

## Editorial

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# Introduction to the special section on myalgic encephalomyelitis/chronic fatigue syndrome and Long COVID

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Thank you to WORK: A Journal of Prevention, Assessment & Rehabilitation Editor-in-Chief, Karen Jacobs, and team for the opportunity to coordinate the special edition focusing on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and Long COVID. The collection of research articles in this special edition includes reflections of patient experiences, examines the impact of symptoms on activities of daily living, compares post-exertional malaise in ME/CFS and Long COVID populations, and identifies measurements for therapeutic interventions. The ME/CFS and Long COVID patient, researcher, and advocate communities value the WORK Journal's commitment to publish the most up to date ME/CFS and Long COVID research in open-access format.

While ME/CFS and Long COVID are not the same disease, they appear to have features of overlapping biological and symptomatic presentations [1–3]. For decades, ME/CFS patients, advocacy groups and scientists have called for an increase in research funding to examine ME/CFS's complex multisystem disease process and needed therapies [4]. Recent research shows metabolic defect of the aerobic energy production cycle and excessive production of lactate acid upon exertion, possibly explaining exertion intolerance in ME/CFS patients [5, 6]. The hallmark criteria of ME/CFS, post-exertional malaise (PEM), is the worsening of symptoms and function following a previously tolerated physical, cognitive, orthostatic,

emotional, or sensory stressor [1, 7]. Symptoms of ME/CFS leave patients with “substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities” [2] and dependent on others for care [1]. In addition to PEM, patients with ME/CFS commonly experience overwhelming fatigue that is not alleviated with rest, cognitive impairment, orthostatic intolerance, muscle/joint pain, neurological abnormalities, extreme sensitivity to sensory input, and more debilitating symptoms [1, 2, 8]. Patients often describe PEM as a “crash”; feeling poisoned, drowning in cement, having the flu over and over, and being hit by a bus [4].

Research shows, due to the severity of symptoms, 75% of patients with ME/CFS are unable to work and 25–29% are home bound or bed bound [7]. ME/CFS is more debilitating than “many chronic diseases including multiple sclerosis, chronic renal failure, lung cancer, stroke, and type-2 diabetes” [9]. For the millions of patients suffering from the intense symptoms of ME/CFS, additional research is needed to understand the disease process, identify biomarkers for diagnostic criteria, and determine appropriate treatment for care. This special edition of the WORK Journal aims to provide a better understanding of the ME/CFS and Long COVID disease process, lived experience, and provide tools to improve the overall care of patients.

ME/CFS is a chronic, multi-system disease that affects an estimated 1 to 2.5 million Americans [1, 7, 10]. Many patients identify the onset of ME/CFS after an infectious illness [2, 11]. Following the COVID-19 outbreak of the SARS-CoV-2 virus, patients, clinicians, and researchers have identified similarities between those living with ME/CFS and those living with Long COVID [3, 4, 13]. Dr. Anthony Fauci, the former Director of the National Institute for Allergy and Infectious Diseases, stated that Long COVID patients present with symptoms that are “strikingly similar to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome” [12]. Some patients with Long COVID have a post-exertional symptom exacerbation feature, PESE, that is synonymous with PEM [3]. Without clarity on the disease pathophysiology and a path for treatment, both patient groups are left suffering from the debilitating effects of PEM/PESE.

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 [3, 13, 14]. 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. The goal of pacing for PEM/PESE is to limit cycles of symptom exacerbation (crashes) and prioritize tasks that are meaningful to the individual [14–16]. 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.

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 the activities for modifications and adaptations [15]. Patients with PEM/PESE do not need tasks to be practiced or exercised for reconditioning, as ME/CFS nor Long COVID are a result of deconditioning. Patients with ME/CFS and Long COVID similarly are not displaying an illness behavior that is a result of depression, anxiety or some other form of mental health concern [1, 2, 7, 13, 14]. Patients with PEM/PESE are struggling to perform their daily activities due to the chronic multi-system disease [4, 5, 9, 13, 16]. With the assistance of PEM/PESE

knowledgeable clinicians, patients will learn pacing techniques to function safely within their energy threshold and potentially restore meaning and purpose to their daily living.

Thank you to the researchers for trusting me with your valuable work and to the many peer experts who took the time out of your busy schedules to review the manuscripts. The patient community and their allies are grateful for all your efforts.

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Guest Editor

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