

Myalgic Encephalomyelitis or Chronic Fatigue Syndrome and Risk of Post-Exertional Malaise from Functional Capacity Evaluations

Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) Overview:

Currently, the U.S. Centers for Disease Control and Prevention (CDC)ⁱ notes that “ME/CFS is a complex, chronic, debilitating disease with systemic effects. ME/CFS is characterized by reduced ability to perform pre-illness activities that lasts for more than 6 months and is accompanied by profound fatigue, which is not improved by rest.” In addition, the CDC notes “The severity and frequency of the symptoms can vary among patients and can vary for an individual patient. Symptoms can fluctuate during the day, from day to day, and throughout the illness. Some patients may not be obviously ill-appearing during clinical evaluation”

ME/CFS and Post-Exertional Malaise (PEM):

The CDC also notes that a “hallmark of ME/CFS is that symptoms can worsen after physical, mental, or emotional effort, a manifestation known as post-exertional malaise (PEM)”. Recent 2021 guidance from National Institute of Health and Care Excellence (NICE) defines PEM as “The worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. Symptoms can typically worsen 12 to 48 hours after activity and last for days or even weeks, sometimes leading to a relapseⁱⁱ.”

Further, CDC guidance for management of ME/CFS for healthcare providers notes that “One of the best options to minimize or prevent PEM is to help patients learn to keep all energy expenditures, physical, cognitive and emotional, within limits that can be tolerated by planning when and how to use their limited energy. Minimizing PEM can prevent worsening of these symptoms [...] Increased activity can thus be harmful if it leads to PEM. For some patients, even activities of daily living can trigger PEM. Any recommendation for increased activity or movement should take into account the patient’s energy limits [...] and must be specific regarding the intensity, duration, frequency, and type of activity, especially for patients who are severely ill or experience orthostatic intolerance when upright”ⁱⁱⁱ.

Importantly, CDC guidance also states, “Healthcare providers need to keep in mind that when patients with ME/CFS exceed their individual capacities, PEM and serious deterioration of function may result”.^{iv}

Guidance from Euromeme^v (European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) published in 2021 notes that intolerance to effort is a key symptom of ME/CFS and states “Both mental and physical activities should be undertaken in such a way to avoid over-exertion, which may trigger post-exertional aggravation of symptoms or “crashes”, and as a key strategy to optimize chances of recovery. “Pacing” refers to breaking up physical or mental activities with periods of rest, before a significant level of tiredness or exacerbation of symptoms is achieved or is expected following exertion, e.g., PEM, which may manifest many hours after the effort”

Recent 2021 guidance from NICE^{vi} also notes under section 1.3. Advice for people with suspected ME/CFS, “not to use more energy than they perceive they have – they should manage their daily activity and not 'push through' their symptoms”

The Concern with Functional Capacity Evaluations (FCE) and PEM:

Frequently FCE providers do not follow up with individuals in the period 24 to 48 hours after an FCE and therefore the likely impact of the FCE in precipitating PEM is not documented and taken into account regarding assessing sustained functioning. PEM is frequently significant and can preclude regular consistent employment which is usually not taken into consideration as a limiting factor in the FCE report.

Importantly, some individuals with ME/CFS may have medical restrictions outlined by their healthcare providers. Medical restrictions are defined as activities that a patient should not do because of risk of harm. Individuals with epilepsy for instance will be restricted from driving for a period of time. Informed treatment providers will work with individuals with ME/CFS to provide medical restrictions in physical and cognitive effort in order to avoid PEM and potential harmful effects of severe or repetitive PEM.

FCEs typically track reports of the individual's pain but often do not track fatigue as a limiting symptom and fatigue is the primary symptom of ME/CFS. This may result in the FCE provider simply stating that the individual self-limited their efforts and interpreting this as invalid effort.

Conclusion:

FCE likely do not accurately measure function amongst those with a diagnosis of ME/CFS as they do not routinely take into account the effects of post exertional malaise on functioning and therefore may significantly overestimate functioning. Importantly as noted above, if an individual exceed their capacities, PEM and serious deterioration of function may result. **Based on current guidance from major institutions as above, FCEs are not recommended for assessment of functioning in individuals with a diagnosis of ME/CFS.**

ⁱ <https://www.cdc.gov/me-cfs/healthcare-providers/index.html>; Accessed September 3rd 2023

ⁱⁱ Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management NICE (National Institute of Health and Care Excellence) guideline [NG206]Published: 29 October 2021

ⁱⁱⁱ https://www.cdc.gov/me-cfs/pdfs/toolkit/Managing-PEM_508.pdf Accessed September 3rd 2023

^{iv} <https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/treating-most-disruptive-symptoms.html>; Accessed September 30th 2023

^v Nacul et al Medicina (Kaunas) 2021 May 19;57(5):510. European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE): Expert Consensus on the Diagnosis, Service Provision, and Care of People with ME/CFS in Europe

^{vi} Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management NICE (National Institute of Health and Care Excellence) guideline [NG206]Published: 29 October 2021