

What is pacing?

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What is pacing?

Pacing is a self-management technique that is used to learn how to stay within your energy envelope and the balance of rest and activity.

Self-management is a broad description of a combination of knowledge, skills and strategies which people can use to reduce the impact of a health problem on their quality of life.

Pacing as self-management should not be seen as a treatment, but more as a way of managing symptoms and the impact of ME.

Pacing means taking control of the balance of activity and rest to prevent postexertional malaise; and learning how to communicate to other people about the balance that usually works best for you.

Understanding and accepting your current abilities and level of functionality can help you keep your activity levels within your "<u>energy envelope</u>." This can help avoid aggravating symptoms and support you to plan more confidently.

It's very important to note that "activity" does not just mean physical activity.

Mental (also known as cognitive) activity such as reading a book, watching television, having a conversation in person or by phone, also counts – as does emotional activity.

For some, activities done in sitting unsupported or standing up can be particularly challenging (this may relate to an overlapping condition known as orthostatic intolerance).

Sensory overload (when one or more of the body's senses experiences overstimulation) may also affect symptoms.

For others, activity may be very minimal (especially for those who are severely affected) yet still cause considerable impact on energy and symptoms.

Unfortunately, in our experience, not all health professionals are aware of this, and/or accept that this is the case.

If you are in this situation, please <u>contact us</u> for information and support.

A note on terminology

Self-management is a broad description of a combination of knowledge, skills and strategies.

Balancing out activity and rest is sometimes called "energy management," "activity management" or simply "pacing," which is the term Action for ME – and the people we support – most often use, which people can use to reduce the impact of a health problem on their quality of life.

"Energy management" is a term more often used by health professionals – and in the NICE guideline, see below – as it includes more than just pacing, such as planning and prioritising and managing sleep.

It's important to note that pacing can mean different things to different people.

Some clinicians consider pacing to be about carefully managing activity and other stressors to avoid post-exertional malaise.

What does the NICE guideline say about pacing?

The <u>2021 NICE guideline for ME/CFS</u> calls pacing "energy management" and advises health professionals as follows (section 1.11.2):

"Discuss with people with ME/CFS the principles of energy management, the potential benefits and risks and what they should expect. Explain that it:

- is not curative
- is a self-management strategy led by the person themselves with support from a healthcare professional in an ME/CFS specialist team
- includes all types of activity (cognitive, physical, emotional and social) and takes into account overall level of activity
- helps people learn to use the amount of energy they have while reducing their risk of post-exertional malaise or worsening their symptoms by exceeding their limits
- recognises that each person has a different and fluctuating energy limit, and they are experts in judging their own limits

- can include help from a healthcare professional to recognise when they are approaching their limit (children and young people in particular may find it harder to judge their limits and can overreach them)
- uses a flexible, tailored approach so that activity is never automatically increased but is maintained or adjusted (upwards after a period of stability or downwards when symptoms are worse)
- is a long-term approach it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity."

Is pacing right for you?

Pacing is one option that can help to manage ME.

Other measures to help manage your symptoms, and reduce their impact on your life, might include:

- medication for individual symptoms
- support from a specialist ME service
- diet and nutrition
- sleep management.

To decide what self-management approach is right for you, you should look at the evidence, and make sure you fully understand what it involves.

It's your decision, and yours alone, which approach you try, and which you don't. You should never be pressured into trying something you feel strongly against or be dismissed for wanting to try an approach that you believe might be of value to you.

The nature of pacing, as an approach entirely tailored to your individual situation, makes it suitable for many people with ME.

Once you have understood the basic principles you can apply them to your own circumstances, whatever they might be.

The key point to remember is that your pacing plan must be appropriate for your own capabilities, however limited.

To learn more, check out our <u>Step-by-step pacing guide</u>.



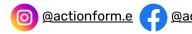
Registered office:

Action for ME Unit 2.2 Streamline 436-441 Paintworks Bristol, BS4 3AS

Telephone: 0117 927 9551 **Info & Support:** <u>infosupport@actionforme.org.uk</u> **Fundraising:** <u>fundraising@actionforme.org.uk</u>

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