

Post-Exertional Malaise

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Post-Exertional Malaise (PEM) refers to the inability for the body to recover in a normal manner after exertion. It could be triggered by:

- Physical
- Emotional
- Cognitive
- Orthostatic
- Environmental
- Sensory stressors

What does PEM look like?

PEM can look slightly different in everybody, but the main characteristics are:

- Disabling and delayed fatigue response.
- Exacerbation of symptoms which are disproportionate to the effort made.
- It can worsen 12 - 48 hours after the activity.
- The response can last for days, weeks or months.
- PEM is an identifying feature of ME / CFS and can be present in Long-COVID.

What causes PEM?

- When your cellular level expenditure exceeds the ability of the body to produce more energy, resulting in a drastic reduction in capacity.
- Symptoms often worsen until the body's stores of energy are restored.
- PEM is triggered by exertion that is outside your unique energy envelope, or limit (The energy envelope is the amount of energy a person with ME / CFS has available each day that can be safely used without triggering PEM).

Understanding the role of the Mitochondria

- The mitochondria are responsible for producing energy in our cells.
- They are responsible for converting chemical energy from food into a type of energy that is easily and readily available for the cells to use, called ATP.
- The body uses ATP for all its processes including organ function, body repair processes and movement.

- Studies have found that in people with ME / CFS, their mitochondria have lower reserves for energy production capacity compared to people without ME / CFS.
- Impaired ATP production results in all slower cellular processes.
- Studies have also shown that people with ME / CFS have low levels of helpful mitochondrial compounds, but they also have high levels of other compounds that cause damage to the mitochondria.
- These compounds can create, use or breakdown molecules that keep ATP flowing in the body. The creation and use of ATP plays a key role in the metabolism of these compounds. When they are not creating or breaking down molecules correctly, the mitochondria is affected and unable to produce ATP properly.
- This is why people with ME / CFS find it hard to sustain both physical and cognitive activity, because the body is unable to produce sufficient ATP to function properly.
- How much ATP is being produced and how the body recycles it to produce energy can be measured in a blood test.
- To support the reproduction and recycling system we can use supplements, nutrients and pacing.

The Push-Crash Cycle - Why is it important to understand how we can avoid it?

- Pushing through PEM can cause an individual to get stuck in a push-crash cycle.
- This can then cause people to continue to push through the crashed state, not allowing for energy restoration to occur in the body.
- Consider a repeated crash like a repeated injury, which over time can have long lasting effects and consequences, as well as decreasing the ability to function. Like breaking a leg and continuing to trip and fall on the injured leg.
- Over time, the body needs more and more time to recover and refill the energy stores after repeated crashes, by constantly being depleted and pushed into "debt zone".
- The body will then find it harder each time to return to its baseline.

Everyone can experience PEM symptoms differently, but some of the common symptoms you might experience during a crash include:

- Pain
- Sleep disturbances
- Brain fog
- Increased sensitivity to noise, light or touch
- Muscle weakness
- Flu like symptoms

Long-COVID and PEM:

- Studies show that people with Long-COVID experience PEM.
- The most common trigger found in the studies for both Long-COVID and ME / CFS participants was low and medium physical and cognitive exertion.
- The Long-COVID participants who had been ill for less than a year, experienced more triggers than the CFS / ME participants who had been ill for longer.
- Stress was reported as a trigger.
- In both groups of participants, the results showed that rest helped recovery for PEM and pacing helped prevent PEM.
- Sleep, hydration and diet were also reported as useful management strategies.

What can we do when we experience a crash?

It is important to plan ahead before you experience the crash, you can do this by:

- Alert your emergency contacts, make sure that they have access to any health information they might need if they have to act on your behalf.
- Have everything you need prepared by your bedside. For example, things to make sure your vitals are stable (thermometer, medical bracelet).
- bottled water, electrolyte drinks to make sure you are hydrated.
- Have foods by your side that can be consumed in a variety of ways, for example, some that you may be able to drink or suck on, as well as chew. Avoid foods that are well known triggers.
- Have medication at hand, pill boxes and pill reminder alarms close by.
- Conserve energy by aggressively minimising all activity and movement.
- Turn down any sensory and environmental stimulus, cognitive demands and physiological fluctuations such as body temperature and body positioning.
- Practice self-compassion and wellness to accelerate recovery.
- Be patient and learn how to figure out your thresholds, this will help you prevent the next crash. Have everything at hand if a crash happens, but most importantly, give yourself permission to rest and heal.

What can we do to avoid PEM?

It is very important that you prioritise yourself and what is important to you.

- Find your energy envelope: Activity diaries can be a great tool to help you identify patterns of fatigue and the possible causes. Keeping a diary can help you be conscious of energy depleting interactions.
- Creating a pacing plan designed around your energy envelope can help prevent the push crash cycle. When pacing, a person undertakes less activity than they have energy for.

- Think about your body as having an internal battery which can only be partially charged, so think ahead and plan your day's activities depending on how much energy you have available in the battery.
- Recharge between activities - Like when charging a phone, it is best to do so without using it and charging it at the same time. There are several ways in which you can charge the battery, a long charge involves fully resting, minimising all physical and cognitive activity, and low environmental stimulation. Or a quick charge involves breathing exercises, small meditation and a body check in.
- Learn to manage your energy even on days when you feel like you can do more. It is important to not be tempted to overdo it.
- Be mindful of your dashboard lights!
- Be flexible and manage your expectations on days when you may need more rest. Every day can be different.
- Learn to say no and modify tasks, spread activities over a few days, try and figure out some short cuts, or use technology to minimise the energy expenditure and stay within your envelope.

Do what brings you joy!

- Prioritise something you love to do, like spending time with family and friends, attending a social gathering, taking time to spend outside in nature, doing arts and crafts.
- Recognise that the things that give you joy are important, therefore saving energy or planning these around your pacing schedule is really important. Because joy can also bring you health.
- Nurture yourself- This can look like letting yourself rest, calming your system by using techniques such as meditation and deep breathing. Practice self-compassion and acceptance.

Here are some strategies to avoid PEM:

- Do some detective work and find out your own triggers of PEM.
- Learn about your health patterns.
- Treat any other medical conditions.
- Plan your day.
- Pace yourself.
- Ensure that you sleep the best you can.
- Maintain emotional health.
- Build your support network.
- Give your body good nutrition.
- Track your progress.