National Health and Medical Research Council
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Via email: me_cfs@nhmrc.gov.au

17 April 2024

Dear NHMRC Clinical Guidelines Committee

Thank you for the opportunity to respond to a scoping survey for Clinical Practice Guidelines for myalgic encephalomyelitis / chronic fatigue syndrome. This submission is sent via email as our responses require more characters than the limits available in the online survey. We have reproduced the survey below with responses to all question required of an organisational response.

1. **Privacy Collection notice**

Yes, I have read the security warning/disclaimer in the Privacy Collection Notice and accept the risks and conditions outlined.

2. **What is your interest in completing this survey?**

Emerge Australia is the national patient organisation for people living with ME/CFS, long COVID and associated conditions. Our work includes:

- patient services including education and a free, national telehealth service
- operating a biobank, patient registry, collaborating on research projects
- delivering clinical education for GPs and allied health professionals
- systemic advocacy.

3. **Are you responding as an individual or on behalf of an organisation?**

An organisation

18. **Please identify the best term to describe the organisation**

Non-government organisation

19. **What is the name of your organisation?**

Emerge Australia

20. **What are the three most important topics that you would like to see in an Australian clinical practice guideline for ME/CFS and related conditions?**

One
ME/CFS is biomedical, not psychsomatic. Guidelines must include research/evidence about its physiological abnormalities to end the stigma, gaslighting and disbelief patients have experienced from clinicians.

Two
Post exertional malaise (PEM) is the core feature of ME/CFS. PEM is not fatigue. Understanding the nature of PEM is core to managing the condition and PEM consists of a wide range of symptoms. Ongoing misunderstanding of PEM will result in continued harm to patients.

Three
Healthcare must be safe and appropriate. As there are no evidence-based treatments for ME/CFS, clinicians should focus on pacing, rest and frontline management strategies to reduce the risk of PEM. In addition, clinicians should use stepwise symptom management to address individual symptoms. Behavourial approaches, such as GET/CBT, are not safe, appropriate or effective treatments for ME/CFS.

21. **In a guideline development process, health outcomes (or symptoms) are identified and prioritised before searching for evidence. What health outcomes would you consider important to review the evidence for?**

We have ranked the symptoms and health outcomes listed in the survey in order of priority, from highest to lowest.

Post-exertional malaise
Functional capacity
Cognitive management
Quality of life
Capacity to work/study
Quality of sleep
Pain management
Impact on comorbidities
Fatigue management

Please describe other health outcomes not mentioned in the list.

Fatigue management

We have ranked fatigue management last, as ME/CFS is an energy limiting chronic illness (ELCI), not a fatiguing illness. Clinically, PEM has often been mistaken for fatigue and management, which may be appropriate for fatigue but not for PEM, applied. This misconception has resulted in medical mismanagement and harm. The clinical guidelines must make a clear distinction between PEM and fatigue.

In addition to the symptoms listed in the survey, we believe the following are also important for the clinical guidelines to address:

Orthostatic intolerance (OI)

This is a key symptom of ME/CFS and is a diagnostic criterion. Many patients experience a form of OI, and treatment, while not curative, can improve quality of life. OI can also be measured objectively, through a standing test, which a GP can conduct in their consulting room. Using such an objective measure further dispels the myth that ME/CFS is psycho behavioural.

Sensory sensitivities

People with ME/CFS can experience a range of sensory sensitivities, which are highly disabling. While there is growing acceptance and understanding of the impact of sensory sensitivities on people with other conditions, such as autism, this is not the case for people with ME/CFS. The clinical guidelines must help raise awareness and normalise the need for accommodation of these sensitivities.

Energy management – pacing and rest

The most useful tool for management of ME/CFS is energy management**:** pacing activity and rest. The clinical guidelines must help educate clinicians about the usefulness of these tools and help them understand that pacing is not a treatment as it does not lead to recovery. It is also not a step on the path to increasing activity. The focus of pacing is to reduce symptoms and improve quality of life by minimising PEM. For some people, this can lead to increased capacity, but this is not the norm and shouldn't be the expectation. Patients must no longer be gaslit when they are unable to increase their activity levels. The new clinical guidelines must also set realistic expectations about patients' ability to pace. Pacing is never perfect and there can be many real-world limitations that impact a patients' ability to pace, such as caring responsibilities.

Key patient cohorts
There are three patient subgroups which have particular needs, but which are often overlooked.

Severe ME/CFS
These patients are more vulnerable and require more careful management. They often require in-home or telehealth care and can be very sensitive to medications. The most severe may require hospitalisation or tube feeding and have tended to be treated as psychiatric cases, for example, misdiagnosed as having an eating disorder, rather than treated as the severely ill patients they are. While deaths from ME/CFS have been few, it is patients who are severely unwell and unable to get access to necessary treatments like tube feeding, who are at greatest risk of mortality.

Paediatric ME/CFS
Young people with ME/CFS are often misdiagnosed as having behavioural issues, such as school refusal. The clinical guidelines need to provide guidance for clinicians, as well as others who engage with young people with ME/CFS, such as parents, schools and teachers.

Older people with ME/CFS
There is a lack of research and understanding of the long-term prognosis of ME/CFS, and the interaction of ME/CFS and aging. People with ME/CFS who are entering aged care have little or no support due to lack of understanding of the condition and/or an unwillingness to accommodate their needs.

22. **Are there any other issues you feel are important to address in the guideline?**

Diagnosis must be made as accessible as possible. ME/CFS does not require a specialist for diagnosis; GPs can diagnose ME/CFS and should be encouraged to do so.

Updated guidelines are important, but without an implementation plan and education, they will change very little for people living with ME/CFS. Implementation and clinical education are crucial steps to creating the real-world change in diagnosis, management and societal acceptance that patients need.

Emerging treatments: while there are currently no evidence-based treatments, clinicians should be aware that there are emerging treatments, some which have been used in clinical practise for many years, like low dose naltrexone (LDN). Long COVID research will also likely assist people with ME/CFS.

Clinicians need greater understanding of their role in helping patients access necessary supports like DSP and NDIS. Too many people with ME/CFS, and increasingly long COVID, have NDIS and DSP applications rejected because government assessors incorrectly believe that CBT and GET are effective and necessary treatments. Applications for these disability supports are also rejected because of a false belief that the conditions are not permanent. The guidelines must make it clear that GET and CBT are ineffective and risk harm, and that recovery rates are low; these conditions are lifelong for most who live with them. Clinical guidelines, and clinicians, must dispel this myth once and for all.

23. Permission to Publish

Yes, NHMRC may include my de-identified responses in public summaries of comments received.

Thank you once again for the opportunity to comment on these topics. Please do not hesitate to contact me if I can provide any further information.

Kind regards

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Policy and Advocacy Manager