

# Collection of studies on myalgic encephalomyelitis/chronic fatigue syndrome could benefit long COVID patients

August 23 2023

---



A child with myalgic encephalomyelitis/chronic fatigue syndrome. Credit: Lily Williams

While myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)

and long COVID are not the same disease, they appear to have features of overlapping biological and symptomatic presentations. Many people with long COVID meet the diagnostic criteria of ME/CFS. Long COVID scientists and clinicians can expedite research and care protocols by utilizing information and experiences gained from the ME/CFS community.

A special section of the journal *Work* aims to provide a better understanding of the ME/CFS and long COVID disease process and lived experience and provides tools to improve the overall care of patients.

ME/CFS is a multisystem complex disease with the cardinal symptom being post-exertional malaise (PEM); the worsening of symptoms following exertion. The long COVID community refers to this symptom as post-exertional symptom exacerbation (PESE). ME/CFS deprives individuals of their occupations, relationships, and the ability to receive adequate health care.

"Access to appropriate [medical care](#) and progress in developing treatment has been very slow for ME/CFS patients. This is further complicated by having to fight the stigma of ME/CFS being viewed as a lazy or anxious person's disease and not as the serious life-altering disease it is," Guest Editor of this curated collection, Amy Mooney, MS OTR/L, whose occupational therapy practice OT4ME is based in Riverside, IL, U.S., explains.

"However, with the onslaught of long COVID, more attention has been given to the devastating impact this disease has on quality of life. These patients need more qualified care providers who have the most up-to-date research, care guidelines, and the inquisitiveness to solve difficult medically complex cases."

The collection of research articles in this special issue of *Work* includes reflections of patient experiences, examines the impact of symptoms on activities of daily living, compares PEM in ME/CFS and long COVID populations, and identifies measurements for therapeutic interventions. Patients often describe PEM as a "crash," simultaneously feeling poisoned, drowning in cement, having the flu over and over, and being hit by a bus.

The research presented in this special issue demonstrates the importance of early recognition of PEM for symptom management and improved quality of life. It describes a screening method for identifying who has and who does not have PEM and summarizes symptoms of PEM to differentiate people with ME/CFS and a control group.

It is the clinician's role in the care of patients with PEM/PESE to identify the symptoms that most interfere with activities of daily living; assist the patient with prioritizing meaningful and purposeful tasks; and analyze activities for modifications and adaptations.

"Rehabilitation programs are often centered on reconditioning and exercising patients under the premise that patients are deconditioned due to illness or injury. But this premise that patients with ME/CFS have become deconditioned and increasing activity will restore health is inaccurate and misidentifies the root of the disease. People with PEM/PESE require specialized care and providers must screen for and identify who has and who does not have PEM/PESE," according to Mooney.

"Currently, there are no FDA-approved drugs to treat the metabolic dysfunction or the wide range of debilitating symptoms of ME/CFS. The most effective therapeutic strategy for both ME/CFS and long COVID appears to be pacing. Pacing is a therapeutic strategy and a lifestyle of managing symptoms and exertion within the patient's current energy

threshold. Pacing focuses on identifying the patient's symptoms and level of functioning, analyzing tasks and activities, and providing modification and adaptations for performance outcomes," Mooney adds.

"The goal of pacing for PEM/PESE is to limit cycles of symptom exacerbation (crashes) and prioritize tasks that are meaningful to the individual. With better understanding of how stable or fragile a person's PEM/PESE response is, patients can make personally important activity choices that improve the quality of their lives."

**More information:** Special issue: [Work \(2023\)](#)

Provided by IOS Press

Citation: Collection of studies on myalgic encephalomyelitis/chronic fatigue syndrome could benefit long COVID patients (2023, August 23) retrieved 4 May 2024 from <https://medicalxpress.com/news/2023-08-myalgic-encephalomyelitischronic-fatigue-syndrome-benefit.html>

<p>This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.</p>
--