

# **Bacimé**

**British Association for CFS/ME**

**Post-Exertional Malaise**

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## Introduction

There are many different causes of fatigue, some of which are not picked up on laboratory tests or routine investigations. It is important to be able to recognise different patterns of fatigue to identify the likely underlying cause as this can help guide management strategies.

One of the hallmark symptoms of ME/CFS (Chronic Fatigue Syndrome) is a pattern of fatigue called Post-Exertional Malaise (PEM), sometimes referred to as Post-Exertional Symptom Exacerbation (PESE). This pattern can also occur in Post-Viral Fatigue and conditions which cause Dysautonomia (problems with the Autonomic Nervous System functioning). PEM is not usually present when fatigue is caused by other conditions or problems.

It is important to identify Post-Exertional Malaise as it requires different management strategies to other types of fatigue, particularly regarding the management of daily activities along with approaches to physical activity including exercise.

The Covid pandemic has led to large numbers of people experiencing prolonged symptoms after Covid-19 infection including fatigue, a common feature of post-Covid problems. Not everyone with ongoing symptoms after Covid infection will have Post-Exertional Malaise but it is important to identify people who do experience PEM in order to provide them with appropriate guidance on management.

The NHS England 'Your Covid Recovery' online resource now includes a section on Post-Exertional Malaise. The following document was written in collaboration with the 'Your Covid Recovery' team and members of the BACME Board.

## **Post Exertional Malaise (PEM)**

It is common to experience fatigue during and after an episode of illness. Fatigue will often vary with regard to intensity and how much it limits you. A typical pattern of fatigue is where you feel more tired when you do an activity and for a while afterwards but starts to improve when you stop and rest. People recovering from an illness often report feeling a little better each day.

Post-Exertional Malaise occurs when there is a significant increase in the level of fatigue after doing your usual level of activity. This fatigue does not quickly improve with rest. There can often be a delay between doing the activity and the fatigue increasing which can make it harder to spot the connection.

### **What are the features of PEM?**

- The fatigue of PEM is different to normal tiredness. It is a feeling of complete exhaustion often leading to an inability to carry out usual daily activities.
- PEM can include increased pain, symptoms of 'brain fog' (cognitive difficulty), headaches, dizziness, sore throats, tender glands and feeling like you have flu, reduced muscle power, nausea and increased sensory sensitivity.
- An increase in symptoms can start while doing an activity, several hours or even a day or more later. Some people feel OK while doing the activity then experience an increase in symptoms and a reduced capacity to function the next day or up to 3 days later which can last for days or weeks.
- PEM can be triggered by any type of activity which includes physical activities, thinking activities, talking and social activities or emotional stressors.
- When PEM is present, rest does not usually have an immediate benefit in reducing the feeling of fatigue. Many people experience a further increase in PEM symptoms even while resting.

### **What are the causes of PEM?**

The causes of PEM are not yet fully understood. PEM is likely to be the result of dysregulated responses in several different body systems including the immune, nervous, and hormonal systems.

### **What triggers PEM?**

The triggers for PEM can vary from person to person and change over time. Any kind of activity can trigger PEM including physical activities like walking, cleaning, or exercise; thinking activities such as dealing with emails, reading and work related tasks; social activities such as visiting friends and family and talking on the phone; and emotional activities such as feeling anxious about going out, frustrated about being ill or excited about more positive events. PEM can vary in terms of how quickly

it starts and how long it takes to improve. As the response is usually delayed, it is often difficult to identify a cause. PEM may start after doing more activity for several days in a row. There can be an unpredictable pattern of bad days and better days. Keeping a daily activity and symptom journal can be helpful so you can look back to try to identify and make sense of your triggers.

Episodes of infection or other illnesses and health conditions can contribute to the variation in fatigue severity and trigger episodes of PEM. Unexpected events can trigger PEM. Fatigue and PEM can also be affected by the menstrual cycle.

A key feature of PEM is that it does not improve with one good night's sleep. If your symptoms do not improve with sleep or rest, you may need specialist rehabilitation support.

### **How long will a PEM episode last?**

PEM is variable in duration, lasting for hours, days or weeks and may feel out of proportion to the triggering event.

### **Principles of PEM Management:**

- The aim is to reduce the number and severity of episodes of PEM by balancing rest and activity. This is referred to as Pacing.
- The first stage is to achieve a degree of stability or the level of activity that you can do each day without triggering a delayed escalation in symptoms.
- Pacing involves breaking activity into small parts and taking a rest break before doing another small amount of activity.
- Changing between different types of activity (e.g. mental and physical) can help rather than doing one type of activity until exhausted.
- Achieving good quality rest (doing nothing) can be difficult but is one of the most important aspects of managing fatigue and PEM. Activities you previously found relaxing may now demand energy and contribute to fatigue. These can include activities like watching TV, reading, talking to friends, looking at social media or gaming. Good quality rest involves reducing the workload of the mind and body. Different people will find different types of rest and relaxation work best for them.
- Slow breathing exercises can be a good starting point to get your body into a restful state. Listening to calming music or using relaxation and mindfulness apps can be helpful. Some people find using a weighted blanket or a heat pack helpful.
- Avoiding all activity and spending long periods of time lying down can cause additional problems due to loss of muscle strength and fitness and make it more likely for you to experience an increase in fatigue when you try to do something. If your fatigue has become so severe that you are spending much of the day in bed, ask your GP for specialist support.

- Ignoring or pushing through fatigue symptoms or trying to use exercise to reduce your fatigue usually results in an increase in PEM episodes causing overall fatigue levels to increase.
- Tracking your daily activity levels and symptoms can help you to find the level of activity you can do without triggering a PEM episode. Once you have identified your individual energy limits, try to stay within these until you have achieved a period of stability.
- Planning, prioritising, and pacing your daily activities can help to manage your energy levels. This reduces the likelihood of PEM episodes by working within your individual energy limits. It might mean doing fewer activities or doing less than you think you can but will allow you to rest when you need to and conserve your energy levels.
- If you feel you are having a good day, try to avoid doing more. Aim to stay within your energy limits and maintain the same activity and rest framework every day for a period of time.
- If you begin to notice a sustained improvement in your symptoms and are having more good days than bad days, gradually increase your activity levels, paying attention to any negative effects or triggers that may cause a PEM episode.
- If an increase in your activity levels does trigger a PEM episode, do not be discouraged. Wait until you feel a bit better, then try a smaller increase in your activity level.
- If your symptoms improve, your energy limits will increase, making it possible to do more activity without triggering a PEM episode.

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