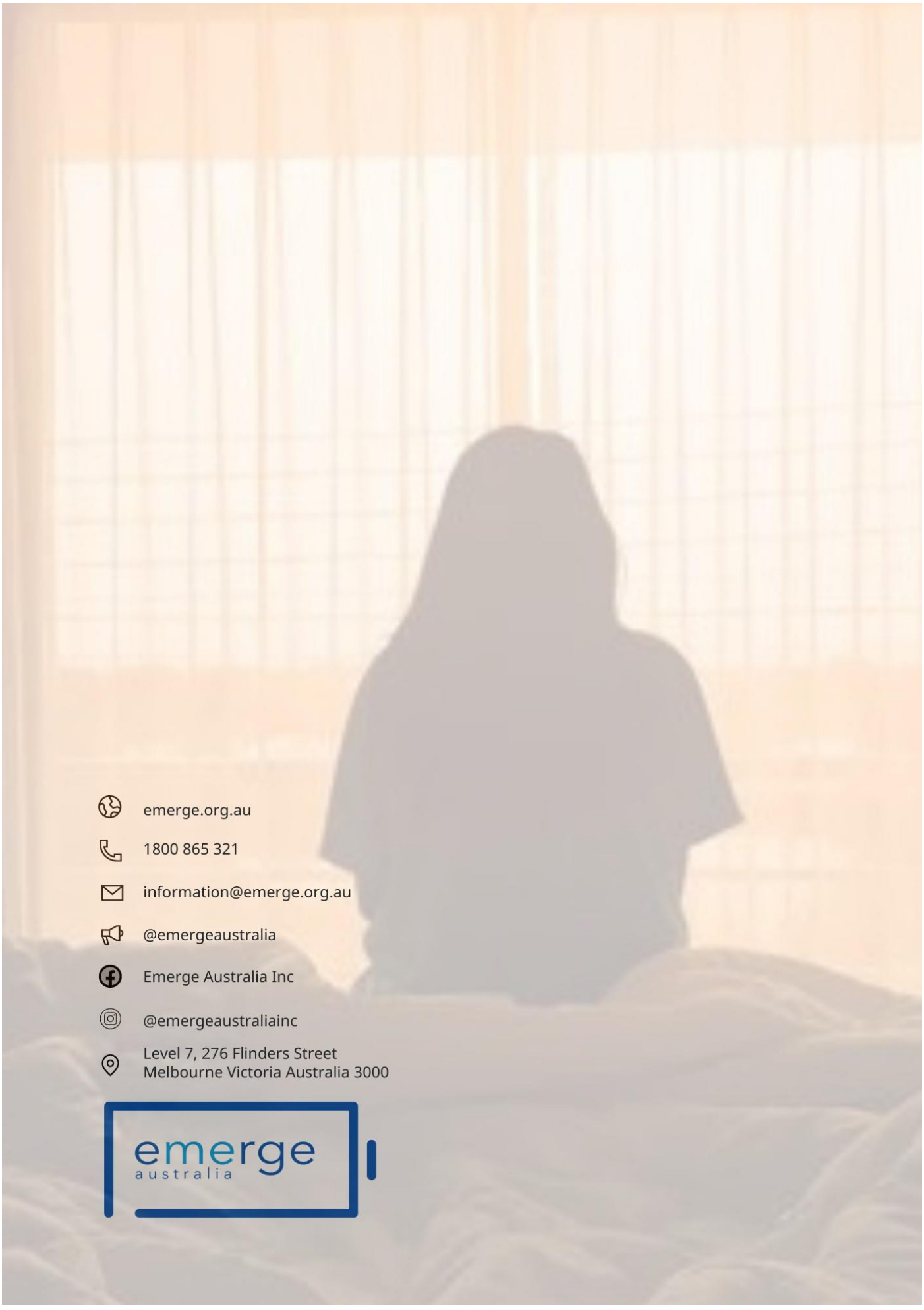

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