Pacing and Rest Position Statement

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Statement

Pacing and rest are individualised and essential management techniques for people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Pacing and rest promote safe levels of activity to manage post-exertional malaise (PEM), the hallmark symptom of ME/CFS. Pacing will not cure or treat ME/CFS, however, in the absence of effective treatments, pacing can assist to improve quality of life and reduce symptom severity. Long COVID and post-infection syndrome patients that experience PEM[1], may also benefit from pacing[2]

Background

There are currently no evidence-based treatments for ME/CFS or Long COVID. In the absence of effective treatments, management of these conditions focuses on symptom reduction. Based on experience and available anecdotal patient evidence, pacing is widely recommended as a strategy to improve energy management, with the hope that pacing can minimise PEM[3] and assist to stabilise ME/CFS and other diseases characterised by PEM.

Pacing does not treat the underlying condition. It is an activity management strategy that patients can use to minimise the frequency and severity of PEM episodes. The aim of pacing is to be as active as possible, without overexertion and triggering PEM. While pacing won't cure the disease, it can help patients have more control over their lives, reduce symptoms and improve their quality of life.

Evidence

Post-exertional malaise (PEM) is a core feature of ME/CFS and is defined as the worsening of symptoms following physical[4–6] and/or cognitive activity[7–9], as well as emotional, physical traumas, orthostatic and sensory stressors[10–12]; that are disproportionate to the activity[13]. The symptoms which are exacerbated during PEM are wide-ranging and include the onset of muscle weakness and stiffness, headache and body pain, dizziness and a flu-like malaise[5,14]. Following overexertion, the increase in symptoms and reduction in functional capacity can be immediate or delayed by hours or days and can last for days, weeks[5,15].

Rest is an important component of pacing as it allows the body to recharge and recover from activity. By encouraging patients to balance activities with rest, pacing encourages patients to manage their illness and limit the deterioration of their condition[3]. Pacing encourages a person living with ME/CFS to recognise 'their' energy limits and by doing so, hopefully, minimises the effects of PEM.

Emerge Australia Inc.
Level 7, 276 Flinders Street
Melbourne VIC 3000

Currently, clinical trial evidence to support pacing is very limited/non-existent - trial scarcity, in combination with limited funding has contributed to our limited knowledge, of the benefits of pacing. Nonetheless, whilst there is a lack of research to support the efficacy of pacing, this management approach reflects research demonstrating that patients with ME/CFS and Long COVID exhibit abnormal immunological and metabolic responses to exercise[36–40]. Furthermore, ME/CFS patient surveys consistently report that pacing is an effective technique to manage their symptoms[16–18].

Emerge Australia's Position

Emerge Australia recommends pacing and rest as an energy management strategy for ME/CFS, Long COVID and post-infection syndrome patients, who are experiencing PEM.

Although it is not a cure or treatment, when used effectively, pacing is a safe practice that can assist patients to regain some control over their ME/CFS symptoms and their lives. Pacing is considered an important self-management tool by doctors and patients around the world. Pacing and rest are currently the most effective management tools for people with ME/CFS and other illnesses exhibiting PEM.

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