# What are fatigue and Post-Exertional Malaise (PEM)?



### LONG COVID ESSENTIALS: A series by The Sick Times & Long COVID Justice

Fatigue is a common symptom in both Long COVID and Myalgic Encephalomyelitis (ME).

**Post-exertional malaise (PEM)** is a specific set of common symptoms and signs that are key features of ME and some cases of Long COVID. PEM is different from fatigue, and is also known as post-exertional neuroimmune exhaustion (PENE) or <u>post-exertional</u> <u>Symptom Exacerbation</u> (PESE).

**Fatigue** can feel like profound tiredness, exhaustion, or low energy. In healthy people, fatigue is usually a short-term state that resolves with rest. In people with Long COVID and ME, fatigue can be more frequent, severe and long-lasting. It is often life-changing.

There are <u>many types of fatigue</u> according to studies. They can include feeling "wired", experiencing <u>"brain fog" or cognitive dysfunction</u>, lacking energy for daily tasks, and even feeling "flu-like."

Debilitating fatigue is a common component of PEM.

**Post-exertional malaise (PEM)** means new or worsened symptoms often triggered by physical, emotional, or mental activity (even very mild activity). Some people describe it as a "crash" or "flare."

Symptoms of PEM can vary for every individual but may include: fatigue, body pain, sleep problems, "brain fog", headaches, muscle weakness, and/or flu-like symptoms (sore throat, headache, nausea, dizziness). You might struggle with simple tasks and/or be bed or house-bound. Recovery can take days, weeks, or longer.



# \* What causes PEM?

Triggers can include physical activity, exercise, stress, mental effort, excitement, or noisy/busy/contaminated environments. **PEM often strikes a day or two after the activity, which can make it difficult to identify the triggering event.** For people with more <u>severe Long COVID</u>, simpler tasks like showering, reading, or talking can be triggers.

PEM is a warning sign: it means your body needs rest. Trying to "push through" can worsen your baseline (your current state of health). PEM is not caused by "deconditioning" (inactivity). This means that some approaches like <u>graded exercise therapy</u> can be harmful to people with PEM. Read more in <u>our resource on exercise</u>.

The root causes of PEM are unclear. Theories include:

- Problems with how your <u>cells produce energy</u>;
- Not enough <u>oxygen</u> getting to your brain and muscles;
- Changes to your immune system.

# **\* Managing PEM**

There are no proven treatments for PEM. But here are some steps that can help to manage or reduce it:

## 1. Stop. Rest. Pace.

- Pacing is a self-management strategy that can help you avoid "crashing."
- Pacing means scheduling radical rest, foregoing activities, setting limits, and other measures to <u>preserve your energy</u> and baseline.
- Avoid the "push and crash" cycle. Try to keep your heart rate low.

# 2. Track your symptoms

 You can use a diary, a <u>free app like Visible</u>, or a smartwatch to <u>record daily</u> <u>symptoms</u>. This can help you identify your baseline (or safe activity level) to help avoid your triggers.



#### 3. Warning: PEM and exercise don't mix!

- Studies show that exercise and graded exercise therapy can worsen a person's baseline and increase the severity of their disease.
- <u>This letter</u> from the Workwell Foundation might be helpful to a medical professional who recommends exercise.

#### 4. Self-care

- Try to avoid stress, protect your sleep, eat well, and stay hydrated.
- Say "no" to activities and events that you think will make you "crash".
- Seek support in online patient communities, trusted friends and family.

# \* Resources

- <u>Video that explains PEM/PESE</u> Long COVID Physio
- Pacing guide for adults, one for children, and another for clinicians #MEAction
- Resources on PEM and fatigue Workwell Foundation
- <u>Possible treatments for people with ME to share with a doctor</u> ME/CFS Clinician
  Coalition
- Article explaining fatigue in Long COVID The Atlantic

#### **FULL SERIES OF FACTSHEETS WITH LINKED RESOURCES + MORE:**

tiny.cc/LCE or scan the QR code with your phone camera



## QUESTIONS? connect@s4hi.org

This series was designed by people living with Long COVID and associated diseases. Each resource sheet has been reviewed by patient and medical experts. This is an informational resource, not medical advice. Publication date: 12/13/2024.