Richmond & Kingston
ME Group

& West London
M.E. Group

Tips on Pacing

What is pacing?

Pacing means being in tune with our bodies, to best manage our limited energy and minimise symptoms. We often walk a tightrope between having some quality of life and having a relapse. Pacing encourages us to operate within our physical and mental limitations, avoiding activities that make our symptoms worse. An ME Association survey found that 71% respondents felt that pacing improved or greatly improved their symptoms.

Pacing involves cutting up activity into manageable chunks and switching between physical, mental, social and emotional activities throughout the day. All these activities should have periods of rest planned around them to keep energy levels as high as possible, and to make sure that you don't become over-tired. This means taking notice of what your own particular 'warning signs' are and stopping your activity before you reach exhaustion point. Do not ignore what your body is telling you. Ignoring the warning signs repeatedly can lead to a long-term deterioration in health.

What is activity?

In ME terms 'activity' means any form of exertion, however small - in other words, anything that is not complete rest. So, for someone with very severe ME, sitting up in bed or being exposed to light or sound can be ‘activity’. Activity may be physical or mental – which may include watching television or using a computer or mobile, or social or emotional which may include seeing friends or being anxious, excited or upset.

What is rest?

While for a healthy person, rest can mean sitting with your feet up, reading or watching the television, for someone with ME, rest means having no stimulation - resting in a darkened room with earplugs may be necessary. Don't watch television, play computer games or listen to music during a rest period. You may find guided meditation, relaxation techniques or breathing exercises help your brain to shut down.

You don't need to sleep to rest completely but some people with ME find that short naps in the day help them to sleep at night.

Rest is the cornerstone, particularly in the early stages of ME

Complete bed rest for the first three to six weeks from onset of the condition can increase your chances of recovery. Sadly for most people reading this, the advice for total rest at onset will have come too late.

Where do I start?

Find a baseline of activity you can manage to do consistently (that is <u>every</u> day) that does not make your symptoms worse. Some people use a rule of thumb that you should aim to use no more than 75% (three quarters) of your available energy every day (even if it's a good day!) to make sure you avoid 'boom and bust'. Finding your baseline can take some time and it may help to keep a diary to track activity and rest and how you feel each day.

Over 4 or 5 weeks, you'll be able to see a pattern that shows you how much activity you can manage and how much rest you need on average each day, good or bad. This is your first baseline. Everyone's baseline is different - there is no 'one size fits all'.

If you follow your baseline for three or four days, but then find you are exhausted for the next three or more days, your baseline is too high.

If your baseline is too high, you'll need to cut back on activity somewhere, which could mean:

- Slightly reducing how long your activities are
- Looking at what kinds of activities you are doing: have you got the right balance of physical, mental, social and emotional?
- Having slightly longer or more frequent rests
- Making sure that rest periods aren't including any mental, social or emotional activity

Switching activity

Doing different types of activities, for example: getting dressed (physical) followed by reading (mental) tends to mean that you are able to do more and you will achieve a balance between using your brain and your body.

It may also help to use a traffic light system to categorise the activities which really set you back as: red - stop and think, "Do I really need to do this now?"; orange -"Approach with caution" or green - "Go ahead". We are all different in the way ME affects us so there are no hard and fast rules on which are the red activities. For instance, walking is a red activity for me, while sitting at the computer or writing is green. I still need to limit the time I spend doing the latter but it will rarely lead to a relapse.

Remember to include activities you enjoy doing in your baseline activity level. Doing things you really enjoy is very good for your health; it will give you an emotional boost. It is also a good idea to have some positive things to look forward to such as seeing family or friends but do plan rest periods around this. Very low-level activities can distract your brain from negative emotions. Mindfulness or living in the present moment is useful here. For instance, watching birds in the garden, smelling the roses or doing jigsaws, word puzzles, colouring or just watching clouds scudding across the sky on a windy day.

Using a heart rate monitor to manage activity

Any aerobic exercise is best avoided as the aerobic respiration pathways are broken in ME patients. At its simplest, heart rate monitoring means watching for the activities that overly raise your heart rate and then either working out how to modify the activity, or taking a decision to avoid it. Sally Burch has blogged about her experience of using a heartrate monitor here:
http://sallyjustme.blogspot.co.uk/2015/12/startingHRmonitoring.html

Visible

A new approach to this is being pioneered by Visible who have developed the first tracker designed for illness rather than fitness. In autumn 2022 Visible Health Inc launched a free app, designed to help individuals manage their energy levels through pacing and activity tracking. A morning check-in measures stability through combining checking resting heart rate and HRV through your phone camera, together with self-reported symptom scores, assessment of activity, and sleep. In the autumn of 2023 Visible added and later upgraded a wearable: a heart rate monitor on an arm band.

Pacing well isn’t easy or intuitive and many people find the Visible armband can take a lot of the work out of getting it right.

The armband tracks your heart rate continuously and gives an automatic Heart Rate Variability score (HRV) at morning check in. During the day it gives you a measure of energy used so far that day, known as “pace points”. Its initial tracking creates your suggested personal daily pace points ‘budget’ and if you keep within your budget, you shouldn’t crash. During the day, the wearable alerts you when you are over exerting yourself, tracks your pace points and tells you how you are doing. You can adjust the settings if you feel they are not working for you.

How can I increase activity?

You should increase activities only when symptoms have been stable for at least 3-4 weeks. Increase only one activity at a time by only 10% and reduce back down straightaway if symptoms worsen. For instance, for young people, a school session of 40 minutes would go up to 44 or 46 minutes. It definitely doesn't mean going from one session to two, as that would be a 100% increase.

It is important though to distinguish between 'normal' tiredness that anyone gets with increased activity such as aching muscles or tired eyes and true ME symptoms known as Post Exertional Malaise (PEM) which are usually delayed and last a prolonged period of time. If you have overdone it and are suffering from PEM, all your ME symptoms will worsen. For example: exhaustion, pain, nausea, tachycardia, sensory overload, feeling of having been hit by a bus.

What are the challenges with pacing?

Pacing isn't easy. It takes some practice, and you need to be willing to go through the 'trial and error' part at the beginning. It can be frustrating sometimes, too.

Keeping your activity diary is essential, as it's your record of what you're doing, how your body has reacted - and as the weeks go by, the progress you're making. Even the tiniest steps count.

However well you manage your activity, there will be setbacks. For instance, if you catch a virus or experience something very stressful. You can deal with this by increasing your rest periods between activities or with a major setback, resting completely until your symptoms have stabilised.

It can be very difficult to pace your activity if you also have caring responsibilities for children or elderly relatives. In this situation, don't hesitate to ask for and accept help whenever possible. You are not showing weakness but sensibly conserving your energy. Rest whenever you can, for instance when children are in school. And be sure to include something you enjoy in your baseline activity, however brief.

We all have to do some things which are we know are above our own personal baseline, for example, a hospital appointment or for someone severely ill, making a phone call. It is a good idea when you know you have something like this coming up to schedule extra rest beforehand to help minimise the payback afterwards. Pacing also means accepting your limitations, and coming to terms with the way you feel about how ME/CFS has affected you.

Benefits of pacing

Pacing means you decide for yourself whether you use physical energy, mental energy or social energy on a particular day, or a mixture of all three. You can start taking more control, rather than ME/CFS always controlling you!

There are no set times for moving forward, no goals, there is no success or failure - you make changes based on your knowledge of your own body. This means listening to it yourself, and understanding what those signs and symptoms are telling you.

Pacing is about first accepting and coming to terms with the limitations that ME/CFS has caused you, and then working around them as best as possible.

This article for Richmond and Kingston ME Group members draws on material from Chapter 10 of Severe ME/CFS: A guide to Living by Emily Collingridge 2010 a copy of which is in our Group Library or it can be purchased from Action for ME.
https://www.actionforme.org.uk/supporting-you/severe-me-cfs-a-guide-to-living/