

# Richmond & Kingston



## ME Group

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# Tips On Pacing

## What Is Pacing?

Pacing means being in tune with our bodies, to manage to the best our limited energy and to 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 per cent 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, mental — which may include watching television or using a PC 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 that guided meditation, relaxation techniques or breathing exercises help your brain 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 the 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 *every 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 per cent (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 four or five 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 can follow your baseline for three or four days, but then find you are exhausted for the next three or more days, then your baseline is too high. This means you'll need to cut back on activity somewhere, which could mean:

- ★ Slightly reducing the length of your activities.
- ★ 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:

- ★ Red: stop and think, do I really need to do this now?
- ★ Orange: approach with caution.
- ★ 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, 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 one should 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, or 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 heart rate monitor here: [http:// sallyjustme.blogspot.co.uk/2015/12/startingHRmonitoring.html](http://sallyjustme.blogspot.co.uk/2015/12/startingHRmonitoring.html).

### How Can I Increase Activity?

You should increase activities only when symptoms have been stable for at least three or four weeks. Increase only one activity at a time by only 10 per cent 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 per cent increase.

It is important, however, to distinguish between 'normal' tiredness that anyone gets with increased activity, such as aching muscles or tired eyes, and true ME symptoms, which are usually delayed and last a prolonged period of time known as Post-Exertional Malaise (PEM). If you have overdone it and are suffering from PEM, all your ME symptoms will worsen; for example, exhaustion, pain, nausea, tachycardia, sensory overload: the familiar 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 sometimes also be frustrating.

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 to 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 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, there are 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 limits that ME/CFS has caused you, and then working around them as best as possible.

This article draws on material from Chapter 10 of Emily Collingridge, *Severe ME/CFS: A Guide To Living* (2010), a copy of which is in our Group Library.