Top Tips for

# Managing Post-Exertional Malaise

A guide for Adults

For people living with mild to moderate ME/CFS or Long Covid.

*Developed and delivered by*

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## Managing Post-Exertional Malaise

# What is Post-Exertional Malaise?

Post-Exertional Malaise (PEM) is a key characteristic of *Myalgic Encephalomyelitis (ME)* or *Chronic Fatigue Syndrome (CFS)* which can lead to a worsening of symptoms that is disproportionate to the activity that has been carried out.

PEM can be triggered by any form of exertion – physical, emotional, cognitive or sensory and is usually only relieved by rest and sleep. Much like fatigue, people living with ME/CFS are unable and should not attempt to 'push through' their experience of PEM, as this can lead to further worsening of symptoms. PEM may occasionally be a symptom of other health conditions.

## Why do I get Post-Exertional Malaise?

ME/CFS remains a poorly understood condition and this is also true for the symptom of PEM. Research is underway to try and explain why PEM occurs however no concrete cause or explanation has yet been found. There are many theories including:

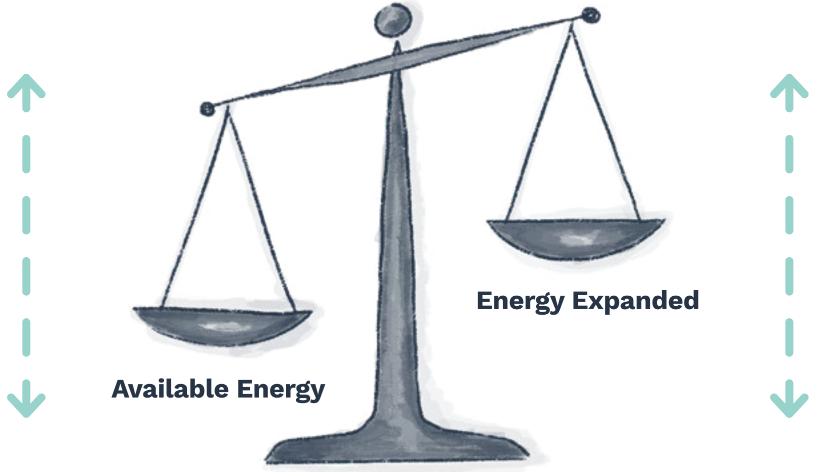
- Metabolic defects within the cells of people with ME/CFS affecting the way that energy is created and used
- Inflammation of the brain and central nervous system
- Changes in blood flow and blood volume
- Dysfunction of the immune system

# How can I reduce the risk of experiencing Post-Exertional Malaise?

> **There are no recommended medications or treatments to prevent people living with ME/CFS from experiencing PEM, therefore current strategies typically involve being aware of your own limits and not working outside of your energy envelope.**

Put simply, working 'within' your energy envelope involves making sure that the amount of energy you use does not outstrip the amount of energy you have available. To achieve this, it's important to practice energy management principles including the **'4 P's' – pacing, permission, prioritising and planning**. Factoring in rest is extremely important as well as knowing your own limits.

The risk of experiencing PEM rises dramatically when you are working 'outside' of your energy envelope – that is, when the energy you have used outstrips the amount of energy you have available. PEM can also be triggered by factors outside of your control such as having an infection, excessive noise, light or other environmental stimuli. One of the difficulties of PEM is that the worsening of symptoms can often be delayed by 24-72 hours therefore some people don't know that they are pushing outside of their energy envelope until they crash or, in a worst case scenario, relapse.



**Working within envelope**

More energy available to engage in activities.

**Pushing outside envelope**

Severity of symptoms and risk of PEM increased.

**Pushing outside envelope**

Less energy, time lost possibly spent recovering from PEM.

**Working within envelope**

Severity of symptoms and risk of PEM reduced.

# The ‘Spoons Theory’

One way to work out and stay within the limits of your available energy is to consider the ‘spoon theory’ as this can help you to recognise the activities you feel able to do and appreciate how much energy will be needed to do them.

Imagine you have 15 spoons of energy available – each spoon is a unit of energy and your goal is to get through the day without using up all your spoons. All the activities you engage in will use spoons of energy, therefore think about how you would spend them? Some of these might use 1 spoon such as brushing your teeth or washing your face, whilst high energy activities such as showering may require 4 spoons. Without using energy management principles, it is likely that you’ll run out of spoons very quickly, therefore it’s important to think about the following:

**How can you spend your spoons more evenly throughout the day?**

- Make sure that you have adequate rest breaks factored into your routine
- Have a mix of activities that use lots of energy and activities that use little energy throughout the day
- Can you breakdown your activities into smaller and more manageable steps

**Are there ways to make a ‘four spoon’ task a ‘three spoon’ task?**

- Can you delegate parts of a task or ask a friend/family member to help you?
- Do you have any equipment that might make the task less effortful e.g. using a long-handled grabber to pick things up from the floor rather than bending
- Can you complete the task in sitting rather than standing?

**Do you have any tasks or activities that might give you an additional spoon of energy?**

- This might include engaging in self-soothing or a mindfulness-based activity
- It could involve spending a few minutes in the garden and noticing what’s going on around you

# Recovering from an episode of Post-Exertional Malaise

> **If you experience an episode of PEM, it’s important that you don’t try to push through your symptoms as this is likely to make you feel more unwell and lead to a longer period of recovery.**

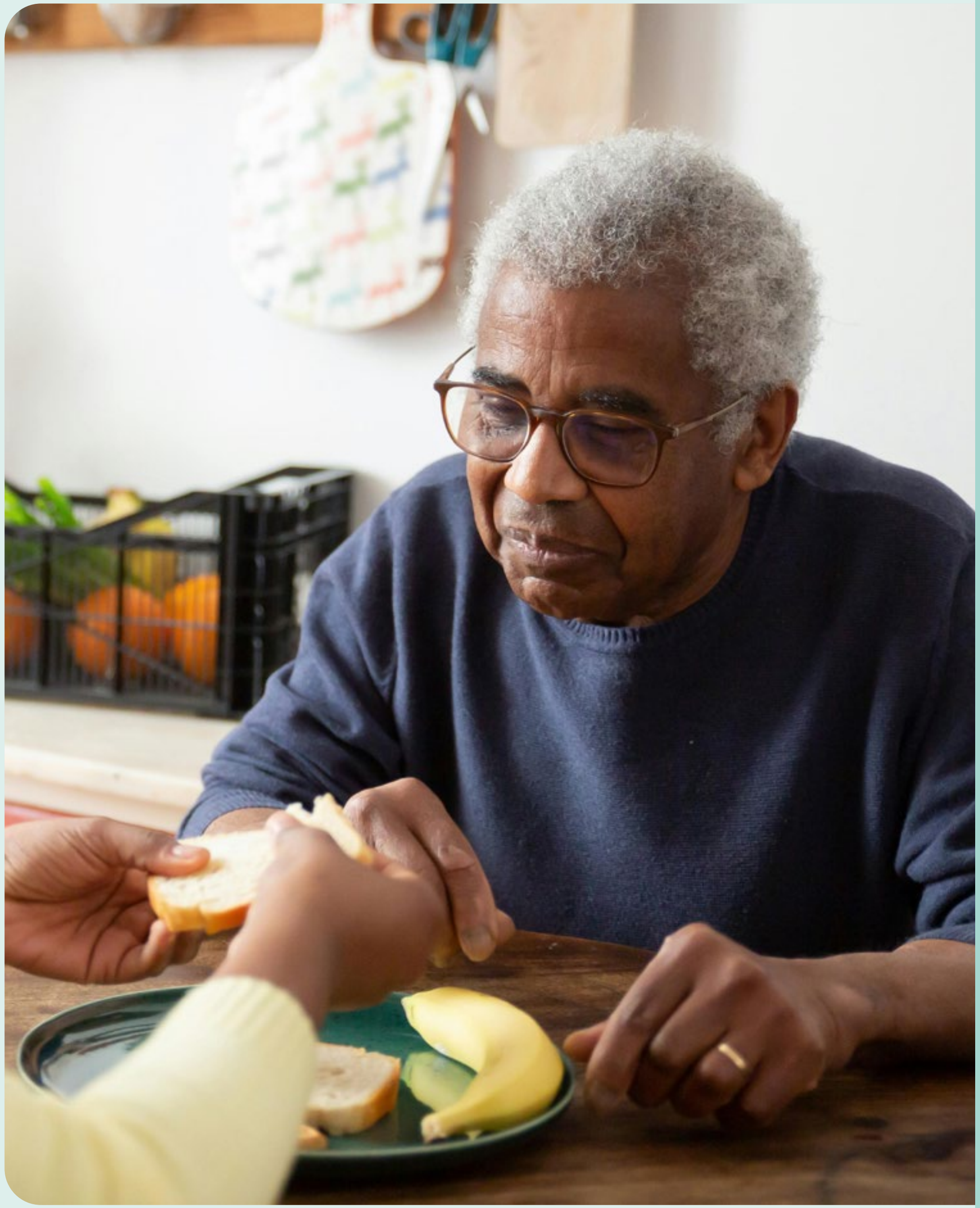
The timeframe for recovery from an episode of PEM is unique to each individual; for some people they may start to feel better after a few days however in some cases it could take weeks or months for the symptoms to improve. Despite this, there are some things that you can do to support yourself depending on the severity of your symptoms and the ‘stage’ that you are at in your recovery from PEM. As an idea of the amount of energy available to you and therefore the amount of activity you can engage in at each stage, we have made reference to the **‘Spoons Theory’**.

## Initial Stage of Recovery (1-2 Spoons of Energy Available)

During the initial stages of PEM, people often experience a worsening of all symptoms (physical, cognitive and sensory), therefore prioritising rest and sleep is very important. This may mean that planned events or social activities will need to be postponed and you may need to request support from family or friends to help you meet your needs. In this acute phase, people can find their sensory environment (i.e. light, noise, touch, taste or smell) very overwhelming therefore measures should also be taken to reduce overload so that recovery can take place in a more ‘rest-conducive’ environment.

- Use an eye-mask or ear-plugs to block out unwanted light or noise. Using black-out blinds may also be helpful.
- Consider the weight of your bedding and clothes – heavy fabrics may make it more difficult for you to re-position and regulate your temperature.
- Request that social interaction is kept to a minimum – is there somebody close-by who can inform friends/relatives/colleagues that you require rest?
- If you do need to interact with someone face-to-face, ask that visits are brief, information is simple to process and sound is kept to a minimum. Consider alternative forms of communication if this is easier i.e. written information.
- Is your place of rest close to a toilet? If not, consider having a commode or portable toilet close-by to avoid long walking distances.
- Whilst you may not have the energy or feel like eating or drinking, maintaining adequate food and fluid intake is very important. You may need a friend or relative to make meals for you and softer textures could be helpful if chewing is tiring. Consider fortifying your meals for additional calories e.g. replacing semi-skimmed with whole milk.

**Seek medical advice if you are concerned about unintentional weight loss or if you think that you aren't getting enough nutrients.**



## Early Stage of Recovery (3-6 Spoons of Energy Available)

Whilst there is no clear timeframe for how long it can take for symptoms to improve, by prioritising rest and avoiding exertion; you may find that your symptoms slowly become less severe. During this stage, it is still vital that you prioritise rest. However, you may start to feel that you can begin to do small things for yourself. This might involve light movement, slow re-exposure to different sensory input and brief participation in meaningful activity. It is advised that you start with one goal at a time and slowly incorporate more into your day as you increase the amount of spoonfuls of energy available to you.

Slowly begin to re-expose yourself to sensory stimuli such as noise and light. If you have been using an eye-mask, blackout blinds or earplugs, try and spend short periods of time without them. You may need to do this very gradually depending on the length of time you have needed them. With time, you should begin to notice a better tolerance to the environment around you. If you notice your symptoms worsening, this may be because you are re-exposing yourself too soon, too frequently or for too long at a time.

If you have been lying down for a prolonged amount of time, the body can sometimes have difficulty getting used to being upright again. People can feel light-headed or nauseous and may notice other symptoms such as increased heart-rate. A gradual approach can be helpful to re-accustom yourself to being 'upright'; you could start by increasing the number of pillows you use to slowly raise your top half before progressing to sitting up in bed. From here, you could progress to sitting on the edge of the bed. Again, this may take some time depending on the severity and duration of your PEM episode but starting small is key. Discomfort and unpleasant symptoms may occur as your body readjusts but this should improve with time. As above, if you notice your symptoms are worsening on rest, it may be that you are trying to do too much, too soon.

**Seek medical advice if symptoms persist.**

Joints and muscles can quickly become stiff when lying, therefore incorporating light stretches and gentle movement into your recovery is important as the risks of not doing so can impact on your mobility and balance. You could start with some gentle stretches whilst you are in bed and slowly incorporate these into a sitting position as your recovery continues.

**The NHS Live Well site has some basic stretches that may be helpful as a starting point -**

www.nhs.uk/live-well/exercise/

Try to participate in small periods of meaningful activity to support your physical and mental wellbeing. Engaging in self-care tasks such as brushing your teeth or washing your face can be a good first-step. If you would like to wash your hair but don't have the energy to shower, consider using dry-shampoo or cleansing wipes. You might like to watch a film or read a book however think about the length of time you do this. Maintaining attention or concentration can be a quick energy drainer.

## Middle Stage of Recovery (6-10 Spoons of Energy Available)

As your recovery continues, you may start to find that your symptoms begin to reduce in intensity and that you have a bit more energy available to you. Prioritising rest is still important during this stage but you may have enough energy that you can participate in short periods of activity. This will depend on the number of 'spoons' available to you, but could include the following:

- Start to rebuild a routine to your day. You may not be able to carry out a full day's routine but you could start small by waking up, getting dressed and having some breakfast. You may need to factor in additional time and several rest breaks between each activity. However, re-engaging in these tasks may help you to feel more in control of your recovery and support your wellbeing.
- If you have the energy, you could consider slowly reconnecting again with those around you. You might not feel up to having visitors but could you pick up the phone or video call a friend or relative? If you don't feel ready, setting a date in advance could give you a goal to work towards. Be mindful of the nature and length of your interactions as high emotional demands could quickly drain your energy.
- You might still need to spend some of your time in bed. Consider if there is an alternative place you could rest i.e., a settee or reclining chair which isn't in the bedroom. This can help your mind associate the bedroom as a place of rest in the evening and can be more helpful to achieving sleep at night.
- Continue to try and factor in short periods of meaningful activity into your day. Again, try to keep these time-limited and consider the physical, emotional, cognitive and sensory demands these expect of you.

> **As in the earlier stages of your recovery, start small and build up over time. You may need several days or weeks to build up your activity tolerance and doing too much, too soon could hamper your progress.**

If in doubt, reduce your activity levels or consider going back to the tips in the earlier stages of recovery.

## Late Stage of Recovery (11-15 Spoons of Energy Available)

By the time you reach the late stage of recovering from an episode of PEM, you should start to feel that your symptoms and energy levels are coming back to their normal 'baseline'. You may find that you continue to experience some residual difficulties but that you are generally able to operate within your 'energy envelope' and that your available energy does not outweigh the energy that you use. Getting to this stage has likely required a lot of resilience and you might be eager to 'push yourself' but caution and pacing is still advised.

- By this stage, you should feel that you are able to engage in some of your daily routine more consistently and with a frequency and duration of breaks that is typical for you.
- You might feel that you don't need the same level of assistance to engage in activities. However, it may be worth accepting support if this will give you back a spoonful of energy which you could use for a different task.
- A calendar or organiser could be helpful to plan out tasks that you may have had to postpone because of your PEM episode. Scheduling over a week or month can help you to feel less overwhelmed and can make you feel more in control of your recovery and energy use.

- If you are able to and if your energy allows, consider spending some time outside. Natural sunlight can help boost mood, but is also important for production of Vitamin D and re-setting the body clock. Be realistic with what this may look like for you and be guided by your spoons of energy; it could be sitting outside in the garden or going out for a short walk.
- Avoid engaging in 'new' activities or tasks that are outside your typical routines. Now is a time to maintain symptom stability and unfamiliar or new activities could place unnecessary demands on you which could cause symptoms to worsen.

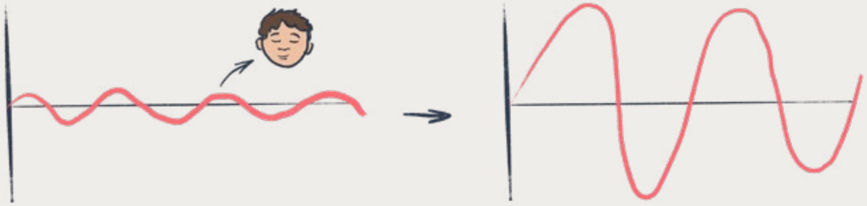
## Back to Baseline
## (15 Spoons of Energy Available)

Whilst there can be no time-scales for the time it takes to return to your 'baseline', reducing your activity, prioritising rest and using the '4 P's' are all methods that support recovery. At this stage, you should feel that your symptoms are stable and in line with what is 'normal' for you. It is important that you continue to remain mindful of your symptoms – if you begin to feel that your symptoms are relapsing, reduce your activity and prioritise rest.

**Further information is available on this in our 'Managing Relapses' top-tips document.**

### Noticing Changes in your Baseline

Some people living with ME/CFS may experience that their baseline changes over time. Sometimes this can be positive, as an increase in your baseline may provide you with a bigger energy envelope and allow you to engage in more activity without experiencing an increase in symptoms. On the other hand, some people may experience a decrease in their baseline which means that they are unable to engage consistently in their usual routines like they used to despite not experiencing PEM.



These changes can be temporary or more permanent and the reasons for this are generally unknown, but a decrease in your baseline could be due to health changes, life events or prolonged-overexertion.

> **If you notice a persistent change in your baseline, it's important that you speak to a GP or medical professional to rule out other medical explanations for this change.**

The difficulty with identifying changes in your baseline is that some people may feel that they are still recovering from an episode of PEM when this is actually their new 'normal'. This can be very disheartening for people living with ME/CFS however being aware of these possible changes may help you to re-adjust and manoeuvre towards your new baseline.

# Supporting your Psychological Well-Being

Experiencing an episode of PEM can have a huge disruption on your life and may generate a great deal of uncertainty. Naturally, this could lead to you feeling *low in mood, anxious or distressed.*

It's important that you take care of your psychological well-being during this time. Where possible, try to prioritise small activities that may help to lift your mood and try to remain compassionate towards yourself. PEM is a symptom that many people with ME/CFS will experience throughout their life, therefore, try not to blame yourself for feeling this way. We have developed a guide which can direct you to various self-help and mindfulness-based resources which you may wish to try.

## Post Exertional Malaise Action Plan

People within the ME/CFS community often learn to cope with episodes of PEM through a mixture of lived experience, trial and error and by reflecting on the situations which may have led to their crash. Therefore, it may be helpful to reflect on your own experiences of recovery and what is helpful by using an action plan. This might be useful if you feel 'stuck' or are struggling to identify things that might help you move forward again.

> **You will find an example of this on the next page and an empty template for you to try.**

**Further information is available on this in our 'Mindfulness Resources" guide.**

Example

| | |
|---|---|
| Where am I now? (Stage of Recovery) | E.g. Early stage |
| What can help me through this stage? | E.g. Start to sit up in bed for short periods of time during the day, listen to some calming music, brush my teeth sitting on the edge of the bed. |
| What help do I need? | Help with meals, Dog walking, Bins need putting out, Get medication from pharmacy |
| Who can help? | Listen to some calming music. |

| | |
|---|---|
| Where am I now? (Stage of Recovery) | |
| What can help me through this stage? | |
| What help do I need? | |
| Who can help? | |

## Jot down some notes

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