

ICD-10-CM Code for Post-Exertional Malaise/Post-Exertional Symptom Exacerbation

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What is post-exertional malaise/ post-exertional symptom exacerbation?

Prolonged exacerbation of symptoms (and/or appearance of new symptoms) and worsening functioning after exertion which was previously tolerated, with onset often delayed by hours to days

Symptoms Exacerbated Include:
Fatigue
Orthostatic intolerance
Joint and muscle pain
Flu-like symptoms
Weakness/instability
Cognitive dysfunction

Types of Exertion / Stressors
Physical (walking, chores, bathing)
Cognitive (working, driving, scheduling)
Emotional (anger, grief, worry)
Positional (standing, sitting up)
Sensory (bright lights, loud noises)

What is post-exertional malaise/ post-exertional symptom exacerbation? continued

- Severity and duration of symptoms is often out-of-proportion to the type, intensity, frequency, and/or duration of exertion, with a prolonged, unpredictable time to return to baseline that is not easily relieved by rest or sleep, and may last days/weeks/longer
 - E.g. Showering or making a meal can result in a patient becoming bedbound
- Research into the symptom shows:
 - Pathological loss of stamina and/or functional capacity that is not due to physical deconditioning
 - Impaired aerobic metabolism and glycolytic system
 - Abnormal changes in gene expression, immune and oxidative stress markers, and neurological function

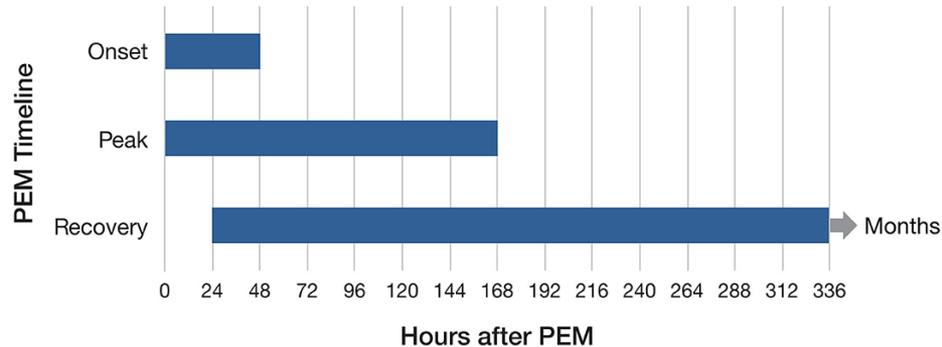


Figure from: Stussman, et al (2020). Characterization of Post-exertional Malaise in Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Front. Neurol.* 11 <https://doi.org/10.3389/fneur.2020.01025>

Prevalence in ME/CFS & Post COVID-19 Condition (Long COVID)

Post-exertional malaise is considered to be the **hallmark symptom of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)**

- **Required for an ME/CFS diagnosis** by Institute of Medicine (IOM), cited by CDC

Reported by a **majority of people with Long COVID** in studies that track the symptom

- 89.1% of survey respondents in Davis et al, 2021 reported the symptom
- 58.7% of participants in Twomey et al, 2022 met the scoring threshold for PEM used for people with ME/CFS

Listed as common symptom of Long COVID by CDC, WHO, AAPM&R, and others



Clinical Care Implications

- With high #s of Long COVID cases, it is now commonly seen in clinical care settings, but providers are not always familiar with what it is
- Significant implications in diagnosis and treatment
 - AAPM&R and World Physiotherapy guidance discuss importance of identifying post-exertional malaise and caution against exercise programs that provoke the symptom
 - Pacing seen as best management for symptom
- Symptom is separate from diagnosis
 - Not all who have the symptom meet ME/CFS diagnosis
 - Symptom often onsets at trigger of condition (e.g. following viral infection)

Rationale for ICD-10-CM Code

- Key symptom of conditions that impact millions of people
- Track morbidity
- More accurate and informative electronic health record (EHR) research
 - Currently, EHR research on Long COVID does not track post-exertional malaise, despite being a top symptom → leads to incomplete phenotype analysis which could lead to inadequate biomarker and therapeutic discovery
- Helps to meet Health and Human Services' National Research Action Plan goal of data harmonization across research studies
- Facilitate communication across providers
- Improved patient care and health outcomes

Support

Clinicians and Researchers

- American Academy of Physical Medicine and Rehabilitation
- ME/CFS Clinician Coalition
- Dr. David Putrino, Icahn School of Medicine at Mount Sinai
- Dr. Eric Topol, Scripps Research
- Dr. Ziyad Al-Aly, VA Saint Louis Health Care System
- Dr. Leonard Jason, DePaul University
- Dr. Steve Deeks, UCSF
- Dr. Michael Peluso, UCSF
- Dr. Monica Verduzco-Gutierrez, UT Health San Antonio
- Dr. Susan Levine
- Dr. Emily Pfaff, UNC Chapel Hill
- RECOVER PIs, including:
 - Dr. Tiffany Walker, Emory University
 - Dr. Sarah Jolley, University of Colorado

Long COVID and ME/CFS organizations

- Long COVID Alliance
- Solve ME
- #MEAction
- Body Politic
- Strategies for High Impact
- Long COVID Justice
- COVID-19 Longhailer Advocacy Project
- Open Medicine Foundation
- Massachusetts ME/CFS & FM Association
- PandoraOrg
- Pandemic Patients
- COVID-19 Health and Safety Taskforce
- The Long COVID Trials Initiative



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