

Clinical Guidelines Position Statement



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Statement

It is a matter of urgency for Australia to update its clinical guidelines for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), to ensure that Australian ME/CFS patients have access to the best possible care, based on current understanding of the condition and latest evidence.

As ME/CFS research continues to evolve, clinical guidelines quickly become outdated. 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.

Emerge Australia supports further research into both the underlying pathophysiology of ME/CFS and treatments which address these underlying abnormalities.

Background

Australia's clinical guidelines for ME/CFS have not been updated since 2002 [1]. These guidelines do not reflect the current understanding of ME/CFS nor best practice for clinical management of the condition.

Outdated clinical guidelines puts Australia out of step with international best practice and denies Australian ME/CFS patients access to the best possible care.

Evidence

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 [1]. However, it should be noted that even at the time of publication, these guidelines were opposed by Australian ME/CFS patient groups who were concerned about the risk of harm from the recommendations of graded exercise therapy and cognitive behaviour therapy as frontline treatments for the condition [2,3].

Disease conceptualisation

The current clinical guidelines conceptualise the condition as one which is predominantly fatigue, and do not consider ME/CFS to be a specific disease entity. This is in contrast to the now accepted definition of ME/CFS as a "serious, chronic, complex, and multisystem disease", and of which post-exertional malaise (PEM) is considered the core feature [4].

Diagnostic criteria

Australia's current clinical guidelines use the Fukuda (1994) criteria [5], developed by the US Centers for Disease Control and Prevention. These criteria are no longer recommended, as they do not include PEM as a mandatory criterion for diagnosis, despite it being a core feature of the condition [3]. The CDC itself no longer recommends these diagnostic criteria [6].

Treatment

The guidelines focus on physical rehabilitation and encourage ME/CFS patients to undertake exercise, while discouraging excessive rest and activity avoidance. They suggest that patient concerns that physical activity may be harmful are “unwarranted”, despite current consensus that physical activity triggers PEM in ME/CFS patients [7]. The guidelines also falsely claim that graded exercise programs have been shown to be effective treatments for ME/CFS, that avoiding activity in order to not trigger symptom exacerbation can become a vicious cycle of increased disability and more avoidance, and that patients' beliefs about their condition contribute to their prognosis.

This approach to managing ME/CFS is no longer recommended [7-9]. Current clinical guidelines for ME/CFS put Australian clinical management of ME/CFS out of step with international best practice, and Australian ME/CFS patients 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 [3].

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