



# Pacing

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*The primary feature of ME/CFS is post-exertional malaise (PEM). PEM is brought on by too much physical or mental activity. It is very different to the normal fatigue that healthy people might feel after exercise.*

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*PEM can make all the symptoms of ME/CFS much worse. This means that when someone with ME/CFS has done too much, things like pain, nausea, trouble with thinking and many other symptoms will get worse. PEM can be triggered by simple activities like having a shower or reading.*

*PEM may start immediately after physical or mental activity. However, it is commonly delayed, often starting 24 to 48 hours after the activity, sometimes even longer. The effects of PEM can last for days, weeks or longer.*

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## What is the energy envelope?

The energy envelope is a way of describing the amount of energy a person with ME/CFS has available each day. This is energy that you can safely use without triggering PEM. How much energy you have will depend on how badly ME/CFS affects you. It can also change from day to day, which means that an activity that you managed yesterday may exhaust you today. Pushing through when experiencing symptoms is not advised for people with ME/CFS. Instead, pacing your activities and resting are recommended.

## What is pacing?

Pacing is a strategy designed to help people live within their energy envelope and minimise PEM. It can help to improve your quality of life and reduce symptoms. Pacing is considered to be an important self-management tool by doctors and patients around the world. Pacing and rest are currently the most effective management tools for people with ME/CFS.

» **When someone is pacing, they are undertaking less activity than they have energy for.**

Pacing also involves keeping periods of activity short, with rest breaks in between.

» **For example, instead of taking a shower, brushing your teeth and combing your hair in one go, pacing would mean you take a shower, and then rest, until you feel ready to undertake the next activity.**


Pacing aims to leave some 'fuel in the tank' at the end of the activity. Some doctors advise their patients to do no more than 50-60% of what they feel they can do.

» **Pacing, like any other skill, must be practised and becomes easier over time.**

Most people can expect to experience setbacks from time to time so it is important to be realistic about what you can achieve. Be kind to yourself, and plan to rest each day.

## 4 steps to pacing

### 1. The first step is becoming familiar with your energy limit.




This will help you to identify when you are experiencing PEM. To do this, start an 'activity and symptom' diary. Categorise each activity as either physical or mental activity. In your diary, rate each activity as high, medium or low energy. Rate your symptoms each day. The diary will help you track what activities, and level of activity, causes PEM.

- » **1.1: If keeping a full diary uses too much energy, keep it simple:** give each day a rating out of five for your symptoms and rate your overall energy use for that day (most people use a % score for this).

### 2. Once you have identified your activity and PEM patterns, the next step is to reduce or modify your activity levels.


Think of your body as a battery, which can only partially charge. Pacing should help you to learn how to use the energy that you do have in the best way possible, without the battery going completely flat (and triggering PEM). Some suggestions for modifying or reducing your activity are as follows:

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- » **2.1: Reduce activity levels** until you find a level which doesn't trigger PEM.
  - » **2.2: Learn to say 'no'.** This can be difficult because we want to please others, and because we want to participate. Learning to say 'no' and prioritising the way you use your limited energy is an important part of pacing.
  - » **2.3: Ask for help.** Asking for help can give the people in your life something they can do to assist you and make them feel connected to you.
  - » **2.4: Outsource and take short cuts.** Some examples are buying pre-packaged meals or pre-chopped vegetables to save some energy when cooking; vacuuming the house less often, or hiring a cleaner if you can afford to do so; ordering groceries online, instead of visiting the shops.

- » **2.5: Avoid the temptation to do 'just a bit more'.** It's important to stop and rest when you start to feel fatigue or any other increase in symptoms. Get to know the early warning signals that tell you when you are overdoing things and listen to your body when it tells you to stop.


- » **2.6: Modify activities to conserve energy.** Use mobility aids (walking stick, wheelchair, etc) and try to find ways to do activities from a seated position rather than standing (such as using a stool in the kitchen when cooking or in the shower). Break activities down into small chunks and spread out the chunks with rest in-between.

### 3. Ensuring rest periods between activities is crucial.



Rest should mean absolutely minimal activity, which means no stimulation. TV, social media, reading or listening to music can all be stimulating — doing these activities stops your body resting fully. Good pacing involves including periods of complete rest throughout your day and especially between activities. If possible, do not attempt more activity until your PEM has reduced.

### 4. Be realistic and flexible.



If possible, try to create a weekly routine. By creating a routine, you can identify what you can achieve on a regular basis.

### Triggers

It is important to know what things can trigger PEM for you, and work to minimise or avoid them. Understanding your triggers, and how much of them you can tolerate before they worsen your symptoms, is an important tool in helping you to manage your illness.

*Disclaimer: This factsheet is purely for informational purposes; it is not intended as a substitute for professional medical advice, diagnosis, or treatment.*