Post-Exertional Malaise

Category: 2 Symptom

What is PEM?

PEM stands for **post-exertional malaise** (pronounced ma-LEH-eez). It is defined as an increase in symptoms (for example, fatigue, brain fog, breathlessness, headaches, body aches) after what doesn't seem like a lot of activity.

The activity can be:

- physical (like taking a walk or getting dressed)
- cognitive (like doing paperwork or spending time in a busy environment)
- social/emotional (like attending a dinner party or taking a phone call)

It might seem like you feel a lot more fatigue and overall symptoms than you think you should, based on the level of effort or time you spend doing an activity.

If you are not sure if you have PEM, you can talk to a healthcare provider about doing a screening for PEM or your healthcare provider may ask you to complete a questionnaire to screen for PEM. Please see the Canadian Guideline for Post COVID-19 Condition (CAN-PCC) recommendation for the use of questionnaires to screen for PEM/PESE.

POST-COVID-19
Interdisciplinary Clinical Care Network
Provincial Health Services Authority

What you will notice

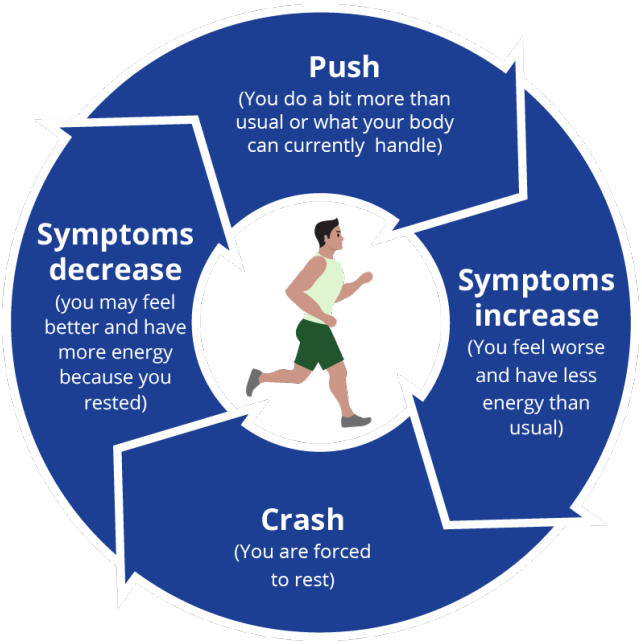
Some days, you may feel drained and unable to do some or any of your normal activities. You will likely notice that some or all of your usual symptoms are worse than normal.

You may be able to trace this 'flare' or 'crash' back to a specific activity or day(s) where you did more than normal.

Maybe you had more energy one day and you wanted to 'take advantage' of feeling well to get caught up on your usual activities or to exercise.

Often, the point where you over-exerted yourself would have happened 1 to 3 days before you felt the fatigue/symptoms get worse.

This pattern is called a **push/crash cycle**.



Stopping the push/crash cycle is crucial to managing the symptoms of Long COVID and improving quality of life. Evidence has shown that people dealing with PEM who continue this pattern tend to get worse over time, meaning less and less activity triggers the symptoms and may result in long term disability. The quicker this cycle can be stopped the greater the chance of recovery or improvement.

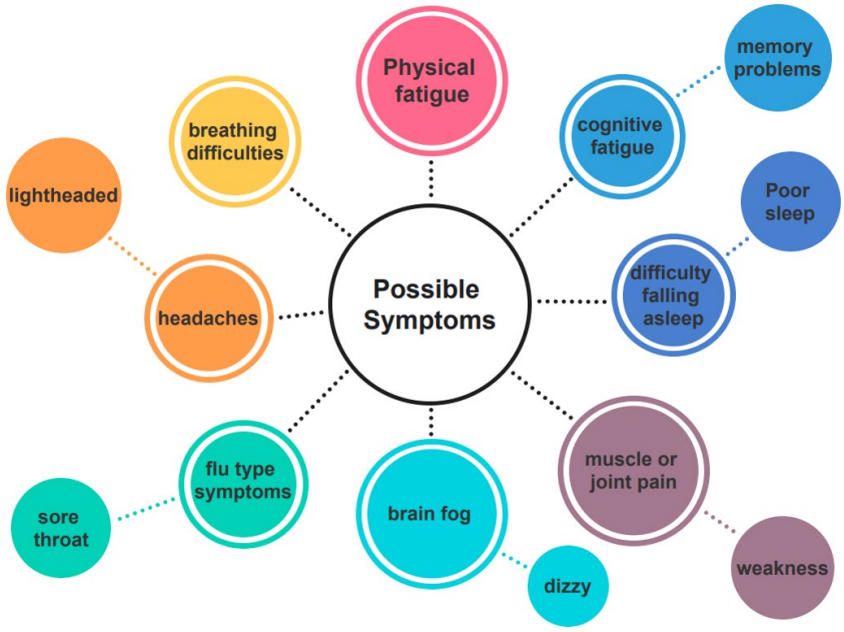
Why PEM happens

There is ongoing research and we certainly don't have all the answers yet. A lot of what we know comes from research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), which can be triggered by a viral infection.

Some evidence suggests that PEM may be related to problems in how our cells produce and use energy. This is known as mitochondrial dysfunction.

The mitochondria are the 'powerhouses' or 'engines' inside our cells (in muscles, brains, organs, nerves) that produce the energy our bodies need to function. When mitochondria produce less energy, our ability to recover from activities decreases. This is typically experienced by people with Long COVID as symptoms such as fatigue, muscle aches/pain, brain fog, headaches, and more.

It is important to realize that the fatigue and other troubling symptoms you may experience with Long COVID are truly pathologic (meaning, they are a result of a physical dysfunction) – not something that is 'in your head.' It is something that is happening at cellular level. It is not fully understood yet by medical science, but it is real and you can't push or exercise your way out of it.



Watch this video

'Mitochondria NOT Hypochondria' - Created by the Complex Chronic Disease Program at the BC Women's Hospital.

Coping with PEM

A **Stop-Rest-Pace** approach can be helpful for getting yourself out of the push/crash cycle.

A key part of the Stop-Rest-Pace approach is to find and stay within your energy envelope. Your **energy envelope** is the level of activity (physical, cognitive, social/emotional) you can sustain without crashing. When an activity takes you outside your energy envelope, it is known as a trigger.

In order to effectively stay with in your envelope, you may need to modify your relationship with:

- Work or school
- Roles and responsibilities at home
- Recreational/volunteer activities

You may need to talk to a primary care provider (doctor or nurse practitioner) when making these changes, as well as your support network (including family, friends, community members).

Depending on the severity of your symptoms, even with the stop-rest-pace strategy, you may also need to seek additional support for activities of daily living.

Seeking support through your journey

Breaking the push-crash cycle and finding your energy envelope is the most important and often most difficult step towards improvement or recovery for people with Long COVID and post-exertional malaise. It often requires several significant life changes and can leave you with a sense of grief or loss.

Often people learn they need to cut back more than they had realized and this experience can be discouraging. It can also be difficult to continue to apply energy conservation strategies when you start to feel you are doing better or when you are forced to deal with situations or stressors that you know can cause symptoms to flare.

Many people find it helpful to connect with others who have experienced PEM. Recovery can be incredibly slow and frustrating, so connecting with others with similar experiences can help you keep on track with continuing to use self management strategies like energy conservation even when you're feeling stuck.

Where to next?

- Watch this video on 'Mitochondria NOT Hypochondria' by the Complex Chronic Disease Program at the BC Women's Hospital.
- Read the recommendation by CAN-PCC on screening for post-exertional malaise (PEM)/Post-exertional symptom exacerbation (PESE)
- Read and watch videos prepared by healthexperiences.ca in which individuals with Long COVID describe different symptoms they experience, including Post-Exertional Malaise.