

## Post-exertional malaise (PEM)

### Key points

- People with ME/CFS have episodes when they are much more ill than usual following physical or mental exertion. This is called post-exertional malaise, or PEM.
- PEM is a hallmark of ME/CFS and is important for diagnosis
- Activities like a short walk or reading a few pages may trigger PEM. For the most severely ill, even chewing may trigger it. For many, light, sound and other sensory stimuli also trigger PEM. Often it is the combined effect of all activities and stimuli over a day or more that triggers PEM.
- PEM usually starts hours or a day or two after it is triggered and can last for hours, days, weeks or longer. During this time, a person cannot do as much as usual and needs to rest.
- There is no effective treatment for PEM.
- PEM is not the same as the fatigue and muscle soreness anyone can experience after more activity than usual.

### Characteristics of PEM

People with ME/CFS experience episodes when they are much more ill and cannot do as much as usual following amounts of physical or mental exertion or sensory stimuli that they could easily tolerate before the illness. This is called post-exertional malaise, or PEM. PEM is the hallmark of ME/CFS and important for diagnosis.

The main features of an episode of PEM are:

- A person feels more ill. Their usual symptoms get much worse, and new symptoms may appear.
- They are much less able to function. They need to rest more, or even to lie still in silence and darkness, until it passes.
- The onset of PEM is typically delayed for hours or up to several days after it is triggered.
- The length and severity of an episode of PEM are out of proportion to the amount of exertion or stimulus that triggered it. An episode can last hours, but more often lasts days, weeks or longer.

## **Symptoms of PEM**

The word 'malaise' is a medical term meaning 'feeling ill'. People with ME/CFS already feel ill, so with PEM, 'malaise' means they feel more ill than usual. Existing symptoms such as exhaustion, problems with thinking, difficulty being upright, and pain are likely to be worse. Many people also get extra symptoms that they only have in PEM, such as headache, sore throat, nausea or flu-like symptoms.

One person's pattern of PEM symptoms may not be exactly the same as another's and may change over time and with different triggers. The type of trigger is often unrelated to the PEM symptoms that follow. For example, a person's PEM triggered by concentrating on reading might include muscle pain and unsteady walking.

## **Exertion and other PEM triggers**

People may think of exertion as strenuous things like running, lifting weights or doing an exam, but the level of exertion that can trigger PEM in someone with ME/CFS is very low. Physical exertion as small as getting dressed or even sitting up, and mental exertion such as concentrating and reading for a short time can trigger PEM.

The word 'exertion' in the term post-exertional malaise is usually taken to mean physical or mental activity or effort. However, many people with ME/CFS also experience PEM episodes triggered by stimuli such as light, sound, smells, touch, temperature changes and vibration. Some people report that strong positive or negative emotions can also trigger PEM.

Just one activity or stimulus can trigger PEM, but the combined effect of all exertion and stimuli over a period of hours or days is more likely to do so. Doing more than one thing at the same time, such as walking and talking, or eating with the light on, may combine to trigger PEM. Someone may not realise they have already triggered PEM, and may keep going with activity during the delay before onset of PEM, making it worse.

The amount of activity someone can do without triggering PEM is sometimes called their PEM 'limit', 'threshold', 'baseline', 'activity capacity', or 'energy envelope'. These terms may not be helpful as they wrongly imply a fixed and known limit.

A person's limit may vary from day to day, and they can only judge it based on their experience, recent activity and symptoms. How exertion is spread across the day and whether it is possible for them to have rests before, during and after an activity influences whether they have PEM.

There is no good-quality evidence that the amount of exertion or sensory stimulus that triggers PEM can be increased, or health improved, by gradually increasing exertion or exposure to other triggers. Many people report interventions such as graded exercise therapy make their ME/CFS much worse.

## **Effects of exertion that are not PEM**

People with ME/CFS get quickly exhausted by exertion, both physically and mentally; this may make it difficult or impossible to continue an activity and is known as fatiguability. Other symptoms such as pain and difficulty being upright may also worsen during and straight after activity. If these immediate effects are eased by rest, and only last for minutes or an hour or so, they are not usually called PEM. It is not known whether these short-term effects of exertion are part of the same process as PEM.

People with some heart or lung conditions who exercise may have to stop because of breathlessness or chest pain which eases with rest. This is an example of exercise intolerance. This is not the same as PEM.

Anyone who does more physical activity than they are used to, especially people who are deconditioned (unfit), may have delayed onset muscle soreness (DOMS) and feel fatigued for a day or two afterwards. DOMS and post-exertional fatigue (PEF) are not the same as PEM. ME/CFS and PEM are not caused by deconditioning.

Some descriptions of PEM wrongly describe it simply as 'symptoms or fatigue after exertion'. People with ME/CFS are likely to experience immediate short term symptom increases, exercise intolerance, DOMS and PEF, but they are not the same as PEM. None of these other effects of exertion have the severity of symptoms, loss of function, delayed onset and long duration of an episode of PEM. Identifying the difference between PEM and other effects of exertion is important for diagnosis and management of the illness.

## **Living with PEM**

Episodes of PEM make the already disabling illness harder to live with. PEM can vary from unpleasant to unbearable. Some people refer to a PEM episode as a crash. Some report episodes of PEM lasting for hours, but they are more likely to last for days or weeks, sometimes longer. There is no treatment for PEM. Someone with PEM has to cut back their activity a lot more than usual or rest completely until the episode of PEM passes.

It can be hard or impossible for someone with ME/CFS to avoid PEM because the level of exertion that triggers it is often lower than the amount of exertion they need to do to live, given the support they have. The amount someone can do and level of stimulus they can tolerate may be so low that PEM is unavoidable just from basic activities such as talking or washing. Factors outside the person's control can trigger PEM, such as work and family demands, infections and sensory stimulation such as a hot day or a noisy neighbour.

These difficulties can lead to frequent episodes of PEM, sometimes called 'push-crash cycles'. Some people report that their ME/CFS became much more severe following repeated episodes of PEM.

Not knowing when an episode may strike and how long it will last makes it difficult or impossible to plan activities in advance, even essential things like medical appointments. Many people with ME/CFS accept some PEM in order to achieve something necessary or important, something that makes life either worth living or possible, for example a financial assistance application or a family event.

Many people with ME/CFS need support with household activities and some need help with personal care. Carers can help by learning about PEM and the person's particular PEM triggers and adapting the way they help. Not wearing perfume, not talking to the person while washing them, and providing practical support and a low-stimulus home so they can rest for as long as they need to during PEM are examples of how carers can adapt.

### **Examples of PEM**

These are examples of how PEM can look for people with ME/CFS of different levels of severity:

- A person can manage a few hours a day working from home at their own pace and at the times when they feel most able to function. After a few hours concentrating on work, despite rest breaks they are exhausted and in worse pain which eases with further rest. This brief worsening is not PEM. But when they have a shower or prepare a meal on a work day, the added effect of the extra exertion triggers PEM with a bad headache and nausea, making them unable to work for several days.
- Someone can still work part-time, but struggles with concentration, pain and exhaustion. After a few days at work they often spend several days in bed feeling like they have the flu with a bad sore throat and stomach pain. After months of repeated PEM their ME/CFS becomes more severe and they are unable to return to work.
- A person can no longer work and is too ill to regularly leave the house. They need help with household tasks. After visiting a friend for lunch they are bed-bound for a week with increased pain and nausea, can't concentrate on reading, and feel increasingly ill when they try to stand up. It is another week before they feel well enough to go out again for a brief visit.
- Someone is so severely ill that they are bedridden and completely unable to do any normal activities. They often experience long episodes of PEM that is made even worse with every tiny stimulus or exertion. They need full time carers that help with washing, feeding and toileting. They need to lie still in complete darkness and silence.

## **Research on PEM**

The biological causes of ME/CFS and PEM are not known. Scientists have investigated the effect of exertion on people with ME/CFS by taking biological measurements during and after exertion. Some differences from healthy people have been found in small studies. These need to be repeated in larger studies, and new approaches taken to find out more.

We based the information in this factsheet on definitions of PEM in UK and US government guidelines, research that uses exercise challenges to trigger PEM, research on people's experiences of PEM, survey-based research on the harmful effects of exercise therapy, and a wide range of reports of experiences of PEM by people with ME/CFS of all severity levels.

## **References**

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