

# AN EXPLANATION OF POST-EXERTIONAL MALAISE (PEM) THE BASICS

▶ **YOU HAVE BEEN DIAGNOSED WITH ME - MYALGIC ENCEPHALOMYELITIS\*.**

\*also called Chronic Fatigue Syndrome, ME/CFS, or Tapanui Flu

▶ **YOU HAVE HEARD ABOUT SOMETHING CALLED POST-EXERTIONAL MALAISE (PEM).**

▶ **YOU WANT TO KNOW WHAT THAT MEANS. HERE ARE SOME ANSWERS.**



## WHAT DOES POST-EXERTIONAL MALAISE MEAN IN PLAIN ENGLISH?

Post-Exertional Malaise simply means "feeling ill after a physical or mental effort" - but if you have ME, a more accurate translation is "feeling even more ill after a physical or mental effort".

## WHO IS AFFECTED BY PEM?

If you've been diagnosed with ME you are highly likely to experience PEM. In fact, the most recent diagnostic guidelines say that only people who experience PEM can be diagnosed with ME. However, some doctors still use different guidelines which do not require PEM.

## WHAT DOES PEM FEEL LIKE?

PEM varies a lot from person to person and can range from mild to severe. Two examples:

- Mild PEM can feel similar to being run-down or to having a common cold - without the runny nose and cough.
- Severe PEM can feel like having run a marathon at altitude while jetlagged and having a bad flu plus a hangover - all at the same time.

## IS PEM THE SAME AS POST-EXERTIONAL FATIGUE OR EXERCISE INTOLERANCE?

No. Post-exertional fatigue and exercise intolerance happen in a number of illnesses whereas PEM may be unique to ME. There are differences in the type and timing of symptoms.

- **Exercise intolerance** means physical exercise is difficult. Symptoms happen during exercise or soon after and are directly related to the exercise (e.g. walking uphill makes you puffed and your legs sore). Recovery generally takes less than a day.
- **Post-exertional fatigue** simply means feeling excessively tired or exhausted after exertion (mental or physical). It may take longer than expected for that worn-out feeling to ease.
- **Post-exertional malaise (PEM)** means feeling **ill** after exertion (mental or physical). Feeling ill includes feeling tired and exhausted but there are also many other and varied symptoms (see symptom list). Onset of symptoms is often **delayed** by a few hours or a few days. This delay can make it difficult to see the link between the trigger and the symptoms. Recovery is very slow and can take days, weeks or even longer.

Common causes for exercise intolerance and post-exertional fatigue are lung, heart and muscle problems. The main (and possibly only?) cause of PEM is ME.

Note that people with ME can experience symptoms of exercise intolerance and post-exertional fatigue in addition to PEM.

## WHAT ARE POSSIBLE SYMPTOMS OF PEM?

You may get some additional symptoms during PEM, but mostly **PEM means the ME symptoms you have all the time get much worse**. Individual ME & PEM symptoms vary.

Some examples:

- The ability to function in daily life is significantly reduced (e.g. can't work, prepare meals, shower, talk much, read)
- Feeling ill (e.g. flu-like symptoms)
- Profound exhaustion
- Muscles feel heavy or weak, and tire much more quickly than usual
- Problems with sleep (e.g. insomnia, unrefreshing sleep, frequent waking)
- Pain (e.g. headaches, muscle and joint pains, sore lymph nodes, sore throat)
- Brain fog (e.g. trouble with concentrating, thinking clearly, memory, word-finding)
- Many others (e.g. dizziness, nausea, body temperature too low or high, low blood pressure, raised heart rates, many more)

Many people with ME learn to recognise their own personal pattern of PEM symptoms.

## WHAT CAN SET OFF AN EPISODE OF PEM?

We don't know the exact cause of PEM yet. Research has found abnormalities in the way cells in people with ME work, for example in the way cells make and use energy, and how they talk to each other. It is possible some of those changes are linked to PEM but the exact mechanisms are not yet known. Research continues.

What we do know is that if you have ME you have less energy available than a healthy person. We also know that if you go over your energy limit you will get PEM.

Exactly how much energy you have available varies from person to person, as does what and how much you can do before setting off PEM. Some examples:

**Physical exertion:** Amy can walk 2km but jogging the same 2km sets off PEM. Walking a few steps to the bathroom sets off PEM for Ben. And sitting up in bed for 10 minutes sets off PEM for Charlie.

**Mental exertion:** Debbie can do light office work for half a day but a full day sets off PEM. Writing for an hour sets off PEM for Evan. Reading an email sets off PEM for Fiona.

**Exertion adding up:** Grace feels ok at work on Monday but collapses by Thursday with PEM. Harry can do some grocery shopping but putting them away immediately sets off PEM. Ida can microwave a meal but needs a rest before eating it if he wants to avoid PEM.

**Combined exertion:** Jack can take the dog for a short walk but walking and talking with a friend sets off PEM. Karla can prepare a simple meal but listening to the radio at the same time sets off PEM. Leanne can speak for a few minutes but having the light on at the same time sets off PEM.

## WHAT ARE TYPICAL EXAMPLES OF PEM TRIGGERS?

Note: Not everyone is sensitive to all the factors listed but physical overexertion is likely to cause PEM in all people with ME.

- Physical exertion (e.g. exercise such as walking or running, or simple activities such as showering or even chewing)
- Orthostatic exertion: it takes extra effort to sit or stand up compared to lying down
- Mental exertion (e.g. thinking, planning, reading, writing)
- Strong emotions (all types, including happy emotions)
- Overloading of the senses (e.g. noise, light, touch, smell, taste, vibrations such as in vehicles)
- Stress (e.g. work, financial or relationship stress)

continued...

... continued (examples of typical examples of PEM triggers):

- Fighting infections or other illness
- Intolerances and allergies to foods or chemicals
- Environmental factors (e.g. temperatures that are too high or too low)
- Multiple exertion: doing too many things at once (e.g. talking while walking, or thinking while in a noisy environment)
- Cumulative exertion: not enough rest between activities (e.g. showering one day is ok but showering on two days in a row sets off PEM)

Note: Some people with ME are in a constant state of PEM because they don't - or can't - rest enough between activities!

## WHAT CAN I DO TO MANAGE PEM?

It is important to avoid PEM as much as possible. Not only does PEM make you feel lousy in the short term, too much PEM may also lead to a more permanent worsening of ME.

You will need to adapt your level of activity to your personal energy limits, sometimes called the "energy envelope".

## SOME DO'S AND DON'TS:

1. Do get to know your own, individual energy envelope. This may fluctuate over time and will be different from other people's.
2. Do get to know what sets off PEM for you.
3. Don't do too much. Stay within your energy envelope.
4. Do as much as you can do safely without setting off PEM - you don't want to miss out on life unnecessarily!
5. Do rest as much as you can if you have misjudged your energy envelope and PEM has struck (which will happen because life happens!).
6. Don't be tempted to push through increasing symptoms. While this is often possible for a short while it will lead to much more severe PEM afterwards.
7. A good, short introduction can be found here: [www.emerge.org.au/treatment-and-management](http://www.emerge.org.au/treatment-and-management), or check our website for the detailed pamphlet called "The Art and Science of Pacing".
8. Share this short animation with friends & family: [www.youtube.com/watch?v=TGIo1v7KVJQ](https://www.youtube.com/watch?v=TGIo1v7KVJQ)



## M.E. AWARENESS NZ

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M.E. Awareness NZ is a national collective of People with ME and our carers and supporters. We exist to increase awareness of this debilitating disease and to improve the lives of those affected by it.



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