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

September 13, 2023

Presented by: Lisa McCorkell, MPP, Co-Founder of Patient-Led Research Collaborative
Clinical Questions: Todd Davenport, PT, DPT, MPH, OCS

What is post-exertional malaise/ post-exertional symptom exacerbation (PEM/PESE)?

Abnormal response to previously tolerated exertion/stressors resulting in exacerbation of symptoms (and/or appearance of new symptoms) and worsening functioning, with onset often delayed by hours to days, and prolonged recovery

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)
Environmental (bright lights, loud noises)

What is post-exertional malaise/ post-exertional symptom exacerbation (PEM/PESE)?

- 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

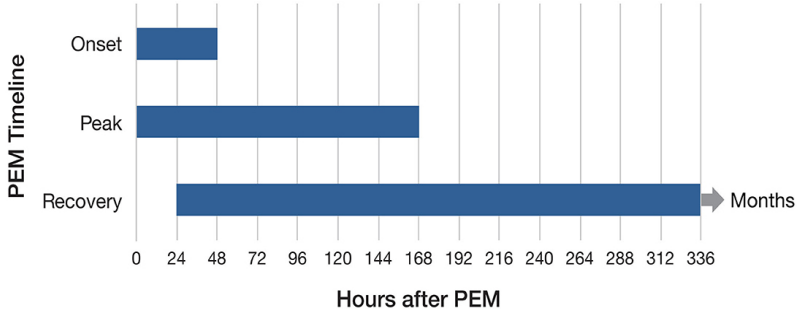

Figure from: Stussman, et al (2020). Characterization of Post-exertional Malaise in Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Front. Neurol. 11 https://doi.org/10.3389/fneur.2020.01025

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)
- Included in definitions of ME/CFS for clinical use by CDC, Mayo Clinic Proceedings, UpToDate, ME/CFS Clinician Coalition

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

- 89.1% of 3,762 survey respondents in Davis *et al.*, 2021 reported the symptom
- 58.7% of 203 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

- Increasing prevalence of Long COVID cases, now commonly seen across clinical care settings
- Significant implications for diagnosis, treatment, and communication among providers
  - 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
  - All of a patient's providers should be aware of symptom to coordinate care
- Symptom is separate from diagnosis
  - Not all patients who have PEM/PESE may meet all the criteria for ME/CFS, depending on the case definition criteria used
  - Symptom often begins soon after the trigger of a condition (e.g., following viral infection)
  - Many potential 'routes of entry' for people with PEM/PESE to enter the medical system
  - Note: per ICD rules, PEM would not be coded in those with ME/CFS as it is required for a diagnosis of ME/CFS

Clinical Care Implications (part 2)

Important to build on the existing educational and guidance efforts on PEM/PESE (e.g., Project ECHO) to ensure:

- Providers understand how to identify PEM in patients
- People who have PEM should be evaluated for ME/CFS

Note: The proposed code does not require any type of testing to be done in order to be listed as having PEM/PESE. The self-report of the patient is all that is required.

Rationale for ICD-10-CM Code for PEM/PESE

- Key symptom of Long COVID which impacts millions of people
- Providers are using the term and putting it in doctor's notes
- Not duplicative of existing diagnosis codes – markedly different than exertional dyspnea, fatigue, and malaise as it is more expansive and/or more specific
- 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
- Mitigate risk of harm to patients from inappropriate treatment recommendations

Support for a PEM/PESE ICD-10-CM code

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 Longhauler Advocacy Project
- Open Medicine Foundation
- Massachusetts ME/CFS & FM Association
- PandoraOrg
- Pandemic Patients
- COVID-19 Health and Safety Taskforce
- The Long COVID Trials Initiative
- Long COVID Physio

From Dr. Tiffany Walker, Clinician & PI at Grady Post COVID Clinic

"Post exertional malaise is a very prevalent and distinctive feature of Long COVID and other post-infectious illness that has been well-characterized in the literature… identification and tracking of PEM advances our understanding of Long COVID natural history and symptom trends. Additionally, documentation of PEM in the medical record facilitates improved large EHR-based retrospective cohort data and simulated real-world data clinical trials, by more accurately reflecting dominant symptoms experienced by Long COVID patients."

References

- Bateman, L.; Bested, A. C.; Bonilla, H. F.; el al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management. Mayo Clinic Proceedings 2021, 0 (0). https://doi.org/10.1016/j.mayocp.2021.07.004
- Centers for Disease Control and Prevention (2022). Long COVID or Post-COVID Conditions. https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html
- Davis, H. E.; Assaf, G. S.; McCorkell, L.; et al. Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact. EClinicalMedicine 2021, 38, 101019. https://doi.org/10.1016/j.eclinm.2021.101019
- Department of Health and Human Services, Office of the Assistant Secretary for Health. 2022. National Research Action Plan on Long COVID, 200 Independence Ave SW, Washington, DC 20201.
- Herrera, J. E.; Niehaus, W. N.; Whiteson, J.; et al. Multidisciplinary Collaborative Consensus Guidance Statement on the Assessment and Treatment of Fatigue in postacute Sequelae of SARS-CoV -2 Infection (PASC) Patients. PM&R 2021, 13 (9), 1027–1043. https://doi.org/10.1002/pmrj.12684
- Keller BA, Pryor JL, Giloteaux L. Inability of myalgic encephalomyelitis/chronic fatigue syndrome patients to repro- duce VO2peak indicates functional impairment. J Transl Med. 2014;12(1):104.
- Pfaff, E. R.; Girvin, A. T.; Bennett, T. D.; et al. Identifying Who Has Long COVID in the USA: A Machine Learning Approach Using N3C Data. The Lancet Digital Health 2022, S2589750022000486. https://doi.org/10.1016/S2589-7500(22)00048-6
- 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
- Twomey, R. et al. Chronic fatigue and postexertional malaise in people living with Long COVID: an observational study. *Phys. Ther.* 102, pzac005 (2022)
- US Institute of Medicine. Beyond myalgic encephalomyelitis/ chronic fatigue syndrome: redefining an illness. Report guide for clinicians. The National Academies Press. February 2015. https://www.nap.edu/resource/19012/MECFSclinicians guide.pdf
- World Health Organization (2021). Support for rehabilitation: self-management after COVID-19-related illness. 2nd edition.https://www.who.int/europe/publications/i/item/WHO-EURO-2021-855-40590-59892
- World Physiotherapy response to COVID-19 Briefing paper 9. World Physiotherapy. June 2021. https://world.physio/sites/default/files/2021-06/Briefing-Paper-9-Long-Covid-FINAL-2021.pdf